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**INVESTIGATING THE IMPACT OF HEALTH DIFFICULTIES IN  
ADOLESCENCE ON THE FORMATION OF VALUED ABILITIES**

**By:**

Daniel Jonathan Gladwell

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## ABSTRACT

The current adolescent health literature indicates that poor health impairs adolescents' ability to flourish during adolescence. If an adolescent has a health difficulty, they are more likely to struggle with school attendance and experience social isolation. The human capital literature suggests that cognitive and socioemotional skills developed earlier in life influence the ongoing formation of these skills over time. The implication of these two streams of research is that poor health in adolescence may have a persisting impact the formation of individuals' valued abilities. In this thesis, I explicitly test this hypothesis.

Given the complex nature of the phenomena of interest, I combine both qualitative and quantitative methods. Both approaches support a combined investigation of how health influences individuals' current and future ability to flourish in the wider aspects of life they consider of inherent value.

The findings of the mixed methods research support the hypothesis that a health difficulty in adolescence has a persisting impact on the formation of valued abilities. Poor health in the period prior to GCSE examinations has a continuing impact on individuals' ability to access education and employment opportunities. It is also associated with an increased risk of having a small friendship network in early adulthood. The accounts of those interviewed with health difficulties indicate they sought to overcome the constraints imposed by their health difficulty. However, their poor experienced health often led to a negative sense of "difference" – undermining a positive sense of self.

A health difficulty in adolescence disrupts an individual's current and future ability to enjoy a number of valued abilities. To efficiently allocate health care resources, policy makers should consider whether a greater priority needs to be apportioned to alleviating the poor experienced health of those populations in which these valued abilities are still at a highly formative stage.

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All glory be to the Father, Son and Spirit whose power is made perfect in our weakness.

## STATEMENT OF AUTHORSHIP

This research is my own original work. It includes nothing which is the outcome of work done in collaboration with others except as declared directly below and subsequently specified in the text.

A single collaborative effort did inform the research. This was a quantitative analysis undertaken by Dr Popli, Professor Tsuchiya and myself (Gladwell et al., 2016). I note the contribution of this shared effort in Chapter 8.

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## LIST OF ABBREVIATIONS

Add Health	National Longitudinal Study of Adolescent Health
BHPI	Behaviour Problem Index
BHPS	British Household Panel Survey
BMJ	British Medical Journal
BNIM	Biographic narrative interpretive method
BTS	British Thoracic Society
CASP	Critical Appraisal Skills Programme
CF	Cystic fibrosis
CFI	Comparative fit index
CFS	Chronic fatigue syndrome
EHRC	Equality and Human Rights Commission
EQ-5D	Euroqol 5 dimensions
GCSE	General Certificate of Secondary Education
GHD	General health difficulty
GHQ-12	12-item General Health Questionnaire
GP	General practitioner
GSS	General Social Survey
ICECAP	ICEpop CAPability
ICECAP-A	ICEpop CAPability measure for Adults
LC	Locus of control
LSYPE1	First Longitudinal Survey of Young People in England
MAR	Missing at random
MARX	Missing at random with respect to X
MHD	Mental health difficulty
NEET	Not being in education, employment or training
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
NPD	National Pupil Database
NSWL	Not satisfied with life
PRO	Patient Reported Outcome
PECOS	Population, Exposure, Control, Outcome, Study-type
PICOS	Population, Intervention, Control, Outcome, Study-type
PIN	Particular incident narrative
OLS	Ordinary least squares
ONS	Office for National Statistics
QALY	Quality Adjusted Life Year
QUAL	Qualitative
QUAN	Quantitative
RMSEA	Root mean square error of approximation
SchHARR	School of Health and Related Research
SEM	Structural equation model
SWB	Subjective Well-Being
UK	United Kingdom
USA	United States of America
WHO	World Health Organization
WLS	Weighted least squares
WLSMV	Weighted least squares mean and variance adjusted
YAQOL	Young Adult Quality of Life
YP	Young person

## PART 1: SETTING THE CONTEXT



# 1. Introduction

## 1.1. Rationale

Living in good health, without pain or depression, is of *inherent* value to the individual. Health also has *instrumental* value: it can indirectly improve an individual's life by enabling them to undertake activities through which they flourish. The adolescent health literature indicates that if a young person has a severe health difficulty they are more likely to miss school and experience greater isolation from peers (Snelgrove, 2015; Suris et al., 2004; Westborn, 1992). On the other hand, the human capital literature suggests that cognitive and socioemotional skills developed earlier in life not only persist into future periods but also make further investments in those skills more productive (Cunha et al., 2010a; Cunha and Heckman, 2008; Heckman, 2006). The implication of the two streams of literature is the possibility that poor health earlier in life may have a persisting impact on an individual's subsequent well-being by impairing through time the accumulation of valued skills and abilities.

Health care priority setting in England focuses on: (i) health's innate value to the individual; and (ii) the benefits it offers the individual by enabling them to productively engage in their "usual activities" (NICE, 2013a). However, when evaluating interventions, the National Institute of Health and Care Excellence (NICE) does not consider the impact of an improvement in health on an individual's accumulation of skills or the subsequent consequences in terms of their ability to produce valued outcomes over time. The potential importance of this omitted characteristic of health, as an enabler of skill accumulation, is likely to differ according to the development stage of the individual. It is likely most important for those whose cognitive and socioemotional skills are still at a formative stage.

Adolescence is one such formative stage. It is a period of biological, psychological and social transition when individuals experience substantial change in their abilities and agency (Christie and Viner, 2005; Zimmermann and Cleary, 2006). It is also a time when key educational milestones are being reached; individuals are selecting and being selected for different educational and employment pathways. Adolescence is therefore a period when health's role in facilitating the accumulation of valued skills and abilities may be of particular importance. The empirical literature to date leaves unclear the pathways via which health dynamically influences the formation of valued abilities and skills in

adolescence and fails to provide an integrated estimate of health's impact on well-being. This thesis seeks to address this gap in the research to date.

## 1.2. Study aims and objectives

The aim of the thesis is to research the immediate and future impact of health difficulties during adolescence on the formation of valued abilities which foster well-being (note an overview of the concepts of central relevance to the thesis is provided in chapter 2). In order to address this aim, the objectives of the thesis are to:

1. investigate the lived experience of adolescents, noting their accounts of how health affects their valued abilities; and
2. examine the pathways through which health difficulties impact the *formation* of valued abilities.

Achieving these objectives will increase current levels of understanding on how health difficulties impact adolescents' current and future valued abilities. Understanding this impact and its pathways may inform future efforts to limit these negative consequences.

Additionally, if there is a substantial negative impact that is currently under-theorised, deepening our understanding of the longer-term effects of health difficulties on the formation of valued abilities may enable adolescent health interventions to be more efficiently prioritised. The research aim and objectives outlined above will be investigated for the contemporary context of the United Kingdom (UK).

The novel contribution of the thesis is to combine both longitudinal qualitative and longitudinal quantitative strands of research to derive an *integrated* understanding of health's role in the formation of the wider abilities that individuals value. I now turn to explicitly consider my epistemological position and why it supports the adoption of a mixed-methods approach.

## 1.3. Study methodology

For the thesis, I will take an epistemological position which can be categorised as a "subtle realist perspective" (Seale, 1999). This position affirms ontologically that reality exists and, to an extent, can be known. However, it also emphasises that any attempts to know this reality are affected by our perspective. Research should endeavour to strengthen the wider understanding of reality but will be unable to establish "objective truths" (Mays and Pope, 2000; Seale, 1999).



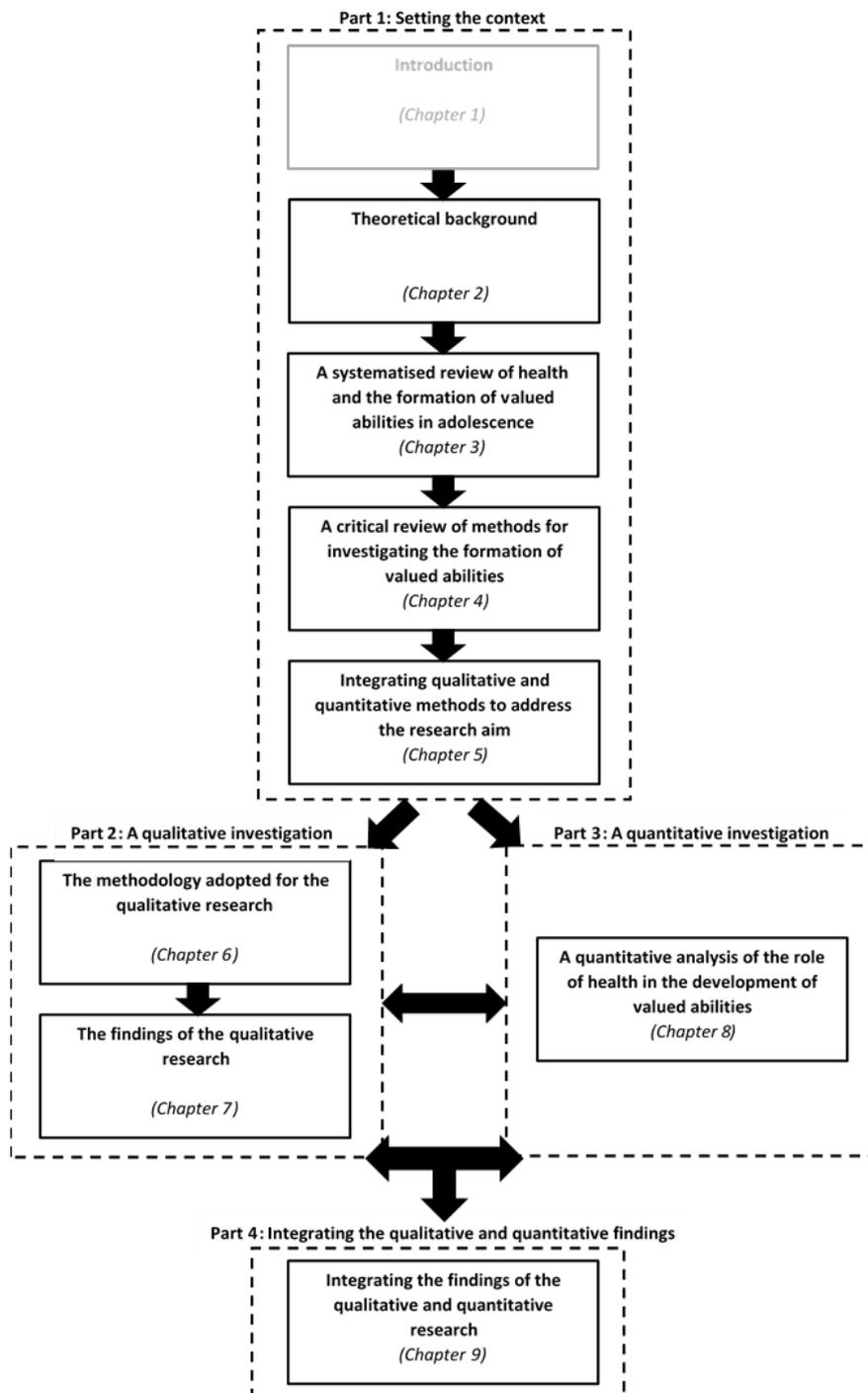
This epistemological position has implications for the methodology and methods employed in the research informing this thesis. As an individual, I have a constrained perspective. It is therefore important to gain the views of others, particularly those who are affected by the issue of relevance – negative health. A reflexive engagement with the perspectives of others will help broaden the research, allowing an in-depth engagement with the reality that exists.

Perspectives are not only framed by an individual's background and prior experiences but also arguably by the *method* adopted. Using both qualitative and quantitative methods together enables the research aim to be investigated from a broader range of perspectives. Undertaking qualitative interviews with adolescents, some of whom were interviewed on three occasions over an 18 month period, enables me to engage with their perspectives, compare their perspectives with current theory and then consider how current theory may need to develop in order to better fit the young people's lived experiences (Crouch and McKenzie, 2006). Using a nationally representative longitudinal quantitative dataset to test hypotheses that are informed by young people's lived experiences helps ensure the supported findings are likely to be of relevance to those outside my qualitative interview sample. Adopting a mixed methods approach (applying and integrating both qualitative and quantitative methods) to the research aim is therefore consistent with my epistemological position. Additionally, by enabling a process of comparison and corroboration, a mixed methods approach should enable a more rigorous investigation of the complex phenomena concerning health, lived experience and skill formation than if either method was used in isolation (Johnson et al., 2007; Tashakkori and Teddlie, 2010).

## 1.4. Overview of the thesis

Figure 1-1 below provides a visual summary of the thesis. The thesis is separated into “parts” purely to support the clarity of the document. The objective of adopting this approach is to enable me to conform to the different writing styles commonly expected in qualitative and quantitative research while maintaining conceptual symmetry as regards the relative contribution of each to the overall thesis.

Figure 1-1: Structure of the thesis



In chapter 2, I review the theoretical literature of relevance to the aims and objectives of the thesis. I first review different conceptualisations of well-being and then health. This is followed by a consideration of theory as regards the researcher and the research participant (which in turn influences the choice of methods used to engage with individuals' lived experiences). Given the centrality of the dynamic formation of valued abilities over time to my research aim and objectives, I then consider the literature on change before finally considering adolescence as a period of life in which substantive change is experienced.

In chapter 3, I present the findings of a review of the empirical literature to date to investigate the role of health in the formation of valued abilities and skills. Having identified via the review that the research to date fails to fulfil the thesis' aim and objectives, in chapter 4, I review the methodological literature that has the potential to inform my pursuit of the research aim and objectives. Specifically, I consider which methods may be appropriate for: (i) engaging with individuals' lived experiences; (ii) identifying which abilities and opportunities are given particular importance by individuals; and (iii) investigating how valued abilities develop over time.

In chapter 5, I summarise my approach to combining qualitative and quantitative methods to address the research aims and objectives. I first review some important considerations when integrating different methods before providing an overview of my overall mixed methods study design.

As shown by Figure 1-1, I then report the qualitative investigation in part 2 (consisting of chapters 6 and 7). In chapter 6, I report the methodology employed in the qualitative study. Having provided a reflexive account of how my own background influences the perspective I bring to the research area, I then summarise: the preparations I undertook prior to data collection, the interview methods I used, and the approach I adopted to analyse the data generated by the three waves of qualitative interviews.

In chapter 7, I report the findings of the qualitative study. For clarity, I separately present the findings of two intertwined aspects of the qualitative research. First, I report the findings that emerge from an investigation of the aspects of life of particular importance to adolescents. Second, via an analysis of the participants' biographical data, I consider how a health difficulty in adolescence disrupts individuals' lived experience, including their evolving ability to enjoy the aspects of life identified as being of particular importance.

In part 3, which contains chapter 8, I report a quantitative analysis of data from the First Longitudinal Survey of Young People in England (LSYPE1): a secondary dataset which enrolled approximately 15,000 adolescents aged 13-14 and continued to interview the participants annually for an additional six waves. I report the findings of analyses which use structural equation models to investigate associations through time between health difficulties and an impaired ability to subsequently enjoy some of the aspects of life identified as being of particular importance to adolescents. The quantitative analyses enable me to: (i) test hypotheses that are informed by the qualitative research on a dataset designed to be nationally representative of an age matched cohort; and (ii) identify pathways through which negative health impacts the dynamic formation of valued abilities.

In part 4, which contains chapter 9, I formally integrate the findings of the qualitative and quantitative studies. Using a triangulation protocol adapted from the approach suggested by Farmer et al. (2006), I consider the extent to which there is agreement, silence and dissonance between the two strands of the research. I then endeavour, via dialectic analysis of the findings provided by the two separate studies, to identify how health difficulties in adolescence impact individuals' evolving ability enjoy the aspects of life identified as being of particular importance. Following a consideration of the limitations and strengths of the mixed methods study, I make recommendations for further research and policy.

## 2. Theoretical background

This chapter contains an overview of the theoretical literature of relevance to the thesis aim and objectives. Specifically, I review literature concerning: (i) well-being; (ii) health; (iii) the defended subjectivity of individuals; (iv) change in the lives of individuals; and (v) adolescence.

### 2.1. Well-being

Well-being is a concept that is rarely explicitly defined – a term which is used by different schools of thought to allude to competing related, but diverse, underlying concepts. It may therefore be helpful to have a brief historical overview in order to define the concept. For brevity here, and when reviewing the wider theoretical literature of relevance, I focus on the Western intellectual tradition.

It can be argued that “ ‘Well-being’ signifies the good life, the life which is good for the person whose life it is.” (Raz, 2004: 269). The understanding of what constitutes living the good life has varied over time.

#### 2.1.1. Historical conceptualisations of well-being

Aristotle, living in the fourth century B.C., believed those who excelled in living the good life had accomplished eudaimonia (or human flourishing). Eudaimonia was the goal or telos to which community and individual life should be orientated (MacIntyre, 2002). Aristotle argued that the goal of life was not to accomplish pleasure or avoid suffering. Instead, the goal was to live a life characterised by a plurality of valuable activities involving love and friendship, which were coherent with ethical, intellectual and political virtues, or excellences (Nussbaum, 2004). By living in such a manner, Aristotle argued, a human flourishes – fulfilling their purpose by living a life characterised by reason (McMahon, 2004). At times, pleasure may result from a life lived in such a manner but according to Aristotle pleasure is not the aim. McMahon argues that, for Aristotle, eudaimonic happiness “is not a fleeting feeling or an ephemeral passion. It is, rather, the product of a life well lived, the summation of a full, flourishing existence...” (McMahon, 2004: 6).

Following Aristotle, Christian theologians, such as Augustine in the fourth century A.D. and Aquinas in the thirteenth century, further distanced well-being from the achievement of immediate pleasure in this lifetime. Aquinas synthesised the teachings of Aristotle and the Beatitudes of Jesus and argued that happiness in its fullest sense could not be

obtained in the present life. The good life, that of the blessed individual, was characterised by Godliness in the earthly life, making possible the realisation of that life's goal: access to Heaven where full happiness and ultimate pleasure were available (McMahon, 2006).

The enlightenment resulted in a dramatic shift in the world-view of Western philosophers. This shift included a scepticism about the authority and ability of institutions to comprehend and define humanity's telos (MacIntyre, 2007). The concept of what constituted a good life could therefore not be defined in reference to the full achievement of a goal. In this context, Bentham arguably most clearly articulated a purely hedonic reconceptualisation of happiness and well-being. The actions of individuals, according to Bentham's utilitarianism, were to be guided by the aim of maximising pleasure and minimising pain. Bentham wrote, "Nature has placed mankind under the governance of two sovereign masters, pain and pleasure. It is for them alone to point out what we ought to do, as well as to determine what we shall do." (Bentham, 1996: 11). Bentham reduced happiness to pleasure and held pleasure to be qualitatively homogenous (Nussbaum, 2004).

Mill, a student of Bentham, modified utilitarianism by incorporating increased complexity in the conceptualisation of pleasure. Mill considered the pleasures to not be homogenous and to differ in kind as well as in intensity. Amongst Mill's major pleasures were music, virtue and health, which are inherently linked with activities. Importantly these are considered major pleasures as they lead to a manner of existence worth having (Nussbaum, 2004). Mill's conceptualisation of well-being therefore incorporated pleasure, valued activities and contentment with one's life as a whole. Nussbaum argues that Mill held both Aristotelian and Benthamite conceptualisations in tension. In doing so, Mill could be considered a forerunner of an "evaluative approach" to well-being.

#### 2.1.2. Current conceptualisations of well-being

Dolan and colleagues classify current conceptualisations of well-being into five approaches: the objective list approach, the preference satisfaction approach, the human flourishing approach, the hedonic approach and the evaluative approach (Dolan et al., 2006). Each of the current approaches draws on historical conceptualisations of well-being.

Both the preference satisfaction approach and the hedonic approach derive from Benthamite utilitarianism. The former focuses on decision utility (in which utility

represents the desirability of a good or service). The latter focusses on experienced utility (in which utility represents experienced happiness). The preference satisfaction approach assumes that what people desire is what they will subsequently enjoy (Kahneman et al., 1997). Empirical researchers may choose to adopt a preference satisfaction approach over the hedonic approach because of a belief that an individual's preferences are observable, enabling a comparative analysis (Bruno and Stutzer, 2002). In contrast, there is an extensive literature critiquing the extent to which interpersonal comparisons of hedonic utility are plausible (Harrod, 1938; Kaldor, 1939; Robbins, 1938; Sen, 1985). Typically, empirical work informed by the preference satisfaction approach focuses on income in order to assess well-being. This is because, to the extent that money allows the consumption of market goods and services that help satisfy (certain kinds) of preferences, the more income an individual has, the more of their preferences can be satisfied (Dolan et al., 2006).

The hedonic approach is similar to the preference satisfaction approach but instead of empirically focussing on money, attempts are made to directly measure *experienced* utility (experienced happiness) (Dolan and Kahneman, 2007). Individuals are asked to self-report their recent moods or emotions. An example is a question from the General Social Survey (GSS): "Taken all together, how would you say things are these days—would you say you were very happy, pretty happy, or not too happy?" (GSS, 2010: 67). Such questions can be incorporated into large scale studies and allow an analysis of the correlation between self-reported moods and other variables such as education or income. Philosophically it is similar to the preference satisfaction approach in that both reduce everything to pleasure (whether anticipated or achieved) and its absence.

The subjective well-being (SWB) approach (Diener et al., 1985) could be seen as a more nuanced form of the hedonic approach. The SWB approach, while giving significance to pleasure and the effects of pleasure and pain on well-being, also attempts to broaden the conceptualisation of well-being by considering factors beyond pleasure. Typically, in an empirical study informed by the SWB approach, an individual is asked to evaluate their satisfaction with their life as a whole. This allows the individual to weight how important both pleasure and valued activities and achievements are to their well-being. An example is the Satisfaction With Life Scale developed by Diener and colleagues (Diener et al., 1985).

The objective list approach and the human flourishing approach can be seen as having Aristotelian roots. In line with Aristotle, but in sharp contrast to the other approaches outlined so far, the objective list approach leaves it to the theorist to define a list of attributes and characteristics, such as literacy rates, which are of importance when assessing well-being (Dolan et al., 2006). The more positive attributes an individual possesses, the better the state of well-being they are deemed to be in. The human flourishing approach informs two schools of thought: the psychological well-being approach (Ryff, 1989) and the capability approach. In both, well-being is conceptualised primarily in terms of the individual's freedom to fulfil their potential.

Both the psychological well-being approach and the capability approach attempt, to an extent, to analyse not only well-being but the causes of well-being. They consider the extent to which an individual is able to undertake activities they value (good functionings). They share Aristotle's conceptual perspective that the good life results from undertaking activities that result in the individual flourishing. As such, they could be seen as having greater explanatory power for understanding the determinants of well-being relative to the alternative approaches as they attempt to provide a causal, theoretical framework for well-being's formation. However, the enlightenment critique of Aristotle and Aquinas – that philosophically we cannot know a person's telos, and therefore, by extension we cannot know the activities that they believe will lead to the good life – can be levelled at both schools of thought. By contrast, the SWB approach asks the individual to self-report their life satisfaction, allowing the individual rather than the theorist to make the judgements. This thesis will therefore seek insights from both the human flourishing approach (in particular the capability approach) and the SWB approach. It is worth noting that when I use the term SWB I am referring to this specific conceptualisation of well-being. In contrast when I solely use the term well-being I am referring to a less restricted conceptualisation, i.e. a good life.

### 2.1.3. The capability approach and its operational challenges

The capability approach, developed by Sen (1990, 1985, 1980) and enhanced by Nussbaum (2001, 1988), has grown in academic and policy-making influence. The approach could be categorised as belonging to the "human flourishing" approach of the conceptualisation of well-being and has Aristotelian roots (Dolan and White, 2006; Nussbaum, 1988; Sen, 1990). The approach considers the extent to which an individual is able to undertake activities they value, termed good functionings (Sen, 1993, 1990). It shares Aristotle's conceptual perspective that the good life results from being able to



undertake activities of inherent value (Dolan and White, 2006; Nussbaum, 1988; Sen, 1990). The capability approach could be considered as conceptually related to the extra-welfarist approach within health economics, because it considers issues other than the aggregation of individual utility to be of importance to well-being (Culyer, 1989; Sugden and Williams, 1978). In contrast, welfarism, is derived from Benthamite utilitarianism, which posits that an individual's well-being can be conceptualised purely in terms of their utility or happiness (Sen, 1979).

Morally the capability approach has appeal: the approach's insistence on the centrality of the advancement of individuals rather than economies as the goal of societal development has intuitive appeal and instrumental as well as substantive implications. Additionally, it has philosophical appeal: the approach's ability to handle the tension of objectively defining functionings that lead to well-being (Nussbaum, 2001) while supporting the individual's fundamental freedom to make choices (Sen, 1993). This allows ideas with authors as culturally, chronologically and philosophically diverse as Aristotle and Mill to co-exist in a single framework (Sen, 2004a).

Operationalising the approach though is not without its difficulties. One of the challenges posed by the approach is the abstract nature of its core concept – Capability. Capability can be defined as “...the alternative combinations of things a person is able to do or be – the various ‘functionings’ he or she can achieve” (Sen, 1993: 30). However, population level data recording individuals' capabilities are often not readily available; instead, most secondary data sets record individuals' ‘functionings’ – what they choose to do and who they choose to be, given their available options. The counterfactual functionings in their capability set which individuals choose not to exercise, by definition, are not recorded. From the theoretical perspective of the capability approach, rooted in a liberal philosophical framework, it is these opportunities to function, rather than the functioning chosen, which are of paramount importance (Robeyns, 2005a).

Gathering primary data through surveys on how individuals perceive functioning options, or capability sets, does not fully reconcile the difficulties. The abstract nature of the concept 'capability' means it has to be re-interpreted into ideas with which the general population is more familiar in order for research that relies on self-reported data to be conducted (Coast et al., 2008a).

In spite of the challenges of operationalising the approach, steps are being made. One example of the capability approach being used in the context of an industrialised country

is provided by Germany. The official German Poverty and Wealth Reports in 2004 adopted the enhancement of capabilities as a primary goal (Arndt and Volkert, 2007). Increasingly, other industrialised countries are attempting to incorporate insights from the capability approach in their efforts to assess national well-being. The French President, Nicolas Sarkozy, in 2008, invited Sen to join the CMEPSP. In 2010, the UK Prime Minister, David Cameron, commissioned the Office for National Statistics (ONS) to develop measures of national well-being and progress (Matheson, 2011), measuring *objective* well-being as well as SWB. Efforts are now also being made to utilise the capability approach in the evaluation of health policy (Coast et al., 2008b; Lorgelly et al., 2010, 2008). Enhancing well-being, when using the term in its broader sense, is therefore now explicitly recognised as an important policy goal (Bernanke, 2012; O'Donnell et al., 2014).

#### 2.1.4. The capability approach and the thesis

The capability approach is the theoretical approach which, in combination with the prior life experiences outlined in 6.1.2, sparked my interest in this area of research. As such, it could be described as the sensitising theoretical framework (Charmaz, 1990). The capability approach has therefore informed my research aims and objectives (see 1.2), been my starting point for reviewing the literature (chapters 3 and 4) and is a point to which I return when contextualising my findings (chapter 9).

While the capability approach has a great influence on the research reported in this thesis, I will aim to restrict its influence so that I can avoid the adoption of a solely deductive approach. Rather than using data purely for the purpose of testing hypotheses generated from theory, I will additionally aim to use data to generate theory which can in turn be tested (Glaser and Strauss, 1967a). I will therefore aim to combine inductive and deductive approaches to meet the study aims and objectives. As such, apart from when explicitly discussing the capability literature, I will endeavour to avoid the use of vocabulary that is predominantly restricted in its usage to the capability approach. This should not only enable conceptual freedom in my analysis of the data, facilitating the process by which the data can be used to generate theory as well as test it (see 5.1), but also enable the research to be readily accessible to readers from a number of academic backgrounds. When not explicitly referring to the capability literature, I will therefore use commonly used synonyms for “capability” such as opportunity or ability (Gasper, 2002). Similarly, when referring to a capability domain, I will most frequently use the term

“valued aspect of life”. “Functionings” will often be referred to as the extent to which an individual is achieving positive outcomes in an aspect of life that is widely valued.

Both sociology and psychology have particular relevance for my research aim; therefore, to an extent, I will endeavour to draw on the methods, practices and theories that emerge from these disciplines. Specifically, as outlined in greater detail in 2.2, 2.3, 2.4 and 2.5 the psychological and sociological literature has influenced my conceptualisation of health, the nature of the individual, the formation of the self and of adolescence.

However, while I aim for this research to both be accessible to individuals from a broad range of disciplines and to be informed by different disciplines, I will write as an individual who is trained as an economist. I will therefore primarily seek to locate this literature within the discipline of economics. I have no formal training in neither psychology nor sociology; at this stage of my research career any attempt to be truly “post disciplinary” risks the thesis becoming under contextualised, unstructured, and unfocussed.

## 2.2. Health

Health “is difficult to define but easy to spot when we see it” (Bury, 2005: 1).

Conceptualisations vary on a continuum from the relatively narrow medical model of health, “the condition of being sound in body, mind, or spirit; especially: freedom from physical disease or pain” (Merriam-Webster Online, 2015) to an all-encompassing, positive notion of health that is synonymous with well-being “... a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1948). I will now consider some different approaches to conceptualising health – each will be drawn on during the thesis.

### 2.2.1. Medical model of health

The medical model of health, which rose to prominence in the eighteenth and nineteenth centuries in Europe and North America, focuses on uncovering the underlying pathological processes of a disease and its effects (Bury, 2005a). According to this model, the physician’s role is to trace the patient’s symptoms back to their underlying causal origins; once these origins have been diagnosed, the clinician is then expected to prescribe a medical or surgical intervention as a counter remedy (Bendelow, 2009a). Due to its focus on the aetiology of the disease within an individual’s body, the medical model is often individualistic in orientation and implicitly assumes that:

- health is the absence of diagnosable disease,

- health is a natural and desired state of nature, and
- identifiable diseases have biological causes which can be combated by counter remedies (Bendelow, 2009a).

Given this conceptualisation of health, and the physician's central role, the medical model places the doctors as being the experts. Arguably the medical model has facilitated substantial progress in the treatment of disease from the eighteenth century to the present time. However, the model has limitations. It has a limited capacity to account for health difficulties for which there is no readily identifiable cause, such as chronic fatigue syndrome. Additionally, it arguably underemphasises the societal causes of disease which are outside the individual's body. For example: (i) the physical environment may disincentivise activity; which (ii) may lead to a general increase in population obesity; and therefore (iii) there may be an increased population prevalence of chronic health difficulties (Bury, 2005a; Lake and Townshend, 2006). The medical model is well placed to predict at the individual level that "iii" follows from "ii" but may neglect to explore the role of the environment, solely emphasising the individual's need to control their calorie intake and expenditure.

#### 2.2.2. Social model of health

Epidemiological analyses by McKeown (1979) and Szreter (1988) investigated the decline in mortality in the nineteenth and twentieth centuries using European data and argued that the role of medical interventions in the declining mortality had been overemphasised. Social factors such as better sanitation, purer water supply and improved nutrition had contributed to a decline in the deaths caused by infectious diseases before effective immunisation and antibiotics became available (Bendelow, 2009a).

The organisation of society and the socioeconomic distribution of roles and resources have a substantial impact on the health of individuals. Material deprivation is associated with higher rates of morbidity and mortality (Bury, 2005b). There are clear potential causal pathways for this relationship. For example, respiratory disease, and the morbidity and mortality that it causes, may be more common among lower socioeconomic groups in part because of lower quality accommodation (i.e. dampness in the home). Additionally, a greater sense of powerlessness in the work environment may, amongst other factors, have a role in explaining the desire to relieve stress through behaviours such as smoking (a risk factor for respiratory disease that is also more common among

lower socioeconomic groups) (Bury, 2005b). Research indicates that it is not only *absolute* material deprivation that has an adverse effect on individuals' morbidity and risk of mortality but also occupying a lower socioeconomic position *relative* to the wider population (Bury, 2005b; Wilkinson, 1996a). Furthermore, there appears to be an association between the degree of socioeconomic inequality within a society and the extent of health inequalities. Sweden for example has both relatively low income and health inequalities whereas the USA and UK have a relatively high level of both income and health inequality (Bury, 2005b; Wilkinson, 1996b). It has been argued that higher levels of socioeconomic inequality lead to higher levels of health inequality (Wilkinson, 1996b). An effective conceptualisation of health must therefore not only consider the individual, their health difficulty and the possible medical remedies, but the societal dimension including environmental factors and inequalities in access to resources (Bendelow, 2009a).

Considering society as a whole is not only important for considering the wider determinants, but it is also important when analysing how health itself is defined and individuals' health is evaluated – who decides whether or not an individual is ill? Should it be the physician trained in understanding the body, aetiology, pathology and remedy or should it be the individual with a first-person experience of their health? A social conceptualisation of health would explicitly recognise the different actors involved in the negotiation as to what is a health difficulty and as to whether the patient is truly in need of being a recipient of further care (Bury, 2005a; Parsons, 1975).

A social model of health does not negate the medical model or rule out the remedies offered. However, its emphasis is different, focusing more on society and less on the individual, and remaining cognisant of how different actors within society perceive and experience health rather than primarily focussing on the knowledge contained within the medical community (Bury, 2005a).

### 2.2.3. Physical health, mental health and the body

Diseases that primarily affect the physical dimensions of the body can often readily fit into an approach informed by the medical model. Health difficulties such as tuberculosis may be influenced by societal factors (Hargreaves et al., 2011) but they are also susceptible to an approach based on diagnosis and treatment of the underlying aetiology; in the case of tuberculosis, anti-tubercular drugs work effectively against the bacteria that damage the lungs (Bury, 2005a).

Following the success of the medical model in supporting the treatment of health difficulties primarily affecting the physical dimension of the body, similar approaches have been taken to illnesses that primarily affect the mental dimension. A materialist view of the brain, with its structures and linkages, has come to dominate medical and psychiatric thought, and mental illness has therefore been located in the individual's biological make up. This has proved attractive to both professional and lay audiences. Historically, mental illness was often linked to behaviours that came with stigma; locating illness in the individual's biology can to some extent reduce this stigma and legitimate the individual suffering as one who is in need of care (Bury, 2005a; Parsons, 1975).

While a conceptualisation of mental health based on the medical model has proved appealing, the social model still has much to offer. Research indicates mental health is not a random event but patterned by social class, poverty and the absence of confiding relationships. There is therefore much beyond the individual's body that influences the extent to which they enjoy good mental health (Bury, 2005a).

The categorisation of physical health and mental health as separate entities is itself contentious. It is based on Descartes' conceptualisation of the mind and the body as not only separate but operating according to different laws; he saw the mind (or soul) as eternal whereas at death the body decomposed (Bury, 2005c). This conceptualisation of the body as material, and therefore scientifically investigable, supported viewing the body as a machine. This mechanistic view of the body led to significant medical advances such as in the treatment of heart disease (Bury, 2005c). However, Bendelow (2009) argues a Cartesian view of the mind and body has substantial limitations – health difficulties such as Alzheimer's disease, chronic pain, cancer and chronic obstructive pulmonary disease (COPD) have emotional as well as physiological characteristics. Therefore, it is arguably more helpful to see the mental and physical dimensions of the individual as interconnected *within their body*. For example, excessive psychological stress can cause

the individual's heart rate and blood pressure to increase, which can increase the risk of a heart attack (Bendelow, 2009b; Rosengren et al., 2004).

Sociologists such as Freund (1990), Parsons (1978) and Shilling (2001) have argued that the body is not only the location where the individual's physical and mental dimensions connect but also the medium through which the individual and society interact. The body is central to our experience of the lived life and to our self-identity. Individuals live "embodied" lives – it is through our bodies that we sense, understand and communicate with the world (Shilling, 2006a). Understanding the centrality of the *body* in the individual's experience of life helps with anticipating the impact of *illness* on individuals. Illness, whether "physical" or "mental" in dimension, is situated within the body of the individual. It is therefore through the body that illness disrupts the individual's experience of life (Bury, 2005:64), although sometimes mediated through medical or assistive technologies. In turn, the body is central to the diverse capacities on which individuals draw in order to flourish (Freund, 1990; Parsons, 1978; Shilling, 2001). These include the capacities to enjoy social relationships, to gain knowledge and skills, and to undertake meaningful work and social activities. Conceptualising the body as the site:

- where the individuals' physical and mental dimensions are integrated (Bendelow, 2009b) and
- where the individual interacts with society (Shilling, 2006a),

therefore, offers a theoretical lens through which to anticipate and explain how poor health may affect an individual's capacity to enjoy the wider aspects of life they value.

#### 2.2.4. Health as capability

Good health is a valued "being", or functioning, and therefore an individual's ability to enjoy good health can be considered a capability. Sen includes avoiding morbidity and mortality in an informal list of functionings necessary to achieve well-being (Sen, 1993: 36). Health is also included in Nussbaum's list of functionings in the domains of "Life" and "Bodily Health" (Nussbaum 2001: 87). In health economics, there has increasingly been consideration of how to apply the capability approach to the evaluation of health care interventions (Coast et al., 2008b).

In the economic evaluation of health interventions in the UK, there is a precedent for using approaches which incorporate criteria beyond utility, the traditional maximand used in analyses based on a welfarist approach. An example is the use of the Quality

Adjusted Life Year (QALY), which, in analysis informed by extra-welfarism, is used as a proxy measure for health rather than utility (Brouwer et al., 2008). Brouwer et al. argue that Sen's work was especially influential in the formation of extra-welfarism, arguing that the capability approach made possible, "a broader perspective that took account of the quality of utility and of people's capabilities rather than exclusively of the emotional reaction (i.e. utility) of individuals to the possession of goods or capabilities" (2008: 330-331).

While the QALY is not without critics, it has provided a useful measure of health for the economic evaluation of medical technologies. However, the QALY has limitations when applied in a public health context if measured using the Euroqol 5 dimensions (EQ-5D) instrument, as recommended in NICE's guide to the methods of technology appraisal (NICE, 2013a) and conceptualised as a unit of *health* related quality of life. Lorgelly et al. argue that "Many public health interventions seek to impact on broader aspects of quality of life, not just health, but also non-health outcomes such as empowerment, participation and crime" (2010: 2278). One attempt to rectify these perceived shortcomings is the development of the ICEpop CAPability (ICECAP) measures: outcome measures based on the capability approach, which can be incorporated in economic evaluations (Al-Janabi et al., 2011; Coast et al., 2008a; Makai et al., 2011). Qualitative methods were used to identify aspects of life that were of value to the participants. For the adult population the domains identified as being of importance were: attachment, stability, enjoyment, autonomy and achievement (Al-Janabi et al., 2011). This measure may enable policy makers to identify how changes in health are related to individuals' ability to flourish across these different domains.

#### 2.2.5. Health and the thesis

In this thesis, when conceptualising health, I will look to draw on the differing approaches above. In line with the social model, I will be cognisant of the literature, which indicates that the wider organisation of society and the individual's relationships with significant others can have an important influence on the distinct but interconnected physical and mental dimensions of their health. Nevertheless, for the purposes of analytical clarity, in line with the medical model, I will primarily conceptualise health as the absence of illness. This should support my aim of investigating how health supports the formation of valued abilities which foster *well-being*. An all-encompassing, positive view of health such as that used by the World Health Organization (WHO) has its strengths, but for my purposes,



given its synonymy with well-being (Evans and Wolfson, 1980), risks a lack of clarity when talking about the relationship between health and well-being.

At the same time for this thesis, as regards the social determinants of both health and the ability to enjoy a range of other valued abilities, there is a need to constrain the scope of my research ambitions to the research aim and objectives specified in 1.2. Therefore, although socioeconomic factors play an important role in both influencing individuals' health and the wider valued abilities individuals are able to enjoy (Kuklys, 2005), I will not undertake an investigation of how socioeconomic factors affect the influence of *health* on the formation of these abilities. In my later qualitative and quantitative analyses, I will endeavour to prevent the underlying influence of socioeconomic factors, on both health and the formation of other wider abilities, distorting any observation I make about the relationship of interest for this thesis (the relationship between health difficulties and the impaired formation of valued abilities). However, in both the qualitative and quantitative strands of the research I will not explicitly investigate how health difficulties, socioeconomic factors and the formation of valued abilities *interact* (i.e. I will not investigate how the influence of a health difficulty on the formation of wider abilities differs by socioeconomic group). Further research that undertakes a detailed analysis of the moderating role of socioeconomic factors may well be of worth, but I consider it beyond the scope of this thesis.

In line with Shilling (2001b) and Bendelow (2009b), I will aim to explicitly consider the body both when conceptualising the individual and when considering the impact of health difficulties on their wider experience of life. Doing so should support me in conceptualising the individual as a holistic entity. Additionally, it may help me anticipate the possible impact of poor health on the individual via its impact on the body, a site through which individuals interact with society. An explicit consideration of the body when considering health is consistent with the capability literature – health is then not only an inherently valued aspect of life but is also a resource or capacity (Freund, 1990; Parsons, 1978; Shilling, 2001) that facilitates the individual flourishing in the wider aspects of life they value. Often there will be a need to refer to individuals who have poor experienced health. When doing so I will predominantly use the term “health difficulty”. I choose to use this term rather than “health condition” because of the social model’s influence on my conceptualisation of health. Specifically, a “health condition” may be taken to refer to a difficulty that is explicitly recognised by the medical community

whereas the term “health difficulty” can include both these difficulties and those that are contentious in nature (Bury, 2005a).

### 2.3. Considering the individual as a “psycho-social” subject

Prior to a detailed evaluation of previous research undertaken in this area and the methods I will adopt in this thesis to achieve the study aims and objectives, it is useful to briefly consider the dynamic between individuals involved in research – the researcher and the research participant. Below, I will briefly consider the general theory of the individual which, as will be outlined in greater detail in 4.2, 4.3 and 4.4, informs the approach taken in this thesis.

#### *Individuals’ inner and outer worlds*

In order to understand both how individuals are influenced by the world around them and how they choose to engage with that world, it is useful to consider both the individual’s “inner world” and their experience of the “outer world”. As Holloway and Jefferson argue, there is a “need to posit research subjects whose inner worlds cannot be understood without knowledge of their experiences in the world, and whose experiences of the world cannot be understood without knowledge of the way in which their inner worlds allow them to experience the outer world” (2000: 5). An approach which jointly considers individuals experience of and engagement with the world as characterised by the interaction between inner and outer worlds can be termed psycho-social: it is the approach I will take in this thesis. I will often use the term “*lived experience*” (the terminology used in the first objective of the thesis) when referring to individuals’ experiences that are: personal in nature; often have emotive resonance for that individual; and likely shape their perception of the outer world as well as their actions within it (Boylorn, 2008). I use this term both to underscore the rich nature of the experiences that I am seeking to learn about; and because using this phrase in this manner is consistent with its use within the wider sociological literature (see Ellis and Flaherty (1992) and Boylorn (2008)).

#### *Agency and the choices in our everyday lives*

Holding the position that the outer world influences an individual’s lived experience, and that these rich experiences influence how they *conduct* themselves in the outer world, requires the assumption that individuals possess agency. While the structure of society provides the context for individuals’ actions, these actions can partially modify as well as

confirm the existing social structure (Wengraf, 2002). There is therefore a dynamic interaction between individuals and the society they are a part of – the life of the individual is not independent of wider society or those in which they are in close relationships, but they, as agents, make decisions which in turn shape the ongoing formation of the society they inhabit. Dolan and White (2006), when discussing their Dynamic Well-being Approach, echo the importance of individual agency. They argue that after individuals have anticipated how they would feel following a range of outcomes, they then plan what they have to do to achieve their most favoured. Individuals then attempt to behave, and therefore make choices, in a way which will increase the likelihood of a positive outcome or reduce the likelihood of a negative outcome (Dolan and White, 2006). A belief in agency is also fundamental to the capability approach. Sen (1985) emphasises both the existence and intrinsic value of agency. Without such an emphasis, the capability approach would neither distinguish between capabilities and functionings nor place the greater emphasis on capabilities, the “freedom to choose between different ways of living” (Sen, 1990: 44).

#### *Agency and the role of narrative*

Arguably, individuals not only have a degree of influence over the events that happen in their lives; they also possess agency over how these “outer world” events impact on their inner world. It has been argued that individuals use constructed recollections of their life stories, or narratives, to not only tell others of their experiences, but to also construct meaning from the events they experience. Our adopted identities shape the narratives we tell, just as the narratives we tell (to ourselves and others) help shape our adopted identities (Bruner, 1987). Rosenthal (1993) argues that when we tell ourselves or others our life stories, we are forced to deliberately select between important events that have occurred and ascribe interpretive links between these events – the very construction of a narrative involves the narrator considering how one key event led to another. The narratives we tell may therefore change over time – new events have to be integrated into the story. Importantly, narrative can enable people to negotiate the meaning they give to these experiences (Bury, 1982).

#### *The defended self*

Investigating how an individual has exerted their agency by making specific choices requires consideration of their inner world (Hollway and Jefferson, 2000a). However, a psychosocial approach acknowledges that furthering one’s understanding of another’s

inner world is fraught with difficulties. One crucial barrier to consider is that individuals are careful as to how they present their embodied selves to both themselves and others: their self, or essence is defended (Hollway, 2009). Not only will the research participant be careful as to how they present themselves but so will the researcher. This will affect not only the interaction within the interview but, to the extent the researcher is unaware of their unconscious bias, the researcher's ability to analyse the interview data in an open-handed manner.

This premise of defended subjectivity therefore has implications for the research methods used to investigate the lived experiences of individuals. Holloway and Jefferson argue that a flaw of the semi-structured interview, a method frequently used by qualitative researchers, is that they assume research participants (and researchers) know who they are, what motivates them and are willing to give transparent accounts. An alternative approach which explicitly accounts for individuals' defended subjectivity will be reviewed in chapter 4.

## 2.4. Change

Life is characterised by change – change in our contexts, our relationships and within individual themselves. Not only do individuals' capacities change over time but their subjectivity, their sense of self, is dynamic (Somers, 1994; Wengraf, 2013; Zimmermann and Cleary, 2006). Narrative is a format through which individuals understand and make sense of the social world; through the narratives we tell, we also constitute and communicate our social identities (Somers, 1994).

### 2.4.1. Health, the evolving self and the role of narrative

Substantive life events can lead to changes in both the individual's sense of self, their relationships with others and the narratives as they tell both themselves and others in order to make sense of their new situation (Bury, 1982). Bury undertook semi-structured interviews with 30 adults who were referred for the first time to a rheumatology clinic. An analysis of their interview data led Bury to the conclusion that a chronic health difficulty can creep up on the individual, disrupting day to day activities, relationships and one's identity within the wider community. Narratives provided individuals with a format through which they could make sense of their health difficulty. Bury's participants described not only how their health difficulty had disrupted their biography but also that they thought disturbing changes in their lives had caused the disruptive health difficulty (Bury, 1982). Those experiencing the chronic illness therefore believed that not only did

their bodies influence their ability to perform in the social sphere but also that their bodies were affected by the social world they inhabited.

Even in the context of health problems, change over time can eventually be positive as well as negative. Charmaz (1994) undertook forty interviews with twenty men experiencing chronic illness. The data indicated that the onset of a chronic illness was initially very disruptive: the men interviewed were forced by their health difficulty to face both their mortality and to accommodate increased uncertainty in their lives as their abilities to be economically productive and physically independent diminished. However, over time they learnt to preserve their sense of self. Charmaz reports that once the men relinquished the aim of recapturing their past independent self they became increasingly able to define and restrict the role illness played in their private sense of self and their public persona. Some worked to find meaning in their illness and recast their health difficulty into something which could enhance rather than subvert their identity; their illness then switched to being conceptualised as an ally rather than an enemy as they chose to identify living with the illness as an opportunity for reflection and change. Holding past “masculine” identities became more difficult but, for some, an evolution in their identity enabled them to use their illness to enrich their lived experience and told narrative (Charmaz, 1994).

#### 2.4.2. Theoretical foundations for a dynamic conceptualisation of well-being

The work of Bury and Charmaz amongst others indicates a dynamic interaction between an individual’s capacity to enjoy valued beings (such as enjoying good health) and doings (being able to undertake work) and an individual’s evolving sense of self. However, in both health economics and the wider capability literature, capabilities, or valued abilities, have primarily been conceptualised using a comparative static model (Leßmann, 2009). Arguably, the interaction between different resources, functionings and capabilities over time has been both under-theorised and empirically under-investigated (Ballet et al., 2011; Binder and Coad, 2010; Leßmann, 2009).

Different disciplines may prove particularly useful for informing a theory of the inter-temporal interactions between valued abilities over time. These disciplines include ethical philosophy, educational theory and welfare economics. Theorists within these disciplines all explicitly consider how individuals and their abilities develop over time.

The philosopher and capability theorist Nussbaum (1988) articulates an outline for a theory of capability formation grounded in the writings of Aristotle. Nussbaum argues

that innate abilities are honed further through the process of education and experience. Education is not only important for developing individuals' ability to enjoy valued functionings such as enjoying good relationships or living healthfully, education is also vital for developing the ability to choose well. The very act of transforming a latent capability into a valued functioning relies on the capability to choose well – to employ practical reason (Nussbaum, 1988). As such, practical reason could be considered the master ability. It is the ability closest to the domain of Aristotle's virtue of prudence, described by McIntyre as the keystone of all the virtues (MacIntyre, 2002: 71).

Leßmann (2009) reinforces this idea by drawing on the work of the educational theorist Dewey (1938) and argues that the ability to choose well is developed dynamically over time as it is informed by different experiences. Dewey proposes that individuals have desires and that, through a combination of self control and reflection, convert these desires into purposes which lead to actions. Reflecting on prior experiences enables the individual to estimate the likely results and therefore benefits of different actions. For Dewey, as for Nussbaum, education in its broad sense should lead to a dynamic increase over time in the ability to choose well.

Concerning the coevolution of individuals' capacities economists, such as Grossman (1972, 2006) , Heckmann (Cunha et al., 2010a; Cunha and Heckman, 2007; Doyle et al., 2009; Heckman, 2008, 2006; Heckman and Masterov, 2007) and Fuchs (1982; 1972), amongst others, have theorised on the formation over time of an individual's human capital. Fuchs (1972) argues that increased population health leads to a reduction in the number of days the individual misses work – across workers this will aid economic performance. Grossman (2006) builds on this notion of health as a pillar of human capital by stating that the most important sources of human capital are knowledge capital and health capital such that they interact in their accumulation at the individual level. Accumulated health capital aids the future accumulation of knowledge capital and vice versa. Heckmann and colleagues take this one step further and provide evidence of "sensitive" periods when additional investments in children's human capital are particularly productive in facilitating further capital accumulation. They find evidence for the notion that, "early learning begets later learning, and skills beget skills", (Heckman, 2006: 4).

Binder and Coad (2010) have undertaken one of the few studies informed by the capability approach to empirically investigate the interaction between resources,

functionings and capabilities over time. They find statistically significant relationships between the functioning levels for different domains over time. One example of this is that “having fulfilling social relationships” is positively correlated with mental well-being in the following time period (Binder and Coad, 2010). Because of this and other similar findings Binder and Coad (2010) emphasise that a characteristic of life of inherent value, and therefore when achieved a functioning, can also simultaneously be of instrumental value (in that it supports the achievement of positive outcomes in another aspect of life). Using the terminology of the capability approach they therefore argue that the *functionings* individuals achieve in an earlier period provide the *resources* individuals need to flourish in the next (Ballet et al., 2011; Binder and Coad, 2010). The empirical evidence therefore supports the notion that it is possible to conceptualise a positive, achieved life outcome as either a functioning or a resource (Ballet et al., 2011; Binder and Coad, 2010).

Their analysis is undertaken using the British Household Panel Survey and focuses on adults. Because of this, education levels were empirically invariant by time, which impeded the inclusion of “being educated” as a functioning in the study (Binder and Coad, 2010). Binder and Coad conclude their study by stating that further research “would also benefit from focusing on younger individuals (so that education is not fixed), given that development at a very early stage in life has long-term effects for later life” (Binder & Coad, 2010: 346). The thesis will now go on to consider the theoretical issues associated with one such group of younger individuals – adolescents.

## 2.5. Adolescence

Defining adolescence is not a simple matter. Selecting a particular age range seems somewhat arbitrary given the heterogeneity in individuals’ speed of development. Conceptually, what does seem clear is that in a Western, post-industrial context adolescence is a time of transition from being considered by society a child to being considered an adult (Coleman, 1999).

Perhaps the predominant way to conceptualise adolescence is in terms of biological change – puberty. Individuals reach sexual maturity during adolescence and therefore become physically prepared to undertake roles associated with adulthood. In industrial and pre-industrial societies for males, puberty led to the development of the strength necessary for manual labour. For females, puberty led to the physical developments necessary for motherhood.

In a post-industrial society where physical strength is less of a pre-requisite for entering the labour market, and where the formal labour market is open to both men and women, it could be argued that psychological developments during this period are of equal importance. Psychologists, informed by the work of Piaget and Inhelder (1958), have undertaken numerous studies to investigate how the ability to use formal logic develops as individuals transition from childhood to adolescence. In general, the research suggests that formal logical reasoning is rarely seen in individuals younger than 11 but is common in adolescents and adults (Moshman, 2011a). However, individuals' cognitive development arguably goes beyond their ability to employ formal logic. In order to think in a manner that leads to justifiable conclusions about abstract issues, it is necessary to combine both logical reasoning and inductive reasoning. Furthermore, the individual must develop the ability to co-ordinate these different types of reasoning in order to produce arguments and evaluate the arguments of others (Moshman, 2011b). While inductive reasoning begins to develop from early childhood, it continues to develop in adolescence and adulthood. It is not until early adolescence that individuals can commonly disentangle the form of an argument from its content and make judgements about the line of logic that undergirds the argument being made. It could therefore be argued that during adolescence many, but not all, individuals develop advanced forms of rationality that are rarely observed in childhood (Moshman, 2011c).

Not only do an individual's physical and rational capacities frequently undergo substantive development in adolescence, their sense of self is also in transition. Research by psychologists indicates that the most active period of identity formation, the development of a coherent theory of oneself, is adolescence (Moshman, 2011d). The research suggests that this process of identity formation is not without turbulence. The work of Marcia (1966) indicates that for an individual to develop a strong, intentionally chosen identity they must first go through a period of identity crisis. Perhaps unsurprisingly, the research to date indicates this period of identity crisis, which often first occurs in adolescence or early adulthood, is frequently associated with anxiety (Moshman, 2011d). Marcia (1966) posited that during this time the individual either explicitly questions the commitments regarding religion, sexuality and politics they have learned or, if there are no previous commitments to be displaced, actively considers the different commitments they could make.

This flux in an adolescent's personal identity also corresponds with a transitioning social identity (Moshman, 2011e). Sociologically, an adult could be defined as an independent



individual within the society, while a child could be defined as a young, dependent individual (Coleman, 1999). While children are proactive “actors” in their social worlds who are able to actively respond to many of its customs, society often delegates them a subordinate role in which many of their freedoms are restricted (Christensen and James, 2008; Woodhead and Faulkner, 2008). Adolescents are transitioning between the two social positions of childhood and adulthood. This transition arguably occurs at different rates in different spheres. For example, an individual who has gone to work aged 16 but lives with their parents may be viewed as an adult in their workplace but in a childlike manner at home.

In addition to the numerous dimensions of transition experienced by the individual, adolescence is also a period where they must navigate important vocational milestones. In economically advanced societies adolescence is a time when individuals are being selected for the educational investment which will, to an extent, affect their adult opportunities. In the UK and other countries, formal exams are taken throughout this period, and in late adolescence, apprenticeships or university places are applied for. The results of these exams will affect the ability of the individual to obtain an apprenticeship or a university place. This could have long-term implications for the roles available to that individual within society. Despite the pressures and the myriad of changes occurring during adolescence, biologically, psychologically and sociologically most individuals adapt and adjust in a manner that does not damage their external relationships or their internal mental health (Coleman, 1999). To use the language of the capability approach, which originally motivated this research, during adolescence, an individual’s capabilities are developing substantially, the different capabilities are likely to be changing at different speeds, and the individual’s place in society may, in different spheres, impair their opportunities to convert these capabilities into functionings. According to the research reviewed by Coleman (1999), *most* (but not all) individuals manage to go through this process relatively smoothly: their functionings, across the different domains, effectively co-resource ongoing capability formation.

This leaves open the question as to what happens when a functioning is substantially impaired and therefore cannot act as a resource for the further formation of capabilities in other domains. More specifically, what is the effect on the development process during this time of transition when health is impaired, and how does this affect the formation of the other abilities that are of inherent value?

### 3. A systematised review of health and the formation of abilities in adolescence

#### 3.1. Introducing the systematised review

Having reviewed the theoretical literature which relates to valued abilities (capabilities), health and adolescence, I now turn to considering empirical studies which have been undertaken in the area. Previous scoping searches have indicated that there is a scarcity of studies which have previously investigated the impact of a health difficulty on the formation of valued abilities in the adolescent population. This is tested more rigorously in this chapter. (In the chapter following, I focus on reviewing and evaluating papers which, while not answering the same research questions, can inform the methodology of the empirical work.)

The literature review below adopts an approach labelled by Grant and Booth (2009) as a 'systematised' review. This approach seeks to adopt many of the practices used in a systematic review while, often as a result of resource constraints, stopping short of undertaking all of the tasks associated with a full systematic review. This approach allows me to search the literature in a coherent and transparent manner while pragmatically recognising that as a postgraduate student I do not have the resources required to comprehensively identify all the articles of potential relevance to this broad topic (Grant and Booth, 2009). Neither can I undertake tasks such as double data extraction (an impossible task for a single researcher) (Grant and Booth, 2009). In this chapter I: (i) summarise the methods used to identify the studies of relevance; (ii) descriptively outline the number of studies identified and their characteristics; (iii) synthesise the findings of studies relevant to the review; (iv) critically evaluate the research to date; and (v) outline areas where future research is required in order to meet the study aims and objectives.

## 3.2. Method

### 3.2.1. Inclusion and exclusion criteria

Because health changes experienced by the population are an exposure rather than an intentional intervention, I adopted the PECOS (Population, Exposure, Control, Outcome, Study-type) framework instead of the PICOS (Population, Intervention, Control, Outcome, Study-type) framework typically used for systematic reviews (Tomioka et al., 2014). The inclusion criteria are listed by category below and discussed in greater detail in 3.2.2.

#### **Population**

- Adolescents as defined by the study itself – synonyms such as youth or young person will also be taken to refer to this population; and
- Individuals from societies which have advanced economies.

#### **Exposure**

- Exposure to a physical health difficulty; or
- Exposure to a mental health difficulty.

#### **Control/Comparison Group**

- Adolescent population who are not exposed to a physical or mental health difficulty.

#### **Outcome**

- Change in capabilities; or
- Change in functioning levels; or
- Change in abilities or skills judged conceptually similar to capabilities or functionings.

#### **Study Type**

- Quantitative analysis using longitudinal cohort data; or
- Qualitative analysis using longitudinal cohort data; or
- Studies reporting analyses of longitudinal qualitative and quantitative data (Longitudinal mixed methods studies).

I excluded quantitative studies if they did not attempt to control for observable factors which might confound the correlation between the exposure and outcome variables. I excluded qualitative studies if they did not contain a comparison group of individuals with a severe health difficulty. Additionally, I only included studies if they were available in English. This final criterion is solely a result of my linguistic limitations.

### 3.2.2. Rationale for the criteria

#### *Population*

As discussed in 2.5, conceptualising and defining adolescence is a complex issue. From a societal perspective, different countries may differ in the exact age at which children enter systems associated with adolescence such as secondary school. When investigating studies from a range of countries, selecting an age at which an individual is considered to become an adolescent is quite arbitrary. For this literature review, I considered the population to be of relevance if the author defines them as an adolescent or uses a synonym for this stage of life such as “youth”, “teenagers” or “young people”. For the study population to meet this criterion, subjects of the study must have been in adolescence in the periods at or between the data time points included in the study. If a study contains a sample with a broad range of ages, for the study to meet the inclusion criteria, it must have reported results specific to the sub-sample that has been in adolescence at or between the data time points included in the study.

While the capability approach was originally operationalised in economically developing countries, the aim of this study is to investigate the effect of a health difficulty on adolescents in the United Kingdom. For this review, I therefore only considered studies which drew their sample from societies with advanced economies<sup>1</sup> as the capabilities considered to be fundamental are likely to be closer in similarity to the UK.

#### *Exposure*

For this review, I considered a study to be relevant if it contains individuals with a health difficulty which either: the participant or their parent reports during adolescence or is reported prior to adolescence but is of a chronic nature and can therefore be assumed to continue through adolescence (for example type 1 Diabetes). As discussed in 2.2, defining health is complex. For the purpose of this systematised review, I have attempted to remain open to the differing conceptualisations of health that were previously discussed while also aiming to ensure both: (i) that the scope of the review remains feasible to implement; and (ii) that the health difficulties are similar enough that the studies, and therefore their findings, are comparable. Obesity was therefore not considered a relevant health difficulty. Defining obesity as a health difficulty in its own right is contentious – it is

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<sup>1</sup>Countries will be categorised as being advanced if they are included in the International Monetary Fund’s list of advanced economies (IMF, 2014).

arguably more accurately conceptualised as a risk factor for the development of a health difficulty rather than being a health difficulty in and of itself (Heshka and Allison, 2001).

#### *Control/Comparator*

For this literature review, I required that a study must have a control or comparator arm to be included. While this is not a standard requirement in qualitative research, I have included this criterion because a control/comparator arm arguably increases the confidence with which inferences can be made concerning the impact of a health difficulty on individuals' lives. Without a control/comparator arm, there is an increased risk that the researcher will miss some of the influence a health difficulty has on individuals' lives as a result of adaptive behaviour reducing its visibility (Biggeri and Mehrotra, 2011). Alternatively, the absence of a control/comparator arm may increase the risk that difficulties are attributed to an individual's health difficulty when they are in fact common amongst individuals who both do and do not have a health difficulty<sup>2</sup>. For both quantitative and qualitative studies, therefore, the overall sample population must have included individuals without a health difficulty in order to meet the inclusion criteria. I undertake a more detailed discussion of adaptation and its implications for the appropriate analytical sample in 4.3.1.

#### *Outcomes*

Concerning the outcomes of investigation, the capacity of individuals to obtain valued beings and undertake valued doings (capabilities) and the extent to which they actualise these capabilities (the functioning, or outcome, they achieve) is of interest. As discussed in chapter 2, the two concepts are inextricably linked. Capabilities cannot be conceived without referring to functionings. As discussed in chapter 2, my aim is that the capability approach informs rather than restricts the research undertaken in this thesis. As such, studies which do not explicitly discuss capabilities or functionings were considered of

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<sup>2</sup> For example, it is feasible that an adolescent with a health difficulty might report tensions in their relationship with their parents. Without data from individuals who have no health difficulty, it would be difficult to assess the tensions that would normally be expected as a result of adolescence. Arguably, having this additional perspective enables the researcher to make clearer comparisons and therefore clearer inferences about the extent to which the tensions between the adolescent and their parents are exacerbated as a result of the health difficulty.

relevance if they refer to valued abilities, skills or outcomes that appear conceptually similar to either functionings or capabilities<sup>3</sup>.

While outcomes broader than capabilities were incorporated into the search string, I only accepted studies if they enabled the evaluation the effect of a health difficulty on valued, non-market outcomes. This is necessary in order for the literature search to coherently remain within the theoretical underpinnings outlined by Sen, who echoed Marx in strongly critiquing what he perceived to be “commodity fetishism” in orthodox economic theory due to its focus on financial outcomes. Sen argues that money is a means and not an end in the accomplishment of well-being (1990). Given my desire to investigate the impact of a health difficulty on the broader aspects of life valued by individuals, studies were also excluded if the only valued abilities considered were future health or mortality. Additionally, measures designed to be completed by the participant were only considered of relevance if they were reported by the young people themselves, not by a proxy such as their parent. This is because the research to date indicates that parent’s proxy reports cannot be accepted as a consistently accurate representation of their child’s experiences (Matza et al., 2013).

#### *Study type*

A central objective of the thesis is to investigate the effect of health problems on an individual’s future valued abilities. In order to achieve this objective empirically, it was necessary for a study to undertake analysis on data taken from more than one time point

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<sup>3</sup> When undertaking a search, it is necessary to balance the sensitivity and specificity of the search terms employed (Lee et al., 2012). Attempting to search for all the *specific* outcomes of potential relevance would not be a feasible search strategy (as the number of studies initially identified would be too large and many would likely be of limited relevance). Therefore, as can be seen in appendix A.1, for the outcome filter, I instead included search terms linked to the theoretical backgrounds I know to be of relevance; i.e. terms relating to the literature summarised in chapter 2 (examples included eudaimonia, human capital and psychological well-being).

to be considered of direct relevance to the objectives of the thesis. I therefore excluded studies if they did not report an analysis of longitudinal data<sup>4</sup>.

### 3.2.3. Search strategy

I undertook the systematised review using the Web of Science database. The search was undertaken in August 2015<sup>5</sup>. The Web of Science database was selected following conversations with University librarians as it was considered to contain most comprehensively the published literature of relevance<sup>6</sup>. Search strings were constructed to reflect the inclusion/exclusion criteria. The search strings used the relevant code to identify articles which met the PECOS criteria of adolescent AND illness AND capability/functioning (or synonym of capability/functioning) AND longitudinal study. For the search, I did not filter by document type. Studies indexed on the databases reviewed by Web of Science which were either proceedings papers, books or book chapters could therefore also be identified and included in the review. Following the initial search, I further filtered the studies according to whether or not the study population was from an advanced economy and as to whether or not they included healthy participants who

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<sup>4</sup> Articles which did not report an analysis of longitudinal data but instead reported a review of previous research were also excluded. Initially, I considered including systematic reviews. However, the search only identified one systematic review of relevance (Milton et al., 2006). This review only contained one study that met the inclusion criteria (McCarthy et al., 2002). McCarthy et al. was not identified in my search of the Web of Science database. This is likely because the title, abstract and key words did not contain either of the terms longitudinal, cohort or panel (which were included in the search string as shown in appendix A.1). The methodological quality of the study by McCarthy et al. was low. The quantitative analysis relied on a small number of participants (approximately 100 participants were included). Approximately 60 percent of the sample were also missing the demographic data required to control for confounding. For simplicity, given the limitations of the identified study, I decided to restrict studies to those which were both identified through Web of Science and directly reported the analysis of longitudinal data. Additionally, I did not change my search string given: (i) the need to search the literature in an efficient manner and therefore balance the considerations of sensitivity and specificity (Lee et al., 2012); (ii) the importance of studies being longitudinal in nature with regards their relevance to my research aim; and (iii) the low methodological study of the omitted study.

<sup>5</sup> The systematised search was completed at a relatively early stage so that the findings could inform my analysis of the qualitative and quantitative data. In order to ensure I subsequently contextualised the thesis' findings in a manner that was relevant to the evolving literature, I endeavoured to continually review the literature that emerged following my initial search via the use of a search update alert from the Web of Science.

<sup>6</sup> The databases reviewed by the Web of Science are: Arts & Humanities Citation Index, BIOSIS Citation Index<sup>SM</sup>, Book Citation Index– Science, Conference Proceedings Citation Index- Science, Conference Proceedings Citation Index- Social Science & Humanities, Book Citation Index– Social Sciences & Humanities, Current Chemical Reactions, Current Contents Connect<sup>®</sup>, Data Citation Index<sup>SM</sup>, Derwent Innovations Index<sup>SM</sup>, Index Chemicus, KCI-Korean Journal Database, MEDLINE<sup>®</sup>, SciELO Citation Index, Science Citation Index Expanded, Social Sciences Citation Index and Zoological Record<sup>®</sup> (Web of Science, 2015).

could be considered a control group. The syntax of the search strings used is recorded in the search protocol for the literature review (see appendix A.1).

#### 3.2.4. Quality assessment procedure

I used the British Medical Journal (BMJ) Reader's Guide to critical appraisal of cohort studies to evaluate the quality of the quantitative studies identified in the literature search (Gurwitz et al., 2005; Mamdani et al., 2005; Normand et al., 2005). The questions considered in the critical appraisal are outlined in appendix A.2. This process was only undertaken by me. This resulted from the constraint of operating as an individual research student undertaking work for a thesis rather than working as part of a wider research team. The checklist used was designed for critically assessing quantitative studies.

If the search had identified a longitudinal qualitative study, I would have used the Critical Appraisal Skills Programme (CASP) tool "10 questions to help you make sense of qualitative research" (CASP, 2013). If the search had identified a longitudinal mixed methods study, I would have used the questions in table 2 of the study by O'Cathain et al. (2008). However, as reported in 3.3, all of the studies which met the inclusion/exclusion criteria analysed longitudinal quantitative data.

I systematically reviewed studies meeting the inclusion criteria to extract all the information of relevance to: (i) the quality assessment; and (ii) the review objective. Data were extracted using the extraction form in appendix A.2<sup>7</sup>.

#### 3.2.5. Data synthesis

Data extracted from the studies were analysed using narrative synthesis. Narrative synthesis uses a textual approach to summarise and explain the findings of multiple studies (Popay et al., 2006). I synthesised the study findings in two stages. Firstly, I populated a table which both contained a summary of the studies' characteristics and their findings. I then sought to identify trends with respect to the relationship between exposure and outcomes and any trends in how the strength of these associations varied

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<sup>7</sup> I did not identify in advance suitable extraction forms for qualitative and mixed methods studies. Such studies are arguably more diverse in nature than quantitative studies and less amenable to extraction using a pre-determined form. If my search had identified one or more qualitative (or mixed methods) studies which met the search criteria I would have: (i) critically assessed the study(ies) using the checklists mentioned in the main text above; (ii) considered which summary information was most pertinent to record for each of the studies within any tables that would have been included in the thesis; and (iii) populated these tables directly from the relevant studies.

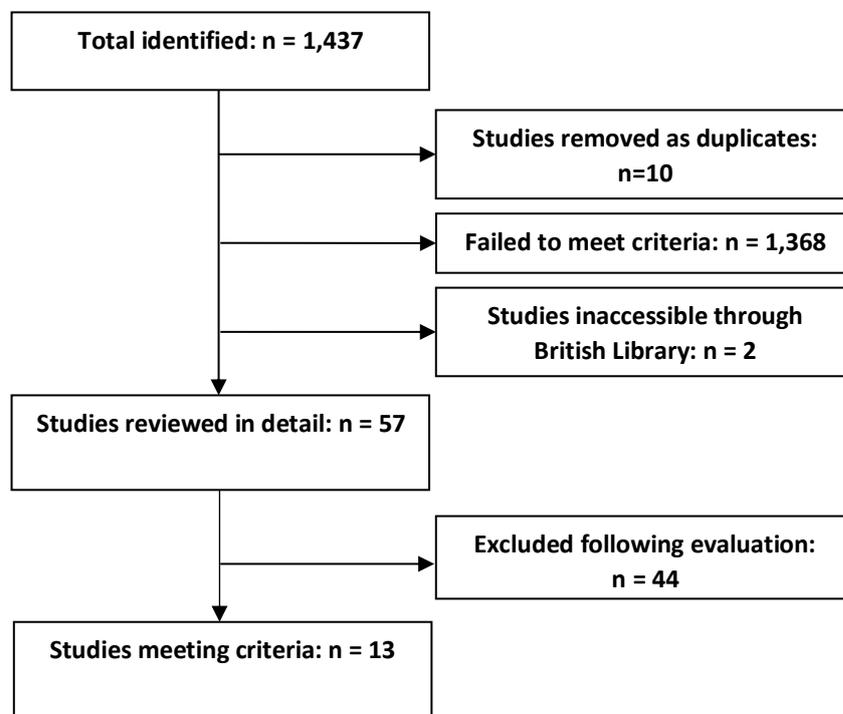


by the methodology employed. During this this second stage, given the breadth of exposures and outcomes covered by the review, I clustered the study findings in the following manner by: (i) the nature of the outcome reported; and (ii) the nature of the exposure – specifically, whether the exposure was a mental health difficulty or a physical health difficulty<sup>8</sup>.

### 3.3. Results

Figure 3-1 below provides an overview of the number of studies initially identified using the search strategy and the number that met the inclusion criteria. Studies were excluded if they failed to meet any one of the inclusion criteria<sup>9</sup>.

Figure 3-1: Flow diagram of the study selection process



The PRISMA in Figure 3-1 indicates a relatively high ratio between the number of articles originally identified and the number of studies meeting the criteria for inclusion. This

<sup>8</sup> Considering the study findings separately, depending on whether the exposure is primarily a mental or a physical health difficulty, risks the limitations of a Cartesian model of the body. As discussed in 2.2.3, there is great merit in seeing the mind and body as interconnected entities (Bendelow, 2009b). When synthesising the results, I therefore only consider findings relating to the two exposures separately for the purpose of maximising the comparability of the association being investigated.

<sup>9</sup> For the purposes of efficiency, having identified a study that failed to meet one of the criteria, the study was excluded. No further attempt was made to identify whether the study failed multiple criteria. An expanded summary of the study selection process, which outlines the number of studies that were excluded per criterion, is provided in appendix A.3.

reflects the decision to prioritise sensitivity over specificity when searching the Web of Knowledge (Lee et al., 2012)<sup>10</sup>.

All of the studies that fulfilled the inclusion criteria used quantitative methods. This is likely a result of the criterion that a study must have a control or comparator group that represented adolescents without a health difficulty. As noted in 3.2, this is not a standard requirement for qualitative studies but is considered of relevance for this review. As discussed above, a comparator arm helps reduce the risk that the impact of a health difficulty will be underestimated as a result of individuals with a health difficulty adapting. Additionally, it helps reduce the risk that a difficulty commonly experienced by adolescents will be wrongly considered a result of the health difficulty experienced by the individual.

### 3.3.1. Summary of the identified studies

Table 3-1 below summarises the studies which met the inclusion criteria. For brevity, in here and in 3.3.2, I refer to the relevant studies using the Vancouver referencing system. The number attributed to each of the studies is listed in the second column of Table 3-1. My general preference is to use the Harvard system, and I therefore return to this approach from 3.3.3 onwards.

Concerning the location of the studies identified, seven of the 13 studies were undertaken in the United States of America (USA)<sup>3, 6, 7, 8, 10, 12, 13</sup>. Five of the seven studies undertaken using data from the USA drew their analytic sample from the National Longitudinal Study of Adolescent Health (Add Health)<sup>6, 7, 8, 10, 12</sup>, a school-based longitudinal study of adolescents' health-related behaviours and the individuals' outcomes in early adulthood.

Concerning the studies' theoretical backgrounds, eight were informed by human capital theory<sup>1, 4, 6, 7, 8, 10, 12, 13</sup> and four by the theoretical model of psychological well-being<sup>2, 3, 9, 11</sup>. For one study, its theoretical background was unclear<sup>5</sup>. None of the studies meeting the inclusion criteria were explicitly informed by the capability approach. The theoretical backgrounds of the different studies likely influenced their research emphasis and therefore the outcomes of interest. Given the number of studies informed by human

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<sup>10</sup> The low specificity of the search results from the decision to not filter by document type. While this decision led to an increased number of articles needing to be reviewed, it arguably increased the sensitivity of the search, reducing the risk that research of relevance would be excluded because it was reported in a book or book chapter rather than in a peer reviewed journal.

capital theory, it is maybe unsurprising that 11 of the studies solely investigated outcomes relating to the domains of education and employment<sup>1, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13</sup>. Two studies investigated outcomes relating to broader life domains, both of which were informed by the theoretical model of psychological well-being<sup>2, 3</sup>.

Concerning the studies' exposures that were of relevance to this review, six of the studies included mental health difficulties as an exposure while not including physical health difficulties<sup>4, 6, 7, 8, 11, 12</sup>. Two studies reported results for both mental health difficulties and physical health difficulties separately<sup>3, 5</sup>. Three studies reported results for physical health difficulties but not mental health difficulties<sup>2, 9, 10</sup>, and two studies reported results for health difficulties which were not clearly specific to either the mental or physical domains of health – they reported either self-assessed health or health difficulties that affected work<sup>1, 13</sup>.

As stipulated by the inclusion criteria, all of the quantitative studies attempted to control for observable confounders. For the exposures and outcomes of relevance to this study, six of the studies also attempted to control for unobservable confounders through the use of school or sibling fixed effects<sup>4, 5, 7, 8, 10, 13</sup>.

Table 3-1: Summary of the selected studies

Study	Study I.D. number	Country	Theoretical perspective	Central estimate of age at each time point*	Data source(s) used	Type of exposure	Exposed (#)	Controls (#)	Outcomes of interest	Explanatory variables	Techniques used	Statistically significant detrimental association? (p<0.05)		
												WS unless stated	Girls unless stated	Boys unless stated
Brekke (2015)	1	Norway	Human Capital Theory	TP <sub>0</sub> : 15.5** TP <sub>1</sub> : 26.5	Oslo Health Survey linked to national databases	SAH	607 (SAH "poor")	4748	Enrolment in higher education	Different models are fitted. Model 1 has the least covariates, model 5 the most.	Logistic regression.	Household Controls (Mod. 3)		
												✓	NA	NA
												Extensive Controls (Mod. 5)		
												×	NA	NA
Bussing and Aro (1996)	2	Finland	Psychological Well-being	TP <sub>0</sub> : 16 TP <sub>1</sub> : 22	Initial survey given in school; Second via post	1) Any condition 2) Any serious condition <sup>s</sup>	423 had a condition; 53 had a serious condition <sup>s</sup>	779	1) Pursuing university education; 2) Pursuing higher education; 3) Living with parents; 4) married or cohabiting; 5) not dating; 6) living with children	Include socioeconomic status as a covariate.	ANOVA for continuous outcomes; Logistic regression for dichotomous outcomes	Interpersonal problems		
												ANOVA : ✓	ANOVA : ×	ANOVA : ✓
												Pursuing university education		
												Logit: ✓	Logit: ×	Logit: ×
												Pursuing higher education		
												Logit: ×	Logit: ×	Logit: ×
												Living with parents <sup>ss</sup>		
												Logit: ×	Logit: ×	Logit: ×
												Married or cohabiting <sup>ss</sup>		
												Logit: ×	Logit: ×	Logit: ×
												Not dating		
												Logit: ×	Logit: ×	Logit: ×
Living with children														
Logit: ×	Logit: ×	Logit: ×												

Study	Study I.D. number	Country	Theoretical perspective	Central estimate of age at each time point*	Data source(s) used	Type of exposure	Exposed (#)	Controls (#)	Outcomes of interest	Explanatory variables	Techniques used	Statistically significant detrimental association? (p≤0.05)		
												WS unless stated	Girls unless stated	Boys unless stated
Chen et al. (2006)	3	USA	Psychological Well-being	TP <sub>0</sub> : 16 TP <sub>1</sub> : 33	Children in the Community Study	1) Mental Disorders (MD); 2) Physical illness (PI); 3) MD & PI	MD (89) PI (167) MD & PI (96)	No Disorders (256)	1) Social relationships; 2) Role function; 3) Environmental context	Include ethnicity, sex, age and family socioeconomic status.	Linear regression analyses (LRA)	MD (WS)	PI (WS)	MD&PI (WS)
												Social Relationships		
												✓	×	✓
												Role Function		
												×	×	✓
Environmental Context														
×	✓	✓												
Cornaglia et al. (2015)	4	England	Human Capital Theory	TP <sub>0</sub> : 14.5 TP <sub>1</sub> : 17.5	LSYPE1	Poor mental health (measured using GHQ-12)	1,429	6,693	1) GCSE points score; 2) NEET aged 17/18	The basic covariates (BC) include income, ethnicity and parental education. The additional covariates (AC) include prior educational attainment age 11 and employment status of parents.	For both outcomes the paper reports results with: BC; AC and ScFE. It appears OLS is used for both outcomes.	GCSE points		
												NA	BC: ✓ AC: ✓ ScFE: ✓	BC: × AC: × ScFE: ✓
												NEET status		
												NA	BC: ✓ AC: ✓ ScFE: ✓	BC: × AC: × ScFE: ×

Study	Study I.D. number	Country	Theoretical perspective	Central estimate of age at each time point*	Data source(s) used	Type of exposure	Exposed (#)	Controls (#)	Outcomes of interest	Explanatory variables	Techniques used	Statistically significant detrimental association? (p≤0.05)		
												WS unless stated	Girls unless stated	Boys unless stated
De Ridder et al. (2013)	5	Norway	Not stated	TP <sub>0</sub> : 16 TP <sub>1</sub> : 24	Young-Hunt study <sup>^</sup>	1) Somatic disease <sup>^^</sup> ; 2) Two or more somatic symptoms <sup>^^</sup> ; 3) Psych. distress; 4) Insomnia; 5) concen. difficulties; 6) self-rated health	Varies (879-3,094)	Varies (5,779-7,994)	Dropping out of secondary school	The adjusted analysis (AD) incorporates individuals' age, sex, maternal education level and family living situation as covariates.	Logistic regression is used for both the AD analysis and the SibFE analysis. (Genders combined)	Dropping out of Secondary School		
												Somatic disease		
												AD: ✓	NA	NA
												SibFE: x		
												Somatic symptoms (2+)		
												AD: ✓	NA	NA
												SibFE: x		
												Psychological distress		
												AD: ✓	NA	NA
SibFE: x														
Insomnia														
AD: ✓	NA	NA												
SibFE: x														
Concentration difficulties														
AD: ✓	NA	NA												
SibFE: ✓														
Self-rated health														
AD: ✓	NA	NA												
SibFE: x														
Fletcher (2008)	6	USA	Human Capital Theory	TP <sub>0</sub> : 15 TP <sub>1</sub> : 22	Add Health <sup>~</sup>	Depression (CES-D)	1,031	11,859	1) Dropping out of high school; 2) enrolling in college;	Include GPA, Mother's education, family income, ethnicity, community unemployment rate	Probit regression	Drop out of high school		
												x	x	✓
												Enrol in college		
✓	x	x												

Study	Study I.D. number	Country	Theoretical perspective	Central estimate of age at each time point*	Data source(s) used	Type of exposure	Exposed (#)	Controls (#)	Outcomes of interest	Explanatory variables	Techniques used	Statistically significant detrimental association? (p≤0.05)		
												WS unless stated	Girls unless stated	Boys unless stated
Fletcher (2010)	7	USA	Human Capital Theory	TP <sub>0</sub> : 15 TP <sub>1</sub> : 22	Add Health~ (siblings from the study)	Depression (CES-D). Measured as either binary or as a scale.	192	2,208	1) Years of schooling; 2) Dropping out of high school; 3) Enrolling in college	Include gender, maternal education, family income and ethnicity.	OLS; OLS with ScFE; OLS with FFE <sup>++</sup> . (Genders combined)	Depression as binary	Depression as scale	
												Years of schooling		
												OLS: ✓ ScFE: × FFE: ×	OLS: ✓ ScFE: ✓ FFE: ×	
												Drop out of high school		
												OLS: × ScFE: × FFE: ×	OLS: ✓ ScFE: ✓ FFE: ×	
												Enrol in college		
Fletcher (2013)	8	USA	Human Capital Theory	TP <sub>0</sub> : 15 TP <sub>1</sub> : 28	Add Health~	Depression (CES-D). Primarily measured as binary.	972	11,174	Employment status	Include gender (in pooled sample), maternal education, ethnicity and verbal reasoning in wave 1	OLS; OLS with ScFE <sup>~</sup> ; OLS with FFE <sup>~</sup> ;	Employment status		
												OLS: ✓ ScFE: ✓ FFE: ×	OLS: ✓ NA NA	OLS: ✓ NA NA
Northam et al. (2010)	9	Australia	Psych. Well-being	TP <sub>0</sub> : 8.7 TP <sub>1</sub> : 20.7	Data collected as a prospective cohort	Type 1 Diabetes	110	76	1) Completed school; 2) Full time study/work participation	Limited number of controls: gender and socioeconomic status.	χ <sup>2</sup> analyses. (Genders combined)	Completed school (WS)		
												✓	NA	NA
												Full time study or working		
			×	NA	NA									

Study	Study I.D. number	Country	Theoretical perspective	Central estimate of age at each time point*	Data source(s) used	Type of exposure	Exposed (#)	Controls (#)	Outcomes of interest	Explanatory variables	Techniques used	Statistically significant detrimental association? (p≤0.05)		
												WS unless stated	Girls unless stated	Boys unless stated
Rees and Sabia (2011)	10	USA	Human Capital Theory	TP <sub>0</sub> : 15.7 TP <sub>1</sub> : 22.7	Add Health~	Migraine as reported by the individual's mother	1,170	8,430	1) Grade Point Average; 2) High School Graduation; 3) College Attendance	Include gender (in pooled sample), household income, parental education, ethnicity, number of siblings and verbal reasoning at time of exposure	OLS, PSM and FFE	GPA		
												OLS: ✓ PSM: × FFE: ×	OLS: ✓ PSM: × FFE: ×	OLS: ✓ PSM: × FFE: ✓
												High School Graduation		
												OLS: ✓ PSM: × FFE: ×	OLS: ✓ PSM: × FFE: ×	OLS: × PSM: × FFE: ✓
												College Attendance		
OLS: ✓ PSM: ✓ FFE: ×	OLS: ✓ PSM: × FFE: ✓	OLS: ✓ PSM: × FFE: ×												
Sagatun et al. (2014)	11	Norway	Psych. Well-being	TP <sub>0</sub> : 15.5 TP <sub>1</sub> : 20.5	Cross sectional health survey linked to registries	Behavioural problems (split into internal. external. problems) measured using SDQ	Not provided	Not provided (total sample size ~ 10,800)	Non-completion of upper secondary school	Include ethnicity, county of residence, parents' education, parents' income and individual's health behaviours.	Logistic regression	Non-completion of upper secondary school		
												Exposure: externalising mental health problem		
												NA	✓	✓
												Exposure: internalising mental health problem		
NA	✓	×												



Study	Study I.D. number	Country	Theoretical perspective	Central estimate of age at each time point*	Data source(s) used	Type of exposure	Exposed (#)	Controls (#)	Outcomes of interest	Explanatory variables	Techniques used	Statistically significant detrimental association? ( $p \leq 0.05$ )		
												WS unless stated	Girls unless stated	Boys unless stated
Tekin and Markowitz (2008)	12	USA	Human Capital Theory	TP <sub>0</sub> : 15 TP <sub>1</sub> : 22	Add Health <sup>~</sup>	Depressed at wave 1	2,967	11,434	Whether an individual is engaged in a productive activity (school or work) at TP <sub>1</sub>	Include gender, ethnicity, age, verbal reasoning, mother's education, suicidal behaviour and health behaviour	OLS; multinomial logit (ML) (genders combined)	Engaged in a productive activity		
												OLS: ✓ ML: ✓	NA	NA
Zajacova et al. (2015)	13	USA	Human Capital Theory	TP <sub>0</sub> : 17.7 TP <sub>1</sub> : 44.7	NLSY79	Health which affects work	430	7,916	1) Highest completed year of school; 2) Highest degree; 3) High School diploma or more; 4) BA diploma or more	OLS with reduced controls includes age and ethnicity; OLS with expanded controls includes the addition of Parent's education, number of siblings, whether family spoke foreign language and individual's GPA; SibFE include gender and age.	OLS with reduced controls (OLS <sub>Rd</sub> ); OLS with expanded controls (OLS <sub>Exp</sub> ); sibFE	Highest completed year of school		
												SibFE: ×	OLS <sub>Rd</sub> : ✓ OLS <sub>Exp</sub> : ×	OLS <sub>Rd</sub> : ✓ OLS <sub>Exp</sub> : ×
												Highest degree		
												SibFE: ×	NA	NA
												SibFE: ×	NA	NA
												High School diploma or more		
												SibFE: ×	NA	NA
												BA diploma or more		
												SibFE: ×	NA	NA

**Notes:** \*TP<sub>0</sub> is the time point of the earliest exposure, TP<sub>1</sub> the time point of the latest outcome variable used in the study; \*\*Individuals at TP<sub>0</sub> were generally aged 15-16 and individuals were followed up to a maximum of 11 years; § Conditions later determined to be serious included diabetes mellitus, asthma, seizure disorder, kidney disease, cerebral palsy and poly neuropathy (results however are presented only for those with “any condition” as few outcomes reached significance for the “serious condition” category – potentially as a result of low numbers); §§ Arguably normative behaviour in Western countries is to move away from parents and to marry or cohabit – this behaviour is therefore attributed “positive” status in the above table. There is actually a statistically significant positive relationship between moving away from home and marrying and cohabiting for girls (and the whole sample) but this is not reported as I am identifying negative associations. ^ Somatic disease was defined as having asthma, diabetes, migraine, or epilepsy diagnosed by a doctor or any other illness that lasted longer than 3 months, individuals were categorised as having two or more somatic symptoms if in the last 12 months they had sometimes or often had two or more of: headache, neck or shoulder pain, joint or muscle pain, stomach pain, nausea, constipation, diarrhoea or heart palpitations ; ^^ The Young-Hunt study is the adolescent component of the HUNT study (The Nord-Trøndelag Health Study, <http://www.ntnu.no/hunt>). ~ National Longitudinal Study of Adolescent Health; ~~ For brevity only report the FFE results undertaken with extensive rather than reduced controls; ^^For the fixed effects models report the results that include controls for health behaviours and difficulties (not available for the OLS results). **ANOVA**, Analysis of Variance; **FFE**, Family Fixed Effects; **CES-D**, Center for Epidemiologic Studies Depression Scale ; **GCSE**, General Certificate of Secondary Education; **GPA**, Grade Point Average **GHQ-12**, General Health Questionnaire (12 items); **LSYPE1**, First Longitudinal Study of Young People in England; **NEET**, Not in Education, Employment or Training; **NLSY79**, National Longitudinal Study of Youth 1979 cohort; **OLS**, Ordinary Least Squares; **PSM**, Propensity Score Matching; **SAH**, Self-assessed health; **SchFE**, School Fixed Effects; **SDQ**, Strengths and Difficulties Questionnaire; **SibFE**, Sibling Fixed Effects; **StateFE**, State Fixed Effects; **WS**, Whole Sample.

It is worth noting that for the purposes of brevity for some of the papers reported in Table 3-1, I report the results for only a selection of the analyses undertaken in the study. For those studies reporting numerous sub analyses, I endeavour to report those which: (i) are of greatest relevance to my research aim and objectives; and (ii) best as a collective illustrate any trend in the findings of relevance as the authors' attempts to control for potentially confounding factors are intensified.

### 3.3.2. Review of the studies' methodological quality

For confidence to be placed in the studies' findings, it is necessary to be convinced of their methodological quality. Other things equal, greater emphasis can then be placed on the findings of those which are methodologically the most robust. Table 3-2 below outlines the studies' methodological quality. The headings from the table are derived from questions two to nine of the BMJ Reader's Guide to critical appraisal of cohort studies (Gurwitz et al., 2005; Mamdani et al., 2005; Normand et al., 2005).

As outlined in 3.2, for a study to be included, it needs to report an analysis of longitudinal data. As discussed, an advantage of longitudinal studies, if they contain the relevant exposure and outcomes, is that they enable an investigation of the association through time between a health difficulty and impaired future outcomes. As such, the studies meeting the inclusion criteria are in line with the thesis' research aim to investigate the future impact of negative health in adolescence on valued abilities. However, as reported in Table 3-2, a substantive disadvantage of longitudinal studies is the possible impact of attrition on the representativeness of the analytic sample. Individuals who leave the study over time may differ from those who remain with respect to both observable and unobservable characteristics. Even if the original sample was representative of the age adjusted general population, it is possible that the sample who remain in the study over time differ from the general population. As discussed in greater detail in chapter 0, methods are available to account for differences between the analytic sample and the general population with respect to observable characteristics, but there remains the possibility that differences will remain with respect to unobservable characteristics. Caution is therefore required when making inferences back to the general population (Deng et al., 2013).

Concerning the representativeness of the sample populations, five of the studies recruited from a limited geographical area within a country<sup>1, 2, 3, 5, 9</sup>. For these studies,

particular caution is required when attempting to draw inferences from the study results to their national populations.

A general limitation of the studies is that they all analyse non-randomised data. This is to be expected given the systematised review's focus on an exposure rather than on an intervention. However, it leaves open the possibility that the exposure and control groups differ with respect to unobservable characteristics which might confound the association between the exposure(s) and the outcome(s). Therefore, other things equal, studies which attempt to control for unobservable characteristics are more likely to provide robust estimates of the association between the exposure(s) and the outcome(s).

Table 3-2: Study methodological quality

Study	Study I.D. number	Does the comparison make sense?	What are the potential selection biases?	Has there been a systematic effort to identify potential confounders?	Is there information on how potential confounders are distributed between the groups?	What methods are used to assess differences in the distribution of potential confounders?	Are the analytical strategies clearly described?	Do the different analytical strategies used yield consistent results?	Are the results plausible?
Brekke (2015)	1	Yes	Those who did not participate (~12%) may be different to the general population	Yes – an attempt has been made to account for observable confounders	No	Regression analyses are used to control for observable confounders	Yes	There is not a large range in the number of analytical techniques used	Yes
Bussing and Aro (1996)	2	Yes	Those who did not participate (~25%) may be different to the general population	Socioeconomic status and gender are controlled for but no other potential confounders	Yes	A table of descriptive statistics outlines differences by exposure group. Regression techniques are used to control for observable confounders	Yes	There is not a large range in the number of analytical techniques used	Yes
Chen et al. (2006)	3	Yes	Approximately 20% of the sample attrits. Those who drop out may differ on unobservable characteristics to those who remain	Yes – an attempt has been made to account for observable confounders	No	Regression analyses are used to control for observable confounders	Yes	There is not a large range in the number of analytical techniques for the question of interest	Yes
Cornaglia et al. (2015)	4	Yes	Individuals who remain in the study for four years may eventually be unrepresentative of the general population	Yes – an attempt has been made to account for observable confounders	No	Regression analyses are used to control for observable confounders and school fixed effects used to control for some	Yes	Yes – generally for girls there is a significant association and for boys most of the strategies lead to	Yes

Study	Study I.D. number	Does the comparison make sense?	What are the potential selection biases?	Has there been a systematic effort to identify potential confounders?	Is there information on how potential confounders are distributed between the groups?	What methods are used to assess differences in the distribution of potential confounders?	Are the analytical strategies clearly described?	Do the different analytical strategies used yield consistent results?	Are the results plausible?
			on unobservable characteristics			unobservable confounders		the association not being significant	
De Ridder et al. (2013)	5	Yes	Individuals who remain in the study for up to 11 years may eventually be unrepresentative of the general population on unobservable characteristics	Yes – an attempt has been made to account for both observable and unobservable confounders	No	Regression analyses are used to control for observable confounders and sibling fixed effects used to control for unobservable confounders at the family level	Yes	The analytical strategies lead to different results. When unobservable confounders at the level of the family are controlled for the associations become insignificant for all health difficulties other than concentration difficulties	Yes
Fletcher (2008)	6	Yes	Individuals who remain in the study for seven years may eventually be unrepresentative of the general population on unobservable characteristics	Yes – an attempt has been made to account for observable confounders	No	Regression analyses control for observable confounders; clustered standard errors minimise the effect of unobserved variance at the school level	Yes	There is not a large range in the number of analytical techniques used	Yes
Fletcher (2010)	7	Yes	Individuals who remain in the study for seven years may eventually be unrepresentative of the general population	Yes – an attempt has been made to account for both observable and	No	Regression analyses for observable confounders; fixed effect techniques for unobservable	Yes	All analytic techniques estimate depression is directionally correlated with a negative outcome.	Yes

Study	Study I.D. number	Does the comparison make sense?	What are the potential selection biases?	Has there been a systematic effort to identify potential confounders?	Is there information on how potential confounders are distributed between the groups?	What methods are used to assess differences in the distribution of potential confounders?	Are the analytical strategies clearly described?	Do the different analytical strategies used yield consistent results?	Are the results plausible?
			on unobservable characteristics	unobservable confounders		confounders at the school and family level		The statistical significance changes between the strategies	
Fletcher (2013)	8	Yes	Individuals who remain in the study for 13 years may eventually be unrepresentative of the general population on unobservable characteristics	Yes – an attempt has been made to account for both observable and unobservable confounders	Yes	Regression analyses for observable confounders; fixed effect techniques for unobservable confounders at the school and family level	Yes	All analytic techniques estimate depression is directionally correlated with a negative outcome. The results become statistically insignificant once unobserved confounders at the level of the family are controlled for	Yes
Northam et al. (2010)	9	Yes	In the selection of the age and sex stratified healthy controls – these could have come from different socioeconomic groups	Socioeconomic status and gender are controlled for but no other potential confounders	Yes – differences between the groups stated as being small	Regression techniques are used to control for observable confounders	Yes	There is not a large range in the number of analytical techniques used	Yes
Rees and Sabia (2009)	10	Yes	Individuals who remain in the study for seven years may eventually be unrepresentative of the general population	Yes – an attempt has been made to account for both observable and	No	Regression analyses for observable confounders; propensity score matching to ensure comparability of groups	Yes	Generally, those methods which attempt to increasingly control for confounders lead	Yes

Study	Study I.D. number	Does the comparison make sense?	What are the potential selection biases?	Has there been a systematic effort to identify potential confounders?	Is there information on how potential confounders are distributed between the groups?	What methods are used to assess differences in the distribution of potential confounders?	Are the analytical strategies clearly described?	Do the different analytical strategies used yield consistent results?	Are the results plausible?
			on unobservable characteristics	unobservable confounders		on observables; fixed effect techniques for unobservable confounders at the level of the family		to weaker associations between having a migraine and lower educational attainment though there are exceptions to this	
Sagatun et al. (2014)	11	Yes	Those who did not participate (~24%) may be different to the general population	Yes – an attempt has been made to account for observable confounders	No	Regression techniques are used to control for observable confounders	Yes	There is not a large range in the number of analytical techniques used	Yes
Tekin and Markowitz (2008)	12	Yes	Individuals who remain in the study for seven years may eventually be unrepresentative of the general population on unobservable characteristics	Yes – an attempt has been made to account for observable confounders	No (not if the exposure of interest is depression)	Regression techniques are used to control for observable confounders.	Yes	There is not a large range in the number of analytical techniques used for the exposure of interest (Depression in wave 1)	Yes
Zajacova et al. (2015)	13	Yes	Individuals who remain in the study for over 20 years may eventually be unrepresentative of the general population on unobservable characteristics	Yes – an attempt has been made to account for observable confounders	No	Regression techniques are used to control for observable confounders.	Yes	Yes – the correlations are only significant if few confounding (or potentially mediating) variables are accounted for.	Yes



### 3.3.3. Synthesis of results

As discussed in 3.2 above, I cluster the studies' results by exposure and outcome. Specifically, I separately consider the associations between: (i) a mental health difficulty and subsequent education or employment outcomes; (ii) a physical health difficulty (or poor self-reported health) and subsequent education or employment outcomes<sup>11</sup>; (iii) a mental health difficulty and outcomes in broader life domains; (iv) and between a physical health difficulty (or poor self-reported health) and outcomes in broader life domains<sup>11</sup>.

#### 3.3.3.1. *Mental health and outcomes relating to human capital theory*

The strength of the association between a mental health difficulty and impaired educational or employment outcomes differed depending on the quantitative technique adopted. When controlling only for observable factors which had the potential to confound the association, a number of studies identified a significant association between having mental health difficulties in adolescence and having an increased risk of an impaired educational or employment outcome. However, there was some indication the strength of the association differed by gender.

#### *Associations when only controlling for observable factors*

De Ridder et al. (2013), Fletcher (2013, 2010, 2008) and Tekin and Markowitz (2008) included in their studies an analysis of the association between a mental health difficulty and impaired educational or employment outcomes with a combined gender sample. De Ridder et al. identified a significant association between being psychologically distressed in adolescence and subsequently dropping out of secondary school. Similarly, they found a significant association between having a concentration difficulty in adolescence and subsequently dropping out of high school. In the combined gender sample, Fletcher (2008) found no significant association between being at risk of depression and subsequently dropping out of high school, but did identify a significantly increased risk of subsequently not enrolling in college. When using a variable for depression which treated it as a scale, the extent which the individual experiences depressive symptoms, Fletcher (2010) identified a significant association between depressive symptoms and both

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<sup>11</sup> When considering the studies I combine the exposures of physical health difficulties and poor self-reported health for the following two reasons. Firstly, some of the studies have already collapsed a range of physical health difficulties into a broader class, for example, Bussing and Aro (1996) who cluster a range of physical health difficulties including asthma, migraine and rhinitis into the exposure variable "any condition". Secondly, there are arguably too few studies considering poor self-reported health to attempt a narrative synthesis of their results in isolation.

reduced years of schooling and dropping out of high school. However, the study found no significant association between depressive symptoms and not enrolling in college.

Concerning the association between a mental health difficulty and subsequent employment outcomes both Fletcher (2013) and Tekin and Markowitz (2008) identified a significant association between depression and subsequently not being engaged in a productive activity when they use a combined gender sample. When considering a combined gender sample and employing a method which does not control for unobserved characteristics, the literature therefore broadly supports an association between depression in adolescence and subsequently not being engaged in a productive activity; both of the studies investigating this association obtained statistically significant correlations between the exposure and the outcome (Fletcher, 2013; Tekin and Markowitz, 2008). The significance of the association between a mental health difficulty and subsequent educational outcomes varies by study.

Cornaglia et al. (2015), Fletcher (2013, 2008) and Sagatun et al. (2014) undertook similarly specified analyses separately for girls and boys. For girls, Cornaglia et al. identified a significant correlation between having poor mental health and having lower examination scores and an increased risk of not being in education, employment or training (NEET); neither of these associations were significant when undertaking the analyses for boys. For girls, Fletcher (2008) found no significant association between being at risk of depression and subsequently either dropping out of high school or not enrolling in college. Boys at risk of depression were identified as being significantly more likely to drop out of high school. When undertaking the analyses separately by gender, Fletcher (2013) identified a significant association between being at risk of depression and subsequently not being employed for both girls and boys. For girls, Sagatun et al. identified a significant association between an internalised mental health difficulty, such as depression, anxiety or withdrawal and not completing secondary school. The same association was not significant for boys. For both girls and boys separately, they found a significant association between an externalising difficulty, such as having an attention problem or conduct disorder, and subsequently dropping out of high school.

When considering the results separately by gender and not controlling for unobserved characteristics, the literature generally indicates that for girls there may be a significant association between mental health difficulties and employment outcomes. Both of the studies to investigate this association obtained a significant result (Cornaglia et al., 2015;

Fletcher, 2013). For girls, the literature offers mixed support for the finding that there is also an association between mental health difficulties and educational outcomes. For boys, there is substantial variation across the studies with respect to the significance of the associations between having a mental health difficulty and both subsequent employment and educational outcomes.

*Associations when attempting to control for unobservable factors*

Generally, to control for unobservable characteristics, two approaches are employed in studies investigating the association between mental health difficulties and subsequent educational or employment outcomes. Fixed effects, which account for unobserved time-invariant heterogeneity, were applied either at the level of the school or the family. The former approach attempts to control for unobserved characteristics at the level of the school which might confound the association of interest (for example, the degree to which the child is bullied at school may be unobserved due to an absence of relevant variables). The latter attempted to control for unobserved characteristics at the level of the family that might confound the association of interest (for example, the extent to which the parent's relationship with the child is supportive). As can be seen in Table 3-1, the incorporation of school fixed effects rarely affected the significance of the associations outlined above. For brevity, I therefore focus below on the results when sibling (family) fixed effects are incorporated into the analyses. When adopting this approach, the analyst assumes the same unobserved family fixed effect influences the outcome of both the sibling with and without the health difficulty of relevance.

Within their studies, both De Ridder et al. (2013) and Fletcher (2013, 2010) included analyses which incorporate family fixed effects. All three studies only undertook these analyses with an analytic sample that combined the genders. When considering the exposure of psychological distress (De Ridder et al., 2013) and being at risk of depression (Fletcher, 2013, 2010), the studies indicated the addition of family fixed effects results in the associations switching from being significant to becoming insignificant. The analyses suggest that unobserved characteristics at the level of the family may therefore be causing both mental health difficulties relating to depression and impaired outcomes relating to the accumulation of human capital. De Ridder et al. also incorporated family fixed effects into their analysis of the association between concentration difficulties and dropping out of high school. In contrast to their findings for psychological distress though, when family fixed effects were incorporated, the association remained significant.

As a whole, the studies therefore indicate that the association between depression and impaired education and employment outcomes is likely a result of unobserved confounding factors at the level of the family. However, it is likely that concentration difficulties do impair educational outcomes as the association remained significant even when analyses attempted to control for a range of observed and unobserved characteristics that might confound the association (De Ridder et al., 2013).

### *3.3.3.2. Physical health and outcomes relating to human capital theory*

A number of studies meeting the inclusion criteria investigate the association between a physical health difficulty and the outcomes associated with the human capital theory. As above, I consider the results of the analyses separately according to whether or not the analysis controlled for unobserved characteristics and the genders included in the analytic sample. To avoid parsing my studies into numerous clusters below, I consider the findings of studies where the exposure is self-assessed health alongside those studies where the exposure is a physical health difficulty. Though a self-assessed health difficulty could be primarily physical or mental in its nature, as discussed in 2.2.3 and 3.2, I wish to avoid emphasising the distinction between these two dimensions of health. I therefore adopt the approach below purely to simplify the flow of my reported results and to facilitate a comparison of the studies' findings.

#### *Associations when only controlling for observable factors*

Six studies undertook analyses investigating the significance of this association with a combined gender sample in which they only controlled for observed characteristics (Brekke, 2015; Bussing and Aro, 1996; De Ridder et al., 2013; Northam et al., 2010; Rees and Sabia, 2009). The significance of the association again varied according to the approach taken to specifying the analysis. When undertaking a relatively conventional approach to the regression analyses<sup>12</sup> (i.e. only including a moderate number of covariates and not adopting any approaches to match the exposed and non-exposed populations), all identified a significant association between having a physical health difficulty, or poor self-assessed health, and being at risk of experiencing a worse

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<sup>12</sup> The analyses I am referring to as “conventional” are those where the authors included a moderate number of covariates, typically accounting for the families’ socioeconomic background etc. and no extra steps were taken to match the exposed and non-exposed populations. I use this term to compare these analyses, and their results, with the additional analyses undertaken by: (i) Brekke (2015); (ii) Rees and Sabia (2009); and (iii) Zajacova et al. (2015). As discussed in the main text below these studies included additional analyses which either included an extensive list of covariates or adopted an approach that endeavours to match the exposed and non-exposed populations in their sample.

educational outcome. Concerning employment outcomes only, Northam et al. investigated the association between a physical health difficulty and this outcome. Their analysis indicated there is not a significant association between having type 1 diabetes in adolescence and not being in either full-time work or study.

In addition to undertaking a conventional regression analysis the studies by Brekke; Rees and Sabia; and Zajacova et al. undertook further analyses which, while only controlling for observed characteristics, attempted to further explore the nature and strength of the association. One of Brekke's additional analyses included an extensive number of covariates. Specifically, Brekke explored whether including variables relating to the individual's academic ability and difficulties in family relationships affected the strength of association between having poor self-assessed health and subsequent enrolment in higher education. In the analysis which incorporated these covariates, the association became insignificant. Giving a specific interpretation to this result is difficult as two options are possible. First, these factors may be confounding the association between poor self-assessed health and subsequent enrolment in higher education. Controlling for these variables would then lead to the association of interest becoming insignificant. However, an alternative explanation is that these variables mediate the impact of poor health. Health may still indirectly lead to an increased risk of not enrolling in education but does so via disrupting the individual's accumulation of knowledge and family relationships.

Rees and Sabia undertook analyses using propensity score matching. This method attempts to ensure the exposure and control groups are balanced with respect to their observable characteristics. They adopted this method because there appeared to be substantive differences between the sub-samples of those with and without migraines. Undertaking the analysis with matched individuals in the combined gender sample led to the association between having a migraine and two of the three educational outcomes becoming insignificant. The only association which remained significant is the existence of an increased risk of not attending college if an individual had difficulties with migraines.

Two of the five studies listed above also undertook their analyses separately for girls and boys (Bussing and Aro, 1996; Rees and Sabia, 2009). However, no clear trend with respect to differences by gender emerged. Zajacova et al. (2015) only undertook their analyses with girls and boys separately. Their findings were similar to Brekke et al. When reduced covariates are incorporated, the association between poor self-reported health and the

highest completed year of school was significant. The association became insignificant once covariates relating to the individuals' ability and household characteristics were controlled for.

The literature as a whole therefore offers further tentative support for the possibility that health's impact on subsequent educational outcomes may be mediated by its role in facilitating the accumulation of academic ability. As none of the studies investigated the impact of incorporating school level fixed effects in their analyses, I now consider the impact of controlling for unobserved confounders at the level of the family on the significance of the associations of interest.

*Associations when attempting to control for unobservable factors*

Three studies incorporated family fixed effects in their analyses when investigating the association between physical health difficulties and subsequent educational outcomes (De Ridder et al., 2013; Rees and Sabia, 2009; Zajacova et al., 2015). None of the studies adopted this technique while exploring the association of a physical health difficulty with subsequent employment outcomes. De Ridder et al. only undertook their analyses with a combined gender sample; Zajacova et al. with only separate samples for girls and boys; and Rees and Sabia with genders combined, girls only and boys only. Given the limited number of studies adopting this methodology, I consider the studies' findings together without separating by the gender incorporated in the analysis. In both De Ridder et al. and Zajacova et al., once family fixed effects were incorporated into their analyses, all of the associations reported between a physical health difficulty and subsequent educational outcomes became insignificant. Rees and Sabia's findings differed. While many of the associations became insignificant once family fixed effects were incorporated, for girls migraines were still significantly associated with an increased risk of not attending college. Similarly for boys, even after family fixed effects were incorporated, having a migraine remained significantly associated with obtaining a lower GPA score.

As a whole, the studies which investigated the association between a physical health difficulty, including poor self-reported health, and subsequent educational outcomes included a large number of differing analyses. For brevity not all the analyses undertaken have been summarised above. Their findings as a whole support Rees and Sabia's reflection on the pattern of the associations they identified in their numerous analyses. Rees and Sabia conclude that the impact of migraines on educational outcomes appears

to be mediated via the pathway of increased absence from school and greater difficulty concentrating in class, “Controlling for these factors can reduce the estimated effect of migraine headache on high school GPA by almost half, and can reduce the estimated effect of migraine headache on college attendance by as much as 44 percent” (Rees and Sabia, 2009: 329). Concentration difficulties span the mental/physical health dichotomy. The studies reviewed so far indicate that concentration difficulties, at times exacerbated by physical health problems, can disrupt the accumulation of academic ability. Additionally, the disrupted accumulation of academic *ability* is a potential mediating pathway for the impact of physical health difficulties (and impaired concentration) on subsequent educational *outcomes* such as dropping out of high school or not enrolling in higher education (De Ridder et al., 2013; Rees and Sabia, 2009; Zajacova et al., 2015).

### 3.3.3.3. *Mental health and broader valued outcomes*

I now turn to consider the findings of the review as concerns the association between a mental health difficulty and outcomes relating to domains other than education and/or employment: outcomes broader than those which would typically be included in studies informed by human capital theory. Chen et al. (2006) undertook the only study which meets the inclusion criteria of the review to investigate this association.

Chen et al. included three different exposure groups: individuals with a mental disorder but no physical illness; individuals with a physical illness but no mental disorder; and individuals with both a physical illness and a mental disorder. I consider the outcomes for the group that only has a mental disorder here. Below, I consider the outcomes for the other two exposure groups. The broader outcomes of relevance incorporated in Chen et al.’s analysis include social relationships, role function and environmental context. Each of the domains is measured using different items from the Young Adult Quality of Life (YAQOL) instrument (Chen et al., 2004). Items relating to the social outcomes domain assessed the extent of contact and quality of relationships between the individual and their friends and with a partner or close confidante. The role function domain was measured using items that assessed the stress individuals experienced in a major productive role whether it be in employment, school or at home. Finally, the environmental context domain was measured using items which assessed an individual’s residential comfort, safety and quietness. The study did not control for unobserved confounders.

Compared to individuals with neither a physical illness nor a mental disorder, individuals reporting only a mental disorder were subsequently more likely to report worse outcomes in the domain of social relationships and environmental context. Differences in reported role function were not statistically significant (Chen et al., 2006).

#### *3.3.3.4. Physical health and broader valued outcomes*

As mentioned, Chen et al. also investigated the impact of having: (i) a physical illness but no mental disorder; (ii) or a physical illness and a mental disorder on subsequent social relationships, role function and environmental context. There was no statistically significant difference between individuals with no health difficulty and those with solely a physical illness on any of the three domains of interest. In contrast, individuals who had both a physical illness and a mental disorder subsequently had significantly worse outcomes in all three domains compared to individuals with no health difficulty.

The study by Bussing and Aro (1996) outlined above also investigated the association between having a health difficulty and subsequent outcomes outside of education and employment. In addition to the outcomes mentioned above, Bussing and Aro also studied the associations between a health difficulty and subsequently: having interpersonal problems, living with parents, being married or cohabiting, not dating or living with children. As previously mentioned, the analyses did not attempt to control for unobserved characteristics which might confound the association. For girls and for the combined gender sample, Bussing and Aro identified a significant correlation between having a health difficulty and subsequently having interpersonal problems. They reported that chronic difficulties were associated with increased conflict with significant others. The association was not significant when only undertaking the analysis with boys. For all the other relationally orientated life domains, the study did not find a significant association between having a health difficulty and subsequently being more likely to experience a negative outcome<sup>13</sup>.

To an extent, there is tension between the findings of Chen et al. and those of Bussing and Aro. The former study indicates that individuals who have a physical illness are not at risk of impaired social relationships if they don't also have a mental disorder. In contrast, the study by Bussing and Aro supports the notion that a health difficulty (and those listed

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<sup>13</sup> As mentioned in Table 3-1, for the purpose of this review, I consider living with parents aged 22 and not being married or cohabiting as negative outcomes. To an extent, this is a normative judgement. However, it could be argued the socially endorsed life trajectory is for individuals as they enter adulthood to leave their parents' home and start to establish new family units.



seem to primarily be of a physical nature) can lead to an increased risk of interpersonal problems. Three possible explanations exist for this discrepancy. Firstly, Bussing and Aro do not also control for a mental disorder in their analysis; therefore, strictly speaking, the two exposure groups are not entirely comparable. Secondly, the social domain appears to be measured somewhat differently in the two studies. Bussing and Aro's study focused on interpersonal *problems* (conflicts) whereas Chen et al.'s study focussed on relationship *quality*. While one might expect the two domains to be related, it could be possible to have high quality relationships while also experiencing conflict. Indeed, within a family context, a severe physical health difficulty might lead to a more intense relational dynamic perhaps conducive to high quality relationships punctuated by regular conflict. Finally, the two studies may simply contradict each other, where one or the other may have reported a "false positive" or "false negative" (with perhaps a false negative being the more likely outcome as a result of each study's relatively small sample size).

Caution is required when drawing conclusions about the associations between health difficulties in adolescence, whether mental or physical, and subsequent outcomes in the broader aspects of life of interest. Neither of the studies which investigated these associations controlled for unobserved characteristics that might confound the associations. Additionally, as mentioned in 3.3.2, both of the studies relied on samples drawn from geographically restricted areas, and therefore, caution is necessary when drawing inferences to a broader population (Deng et al., 2013).

With the caveats listed above in mind, the two studies together provide some support for an association between health difficulties and impaired future outcomes in broader domains. This association is likely strongest for individuals who either have both mental and physical health difficulties or solely experience mental health difficulties. Additionally, the study by Bussing and Aro provides a degree of support for the hypothesis that the association between a physical health problem and relational difficulties is stronger for girls than for boys.

### 3.4. Critical Evaluation

Below, I critically evaluate the systematised review: its findings, limitations and implications for the subsequent research.

#### *Summary of main findings*

Firstly, concerning the association between mental health difficulties and subsequent educational or employment outcomes, in totality the literature reviewed indicates that

once unobserved characteristics at the level of the family are controlled for there is little evidence to indicate that depression in adolescence is significantly associated with impaired future educational or employment outcomes (De Ridder et al., 2013; Fletcher, 2013, 2010). However, concentration difficulties in adolescence remain a significant predictor of impaired educational outcomes, even after unobserved characteristics are controlled for (De Ridder et al., 2013).

Secondly, concerning the association between physical health difficulties and subsequent educational or employment outcomes, the literature reviewed indicates that physical health difficulties in adolescence may well disrupt longer-term educational outcomes. Studies indicate that this disruption may occur through the pathways of disrupted school attendance and reduced ability to concentrate in school, which in turn are likely to impair the accumulation of academic skill (Brekke, 2015; De Ridder et al., 2013; Rees and Sabia, 2009).

Thirdly, there is a degree of evidence to suggest that mental health difficulties, particularly if accompanied by a physical comorbidity, are associated with impaired outcomes in the broader domains of value to individuals such as relationships with friends and significant others (Chen et al., 2006). Finally, the literature signals the possibility that the association between having a health difficulty in adolescence and subsequently reporting conflict in significant relationships may be stronger for girls than it is for boys (Bussing and Aro, 1996).

#### *Limitations of the review resulting from the approach adopted*

The resources available to me as a PhD student, as mentioned in 3.2, imposed some limitations on the review reported in this chapter. Certain conventions implemented as standard within a fully systematic review, such as having two researchers both check the eligibility of articles and the accuracy of the data extracted, were therefore not implemented (Grant and Booth, 2009). Additionally, for the purposes of efficiency, I did not attempt to exhaustively identify all of the articles of potential relevance (for example, I did not undertake a detailed review of the grey literature). As mentioned in 3.2.2 it is possible that the search string I adopted led to studies of relevance not being identified. As outlined in greater detail in footnote 4 within that section, one study, of low methodological quality but of some potential relevance, was not identified in the initial search. This is because terms I used in the search string were not included in the article's title, abstract or key words. Though the omitted study arguably had little to offer as a

result of its low methodological quality, it is feasible that I missed other articles that could have made a greater contribution to the review. Using Web of Science, however, did allow the search to identify articles of potential relevance from multiple databases. The search filters used did not limit the search to articles published in peer reviewed journals. An advantage of adopting a systematised approach is that it requires fewer resources to implement than a systematic review while minimising the risk that the articles reviewed are selected in an arbitrary manner, or worse, intentionally selected to support the researcher's preferred position.

A further limitation of my review is the pragmatic approach adopted to synthesising the results, which risks dichotomising physical and mental health. Though there are practical and analytical benefits to jointly considering studies with those to which they are most comparable, the findings of the review support the notion that health is multifaceted; the physical and mental aspects of health interact (Bendelow, 2009b; Chen et al., 2006; Rees and Sabia, 2009).

#### *Limitations of the literature identified*

With regards the thesis' aims, objectives and sensitising theoretical framework, perhaps the most significant limitation of the literature identified is the absence of qualitative studies which meet the inclusion exclusion criteria. No longitudinal qualitative studies were identified which also included a comparator group. There were therefore none which enabled a *comparison* of the lived experience over time of those with and without substantive health difficulties. As discussed in 3.2, a comparison of those with and without health difficulties arguably supports an accurate evaluation of the dynamic impact of a health difficulty on the individual's lived experience (Crouch and McKenzie, 2006).

Additionally, there was an absence of mixed methods studies meeting the inclusion/exclusion criteria. As discussed in 1.3, a mixed method methodology is particularly coherent with my epistemological position of subtle realism. Mixed methods studies have the potential to: (i) draw on the individual strengths of qualitative and quantitative analytical methods; (ii) allow the perspectives of individuals elucidated during the qualitative research to inform the quantitative analysis undertaken; and (iii) enable the findings from the two approaches to be triangulated. A mixed methods approach therefore enables a range of perspectives to inform the study findings. This is

important if one believes there is a reality which can be known but any individual's perspective on that reality is limited (Mays and Pope, 2000; Seale, 1999).

The final major limitation is that only two of the quantitative studies which did meet the study inclusion criteria investigated the impact of a health difficulty on outcomes that were broader than either education or employment. The two studies both had substantial limitations. Both analysed samples which were not intentionally designed to be representative of an age matched national population; caution is therefore required when seeking to make inferences to a wider population. Additionally, neither attempted to control for unobserved characteristics (Bussing and Aro, 1996; Chen et al., 2006), which might confound the associations between the exposure(s) and the broader outcomes of interest. Given the limited number of studies and these studies' limitations, the quantitative literature to date can only support very tentative conclusions as to the impact of a health difficulty during adolescence on future valued abilities which are broader than education and employment.

#### *Implications for subsequent research*

Given the research aim and objectives of the thesis, further research is therefore required to: (i) investigate the lived experience of adolescents, noting their accounts of how health affects their valued abilities; and (ii) examine the pathways through which health difficulties impact the formation of valued abilities.

Given the limitations of the body of literature identified through the systematised review, I now turn to reviewing the methodological literature with the aim of identifying robust approaches to: (i) engage with individuals' lived experience; (ii) identifying the aspects of life that are of particular value to individuals; and (iii) investigating how valued abilities develop over time.

## 4. A critical review of methods for investigating the formation of valued abilities

### 4.1. Introducing the critical review

Having identified in chapter 3 that no empirical work to date fully addresses this study's research aim and objectives, I now turn my focus to identifying methods that could be used to accomplish the thesis' research aims and objectives. Given this chapter's purpose, I now undertake what Grant and Booth (2009) term a critical review. Grant and Booth define a critical review as one which, "goes beyond mere description of identified articles and includes a degree of analysis and conceptual innovation" (2009: 93). A critical review need not be systematic but is well suited to synthesising approaches from different schools of thought.

I review the literature with the aim of identifying the best approach to three linked but distinct methodological issues: (i) how best to meaningfully engage with individuals' lived experiences; (ii) how to identify which aspects of life are of particular importance to individuals; and (iii) how to evaluate individuals' abilities in these different aspects of life – including how these change and interact over time.

### 4.2. Engaging with individuals' lived experiences

The first objective of this thesis is to "investigate the lived experience of adolescents, noting their accounts of how health affects their valued abilities". Engaging with the lived experience of adolescents with and without severe health difficulties broadens the perspectives that are brought to bear on the research aim. This is vital in order to avoid research which amounts to the testing of hypotheses that have been generated from my own limited, and primarily theory driven, perspective on reality (Seale, 1999).

In line with my epistemological position, as discussed in 1.3, I believe that research into complex phenomena is best generated by combining emic knowledge, based on people's personal experiences of phenomena with etic knowledge, that which is generated through the relatively detached analysis of data (Dahlberg et al., 2010; Johnson and Onwuegbuzie, 2009). The adolescents themselves are the experts of their own lives, including the role of health in enabling them to enjoy other valued abilities (capabilities) and achieve valued outcomes (functionings) (Shaw et al., 2011). Engaging with the perspectives of adolescents therefore enables the researcher to enter the inner world of

the individual more fully and in doing so learn from the inner experiences of the individual encountering the phenomena first-hand (Hollway and Jefferson, 2000a).

By engaging with the participant's inner world, the researcher attempts to not only obtain knowledge that is directly of value for the research objective but also incrementally increase their own sensitivity to individuals' life experiences. This allows the researcher to produce theoretically grounded (etic) knowledge which is informed by: (i) the emic knowledge of those directly experiencing the phenomena of interest; and (ii) their own incrementally increasing sensitivity to the experiences of those with this first-hand knowledge. The lived experience of those experiencing the phenomena is then able to both directly and indirectly influence the study findings. Directly, via the analysis and reporting of their experiences, and indirectly via their influence on the hypotheses which are subsequently tested.

As discussed in 2.3, the participant and interviewer's defended subjectivities may impair the conduit via which the researcher can engage with the participant's lived experience (Hollway and Jefferson, 2000a; Wengraf, 2001a, 2001b). Within the interview, as to an extent in many human interactions, both the interviewer and the participant manage the manner with which they present themselves. Both the experiences the participant chooses to communicate and the manner in which they communicate them is therefore influenced by the persona the participant wishes to present (Wengraf, 2001a).

Narratologists argue that narrative provides a useful framework for exploring the inner world of individuals (Wengraf, 2001a). Storytelling is a common part of everyday life; additionally, there are arguably norms as to how individuals in Western culture tell stories (Rosenthal, 1993). This has two important benefits. Firstly, a broad range of individuals should be able to relatively confidently tell their story, perhaps more than would be able to confidently articulate an opinion on an issue and their reason for holding such a view. Secondly, the established genre encourages individuals to order their life events into a story (Rosenthal, 1993). The process of doing so helps reveal their explicit and implicit thoughts, emotions and assumptions about their lives and the surrounding society. Therefore, how the individual forms their life events into a narrative likely reveals something of their inner world (Rosenthal, 1993; Wengraf, 2001a).

For reasons discussed in greater depth below, I identified the biographic-narrative-interpretive method (BNIM) as a credible way of implementing a narrative approach (Wengraf, 2001a, 2001b). Within a BNIM interview there are typically two sessions. In the

first, the interviewer asks a single question aimed at inducing a narrative. Typically, this question focusses the participant on their own life (rather than, for example, asking them to articulate a view on an aspect of society) but remains broad with respect to which aspects of their life they can discuss. Additionally, the interviewer commits to remain silent for the duration of the participant's response. An example might be:

*"I would like you to tell me your life story, all the events and experiences which were important to you. Start wherever you like. Please take the time you need. I'll listen first, I won't interrupt, I'll just take some notes for afterwards"* (Wengraf, 2001a: 126).

After the participant has completed their response, the second session begins. During the second session, the interviewer only asks questions around events mentioned in the initial narrative and those that emerge out of any subsequent responses by the participant. The interviewer frames their questions to encourage the participant to recall in-depth narratives about the particular events which are often only summarised in the initial narrative.

The quest to obtain these "particular incident narratives" (PINs) from the participant is a core component of the second session. Both the journey to obtain these PINs and the PINs themselves combine to provide a transcript which allows the researcher glimpses of the participant's inner world. Perhaps most obviously when the participant chooses to provide the in-depth narrative about a particular incident, they directly provide the interviewer with a facet of their lived experience. Additionally, if after a number of follow-up questions designed to support them in recalling an in-depth narrative they implicitly or explicitly refuse to recall one, the participant may still reveal something of their inner thoughts and emotions concerning that event. This is particularly the case since it allows a comparison of their chosen approach to related events that emerge through their narrative. Comparing the way individuals discuss these related events allows the researcher to make inferences regarding the participant's approach to self-presentation (Charmaz, 2002; Wengraf, 2001b).

Compared to semi-structured interviews, the BNIM approach arguably gives a greater degree of freedom to the participant while constraining the interviewer (Wengraf, 2001a). An open initial question in the first session allows the participant to direct the interview onto the lived experiences they believe to be of most relevance to their life story. In contrast, the interviewer is not only restricted from interrupting but also limited to focussing the second session only on experiences the participant has chosen to raise in the first. With the caveat that the participant may deliberately choose to withhold some

experiences of relevance, the BNIM approach therefore allows the interview to focus on the experiences the participant, with their in-depth emic knowledge, believes to be of greatest relevance. Compared to a semi-structured interview format, it therefore reduces the ability of the interviewer to impose an agenda they believe to be of greatest relevance as a result of their prior theoretically based knowledge (Wengraf, 2001a).

For the purposes of investigating adolescents' lived experience, the BNIM method would appear very suitable. Additionally, a narrative method may contribute towards: (i) identifying the abilities and opportunities that are particularly valued; (ii) and evaluating health's role in facilitating their formation. However, as discussed below, triangulation with other methods is likely required in order to achieve this more robustly. In 4.3.3, I discuss the relative strengths and weaknesses of the BNIM method relative to the more conventional semi-structured interview method. In 6.1.1, I outline my approach to combining the two methods. My approach to combining the two methods is then summarised in greater detail in 6.2.

#### **4.3. Identifying which abilities and opportunities are particularly valued**

In order to pursue the thesis' aim, "to research the immediate and future impact of health difficulties during adolescence on the formation of valued abilities which foster well-being", it is first necessary to identify which abilities are valued by adolescents. Furthermore, for the purposes of pragmatically undertaking the research effectively given the inevitable time, data and analytical constraints, it is necessary to prioritise which valued abilities should be selected for inclusion in the qualitative and quantitative strands of the research. There is unlikely to be time to ask adolescents about every aspect of life the literature may indicate they have reason to value. Trying to incorporate every aspect of life which may be valued into a longitudinal quantitative model will likely be unfeasible both as a result of data constraints and computational demands.

As alluded to in chapter 2, I will frequently use the term "valued ability" as a synonym for capability and "valued aspect of life" as a synonym for capability domain. However, choosing for a moment to use the terminology of the capability approach, in order to fulfil the aim of the thesis, it will be necessary to determine which capability domains are of greatest priority for inclusion in the research. How can this prioritisation be accomplished in a rigorous manner?



#### 4.3.1. Theoretical literature of relevance

Amongst arguably the two leading capability theorists, there is a divergence in the approach suggested for selecting capability domains. While Nussbaum (2001) has explicitly stated the human capabilities she believes to be vital for well-being, Sen has avoided publishing a comprehensive list, arguing that the formation of a list of capabilities should come through a democratic process involving public scrutiny and discussion (Sen, 2004a, 2004b).

Alkire (2008) clarifies these diverging perspectives by characterising five different approaches. Below is an adapted summary of the approaches she more extensively describes:

1. Selection based on a repeated deliberative, participatory exercise which engages a representative group of participants who select central capabilities
2. Selection based on an enduring consensus of lists developed by leading theorists or international institutions
3. Formation from theoretical considerations
4. Selection according to data availability
5. Selection using empirical analysis of individual's behaviours and preferences.

In practice, the different approaches are not entirely distinct (Alkire, 2008); researchers often need to draw from a range of these approaches. Nussbaum reports conversing with affected individuals and leading theorists before constructing her list, which was informed significantly by Aristotelian theory (2011, 2001). It could therefore be argued that Nussbaum's approach combined elements of the first, second and third approaches outlined above.

If a researcher agrees with Sen, and believes that the domains should be selected through a democratic process, it is necessary to establish both what constitutes a distinct individual domain and the procedure through which these domains should be articulated and selected. Robeyns provides guidance for the researcher aiming to pursue this approach (2005b, 2003). Robeyns argues that for a specification of capabilities to be valid, it should meet five criteria. Below is an adapted summary of the approaches she proposes:

1. the criterion of explicit formulation
2. the criterion of methodological justification

3. the criterion of sensitivity to context
4. the criterion of different levels of generality
5. the criterion of exhaustion and non-reduction

While Robeyns highlights the importance of sensitivity to individuals' contexts, an important balancing consideration, as outlined briefly in 3.2, is the influence of adaptation on individuals' evaluations. Though it is important to obtain the perspectives of those who directly experience the difficulty of relevance to the research effort when deciding which aspects of life to incorporate in the evaluation, Biggeri and Libanora (2011) note that solely accessing the perspectives of those affected may result in bias. There is a risk that doing so may cause the derived list to be too contextualised – restricting the domains over which the flourishing life is evaluated to only those judged of importance by individuals who have adapted to difficult life circumstances (Biggeri and Mehrotra, 2011; Sen, 1985).

#### *Adaptation*

The research literature to date indicates that the manner in which individuals adapt to health difficulties is multifaceted (Menzel et al., 2002). Some aspects of this process of adaptation are positive while some may indeed reflect a distortion of the individual's ability to accurately evaluate their own well-being. At its most positive, adaptation may involve the development of new skills which minimise the disruption caused by the health difficulty. For example, an individual with type 1 diabetes may learn to efficiently test their blood sugar and take the pre-emptive steps required to limit the danger and inconvenience that results from their health difficulty. Their health difficulty may not cease to impact on their ability to flourish in life but over time adaptation of this form may objectively reduce the difficulty's impact (Brazier et al., 2005).

An additional manner in which an individual may adapt to a health difficulty is by selecting "substitute" activities to replace those they no longer have the capacity to enjoy. An adolescent unable to competitively engage in football with their peers may seek alternative pastimes such as online computer games in which they can interact with peers in a sociable yet competitive activity. Prior to experiencing poor health difficulty, the "substitute" activity might not have been their favoured option. However, adapting in this manner likely results in an outcome better than might originally have been anticipated and experienced when the individual's experienced health initially declined.

In addition to making changes to their engagement with the external world, individuals may adapt to their health difficulty by making internal, psychological adjustments. As noted by Charmaz (1994) individuals who have a health difficulty may re-evaluate the importance of an aspect of life in which they struggle, such as work, and actively decide that they should have always placed greater relative importance on the relational facet of their life (Brazier et al., 2005; Charmaz, 1994). Perhaps less positively, the health difficulty may affect their inter-domain expectations – leading to a suppressed recognition of an alternative world in which they truly flourished in that aspect of life (Menzel et al., 2002; Sen, 1985). Psychological adaptation may therefore affect both the relative importance the individual attributes to the aspects of life in which they experience difficulties and their expectations within that domain.

Adaptation is therefore multifaceted, and the facets differ in the ease with which they can be readily embraced as *positive* developments. In order to undertake an evaluation of the impact of a health difficulty on an individual's ability to flourish, it would therefore seem of importance to allow the evaluation's informational space, the domains selected, to be informed both by those with and without health difficulties.

*Identifying and specifying the distinct domains of relevance*

Robeyns last criterion, "exhaustion and non-reduction", is relevant to the consideration of what constitutes a distinct domain. Robeyns proposes that the specified domains should include all important elements of a good life but that any element included should not be reducible to another element. Robeyns also argues that lists should be formed through a process constituting of four stages (Robeyns, 2003). Firstly, the researcher should brainstorm a list prior to engaging with the literature. Secondly, a draft list should be tested through engagement with academic, political and grassroots literature. Thirdly, the list should be compared with existing lists. Finally, the list should be debated with others. Importantly, if the researcher subsequently cannot empirically include all of the domains identified as being of importance, Robeyns recommends the researcher explicitly distinguish between their "ideal list" and their "pragmatic list". Robeyns' proposed methodology is consistent with my epistemological position, as outlined in 1.3, as it actively proposes that a range of individuals are consulted and that their varied perspectives inform the selection of capability domains.

There are also similarities between Robeyns' suggested stages and the Food and Drug Administration's recommended process for the development of Patient Reported

Outcomes (PROs) (Food and Drug Administration, 2009). A detailed review of this process is beyond the scope of this thesis. However, it is notable that during the stages relating to hypothesising and adjusting the conceptual framework for a PRO, researchers are instructed to: “Outline hypothesized concepts”, “Perform literature/expert review” and “Obtain patient input” (Food and Drug Administration, 2009: 7). It could therefore be argued that Robeyns’ process is consistent with the Food and Drug Administration’s instructions for conceptualising a health difficulty and the domains affected.

#### 4.3.2. Aspects of life previously identified as of inherent value

Both Burchardt and Vizard (2009) and Anich et al. (2011) have separately undertaken research to identify capability domains that are applicable to children as well as adults. In line with Robeyns’ guidance to maintain sensitivity to context, Biggeri and Mehrotra (2011) note the necessity of considering the age of individuals when considering the domain specifications; previous research has shown that over an individual’s lifetime, the relevance of different capabilities varies (Biggeri et al., 2006).

Table 4-1 contains the capability domains specified in five different studies which were identified by an informal search. The two studies on the left of the table were undertaken to identify domains which are broadly applicable across a variety of contexts. Nussbaum’s approach has been briefly described already; the domains in Alkire (2008) were identified primarily through considering previous academic studies and looking for consensus across their findings.

The study by Al-Janabi et al. (2011) was undertaken to select capability domains for inclusion in the ICEpop CAPability measure for Adults (ICECAP-A), a capability instrument designed to inform the economic evaluation of health and social care interventions undertaken with adults. The study used a participatory approach. Adults from the UK were interviewed to identify domains which should be selected for inclusion in the ICECAP-A instrument. The interviews were undertaken in two phases. However, it is the first phase of interviews that is of greatest relevance with respect to identifying which abilities and opportunities are particularly valued. In the first phase, in-depth, semi-structured interviews were undertaken with 36 individuals. Initially, individuals were asked background questions concerning their living arrangements, family and work. The interviewer then asked follow-up questions to get further information on issues of relevance to understanding the links between the different capabilities and their value to the participant. These follow-up questions were somewhat contingent on the

participant's initial responses to the background questions. While the lightly structured interview format appears to be designed to enable a relatively natural dialogue between the interviewer and participant, the topic schedule was designed to ensure all the domains judged by the researchers to be of potential value were eventually covered in the discussion (Al-Janabi et al., 2011).

The studies on the right of Table 4-1, by Burchardt and Vizard (2009) and Anich et al. (2011), are perhaps of greatest relevance as they explicitly account for a potential difference in the capabilities which are relevant for children compared to adults. Burchardt and Vizard (2009) and Anich et al. (2011) both use the first two approaches described by Alkire (2008) for the selection of domains.

In both studies, prior to seeing any suggested capability domains, the participants were asked to suggest which opportunities in life were of particular importance. In the study reported by Burchardt and Vizard (2009), the participants were then asked to review and comment upon a provisional list of domains which the researchers had constructed by drawing on domains previously identified as being of importance by national and international institutions. The provisional list was then revised to account for the participants' input.

Similarly, Anich et al. (2011) supplemented the original domains included in their questionnaire with domains spontaneously raised by their participants as being of relevance. The domains originally included in their questionnaire were drawn from participatory research involving capability theorists and children (Biggeri et al., 2006). For each of the domains in the supplemented survey, Anich et al. then asked the participants to both: (i) rate their own ability to achieve the valued opportunity in their own life; and (ii) in a more abstract sense, to rate how important in general this opportunity was for children.

Table 4-1: Capability domains identified in previous studies

Nussbaum (2001)	Alkire (2008)	Al-Janabi et al. (2011)	Anich et al. (2011)	Burchardt and Vizard (2009)
Domain Selection Approach: <i>Consensus/Normative Assumptions</i>	Domain Selection Approach: <i>Consensus</i>	Domain Selection Approach: <i>Consensus/Participatory Process</i>	Domain Selection Approach: <i>Consensus/Participatory Process</i>	Domain Selection Approach: <i>Consensus/Participatory Process</i>
Epistemological goal: Normative Theory	Epistemological goal: Welfare/quality of life measurement	Epistemological goal: Welfare/quality of life measurement	Epistemological goal: Welfare/quality of life measurement	Epistemological goal: Welfare/quality of life measurement
		<p><u>Country:</u> UK  <u>Age range of target population:</u> "adults"  <u>Total Sample Size:</u> 36 adults  <u>Sampling frame:</u> purposively selected to ensure variation in socio-economic status, age, sex, ethnicity and health</p>	<p><u>Country:</u> Uganda  <u>Age range of target population:</u> defined by publication as "children"  <u>Total Sample Size:</u> 150  <u>Sampling frame:</u> Randomly sampled from 12 NGO's working with street children and 5 randomly selected public schools</p>	<p><u>Country:</u> UK  <u>Age range of target population:</u> 9-75+  <u>Total Sample Size:</u> 202 individuals including 9 children aged 9-12 and 8 teenagers aged 13-16  <u>Sampling frame:</u> Recruited by engaging individuals on the street and telephone calls (children recruited through their parents)</p>
Life	Health and Security		Life and Physical Health	The capability to be alive
Bodily Health				The capability to be healthy
Bodily Integrity		Stability		Bodily integrity and safety
			Shelter and environment	The capability to enjoy a comfortable standard of living
			Mobility	

Nussbaum (2001)	Alkire (2008)	Al-Janabi et al. (2011)	Anich et al. (2011)	Burchardt and Vizard (2009)
				with independence and security
			Freedom from economic and non-economic exploitation	The capability of knowing you will be protected and treated fairly by the law
Senses, Imagination and Thought	Understanding		Plan/imagine/think	The capability to be knowledgeable, to understand and reason and to have the skills to participate in society
			Understand/interpret	
Play	Achievement	Achievement	Education	The capability to engage in productive and valued activities
		Enjoyment	Leisure activities	
Emotions	Satisfaction	"stability" also comes in here	Mental Health	The capability to enjoy individual, family and social life
Affiliation	Relationships	Attachment	Love and Care	
			Social Relations	
Other Species				
Practical Reason				
Control Over One's Environment	Participation	Autonomy	Participation/information	The capability to participate in decision-making, have a voice and influence
			Personal autonomy (as agency)	The capability of being and expressing yourself and having self-respect
			Personal autonomy	
			Respect	
			Religion and identity (tradition, culture)	
	Harmony		Religion (spirituality)	

In Table 4-1, I have attempted to align the lists so that domains that are conceptually similar are on the same row. Comparing the lists, it is evident that there is a large degree of consensus. There is consensus between the two studies which explicitly involved children and young people in the process, the study which undertook a participatory exercise purely with adults and the specifications formed by Nussbaum and Alkire. The categories identified by Anich et al. appear more detailed than the categories in the other studies. The higher number of domains listed could be a result of the explicit identification of what might be considered capability sub-domains in the overall list. An example is that the domain of “mobility” identified in the list by Anich et al. is a sub-domain of the domain “The capability to enjoy a comfortable standard of living with independence and security” identified in the study by Burchardt and Vizard.

Of all the studies reviewed above, that undertaken by Burchardt and Vizard (2009) has the greatest relevance to the thesis. A participatory approach was undertaken with a British sample that included adolescents. The sample population is therefore of relevance, and the participatory approach is consistent with my epistemological position. However, while their research provides a useful starting point, their findings are not sufficient to fully inform the valued abilities which should be prioritised for inclusion in the qualitative and quantitative strands of the research. Burchardt and Vizard undertook their research on behalf of the Equality and Human Rights Commission (EHRC), a public institution which monitors human rights. The primary aim of their list is to inform the indicators which should be selected to identify when the rights of individuals in society are being violated. Given Burchardt and Vizard’s focus on informing the monitoring of rights, there is an incentive towards specifying an all-encompassing list which, while entirely suitable for their purposes, results in a list that lacks the focus required for enabling an investigation into health’s role in the formation of valued abilities and skills. Further work is likely required to explicitly identify a “pragmatic list” (Robeyns, 2003) of capability domains for which to undertake an in-depth investigation.

An additional limitation of the study undertaken by Burchardt and Vizard is that their method does not fully align with my stated position regarding the nature of the researcher and the research participant as outlined in 2.3 and 4.2 above. If it is reasonable to believe individuals have defended subjectivity and are cautious as to how they present themselves and their stated opinions, then it is also possible that they might not divulge their greatest priorities in the format of an interview (Hollway and Jefferson, 2000a; Wengraf, 2001a). Additionally, the power relations in the interview may result in



adolescents emphasising aspects of life they believe will please the interviewer and therefore giving a greater stated importance to those domains they think the researcher will also judge as being of particular importance (Mayall, 2015; Wengraf, 2001a).

How can aspects of life valued by adolescents be identified in a manner that is: (i) sensitive to the anticipated dynamics of the interview; (ii) coherent with both my stated epistemological position; and (iii) consistent with my belief that both the interviewer and participant are cautious as to how they present themselves in the interview?

4.3.3. Identifying which aspects of life defended subjects particularly value  
As discussed directly above and in 2.3, when consulting the representative group of participants, because of their and my defended subjectivity, the approach likely to be most robust would be to elicit their perspectives both by: firstly, explicitly asking about the importance of different valued abilities; and secondly by attempting to analyse their implicit views on the issue via an analysis of their narratives.

*Using narrative methods to identify which aspects of life individuals value*

The BNIM approach draws on Rosenthal's proposal to analyse each individual by separately considering the individual's biographical data and their approach to narrating their lived life (Rosenthal, 1993; Wengraf, 2001b). Only after each has been considered separately does the researcher draw the two analytical strands together. Considering each separately allows the researcher to obtain a degree of distance from the participant's approach to telling their life story. As discussed in 2.3, this potentially allows the researcher to more accurately analyse how the participant has chosen to present themselves in the interview and account for this when seeking to understand the participant's perspective on different life events (Wengraf, 2001b).

To analyse the individual's biographical data, the researcher reviews the interview transcript and constructs a chronology of the individual's life events. When recording each event, the researcher avoids the use of terms or phrasing that would lead to the participant's perspective being embedded within the chronology (for instance, "the college was awful so I left" might be changed to "Jane left college"). In a chronological order, the researcher then considers each life event one at a time. Individually for each event, while attempting to suspend any recollections of future events, the researcher generates numerous divergent hypotheses as to how the individual will act in the future as a result of their current experience of the chronological event being considered. As the researcher moves through the chronology, they note which of these hypotheses are

supported or contradicted by the future events and observe the pattern that emerges over time concerning how the individual responds to life events and makes decisions.

Having analysed the individual's biographical data and considered their approach to making decisions, the researcher then considers the approach taken by the participant to summarising their life story within the interview (Rosenthal, 1993; Wengraf, 2001b). The text in the transcript is left in the order in which it is told by the participant but sequenced into different units. A new unit is demarcated every time one of the following occurs: (i) the speaker changes; (ii) the topic being discussed changes; or (iii) the way the topic is being discussed changes. Rosenthal outlines three different ways a participant could choose to discuss a topic. Firstly, they could use narration by referring a single sequence of events from the past which they link together either temporally or causally. Secondly, they could use a descriptive way of speaking in which they give an entity properties but in a timeless non-historical way. Thirdly, they could adopt an argumentative manner of speaking in which they abstractly discuss ideas or viewpoints outside of a story-telling sequence (Rosenthal, 1993; Wengraf, 2001b). The researcher then considers each unit of text one at a time in the order it was told in the interview and formulates divergent hypotheses about what the participant was experiencing in the interview when discussing the unit and how this will affect their subsequent topic selection or approach to discussing it. As with the analysis of the biographical data, the researcher is then in a position to observe which of their hypotheses are supported or contradicted by the subsequent units and therefore the pattern that characterises the participant's approach to telling their story.

Arguably the events individuals choose to raise, and the length and manner with which they choose to discuss them, reveal something of their perspective on these events and therefore on the importance of the aspect of life to which they relate (Rosenthal, 1993; Wengraf, 2001b). For example, a positive view about a relationship in an individual's life may be stated in an abstract, argued form. However, if the participant, although prompted to, declines to provide any in-depth stories about the relationship, it *might* mean the participant's stated perspective is because of the defended self they are presenting in the interview. When the researcher draws together the analysis of the participant's lived life and their approach to telling their story, the wider material will help inform whether or not such an inference has wider support. Comparing the individual's lived life and their approach to discussing different events, experiences and relationships therefore allows the researcher to construct a view of the individual's life, and the

aspects of it which are of particular importance, that is not solely formed by the information the participant explicitly divulges.

The BNIM approach was used to investigate the life experiences of individuals in Europe whose lives had been impacted by forms of social exclusion including being made redundant or leaving school without qualifications (Wengraf, 2001b). For brevity, I summarise the analysis undertaken on only one of the many participants interviewed. My aim is that by summarising 'Harold's' narrative, it will help illustrate in a more concrete manner how the material derived from a narrative interview can be used to identify the aspects of life that matter to an individual.

'Harold', was born in the 1960s and grew in a large family before his mother died at the age of 11 (Wengraf, 2001b). His Father then re-married a woman who already had a family of her own. Harold left school aged 16 and started work in the mines, and became increasingly involved in the trade union. In his mid-twenties, Harold was involved in the confrontation between the miners and the Conservative government. The miners lost the confrontation, and Harold experienced tensions with fellow miners who had refused to strike, termed scabs, until the mine he worked in was eventually closed and Harold made redundant.

Of direct relevance to identifying the aspects of life that are of particular importance, Wengraf (2001b) notes both: (i) the continuing strands of relationships and work; and (ii) *how* Harold talks about events relating to these topics. Specifically, in the early phase of his biography summarised above, when discussing the death of his mother and the tense integration of his family with that of his step-mother, Harold gives a sparse summary report that is punctuated by argumentation. His account indicates the stress of the period and his discomfort concerning the relationships within the new, combined family. In contrast, when discussing his work in the mine, he provides a more coherent narrative, telling a story which attributes a link between his family difficulties and the decision to go to work in the mines. The relational and employment aspects of his life are again interconnected as he describes in depth how his work in the mine provided a context for a warm relationship with his union mentor 'Len'.

Critically reviewing Harold's biography allows the researcher to identify the important role a number of relationships have played in Harold's life. Additionally, Harold's work appears to play multiple important roles in his life, including being a source of identity, a context for warm relationships and a context that led to divisions both between Harold

and the government and between Harold and colleagues who chose to side with the government rather than with the union (Wengraf, 2001b).

After analysing each participant interviewed individually the researcher can then make comparisons across the cases (Wengraf, 2001b). Using the informed view of each of the individuals, including what is evidenced in their lives and narratives as mattering to each of them, the researcher can make inferences about the aspects of life that emerge frequently across the cohort as being of inherent importance for living a good life. Additionally, they can consider if there are any characteristics, for example socioeconomic group, gender or health status, which influence what is evidenced as being important in each individual's life.

*Triangulating narrative and semi structured methods to account for defended subjectivity*

As discussed in 2.3, drawing inferences about what matters to the participant from a critical assessment of their approach to both how they have decided to live their life and present themselves in the interview leads to a substantial reliance on the researcher's interpretive lens (Hollway, 2009). Given the researcher has their own background, perspective and defended subjectivity, there is value in triangulating the methods used to elicit the perspectives of the participants. Additionally, though there are benefits to the scope BNIM provides the participant to influence the topics discussed during the interview, it may affect the comparability of different accounts. A semi-structured interview format has the advantage of both ensuring each question of interest to the researcher is answered by each respondent and obtaining an explicit view from each participant which can then be compared to the inferences drawn, using the BNIM approach, by the researcher.

Comparing an individual's explicit responses and the implicit emphases within their narratives helps with the understanding of both. As discussed, an individual's life context provides extra meaning and context to a stated opinion, allowing the researcher to critically interpret their meaning. Additionally, an individual's response to an explicit question may shed light on their narrative as a whole. The explicit question may help by either giving the participant permission to discuss a topic they potentially thought socially awkward to raise or by causing dissonance in the researcher's current understanding of the individual. This dissonance may in turn lead to a helpful revision which makes sense of both the explicit statement and the individual's narrative.

As mentioned in 4.2, I outline my approach for combining the two methods 6.1.1. This approach is then summarised in greater detail in 6.2.

#### 4.4. Investigating how valued abilities develop over time

In order to investigate the *future* impact of a health difficulty in adolescence on the formation of valued abilities, it is necessary to not only identify the abilities and opportunities individuals value but also assess the extent to which they are able to enjoy them. It will otherwise not be possible to assess the relationship between health and the abilities individuals enjoy through time. Without a *dynamic* understanding of how valued abilities develop over the life course, there is the possibility of underestimating the long-term impact of a current limitation that is imposed by a health problem. For example, if we do not account for the dynamic manner in which adolescent academic development is associated with future employment outcomes, we may underestimate the longer-term consequences of health difficulties in adolescence which affect school participation. If we only consider the immediate impact of a health difficulty on a valued ability, we will fail to account for the possibility that health difficulties in adolescence may not only disrupt the individual's ability to undertake the activity of going to school but also subsequently impact their longer-term ability to enjoy a career that they find fulfilling. Below, I will consider how valued abilities and their development can be assessed both qualitatively and quantitatively.

##### 4.4.1. Qualitatively assessing the dynamic formation of valued abilities

Arguably, for many of the different aspects of life, the degree to which an individual is able to enjoy them is primarily a *qualitative* assessment. To take the example of friendship, though this could be assessed quantitatively by asking the individual to report the number of friends they have, such an indicator would fail to capture the quality of the friendships enjoyed by the individual. Life experience would tend to indicate that when it comes to friendship quality is of greater importance than quantity.

Quantitative measures of outcomes individuals have achieved may well have meaning. However, when capturing aspects of life that are primarily qualitative, any single indicator inherently involves a degree of *reductionism*. Qualitative analysis can avoid this reductionism by both maintaining the phenomenon as a qualitative construct and by using a descriptive analysis to outline the dynamics within and between each domain through time (Robeyns, 2005b). To provide an example of this, individuals likely value the ability to form and develop an identity they value (and positive identity could therefore

be considered an inherently valued aspect of life). However, *quantitatively* assessing the extent individuals are able to enjoy this aspect of life will involve a substantive degree of reductionism. Qualitative methods in contrast may be able to investigate individuals' ability to enjoy this aspect of life with far less reductionism. Many psychologists believe that individuals use life stories to construct a narrative identity (Moshman, 2011f). Asking individuals to recall a narrative of their life therefore allows them to *project* to themselves and others a continuous identity which accounts for the different events in their lives. Furthermore, they may use this narrative to implicitly or explicitly *explain* how these different events and experiences have and are forming their identity. A qualitative approach using narrative methods therefore not only avoids the need to reduce this aspect of life but also allows the researcher to elicit the individual's projected theory of identity formation in a manner that many psychologists believe is a natural genre for the individual to articulate this (Moshman, 2011f; Rosenthal, 1993; Wengraf, 2001a).

The biography of 'Harold' shows the interactions between work, relationships and identity formation. Having been made redundant from the mines, as was outlined in 4.3.3, Harold eventually transitioned into working with children with learning disabilities. Subsequently he worked as a social worker. He acquired the necessary qualifications as he went along, in order to enable these transitions. The career transitions not only increased the prestige of his work but also changed the dynamic of his relationships within his community. Later in his career as a social worker, Harold describes being sent to assess a former 'scab', a miner who had previously refused to show solidarity with the union and broken the strike. Given Harold's previous tensions with the scabs in the community, he offered the individual an alternative assessment officer. Harold recalls the man telling him to "Just do your bloody job". The man's wife later called Harold to thank him for the professional way he undertook the assessment (Rustin, 2002: 82).

Harold's narrative shows how changes in his work affected both his social relationships and his personal identity. As a miner, Harold recalls solidarity with fellow union members and tension with the 'scabs' who broke the strike. Having eventually acquired the career security and authority within the community associated with being a social worker, the dynamic of Harold's relationships within his community were again transformed. Similarly, Wengraf emphasises that Harold's self-identity evolved. Perhaps unsurprisingly, given his changing work and relationships within the community, Harold needed to develop a narrative that could account for the changes within his life and identity. Wengraf argues that by emphasising the *good fortune* of finding work as a social worker,

Harold was able, at least in his own mind, to maintain solidarity and identity with his former mining community, of whom many were unemployed (Wengraf, 2001b). Further, Harold projected his identity through narrative by synthesising his career, qualification and relational transitions into a story of self-development. He emphasised how he had navigated the different challenges he had encountered and, by taking his chances, managed to establish himself despite the traumas faced by him and the wider community (Wengraf, 2001b).

The case study of Harold illustrates that narrative methods can make a substantive contribution to understanding how valued abilities develop over time. Narrative methods therefore enable an assessment of: (i) the extent to which an individual is able to enjoy different aspects of life; (ii) how the individual understands themselves; and (iii) how the different aspects of life interconnect through time to support their self-understanding.

While qualitative methods provide a rich understanding of the phenomena of relevance (many of which are innately qualitative), there is often value in combining qualitative and quantitative methods (Johnson and Onwuegbuzie, 2009). Specifically, qualitative methods can be used to observe and understand the phenomena. Using an inductive approach, as patterns are observed relating to the impact of health on individuals' lives from the qualitative data, theoretical observations can be made which in turn can lead to the generation of hypotheses concerning the *process* via which one event, such as an individual developing a severe health difficulty, can lead to another, such as increased social isolation (Maxwell and Mittapalli, 2010; Sayer, 2000). The researcher can then use a *deductive* approach to test the hypotheses generated through the understanding derived from the qualitative research. To an extent, these hypotheses can be tested using qualitative methods; however, these hypotheses can often also be formulated in a manner via which they can be tested using quantitative data. One possible advantage of doing so is that it enables these hypotheses to be tested using large datasets which aim to be representative of the general population (Johnson and Onwuegbuzie, 2009). It is worth noting that a disadvantage of using nationally representative datasets is that the data collected are often unsuitable for establishing a continual flow of events. Specifically, instead of inducing a narrative flow, the structured survey questions often aim to elicit whether a given occurrence has happened in the last year. For panel surveys undertaken annually, a similar question therefore will not be asked again for a substantial period of time. Such data do not allow a detailed investigation of the process via which one event leads to another. If quantitative data from these secondary datasets are used for the

deductive stage, the hypotheses, generated by a *process approach* to the analysis of biographical data, will often have to be reformulated such that they can be tested according to variance theory<sup>14,15</sup>.

Variance theory (or regularity theory) involves the investigation of correlations between variables (Maxwell and Mittapalli, 2010; Mohr, 1996; Sayer, 2000). Typically using a regression model, the researcher investigates the contribution a number of hypothesised explanatory variables make to changes in the outcomes of interest (Mohr, 1996). For example, if the researcher is interested in investigating whether increased education “causes” an increase in pay, the researcher may aim to statistically control for other potential influences (such as age, gender, etc.) and see if increased education is regularly associated with increased pay. Therefore, when adopting variance theory to make inferences about causation instead of trying to directly observe the process via which one event leads to another, the researcher instead attempts to identify if one hypothesised input is regularly associated with the hypothesised output (Maxwell and Mittapalli, 2010; Sayer, 2000). The researcher investigates the strength of the correlation between the hypothesised input and output (while attempting to control for potential confounders). If the association is found to be strong, this supports there being a causal relationship between the hypothesised input and output (although an identified correlation is insufficient to definitively demonstrate causation) (Beran and Violato, 2010)<sup>16</sup>.

When undertaking empirical research, it is possible to draw from both the process and variance approaches to causality to respectively both: (i) learn further about the nature of possible causal relationships and (ii) test their generalisability to the wider population. Using an inductive approach to analyse the biographical data may lead the researcher to a hypothesis concerning the *process* via which a health difficulty affects the lived experience of the adolescent. This hypothesis can be reformulated such that the

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<sup>14</sup>An additional limitation of using a secondary data source is the researcher has likely not influenced the data collected. The specific relevance of this issue to the thesis will be summarised briefly in chapter 0 and discussed in greater depth in 9.4.1.2.

<sup>15</sup> Of course, when combining qualitative and quantitative methods, there is also a potential discrepancy between the epistemological positions that motivate the use of each method. This issue is well discussed in the literature (Brannen, 2005; Greene et al., 1989; Morgan, 2007; Niglas, 2010; Tashakkori and Teddlie, 2003) but I summarise both this issue and the position I adopt in 5.1.

<sup>16</sup> Beran and Violato (2010) that several conditions must be met for causation to be determined: (i) the variables must be significantly correlated; (ii) a common cause of the two variables must be ruled out; (iii) there must be a strong theoretical rationale for the causal relationship; and (iv) the “input” must precede the “output” and if the input changes the output must change (and not vice versa). As Beran and Violato note, it is rare that all these conditions can be met, and therefore, it is also rare that causation can be definitively demonstrated.



regularity of association between input and output can be quantitatively assessed using a deductive approach which accords with variance theory. If an association between the input and output variables is indicated by the quantitative analysis, then to an extent the hypothesised process, informed by the qualitative data, receives additional support.

Below, I now critically review previous approaches to using quantitative data and methods to identify valued abilities and the correlates of their formation.

#### 4.4.2. Quantitatively assessing the dynamic formation of valued abilities

An initial attempt to quantitatively implement the capability approach by investigating the association between the opportunities and abilities individuals enjoyed and SWB was undertaken by Anand et al. (2005). Anand et al. used Nussbaum's Capability Specification (2001) as a framework for the analysis and selected indicators according to the domain descriptions provided by Nussbaum and the data available in the BHPS, combining approaches two and four from Alkire's list of possible approaches (2008). Anand et al. used data from a single year of the BHPS and therefore incorporated it as a cross section rather than a panel. The authors used an ordinary least squares (OLS) regression to identify the relationship between explanatory variables, indicators representing achieved outcomes for each of the different capability domains, and the dependent variable of SWB. The study contributed to the literature by both demonstrating that it is possible to empirically implement research grounded in the capability approach and by demonstrating associations between many of the indicators representing the different capability domains and SWB. However, for the purposes of informing the approach adopted in this thesis, Anand et al.'s study had two substantial limitations. Firstly, the use of data from a single wave prevents any investigation of the dynamic formation of the relevant capabilities. Secondly, as noted by Anand et al., the approach of using individual indicator variables to represent different capabilities leaves open the issues of reductionism (as discussed above), measurement error and whether the variables being incorporated are best conceptualised as capabilities or functionings. While Anand et al. argued that the single indicators used could be interpreted as capabilities, many of the variables represented the opportunities and abilities individuals had actualised and therefore, in the terminology of the capability approach, are more justifiably interpreted as related to functionings (Anand et al., 2005).

I now turn to consider a quantitative approach which, when coupled with longitudinal data, has the potential to reduce these limitations.

*Using structural equation models: a stylised example*

Structural Equation Models (SEMs) (Joreskog and Goldberger, 1975) are now used relatively frequently by capability theorists to investigate the associations between capabilities and the factors such as gender and income which are believed to influence them (Anand et al., 2011). Below, I present a brief stylised example to explain the method before summarising the different ways the approach has been implemented in three studies.

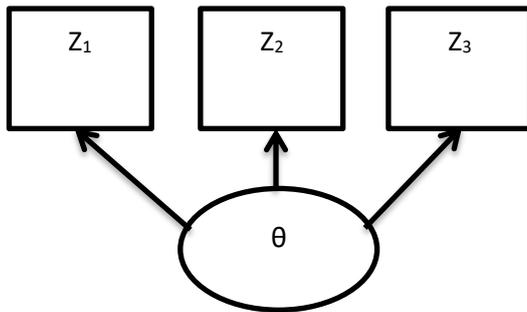
A challenge of quantitatively modelling valued abilities and opportunities is that they are often either not directly observable or can only be observed with measurement error (Popli et al., 2013). For example, individual indicators may be identified that have relevance to “the capability to enjoy individual, family and social life”, a capability listed by Burchardt and Vizard (2009), but it is unlikely that any single indicator will fully represent an individual’s underlying *capability* to enjoy even a single aspect of this domain such as the ability to enjoy social life. Indicators used in secondary datasets such as the British Household Panel Survey (BHPS) and the LSYPE1 are likely only to capture the extent to which an aspect of this domain has been *achieved*.

In the SEM framework, measurement models use factor analysis to make inferences about the underlying latent variable hypothesised to causally influence a number of related observed indicators. These latent variables, captured by the measurement models, can then be incorporated into the structural model. The structural model investigates the relationship between one or more latent variables and other observed variables of interest such as gender or income (Beran and Violato, 2010; Popli et al., 2013). Below, I use diagrams and verbal explanations to summarise the SEM method (I will provide a more formalised description of the method in chapter 0). I adopt the SEM convention of using ovals to represent latent variables and squares to represent observed variables. Arrows represent the hypothesised direction of causality between the variables.

For a measurement model to be independently identifiable at least three observed indicators which are hypothesised to be caused by the underlying latent variable are

required (Acock, 2013a)<sup>17</sup>. Figure 4-1 below schematically presents such a model. To make the example more concrete, the latent variable  $\theta$  could be individuals' underlying academic ability. The observed indicators  $Z_1$ ,  $Z_2$  and  $Z_3$  would then be individuals' scores on different academic tests. The measurement model therefore assumes that the *latent* academic ability influences individuals' *observed* test scores.

Figure 4-1: Measurement model



The measurement model separately estimates the shared variance between the observed indicators and each indicator's unique variance. The unique variance of each indicator, as it is not shared with the other indicators, is conceptualised with respect to the underlying latent variable as being measurement error. By explicitly allowing for and capturing measurement error, a latent variable approach has the potential to enable the underlying latent variable to be more accurately estimated than if a single indicator was used in isolation. Additionally, the relationship between each of the indicators and the underlying latent variable can vary in strength (Acock, 2013a). The researcher therefore does not have to assume each of the indicators has identical relevance with respect to the latent variable they are attempting to measure.

Theoretically informed hypotheses can be tested using the structural model. Based on theory the researcher posits causal relationships between latent variables and observed variables in the structural model. The statistical significance of the correlations between the variables is then tested within the structural model. If the correlation between two variables is statistically significant it leads to the rejection of the null hypothesis: that there is no relationship between the two variables. Finding that there is a significant relationship between the two variables, if the coefficient has the anticipated sign, is

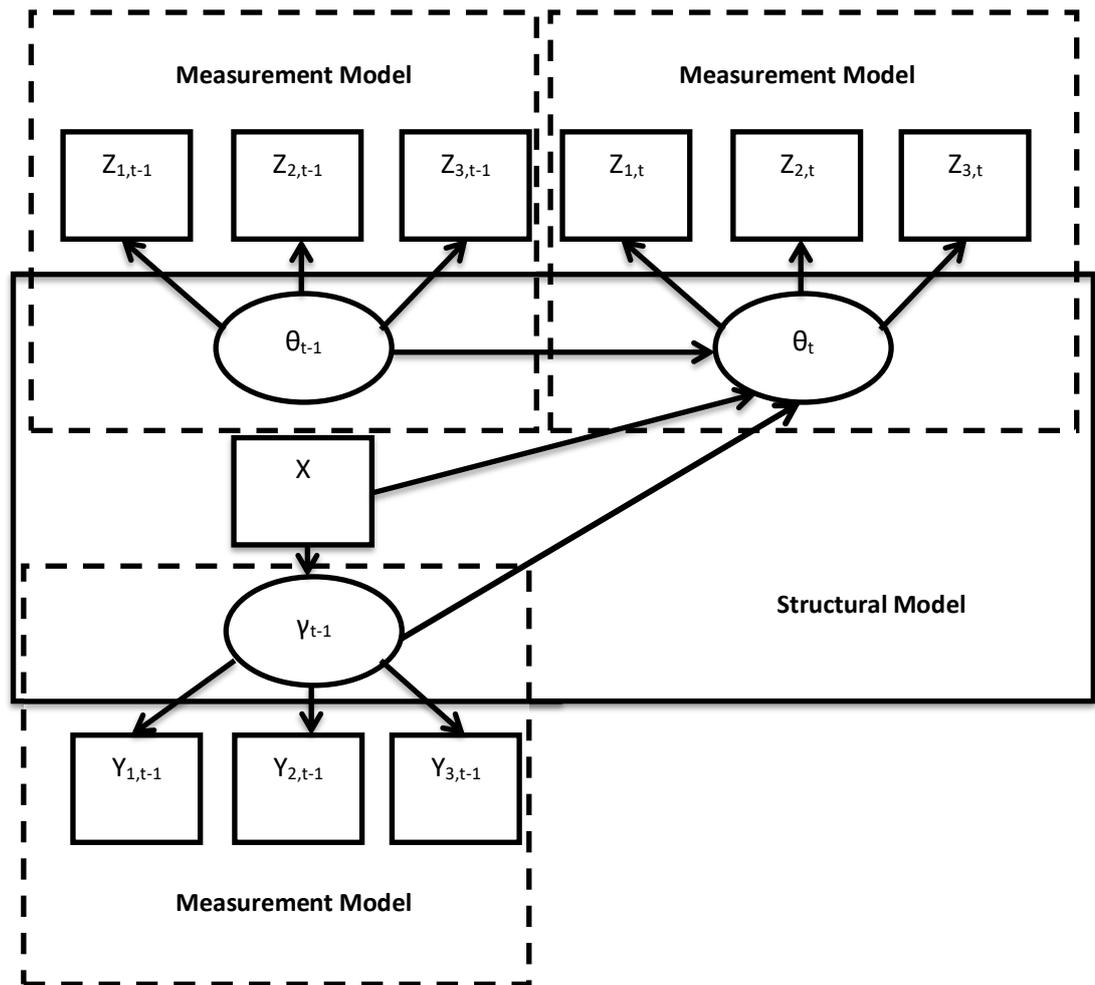
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<sup>17</sup> It is perhaps worth noting that it is possible to estimate a latent variable which has only two indicator variables if additional observed variables are included in the wider SEM. Nevertheless, it is preferable for the measurement model to have three indicator variables so that it can be independently identified, or better, four so that it is "over-identified" and therefore the fit of the measurement model can be independently assessed.

*supportive* of the hypothesised the causal relationship posited by the researcher (Beran and Violato, 2010).

Figure 4-2 below illustrates a stylised structural equation model and includes both measurement models and a structural model. To make the example more concrete, and for consistency with Figure 4-1 above,  $\theta_{t-1}$  and  $\theta_t$  could be interpreted as academic ability in the current and previous years. The observed variables  $Z_{1,t-1}$ ,  $Z_{2,t-1}$  and  $Z_{3,t-1}$  could be the responses to questions from a mental health survey asked in the previous year. The latent variable  $\gamma_{t-1}$  might then be interpreted as mental health in the previous year. The covariate  $X$  is hypothesised as a factor which affects both the pupils' previous mental health and their current academic ability – in this context it could be whether or not they have a chronic physical health difficulty.

Figure 4-2: Stylised structural equation model



The structural model above would therefore allow the researcher to assess the degree of support for the following hypotheses: (i) previous academic ability predicts current academic ability; (ii) mental health difficulties in the previous period impair the accumulation of academic ability; (iii) a chronic health difficulty directly impairs the accumulation of academic ability; (iv) a chronic health difficulty causes mental health difficulties; and (v) a chronic health difficulty indirectly impairs the accumulation of academic ability via the pathway of damaging mental health.

The final three hypotheses show an additional advantage of structural equation modelling that is particularly relevant for the second objective of the thesis: “to examine the pathways through which health difficulties impact the formation of valued abilities”. The method enables the researcher to estimate the statistical significance of the indirect pathways via which one latent or observed variable may influence another. Specific to the stylised example above, if from the descriptive statistics of the data the researcher has noted a correlation between a chronic health difficulty and lower test scores, the SEM above allows the researcher to investigate whether the data indicate the relationship is either predominantly mediated via the chronic health difficulty’s impact on mental health; predominantly a direct relationship between the chronic difficulty and impaired accumulation of academic ability; or there is evidence that the chronic difficulty has an impact via both pathways (Muthen and Asparouhov, 2015).

*Using structural equation models: previous efforts to model valued abilities*

One of the first attempts by a capability theorist to use the SEM approach to empirically investigate the predictors of different valued opportunities was undertaken by Kuklys (2005). Kuklys used data from BHPS to investigate the predictors of individuals’ achieved outcomes, or functioning, with respect to health and being well-sheltered. Measurement models were used to capture individuals’ achieved outcomes in each of the two domains. Separate models were fitted to two waves of data from the BHPS; specifically, the interviews undertaken in 1991 and 2000. In both the models, Kuklys measured health using three indicators: physical illness which affects daily activities, visits to the doctor during the past year and self-assessed health status. Four indicator variables were used for the measurement model relating to being well-sheltered: problems with condensation, problems with rot in windows or floors, problems with heating and problems with space. Kuklys’ hypothesised that gender, job status, marital status, educational level, age and income might all plausibly affect the two domains. In both periods, a structural model was therefore used to regress the two latent variables upon these explanatory variables. While the specific findings of the analyses are of limited relevance to the thesis, the interpretation given to the latent variables is of direct relevance to this methodological review. Kuklys considered the latent variables to be functionings – achieved outcomes. Measurement models were not used to make inferences about the underlying capabilities that might cause these achieved outcomes but rather to explicitly address the imperfection with which any indicator could truly capture individuals’ functioning in that domain. More precisely, measurement models

were therefore used to address the measurement error between the indicators and the functioning of relevance.

An alternative interpretation to the latent variables was adopted by Krishnakumar and Ballon (2008). The authors used cross-sectional data from a national household survey conducted by the Bolivian National Institute of Statistics to investigate children's and adolescents' capability sets across the domains of knowledge and living conditions. Three indicator variables were used in each of the measurement models. While each of the observed indicators used in the measurement model report an achieved outcome, they argue it is legitimate to assume the latent variable which causes the shared variance amongst the observed indicators of relevance is an individual's *capability* to achieve desired outcomes in that specific domain. They report this is possible with the following two assumptions, "(a) the capability set or the freedom to choose is not directly observable but manifests itself in many observable indicators; (b) any single indicator can only be a partial measure of the underlying concept." (Krishnakumar & Ballon 2008: 994). Given a latent variable is a hypothesised construct, a degree of subjectivity is involved when attempting to give it a specific interpretation (Joreskog and Goldberger, 1975). However, it does seem reasonable that the capability to enjoy an opportunity or ability might meaningfully be inferred by the shared variance in a number of indicators relating to the specific domain. Assuming it is reasonable to believe the capability of interest explains the shared variance observed, then adopting a latent variable approach also reduces the need for reductionism. Making inferences at the level of the latent variable, hypothesised to be measured by the indicators included in the measurement model, avoids the need for the researcher to reduce the construct of relevance to a question that can readily be asked in a quantitative questionnaire (Newman and Ramlo, 2010) .

I am currently unaware of any endeavours in the capabilities literature to use the SEM approach to model the formation of capabilities over time. Cunha and Heckman, economists influenced by human capital theory, analysed longitudinal data from the Children of the National Longitudinal Survey of Youth/79 using a SEM to empirically investigate how cognitive and non-cognitive (socioemotional) skills formed through time (Cunha and Heckman, 2008). Indicator variables relating to both cognitive and non-cognitive skills were incorporated into the model at two-year intervals when individuals were: 6 and 7; 8 and 9; 10 and 11; 12 and 13. Cognitive skills were measured using items from the Peabody Individual Achievement Test, which has sub domains relating to mathematics and reading recognition. Items from the Behaviour Problem Index (BPI)

(Peterson and Zill, 1986) were used as indicator variables to measure non-cognitive skills. Five sub scores from the BPI were incorporated: (i) antisocial; (ii) anxious/depressed; (iii) headstrong; (iv) hyperactive; (v) and peer problems. Cunha and Heckman report numerous findings, and of particular interest to this study is that the analysis identified a strong correlation between cognitive and non-cognitive abilities. Non-cognitive skills were positively correlated with higher cognitive skills in the subsequent time period. Additionally, the within period correlation between cognitive and non-cognitive skills increased over time – further supporting the notion that skills (abilities) are “cross fertilizing” and synergistic over time.

Considering the research objectives of the thesis, the SEM approach has substantial strengths. The use of measurement models enables greater accuracy in the evaluation of individuals’ valued abilities (Acock, 2013b). Additionally, these measurement models can be incorporated into structural models enabling both investigations of associations through time and an analysis of the direct and indirect effects of a covariate. The method in principle can therefore support the second objective of the thesis: to identify the pathways via which health difficulties in an earlier period are associated with subsequent impaired formation of valued abilities.

#### 4.5. Conclusion

To engage with the research objectives robustly, both qualitative and quantitative methods are required. Without qualitative methods, it will not be possible to investigate the lived experience of adolescents, noting their accounts of how health affects their valued abilities. Quantitative methods are required to robustly achieve the second objective, to identify the pathways through which health difficulties dynamically impact valued abilities. This is because they enable hypotheses of causality to be tested using a sample that is designed to represent the wider population. This in turn helps ensure the generalisability of the pathways identified and therefore the likely relevance of the findings to the wider population.

The systematised review, reported in chapter 3, indicates that to date there is a paucity of studies which combine qualitative and quantitative methods to investigate the research questions. Indeed, no qualitative studies were identified which met the inclusion criteria. Additionally, the current literature has primarily focussed on the outcomes of primary relevance to human capital theorists and therefore largely fails to inform conclusions



concerning the impact of a health difficulty on the wider aspects of life individuals have reason to value.

The methodological review in this chapter indicates that a number of methods are available which are consistent with: (i) my epistemological position; (ii) my assumptions concerning the individual as a psycho-social subject; and (iii) the study aims and objectives. Specifically, as discussed in 4.3.3, combining narrative and semi-structured interview methods should enable me to investigate the wider perspectives of young people in a manner that accounts for the influence of anxiety on how we present ourselves to others (or more formally that accounts for each of us being defended subjects – for further detail on the concept of defended subjectivity see 2.3) (Hollway and Jefferson, 2000a). Engaging with their lived experience and learning from their emic knowledge should enable me to observe patterns concerning the aspects of life they particularly value and the role health plays in facilitating their enjoyment of these wider skills and abilities. Structural equation models will enable me to analyse longitudinal data from a nationally representative dataset in a manner which: is consistent with my sensitising theoretical framework, explicitly accounts for measurement error and limits the need to reduce qualitative constructs to concepts that can typically be captured with a single quantitative indicator.

In chapter 5, I turn to considering how qualitative and quantitative methods can be combined to build on the current empirical literature in order to more fully address the specific research aim of the thesis.

## 5. Integrating qualitative and quantitative methods to address the research aim

The aim of this chapter is to outline how qualitative and quantitative methods can be integrated to address the thesis' aim and objectives. In 5.1, I outline some important considerations when integrating qualitative and quantitative methods. In 5.2, I then summarise the mixed methods research design. The novel contribution of this chapter is to provide a methodological overview of a mixed methods study which integrates both longitudinal qualitative and longitudinal quantitative strands of research.

### 5.1. Considerations when integrating qualitative and quantitative methods

Mixed methods research can be defined as:

*“the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches...for the purposes of breadth and depth of understanding and corroboration”* (Johnson et al., 2007: 123)

As discussed in 4.5, integrating qualitative and quantitative methods has the potential to enable me to more robustly address my research aim and objectives. By combining both methods, it should be possible to allow the weaknesses of each method to be minimised and the strengths of each to be maximised (Johnson and Onwuegbuzie, 2009). However, careful thought is required when implementing a mixed methods approach given: (i) differences in the nature of the data; (ii) the analytical methods used; and (iii) the different epistemological positions that, explicitly or implicitly, often undergird the analyses of researchers using the different methods.

#### *Epistemological considerations*

As already discussed in depth in the mixed methods literature (Brannen, 2005; Greene et al., 1989; Morgan, 2007; Niglas, 2010; Tashakkori and Teddlie, 2003), there are some who believe that qualitative and quantitative methods cannot be integrated due to incompatibilities in the different epistemological positions often associated with the two methods (Smith and Heshuius, 1986). In short, and to deliberately take two polar positions, researchers adopting quantitative methods are often implicitly or explicitly influenced by epistemological positions that *tend* towards positivism (Niglas, 2010). As such, they assume a singular reality. The *ideal* is to use experimental methods to identify the laws that govern the relationships between objects within this singular reality (Niglas, 2010). In contrast, researchers using qualitative methods may tend towards

constructivism: reality would therefore be viewed not as singular but multiple, a construct of each individual (Crouch and McKenzie, 2006). These two polar positions differ in their fundamental assumptions about the nature of the world. If one's epistemology influences one's methodology, methods, results and finally one's interpretation of the derived results (which are arguably undertaken in the context of one's epistemology), then undertaking research grounded in two very differing epistemological positions will necessarily lead to an incoherent research.

However, as Niglas argues (2010), there are epistemological positions other than positivism and constructivism which provide a coherent position from which to undertake an analysis of *both* qualitative and quantitative data. One such position is that of subtle realism which, as discussed in 1.3, is the one I adopt for this thesis. Subtle realists hold the view that there is a reality which can be known but that any attempt to engage with this reality is constrained by the researcher's perspective (Seale, 1999). Rather than undermining the use of both qualitative and quantitative methods, this position motivates their integrated use. Having acknowledged that my own perspective on reality constrains my ability to engage with (a singular) reality, it is logical that I endeavour to engage with the perspectives of others. Similarly, my knowledge that the perspective of those I engage with is also limited provides me an incentive to test any findings that emerge from their lived experience using data gathered from a wider population.

In summary, I would argue that it is entirely feasible to use both qualitative and quantitative methods in a manner that is coherent with a singular epistemological position (Johnson and Onwuegbuzie, 2009). Nevertheless, a consideration of these potential epistemological tensions should support the researcher implementing a coherent approach to the study's methodology, methods, results (and their subsequent interpretation).

#### *Integrating the qualitative and quantitative components when undertaking the research*

It is often the case that the nature of the data analysed in qualitative and quantitative research differs substantively. As discussed in 4.4, this can go beyond the obvious differences concerning the analysis of concepts represented by words instead of being reduced to numbers. The data may also differ in the extent to which they allow researchers to analyse a flow of events over time (e.g. a narrative told by a participant) compared to "snapshots" taken at particular times (e.g. quantitative data obtained from a secondary dataset which contains responses to structured questions asked annually). As

discussed in 4.4, the differing nature of the data have implications for the type of knowledge the researcher aims to further establish with each. Data that contain a flow of events are particularly suitable for trying to understand the process that leads to events occurring (Maxwell and Mittapalli, 2010; Sayer, 2000). Whereas data from largescale secondary datasets are often most suited to testing whether the associations one would expect, given the hypothesised process, are supported as existing (and therefore significantly different from zero) across a nationally representative population (Maxwell and Mittapalli, 2010; Sayer, 2000).

Given the typically different strengths of qualitative and quantitative data and their different contributions to the inductive/deductive cycle at the study design stage, it is important to consider how the two components can be effectively integrated (Nastasi et al., 2010). Of course, both the qualitative and quantitative strands of the mixed methods study may not be singular items. Complex mixed methods designs allow the researcher to iterate between the two *strands* of the research (Nastasi et al., 2010). As the study continues preliminary findings and hypotheses generated from one strand can then inform the ongoing data collection efforts (or analytical plan) implemented in the other (and vice versa) (Nastasi et al., 2010). Integrating the qualitative and quantitative components in the earlier stages of conducting the research can both help ensure the overall coherence of the research study and allow the findings of the two studies to be rigorously triangulated. Doing so should enable the research yield of the combined mixed methods study to be maximised so that as a whole its research yield is substantively greater than could be obtained by undertaking each component in isolation (Nastasi et al., 2010; Ó'Catháin et al., 2010).

#### *Integrating the findings of the qualitative and quantitative strands*

Thorough triangulation is required if the knowledge derived from the mixed methods research project in its entirety is to be greater than the sum of its qualitative and quantitative strands (Ó'Catháin et al., 2010). Triangulation often includes two complementary facets. Firstly, triangulation involves assessing the degree of corroboration between the findings that emerge from each strand of the research. However, it also involves studying the research problem with both methods to gain a more complete picture (Ó'Catháin et al., 2010). This second facet goes beyond assessing whether the findings from each sub-study agree to dialectically considering how the analysis of divergent findings can lead to a fuller understanding of the phenomenon of interest.

A triangulation protocol is one method for undertaking triangulation in a manner that facilitates both the facets of triangulation. Having conducted the qualitative and quantitative studies the researcher, or research team, constructs a table which simultaneously reports the major findings to emerge from both the qualitative and quantitative research. The qualitative and quantitative findings recorded in the table are then compared, allowing the researcher to note where there is agreement, silence and dissonance between the findings of the sub-studies (Farmer et al., 2006).

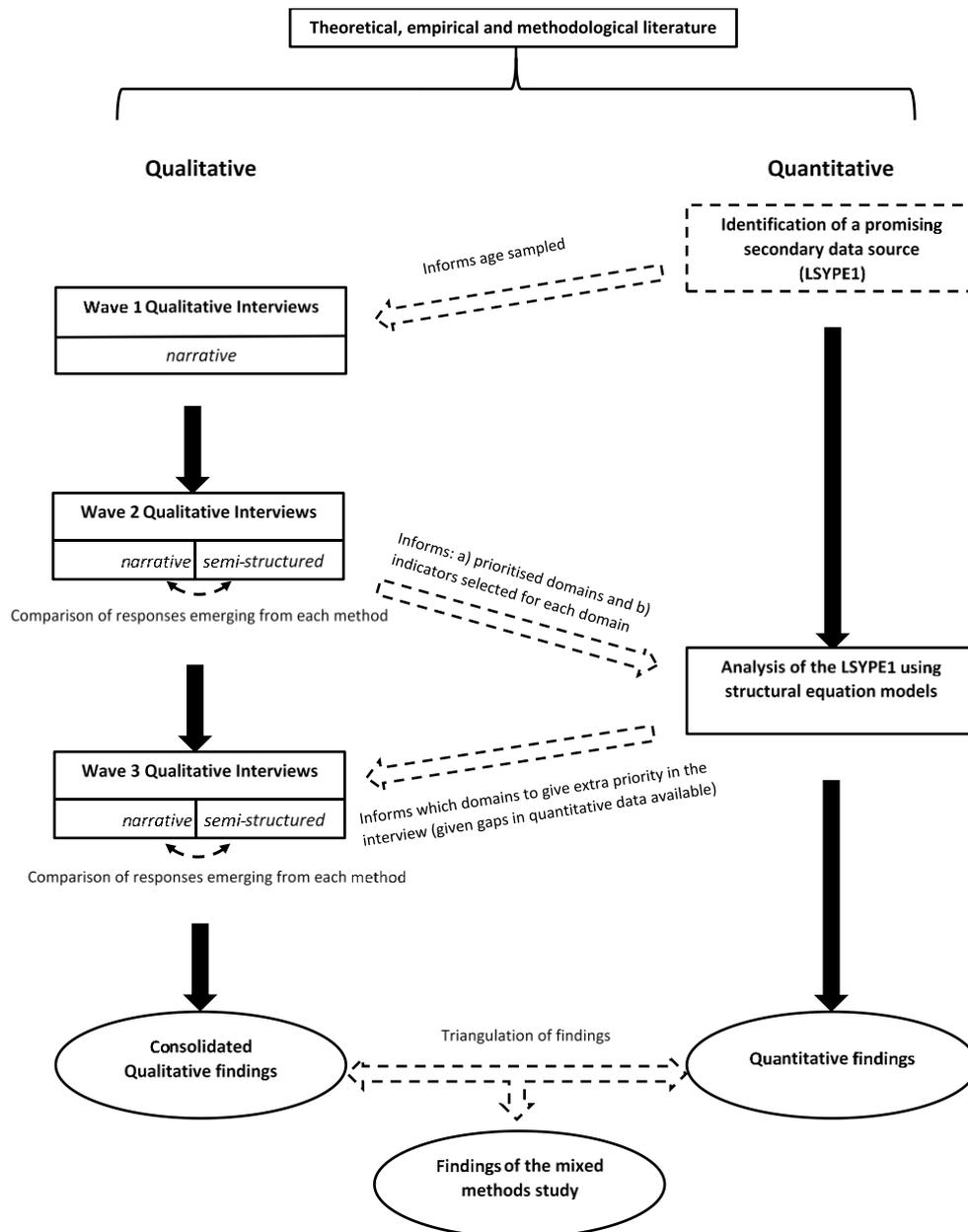
It is worth noting that dissonant findings can eventually strengthen rather than weaken the knowledge derived from a mixed methods study. To enable a fuller understanding of the research question, it is important to explore why the different methods may lead initially to different findings. A dialectical exploration of seemingly contradictory findings may eventually lead to a fuller understanding of the phenomenon and why the methods used, and the perspectives they bring to bear, expose different facets of the same reality (Nastasi et al., 2010; Ó’Catháin et al., 2010).

## 5.2. Overview of the research approach

I now provide an overview of the mixed methods study design implemented in this thesis. It is common practice amongst mixed methods researchers to provide a simple characterisation of their study in order to enable readers to easily conceptualise the study and how the qualitative and quantitative strands interact. While acknowledging Creswell’s observation (2010) that doing so risks over simplification, the design can be characterised as being iterative (QUAL →← QUAN) (Nastasi et al., 2010). The qualitative (QUAL) and quantitative (QUAN) strands are therefore undertaken concurrently and interact with each other throughout the research process. Additionally, as indicated by the use of capitals for both of the sub-studies, equivalent emphasis is given to each of the sub-studies. In accordance with my epistemological position, each method is seen as providing a different but complementary view of the phenomena of interest. Together they should enable a broader and a more robust understanding of the research question (Creswell, 2010).

Figure 5-1 below provides a schematic of the qualitative research, the quantitative research and the approach taken to integrating the two strands.

Figure 5-1: Schematic of the mixed methods study design



As indicated by Figure 5-1, several steps are adopted to integrate the qualitative and quantitative strands of the research. Firstly, the identification of the LSYPE1 (Department for Education, 2011) as a source for subsequent quantitative analysis informs the age group of the sample for the qualitative interviews. Secondly, the findings of the second wave interviews concerning which aspects of life were of particular importance to the young people, informs the conceptual design of the expanded structural equation model (“expanded” in the sense that, unlike much of the previous literature and the exploratory SEM, it incorporates domains that are broader than education and employment). Thirdly,

the conceptual design of the expanded structural equation model influences the manner in which I undertook the wave 3 qualitative interviews. The construction of the expanded SEM makes possible the identification of the aspects of life for which there are sparse quantitative data in the LSYPE1. This allowed me to be particularly cognisant of these domains when choosing which follow-up questions to ask the participant during the wave 3 interviews.

Having concurrently conducted the data collection and analysis of the different studies, allowing each to inform the approach taken to the other, I compare the findings of the two studies. As suggested above, I use a triangulation protocol to note between the study findings where there is agreement, silence or dissonance. Findings falling into each of the three categories may be of value. Findings for which there is agreement between both strands of the research are likely to be those about which we can be most confident. Those findings which initially appear dissonant will spur further investigation. The result is likely either: (i) that the tension cannot be resolved, which will lead to the finding of each strand being called into question; or (ii) further consideration will lead to the conclusion that the two methods, with their differing perspectives, are potentially revealing different facets of a tentative higher level finding which resolves the initial dissonance. As concerns “silence”, this often results from the differing methodologies’ suitability for investigating different types of phenomena. To an extent, the ideal would be for both the qualitative and quantitative studies to generate findings relating to each area of relevance to the study. As discussed in chapter 4, this is unlikely to be feasible (e.g. investigating individuals’ lived experience using longitudinal quantitative data collected annually is problematic). Silence as concerns the specific findings of the two studies prevents these being triangulated. However, findings within this category often illustrate the increased scope of the study enabled by the use of the two differing methodologies.

Further detail on the methods used and the rationale for the approach can be found for the qualitative study in chapters 6 and 7. The quantitative study is reported in chapter 0. I report the approach taken to integrating the findings from each strand of the study in greater depth in chapter 9.





## PART 2: A QUALITATIVE INVESTIGATION



## 6. The methodology adopted for the qualitative research

### 6.1. Introduction

In this chapter I provide a summary of the methods used in the qualitative strand of the mixed methods study. In 6.1.1 I summarise how the thesis' aim and objectives motivate my approach to the qualitative research. In 6.1.2 I reflect on how my own background has the potential to influence my engagements with research participants and my subsequent analysis of the material that emerged from their interviews. In 6.2 I provide an overview of: (i) the preparations I undertook before commencing the qualitative research; (ii) the methods used to interview participants over the three different interview waves; and (iii) the methods used to analyse the qualitative data that resulted from my interaction with the participants during these different interviews. I then summarise the advantages that accrue from my research design in 6.3. The novel contribution of this chapter is to summarise the approach adopted to conducting an innovative and complex qualitative study – one that is not only longitudinal in nature but also combines multiple interview and analytical methods.

#### 6.1.1. Background

An objective of the thesis, as outlined in 1.2 and 4.1, is to “investigate the lived experience of adolescents, noting their accounts of how health affects their valued abilities”. Previously in 4.2, I discussed why qualitative methods are particularly suitable for achieving this research objective. They enable the researcher to analyse the data while remaining close to the word by word account offered by the individual with the lived experience of interest.

As a researcher, having established the value of using a qualitative approach to investigate the first objective of the thesis, it was important to consider which methods to use and what study design to implement. Guidance from senior academics who reviewed the initial study plan<sup>18</sup> helped inform the approach taken to a further review of the qualitative literature relating to health, illness and the strengths and limitations of different interview methods. Having reviewed the literature, which is outlined within chapters 2 and 4, I concluded it would be best to mix the qualitative interview methods

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<sup>18</sup> During the upgrade examination, the qualitative examiner, Professor Paul Bissell, suggested additional references that would be a helpful starting point for furthering my understanding of topics mentioned. Additionally, conversations with Professor Allison James and Dr Julia Davies were very helpful in both orientating my thinking towards undertaking interviews with young people and providing me with useful practical suggestions.

used, including both the biographical-narrative method and semi-structured interview method within the qualitative study. As discussed in chapter 4, there are limitations with both. However, it seemed the adoption of this combination in the qualitative study would allow the limitations associated with each method to be reduced. The biographical-narrative approach would enable a fuller and more critically informed understanding of each individual to be developed. However, the approach does not allow the interviewer to ask participants numerous pre-planned questions. Using a semi-structured approach in later interview waves would allow me to consistently ask the different participants questions of direct relevance to my research objectives (whereas as outlined in 6.2.2, the initial BNIM question I ask is very broad and the subsequent questions differ according to the participants response to the initial question). Combining the two approaches enables me to compare the responses elicited by each type of question. As will be illustrated in greater detail in 6.2, this enables a more robust analysis of: (i) the participants lives; (ii) the aspects of life of particular importance to them; and (iii) the role health plays in their lived experience.

Concerning the study design, the wider literature (Baker and Edwards, 2012; Biggeri and Libanora, 2011; Wengraf, 2013), supervisors and senior academics again supported me in thinking through my approach as to which groups of people to interview, how many from each group to interview and the number of times to interview each person. The approach taken to each of these considerations is discussed in greater detail in 6.2.1. In summary, in order to allow clear comparisons, it was important to interview both young people with health difficulties and those without. Additionally, given the evidence that indicates there may be differences by gender in how health difficulties impact young people, it was important to have a mix of girls and boys both amongst the group experiencing health difficulties and in the group that were not. Finally, given that it is central to the overall research aim to investigate both “the immediate and future impacts of negative health”, it was important that at least some of the young people were interviewed more than once so that there was capacity within the study to consider the dynamic impact of health within the individuals’ lives.

#### 6.1.2. Reflexivity in theory and application

The research reported in this study is a co-production between myself and the research participants (Hollway and Jefferson, 2000b). Indeed, the interview is itself a co-production where I as the interviewer interact with the participant, each of us responding consciously and sub-consciously to the other (Hollway, 2001). Furthermore, the analysis of the data

generated in the interview involves me attempting to empathise, engage with and understand the participant's experiences. As discussed in 4.2, engaging with individuals' lived experiences furthers the research by enabling perspectives other than my own to be considered, enabling the research to be informed by the emotions and experiences of those negotiating both health difficulties and a time of substantive transition. Engaging with another's lived experience is, in the positive sense of the word, "subjective". The interview involves the participant's "subjectivity" engaging with mine. The analysis involves my subjectivity trying to discern something of the participant's (Hollway and Jefferson, 2000c). In order to ensure the rigour of the findings reflexivity is therefore vital (Spencer et al., 2003). Reflexively engaging with the research involves explicitly considering myself and my values. This means considering how my values have influenced: (i) the interaction between me and the participant during the interview; and (ii) my response to the participant's narrative during the analysis (Spencer et al., 2003).

Given this context, it must be of value for me to explicitly consider my own biography and how it affects the perspective I bring to both the research area and the biographies of others. I will endeavour, in an abridged manner, to respond to the question I asked the participants: "...please tell me the story of your life so far, all those events and experiences that were important for you, personally ...".

I grew up in Gloucester, a small and relaxed city in Southwest England, in a relatively large family. I had two older brothers, two younger brothers and a younger sister. My parents were (and are) committed Christians, we all regularly went to church and, prior to secondary school, most of my friends and the "family friends" were also committed Christians. My siblings and I went to a small, parent-led Christian school where there were approximately 60 pupils aged from 4-16.

At age 11, with my mother's encouragement, I made a step that was unusual amongst most of our community and left the small Christian school to go to a selective boy's school. Gloucester still has state funded grammar schools.

The new school had quite a considerable influence on me. It was a school where academic success was aspired to amongst the children; it was something we would compete at. Being perceived as clever, if it also seemed you did not need to work hard to succeed, led to respect. So did being successful in sport. As a boy I enjoyed competition and confrontation. I ended up taking quite naturally to rugby and was involved in the school's teams with a reasonable level of success. In contrast to my previous school, not

everyone was a committed Christian. I was, and continued to be. However, I was now in an environment where this was met with a degree of mickey-taking that was largely well-meaning.

While I was in secondary school, a boy I did not know well, but who was in the same rugby team as me and in many of the same academic sets, became ill with chronic fatigue syndrome (CFS). This severely affected his life, ending his ability to take part in sport and causing him to rarely be present in school. The effect this health difficulty had on the life of a person which previously had, in many ways, been similar to mine is one of the factors that originally caused me to be interested in this area of research.

As school continued, my GCSEs and AS-Levels went well, but during my final year of school I had something of a crisis of faith. During this time, I also experienced a high level of anxiety that permeated many aspects of my life. It was a period when beliefs that had been foundational to me were re-considered and re-examined. While this was of value for my longer-term well-being, it involved some struggles at the time, affecting both my immediate happiness and my ability to enjoy relating to other people.

Following this difficult period, I went to university in York. By this time, I had become more at ease with myself and others. There was much about this environment that was very different to both my home environment and my previous educational contexts. I remember initially noticing that I was subconsciously somewhat confused by both:

- the educational environment containing an even mix of women and men, and
- the social environment having much less tolerance for displays of machismo than had been the case amongst my rugby playing friends in Gloucester.

I like to think that I (slowly) learnt to adapt.

At the end of my undergraduate degree, I married my wife Jen (who I met at university). During our first year of marriage, I undertook a master's in health economics at York University. Following the masters, for two years, I worked for a pharmaceutical company before moving to Sheffield, where I have worked three days a week as a health economist for a small consultancy involved in NICE submissions while researching towards a PhD two days a week. Jen and I now have two young children, Faith and Nathanael.

The reason for telling this story is to explicitly note to myself and any readers my own background, enabling me and the reader to consider how it may have shaped my

perspective. Reflecting on my biography, I can note some important phases within my life; these are to some extent demarcated by switches in my educational environment.

Up to secondary school, I was immersed in quite a distinctive sub-culture in which many people held the same beliefs and adopted a similar way of life. The sub-culture was highly orientated around the relationships between and within a collection of nuclear families. For most of these families, the faith of the parents played a large role in defining the family's pattern of life.

While this changed when I left for secondary school, a continuity between this early phase and my secondary years up to including taking my GCSEs was the importance of my nuclear family and the strong influence of other boys (both in my family and at the all-boys secondary school). Between both: (i) myself and my brothers; and (ii) myself and my school friends; there was a friendly but competitive dynamic to many of the relationships. As noted above, the abilities that commanded particular respect were physical strength, academic intelligence and skill at "banter". "Strength", in the broader sense, was therefore something to be acquired and demonstrated. However, it is perhaps notable that in spite of this environment a fellow team mate becoming ill with CFS left a strong enough impression upon me that it became one of my major motivations for undertaking this research.

Perhaps my period of difficulties with mental health could be considered a third phase. During this time, my ability to demonstrate "strength" in some of the core aspects of life left me. This led to me experiencing distress and vulnerability to a greater extent than I ever had previously. Additionally, it allowed me to question the value of my own beliefs, including my current approach to life.

For brevity, the time from going to university to the present could be considered as a distinct phase. During this period, to some extent, I have been exposed to a more varied, cosmopolitan group of people. However, most of the individuals I have related to closely during this period have been both relatively middle class and academically gifted. Perhaps the most distinct aspect of this phase, compared to previous ones, has been that there is no single way to flourish that is predominantly aspired to. Most individuals I know well have aspirations they work to achieve, but these aspirations are varied. In terms of informing my perspective on the research area, a limitation of this phase of my life is that most people I relate to closely have what could be termed a relatively high level of individual agency.

Arguably being aware of one's background and motivations is just the start of reflexively engaging with the research process. In order to help me maintain a reflexive approach throughout my collection and analysis of the qualitative data, I have undertaken a number of practical steps. Firstly, after each interview I promptly undertook post-interview notes in which, amongst other things, I recorded my initial impressions of the individual and my perception of the dynamics within the interaction between us. Secondly, while undertaking the analysis of the data, I both consulted these post-interview notes and made additional notes concerning the potential for my own background and outlook on life to either influence my perception of an individual or bias my emphases when considering the topics that were seeming to emerge from the interview material. Finally, I attempted to listen to the perspectives of others when considering and analysing the interview material. Specifically, I listened to and talked to the health care workers who helped me recruit the participants. Additionally, as described in 6.2.3, for those participants who would have the greatest impact on the findings of the qualitative research, my supervisors took part in some phases of the data analysis.

## 6.2. Methods

### 6.2.1. Study preparation

#### 6.2.1.1. *Planning a study sample and gaining access*

Discussions with senior academics informed my decision as to whom to interview, and this in turn had consequences in terms of accessing the individuals who I had judged most informative to include in the study. As discussed in 4.3 and 6.1, I decided it would be informative to include healthy controls within the study. Being able to compare the reported lived experiences of individuals who have either cystic fibrosis (CF) or asthma with individuals who had no severe health difficulties potentially enables greater clarity in the analysis of a health *difficulty* impacts on the life of the individual. Additionally, including individuals with no health difficulties can facilitate an understanding of the extent to which *good* health enables the development of wider abilities that support well-being. In order to recruit young people with no severe health difficulties, I approached a school which had a broad socioeconomic catchment area. I knew personally a teacher at the school. He supported me in obtaining the necessary permission from the school to recruit young people into the study.



Gaining access to individuals who have health difficulties proved to be a more complex process. During the upgrade exam, it was suggested by the qualitative examiner that instead of interviewing individuals with a range of health difficulties I should only interview individuals who could be characterised as having one of a limited number of difficulties. Following the upgrade process, I gave this further thought and decided to adopt the suggestion. It struck me that, given the relatively small sample I would be able to include within the study, having individuals with a wide variety of health difficulties would likely hinder my ability to make meaningful comparisons between individuals and therefore limit my confidence in any conclusions drawn from the study. This view had the practical implication that I would need to recruit young people with health difficulties through the National Health Service (NHS). Only by recruiting through a hospital would it be feasible to identify and contact a number of young people characterised by a limited number of health difficulties.

My qualitative supervisor knew a senior medical doctor at a nearby hospital [I deliberately omit further detail to protect the anonymity of the recruited participants] and arranged a meeting between the three of us. Prior to the discussion, I had not finalised the list of health difficulties that would be most appropriate but knew a number of them would likely be suitable based on the criteria that: (i) the health difficulty was severe enough that it typically led to the disruption of daily activities including schooling; (ii) adolescents with the health difficulty could typically expect to live for a number of years; and (iii) the health difficulty was prevalent enough that it would be feasible to recruit a number of participants within a narrow age range who lived in moderately close geographical proximity to myself<sup>19</sup>. He advised interviewing young people with either CF, severe asthma or type 1 diabetes. As well as supporting the study being undertaken in collaboration with the hospital, he also offered to contact the medical doctors responsible for the units treating those patient groups he had recommended. I then continued to liaise with the health care workers from that point on. Eventually, I decided to interview young people with CF and severe asthma. I decided to interview patients with two types of health difficulty rather than one primarily to increase the potential number of eligible participants. As types of health difficulty, CF and asthma seemed to

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<sup>19</sup> Prior to meeting the senior medical doctor, I had contacted a paediatrician I knew well and asked him to suggest types of health difficulty that met the first two of my criteria. The paediatrician suggested the following: epilepsy, juvenile idiopathic arthritis, CF, type 1 diabetes, asthma that requires specialist support, Crohn's disease and sickle cell disease. I undertook further desk research to investigate the prevalence of these health difficulties in an adolescent population.

complement well for the purposes of the research. The two health difficulties are typically associated with prognoses of differing severity; however, both impact on the individuals' lungs. My prior expectation was therefore that there would be some similarities in the impact of the two types of health difficulty but also the potential for a degree of divergence in the reports given by individuals from each of the two populations.

#### *An overview of severe asthma*

Following conversations with health care professionals from the hospital's respiratory unit, I decided to recruit patients who had asthma that could be considered severe, or difficult to treat. As will be outlined further below, this was defined in advance as being at step 3 or above according to the British Thoracic Society (BTS) Guidelines (2011) and having required respiratory input. Limiting the sample to young people with asthma that met these criteria would help ensure the participants had a health difficulty that was likely to disrupt their daily activities.

Asthma is a chronic inflammatory lung condition that makes breathing difficult. The airways undergo changes when stimulated by allergens or other environmental triggers. During the first stage of an attack, airways constrict and narrow excessively, causing the individual to struggle for breath. This is typically followed by an inflammatory response which causes the airways to swell, fill with liquid and produce a sticky mucus resulting in wheezing, breathlessness and a cough (Simon, 2012).

It is common for asthma and allergies to coexist, and allergic responses often trigger asthma exacerbations. Allergic asthma is triggered by inhaling allergens which include: dust mites, animal dander, mould and pollen from plants. An asthma attack can also be exacerbated or induced by irritants to the lungs which include cigarette smoke, and pollution from the air. The symptoms of an asthma attack include wheezing, shortness of breath, a dry cough, chest tightness, a rapid heart rate and sweating. These symptoms may be caused to worsen as a result of exercise, viral infections and exposure to irritants, stress or changes in weather. While an asthma attack often progresses very slowly, it may sometimes develop into a fatal or near fatal attack within a few minutes, and it is very difficult to predict when an attack will become very serious (Simon, 2012).

Asthma patients who, as classified by the BTS guidelines, are at step 3 will typically be treated with an inhaled corticosteroid and an inhaled Long Acting  $\beta_2$  Agonist (British Thoracic Society, 2011). If the patient does not respond to this course of treatment, their inhaled steroid dose may be increased or therapies may be added to increase the

likelihood of achieving control. If the patient continues to experience poor control despite the use of additional therapies such as leukotriene receptor antagonists or short response theophylline, it may be necessary for the young person to take oral steroid tablets (British Thoracic Society and Scottish Intercollegiate Guidelines Network, 2011).

Oral steroid tablets are very efficacious and often bring asthma under control. However, they also cause the adrenal gland to become less active. The patient's body therefore makes fewer natural steroids. This means the patient may have less ability to cope with infections; weight gain is a potential side effect of the sustained use of oral steroids (Asthma UK, 2015; Cleveland Clinic, 2007).

Previous qualitative research undertaken with adolescents suggests that asthma can have a substantive impact on the lived experience (Rhee et al., 2007). Although Rhee et al. did not restrict their recruitment of participants according to the severity of their asthma, the participants frequently reported that asthma constrained their ability to engage in physical exercise. Given the interconnected nature of the lived experience, asthma's impact on the lives of those interviewed was not limited to the physical dimension. Being unable to participate in certain forms of vigorous activity meant many of the participants were at times excluded from joining in activities alongside peers (Rhee et al., 2007; Woodgate, 1998). The physical constraints experienced therefore had social implications with emotional consequences. Many reported that being unable to engage in activities their peers could still enjoy led to a sense of unfairness (Rhee et al., 2007). To minimise the negative impact of asthma on their lived experience, the participants reported a number of ways in which they adapted their behaviour. Some of these adaptations appeared largely positive – for example, learning to be more vigilant in monitoring one's symptoms so as to minimise the risk of a serious exacerbation. However, some of the other adaptive behaviours taken by individuals risked negative consequences. In order to be seen as equal to their peers, some endeavoured to "toughen up" by ignoring their symptoms and pushing themselves beyond their physical limitations.

#### *An overview of cystic fibrosis*

CF is caused by a mutation of a gene called CFTR, which normally creates a protein that regulates the levels of sodium and chloride in cells. If an individual has CF, this bodily process is disrupted. The result is a build-up of a thick mucus in the lungs, pancreas, liver, intestine and reproductive system. CF is a progressive health difficulty that limits life expectancy, though the prognosis of individuals with CF is improving. It is estimated that

on average children born in the 21<sup>st</sup> century will live for more than 50 years (NHS, 2014a; NICE, 2014).

The symptoms of CF vary from person to person in terms of their type and severity. However, they particularly affect the lungs and the digestive system. The accumulation of mucus in the lungs can result in persistent coughing as the body attempts to remove the mucus. The lungs can become inflamed, which can lead to wheezing, shortness of breath and breathing difficulties. This is especially likely to occur after exercise. Some people with CF experience recurring infections in the lungs. Additionally, the build-up of mucus in the lungs provides an environment in which bacteria multiply rapidly. This not only puts the individual with the infection at risk, but through coughing or close personal contact the individual with the infection may pass the infection over to another person with CF. In order to minimise this risk of cross infection, it is therefore recommended that people with CF do not come into contact with each other (NHS, 2014b).

The secretion of mucus in the pancreas can disrupt the production of enzymes that support the digestion of food. Individuals with CF are therefore at risk of malnutrition and may struggle to gain weight. The mucus can damage the pancreas, leading to diabetes if the individual's pancreas does not produce enough insulin. People with CF who develop diabetes typically struggle to gain weight, and they often see a decline in their lung function. CF-related diabetes is usually controlled by injected insulin. As noted, CF does not only affect the lungs and the digestive system. CF also places the individual at increased risk of sinusitis, joint pain, infertility and liver failure (NHS, 2014b).

The treatment burden for CF is often intensive. Individuals often need to take a number of medications, regularly undertake exercises suggested by their physiotherapist and eat a carefully managed diet. Individuals with CF receive support and advice from a team of health care professionals at a CF centre. This team works with the individual, and in the case of a child, the individual's parents, to establish a programme of treatment that best manages the health difficulty (NHS, 2014c).

Many of the medical treatments taken by individuals with CF are for helping to clear and control infections in the lungs and digestive system. Antibiotics are given to fight infections in the lungs. If the infection is not severe, the antibiotics will often be taken as pills or inhaled through a nebuliser. However, if the infection is severe, the antibiotics will be administered intravenously. If an individual requires frequent long-term intravenous antibiotic treatment, they may have surgery to implant a portacath. This makes it easier

to administer the antibiotics when an individual's veins are difficult to access. As well as antibiotics, individuals with CF will often need to inhale enzymes via a nebuliser. The enzymes help thin and break down mucus that is in the lungs so that it is easier to get the mucus out of the body through coughing. Additional medications may also be required for treating some of the other health problems related to CF (NHS, 2014c; Wedlock, 2013)

Given the risk of infection, it is particularly important that individuals with CF maintain a healthy body weight in order to help the body fight off infections. However, as CF affects the pancreas, individuals with CF often have difficulties in digesting all of the food that they eat. It is therefore important that individuals eat a diet that is high in protein and calories. Advice is given by health care professionals as to the diet the individual should eat. It may also be necessary for the individual to take supplementary vitamins and digestive enzymes (NHS, 2014c).

Individuals with CF also have to regularly undertake physiotherapy exercises.

Physiotherapy for individuals with CF focuses on airway clearance but also supports other goals. The most widely used exercise technique in the UK for airway clearance is called active cycle of breathing techniques, where the individual goes through a cycle of different types of breathing followed by coughing. The individual repeats the cycle for 20-30 minutes. Individuals may also engage in exercises which involve leaning or lying down while a physiotherapist or carer uses their hands to vibrate sections of the lungs while the individual undertakes breathing and coughing exercises. These techniques help drain mucus from the body (NHS, 2014c).

Previous qualitative research suggests that for adolescents with CF an issue of great importance is managing their behaviour to reduce the extent they are perceived by peers as "different" (Christian and D'Auria, 1997). The symptoms and medical burden of treating CF sometimes make this problematic. For example, the participants interviewed by Christian and D'Auria mentioned the cough that is common amongst individuals with CF caused social difficulties. The cough sometimes resulted in peers seeing the individual as contagious and therefore someone to be avoided. Similarly, the participants interviewed reported that peers might sometimes shout insults when they saw the young person taking tablets during the school day. To minimise the extent to which they appeared "different", some of the participants did not adhere to their prescribed medication schedules. More positively, the participants also noted how close friends played an important role in helping them navigate the complex lived experience of an

adolescent who has CF. Generally, these close friends seemed to not only help prevent *others* victimising the individual but also helped the individual learn to develop their *own* positive self-identity. The participants indicated that these close friends helped them learn to accept their distinctiveness and weaken their perceived dichotomy between being “normal” and “different”. The interview material reported by Christian and D’Auria (Christian and D’Auria, 1997) therefore indicates that, as with asthma, CF has a wide-ranging influence on the individual’s lived experience. While CF has a direct impact on the individual’s physical body, the interconnectedness of life means individuals with CF often face additional difficulties in developing both positive relationships and a positive self-identity.

#### *Planned study sample*

The sampling strategy I adopted can be characterised as a stratified purposeful sampling approach. Within my overall sample I therefore aimed to collect interview data from six sub-samples; girls and boys who had either no severe health difficulty, severe asthma or CF (Harsh, 2011). When recruiting participants I therefore intentionally approached individuals to join the study in a manner that accorded with the numbers in each of the cells in Table 6-1 below (which summarises my planned sample, including the number I planned to recruit per strata). An advantage of adopting this sampling approach is that it allowed me to ensure I collected data that would enable me to consider both: (i) how different health difficulties affected the formation of individuals’ valued abilities and their lived experience; and (ii) whether there were any substantive differences by gender.

Table 6-1: Planned sample across the study waves

	Wave 1 Interview Method: Narrative		Wave 2 Interview Method: Semi Structured		Wave 3 Interview Method: Semi Structured	
	Female	Male	Female	Male	Female	Male
Planned number with no severe health difficulties	4**	4**	2	2	1	1
Planned number clinically defined as having severe asthma*	4**	4**	2	2	1	1
Planned number clinically defined as having CF	4**	4**	2	2	1	1

**Notes:** \*Defined for the purpose of this study as having a BTS score of 3 or above and having required support from a respiratory consultant in the last two years. \*\*Up to four individuals in each category will be interviewed. However, the aim will be to have undertaken interviews with three girls and three boys from each health category that generate material that can be analysed in depth. Therefore, if after 18 interviews this has clearly been achieved, no further individuals will be interviewed.

In the study design, I decided to include three waves of interviews, over approximately an 18-month period, to allow the qualitative study to inform my perspective of the lived changes faced by the participants over time<sup>20</sup>. As such, this study approach ensures the interview methodology is in line with the aim of the thesis: to research the immediate and future impact of health difficulties during adolescence on the *formation* of valued abilities. It was indicated by both senior academics and the health care workers supporting the study, who had experience in supporting other research projects, that from one wave of interviews to the next a number of participants were likely to drop out of the study. I planned an approach to account for this as much as possible by: (i) undertaking in depth BNIM interviews with a relatively large number of individuals in wave 1 so that there was a relatively high number of participants who would potentially be available to be re-interviewed; and (ii) intentionally planning for a reduction in the number of individuals who would be re-interviewed at each stage.

The planned approach necessarily leads to different quantities of data being generated for the different participants. However, this should not lead to incoherence in the analysis of the data generated by the study. As discussed in greater detail in 6.2.3, within the BNIM school of research, when analysing the materials generated from interviews with

<sup>20</sup> Within a single narrative interview, an individual is encouraged to in effect recall changes over time as they summarise their life story. However, when identifying changes over time, I wished to minimise my reliance on their recollections made over an extended period of time. By re-interviewing a number of individuals, I was able to observe how both their perspective and their circumstances changed over the period of repeat interviews.

individuals, it is not unusual to distinguish between these individuals as being either “focal cases” or “contrastive cases” (Wengraf, 2013). The material that comes from interviews with “focal cases” is then analysed in greater depth (Wengraf, 2013). In a similar manner, it is therefore not inconsistent for a greater number of interviews to have been undertaken with those individuals who will become “focal cases” rather than “contrastive cases”. While proceeding through the waves of interviews, individuals were judged as more likely to eventually become focal cases for their health and gender stratum if: (i) their interview material covered a breadth of issues; (ii) they were able to fully engage with the interview questions; (iii) their experiences exemplified the wider trends being articulated across the sample; and (iv) they indicated they would be willing to be re-interviewed.

In order to aid comparisons between individuals, I decided to restrict the age range of the individuals invited to take part in the study. I decided to interview young people who were aged 13-15 at the start of the study. This particular age range was chosen, firstly, because individuals at this age are starting to prepare for their General Certificate of Secondary Education (GCSE) exams. Given the importance of these exams and the objective of the qualitative study to investigate how health affects their wider abilities, I thought it would be of interest to hear first-hand how health difficulties were affecting individuals’ abilities to engage in their studies during this important period. The second reason for choosing this age range was that it corresponded with the age of individuals in the LSYPE1, the secondary dataset I planned to use for my quantitative analysis. Individuals were aged 13-14 when they were first interviewed for the LSYPE1. As discussed in chapter 5, recruiting a similarly aged sample to those included in the LSYPE1 would support me in comparing the findings that emerged from the qualitative and quantitative studies (Collins, 2010). Finally, given the relatively small number of individuals I could readily access with either CF or severe asthma, I decided to recruit individuals over two school years rather than just one. This decision was informed by conversations with health care workers at the hospital from which I was looking to recruit participants. They indicated that if I recruited individuals from just one school year I was unlikely to have enough participants for the study design.



#### 6.2.1.2. Ethics

##### *Ethical Considerations*

There were a number of issues to consider prior to commencing the study in order to ensure the research was conducted to a high ethical standard. The issues and the approach taken to each are outlined below.

Firstly, it was important to consider the issue of consent. Given the age of the participants, I judged it best to get permission from both the young person and their carer. I therefore sought informed consent from the young person's carer and informed assent from the young person themselves. This was achieved by providing the potential participant and their carer with age appropriate information sheets which described: the project's purpose; why the young person had been invited to take part in the study; what the interview process involved; the potential disadvantages and benefits of taking part; what to do if something went wrong during an interview; how their participation and data would be kept confidential; and how the results of the research project would be used. (See appendices B.1-B.2). On the day of the interview, I asked both the participants and their carers to complete a written consent form before the interview started (see appendices B.3-B.4).

Secondly, it was important to consider issues relating to the data generated including its storage. In order to protect the confidential information disclosed by the research participants, the only individuals permitted to access the recordings were myself and the transcribers. The transcribers were suggested by Dr Jenny Owen, my qualitative supervisor, and were used to working with sensitive data. The identifiable data collected (name of individual, sex, school year group and the link to their pseudonym) were stored separately from the transcripts, and the recordings taken from the interviews. In order to preserve the security of the data, it will be deleted two years after the completion of the study<sup>21</sup>.

Finally, it was important to consider the burden, risks and benefits of the research for the participants. There was a risk that some of the topics covered in the interviews could be emotive for the individual being interviewed. To minimise the burden placed on the participant, every effort was made to be sensitive to the participant and to not press them when there are strong signs they would prefer to not discuss certain topics. If it

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<sup>21</sup> In accordance with the study protocol, the study will be considered completed once a summary of the research findings has been shared with any interested study participants.

became evident that a young person was disturbed during the interview, I planned to notify either the appropriate school teacher or health care professional (depending on whether the young person had been recruited from the secondary school or the hospital). I would then discuss with the appropriate member of staff how the young person could be best supported. While there was a risk the interview could bring up topics that research participants might find distressing, there was also a likelihood that participating in the research would directly benefit them. These potential benefits included both: (i) the opportunity to engage in a conversation about their own experiences and what matters to them; and (ii) the opportunity to hear about the experiences of other individuals who may be encountering similar opportunities and challenges.

#### *Obtaining ethical approval*

The study protocol, study documents (information sheets and consent/assent forms) and the other relevant documentation were submitted to Camden & Islington Research Ethics Committee for ethical review. NHS research ethics approval was obtained (appendix B.5). Additionally, I obtained an NHS research passport so that I could approach potential participants and undertake interviews on the premises of the hospital<sup>22</sup>. Following the research ethics approval for the study, it was necessary to obtain a substantial amendment so that in the first wave of interviews young people could be interviewed at their home, while their parents were also in the house, if it was not possible to access a room at the school or hospital from which they were recruited (appendix B.6). Governance approval was obtained from the hospital from which study participants were recruited<sup>22</sup>. This approval was updated following the substantial amendment<sup>22</sup>.

As the study included research participants who were not recruited through NHS institutions, it was also necessary to receive an ethical review from the University of Sheffield Ethics Committee. This was obtained (see appendix B.7). The Chair of SchARR's Research Ethics Committee confirmed that the University did not need to review the substantial amendment if it had been approved by Camden and Islington Ethics Committee (see appendix B.8).

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<sup>22</sup> In order to protect the anonymity of the study participants, I do not present the research passport in the appendix. Doing so would require me to disclose the hospital from which I recruited study participants.

### 6.2.1.3. Recruitment

The approach used to contact potential participants differed depending upon whether they were recruited as having severe no health difficulties, severe asthma or CF (note from here I use the simplified labelling of “no severe health difficulties”, “severe asthma” or “CF” – I do so with the caveat that, as will be illustrated in 7.3, the experienced health of some in the former two categories likely deviated from these labels over the duration of the different waves of interviews).

Potential participants with CF who were eligible to join the study were identified by a member of staff working within the CF unit. I was then introduced to the young person and their parent when then they next attended the CF unit for a check-up. This approach to recruitment worked well as I was able to meet the participant and their carer face to face, enabling me to easily address any questions they had that were related to the project.

The individuals with severe asthma did not attend the hospital as frequently. The carers of potential participants were therefore called by a member of their child’s care team. If the carer and the young person were open to being involved in the research, I was then given their details and made contact by phone to answer any questions and arrange a convenient time to undertake the interview. Eventually, this approach led to enough young people being recruited. Logistically, it was more of a challenge as it was less easy to identify when a potential participant’s parent would be free to talk. Additionally, there was not the advantage of being able to have a face to face conversation with the young person and their parent when responding to their initial questions about the research project.

Because the potential participants with no severe health difficulties were recruited from a secondary school, they were first approached by the secondary school teacher I knew at the school. This teacher approached students that he taught. Those individuals who were interested in taking part were given an age appropriate information sheet to read and a slightly more detailed information sheet for their parent to read (appendix B.1-B.2) and asked to contact me via email to express their interest in taking part. In order to ensure the young person had no known severe health difficulties, I later called the parent of the young person to further check that as far as they were aware their child had no health difficulty. This approach to recruiting the young people worked well in that, as far as I am aware, all who were approached by the secondary school teacher agreed to take part. I

considered also placing posters within the secondary school to raise awareness of the study and provide an alternative means for interested individuals to contact me. However, I was prevented from using this aid as the NHS ethics committee were concerned that: (i) it would be difficult to select between individuals if more than eight responded as a result of the use of posters; and (ii) the posters might increase the risk of stigmatising those with health difficulties by explicitly stating they were excluded from the study (a necessary step in order for the school pupils to act as a comparator group).

A limitation of the approach I adopted was that the students approached by the secondary school teacher tended to be academically able and from middle class backgrounds. Table 6-2 below shows the number of participants by gender recruited for each of the health groups (note a table providing a more detailed outline of the participants interviewed is provided in Table B-1 in appendix B.10). I did not ask the detailed questions required to accurately characterise the household socioeconomic group of each of the participants. However, it was possible to use the individual's post code to obtain the Index multiple deprivation decile for the Lower Layer Super Output Area in which each individual lived<sup>23</sup>. Higher deciles are associated with lower deprivation. Table 6-2 indicates that though there is substantial overlap, to some extent, the participants with no health difficulties generally came from more affluent households than those who either had severe asthma or CF.

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<sup>23</sup> Lower Layer Super Output Areas typically contain around 1,500 individuals (Health & Social Care Information Centre, 2015).

Table 6-2: Interview Sample

	Number interviewed in Wave 1		Median index of multiple deprivation decile+ (minimum-maximum)
	Female	Male	
No severe health difficulties	4	3	8 (1-10)
Severe asthma*	4	4	3.5 (1-8)
CF	4	4	5 (1-10)

**Notes:** \*Defined for the purpose of this study as having a BTS score of 3 or above and having required support from a respiratory consultant in the last two years.

#### 6.2.1.4. Training

In order to prepare for undertaking the qualitative research, as well as reviewing the literature and engaging in conversations with experienced qualitative researchers, I undertook structured training. Training provided by the University of Sheffield on qualitative methods enabled me to receive an overview of the many different qualitative research methods that are available. I also attended an intensive five-day course on the BNIM approach. This course included six attendees and involved a large amount of practice in undertaking interviews and interpreting the material generated from BNIM interviews. The course was led by Tom Wengraf, a leading proponent of the method. Additionally, as discussed in greater detail below, I undertook 1 pilot interviews with two personal acquaintances, one of whom was a similar age to my interview sample. One of the purposes of these pilot interviews was to further practice the skill of undertaking a BNIM interview (the other purpose was to test my planned approach).

#### 6.2.2. Interviews

Different interview methods were used across the three waves of interviews. The different methods have different strengths and weaknesses. As discussed in 4.3.3 and 6.1.1, I hoped that by using different methods at different stages the study as a whole would be able to benefit from the strengths of each of the methods. Similarly, as outlined in 2.3 and discussed in 4.3.3, comparing the findings generated from the different approaches would allow a process of triangulation within the qualitative study.

### 6.2.2.1. Wave 1

The wave 1 interviews adopted a narrative interview method based on the BNIM approach. The interview starts with an initial opening question designed to elicit a narrative. The participant is not interrupted for the duration of their response to this initial question. After they have completed their initial response, there is a brief pause while the interviewer formulates a number of follow-up questions; these are entirely based on the narrative given by the participant in response to the initial question. The follow-up questions are also designed to prompt detailed narratives concerning life events that were outlined in the individual's initial response.

For the initial opening question, I asked:

*“As you know, I’m researching what matters to young people. So, can you please tell me the story of your life so far, all those events and experiences that were important for you, personally? I’ll listen first, I won’t interrupt. I’ll just take some notes in case I have any questions for after you’ve finished telling me your story. Please take your time. Please begin wherever you like.”*

I deliberately chose to ask a question which enquired about their entire life rather than a question that was specifically related to health because for those individuals with health difficulties, it helped me to avoid imposing upon them the need to tell me a narrative that was framed by their health. An additional benefit was that it allowed me to ask the same question to young people with no health difficulties as well as those who had either severe asthma or CF. Given that the participant's response to the initial question determines much of the agenda for the rest of the interview, the specification of the initial question is of great importance. The question was formulated and revised during the BNIM training and through discussions with my supervisors. The question was then tested in my pilot interviews<sup>24</sup>.

After the participant's response to the initial question and a brief pause to formulate subsequent questions, I asked the participants follow-up questions designed to elicit detailed narratives. The BNIM approach is potentially very powerful in its ability to help individuals vividly recall experiences that occurred much earlier in their life. This also meant I had to proceed with caution as there was a risk the follow-up questions might

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<sup>24</sup> I also undertook pilot interviews with the same two personal acquaintances ahead of my wave 2 and wave 3 interviews. I asked the same individuals to undertake these additional pilot interviews so that I could test the planned approach while to an extent replicating the dynamic of a repeat interview. Appendix B.11 contains a brief overview of how the pilot interviews influenced my adopted approach in wave 1, wave 2 and wave 3.

become overly intrusive. To help reduce this risk I took two specific steps. Firstly, during the pause between their initial response and the follow-up questions, I made clear to the participant that they could tell me whenever they did not want to respond and I would willingly move on to a different life event. Secondly, when pushing for vivid recollections of particular incidents, I would do so while being as sensitive as possible to the participant's emotional state; desisting from a line of questioning if I thought it likely the individual was at risk of becoming distressed.

The follow-up questions, based on the narrative given by the participant in response to the initial question, were raised in the order the individual had articulated them in their initial narrative. To help the interviewer remain within their frame of meaning wherever possible, I also used the terminology of the participant when asking the follow-up questions.

As discussed in chapter 4, one of the strengths of the BNIM method is that it explicitly accounts for the individual's defended subjectivity. Rather than asking an individual to provide an abstract answer to a given discussion topic, where there is a risk the individual will provide the answer that they believe reflects best on them, the approach asks questions that deliberately aim to prompt narratives of lived events (Wengraf, 2001a). As discussed in 2.3 and 4.2, the hope is that the participant eventually begins to articulate stories in a manner which shows that to some extent they are re-living the initial experience. The rationale is that this can allow the researcher both to gain fuller access to the participant's inner world and to later analyse the tacit and unconscious assumptions and values of the individual (Hollway, 2009; Wengraf, 2001a).

A further strength of the BNIM approach is that it limits the researcher's ability to impose their priorities upon the interview material collected. This was a particularly important consideration in view of: (i) the age gap between me and the young people; and (ii) the fact I was introduced to them by either health care workers or school teachers, and as such could be associated with authority figures.

When undertaking the pilot interview with a personal acquaintance of a similar age to my interview sample, one of the particular benefits of the method that I noted was that although I sensed during the interview she wanted to give me the "right" answers, the method's emphasis on obtaining in-depth stories gave me a clear incentive to discern her enthusiasms and passions. The method therefore encouraged me to allow the interview

to follow and focus on events relating to those areas (a fuller consideration of the contribution of the pilot interviews is provided in appendix B.11).

#### 6.2.2.2. *Wave 2*

##### *Wave 2 interview priorities and the implications for the method employed*

The wave 2 interviews followed a semi-structured approach in which I followed the same interview schedule for each participant (see appendix B.12). A priority which was specific to the wave 2 interviews was to elicit explicit opinions on the relative importance of the different valued aspects of life (capability domains). As discussed in 6.1.1, I mixed qualitative methods in order to more fully understand the experienced importance of each of the valued aspects of life.

##### *Overview of the wave 2 interview*

As shown by the wave 2 interview schedule in appendix B.12, the interview started with an abridged BNIM question. The aim of this question was to gain an overview of the individual's narrative since the last interview; I chose to ask this question at the start of the interview so that I could obtain their response prior to imposing a greater degree of structure on the interview. Following their response to the initial question I asked a limited number of follow-up questions based on their narrative that aimed to initiate detailed narratives of particular events.

The interview then switched to a series of exercises that aimed to elicit the participant's explicit views on the importance of each of the different valued aspects of life. These exercises used cards relating to different valued aspects of life. I hoped that a visual representation of each of the domains would facilitate the participant's ability to engage with the numerous concepts necessarily involved. Researchers have previously noted that undertaking visually-based activities with participants enables them to reflexively develop their own thinking about the importance of different aspects of life (Christensen and James, 2008; Stoecklin and Bonvin, 2015). The cards were based on the domains identified in the study undertaken by Burchardt and Vizard (2009: 24-49) (the study is summarised in 4.3.1 above). However, I undertook a number of steps in order to make the cards more accessible to the young people being interviewed. These included: (i) changing the name of the aspect of life so that it used "everyday" vocabulary; (ii) providing a visual representation for each of the different aspects of life; and (iii) listing



three concrete examples on each card that were representative of being able to enjoy that aspect of life <sup>25</sup>.

The initial exercise that used these cards involved me passing the participant one card at a time and for each card asking them: whether or not they felt they understood the aspect of life the card was meant to represent; whether or not they thought the aspect of life was very important for being able to live a “a really good life”; and why they did (or did not) think it was very important. Before passing the cards to the participant I shuffled them within the participant’s view. I did so both to ensure there was no consistent ordering pattern across the interviews, and to emphasise to participant that I was not attributing the cards any given rank order. The first exercise with the cards had three aims: firstly, to help the interviewee become familiar with each of the different aspects of life; secondly, to gain an understanding of each individual’s own understanding of the aspect of life represented by the card; and finally, to understand their initial reasoning on why each of the aspects of life was or was not considered “very important”.

For the second exercise involving the cards, I asked the individual if there was any aspect of life that they considered to be really important that had been left off the list. I made it clear when asking this question that it was fine if no aspect of life came to mind; to provide space so that the individual could add an aspect if they wanted to. The aim was both to increase the individual’s sense of agency within the interview and to allow me to see if consistent additions were made to the list (which would imply that the list needed to be expanded).

The third and final task involving the cards was an exercise in which I asked the interviewee to order the different aspects of life according to the relative importance they thought each one had “for helping someone live a really good life”. The interviewees were asked to order the different aspects of life approximately in the shape of a Christmas tree. A researcher who was experienced in interviewing young people previously suggested I use this approach as she had found it accessible to a range of individuals. My aim with this exercise was to elicit from the participants their broad opinions on the relative importance of each aspect of life.

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<sup>25</sup> The concrete examples for each of the aspects of life were taken from appendix 1 of the study by Burchardt and Vizard (2009). I used the examples relating to each aspect of life that were raised spontaneously by the participants in Burchardt and Vizard’s study. I limited the number of concrete examples to three per aspect of life so that there was a consistent number on each card.

Some capability theorists, including Nussbaum, might disagree with the premise of this exercise. As discussed in 4.3 some capability theorists hold that all of the capability domains are vital for living a good life and it is unhelpful to attempt to order their importance (Nussbaum, 2011, 2001). However, from a pragmatic perspective, this exercise was of value in that it allowed me to hear each individual's thoughts on the importance of each item. Having to prioritise requires the participant to give further thought to each aspect of life and the extent to which they think it is or is not crucial. Additionally, this exercise was designed to inform my quantitative research. It was unlikely that I would be able to include all of the aspects of life that are frequently considered of inherent value within the quantitative analysis. Asking this question allowed my selection of domains for the "pragmatic list" (Robeyns, 2003) to be informed by the explicitly stated views of the young people interviewed.

Following the exercises with the cards, I asked two questions that were taken from the LSYPE1 relating to participants' self-assessed life satisfaction and their self-assessed health (see the interview schedule in appendix B.12). Prior to asking these questions, I informed the participant that the nature of these questions was somewhat different from previous ones, but that I would appreciate their help with them as I might later need to use these variables in a related research project. After each question, I asked the individual to explain the reason behind each of their responses. Caution is required when attempting to make any direct comparison of the responses given to these questions by my sample and the LSYPE1 participants. The responses given may be influenced by both the format of the interview and the dynamic between the interviewer and the participant. However, I hoped that the responses I received to both the initial questions and the follow-up questions concerning why they had given the answer they had would provide me with some information concerning how young people interpreted and thought about these questions.

The final set of interview questions aimed to elicit further factual information that would support the analysis of the material participants provided across the different waves of interviews. Firstly, if necessary, I asked individuals questions to clarify any factual issues about which I was unsure concerning events they had reported during the wave 1 interview. These differed from individual to individual but primarily focussed on getting answers to specific queries that had arisen during the analysis of the wave 1 biographical data (see 6.2.3 for more detail). Secondly, I asked the individuals to draw a condensed family tree. I hoped this would unobtrusively allow me to gain further information about

the individual's family and clarify any relationships about which I was unsure. Finally, I asked the individuals to tell me their parents' occupations.

#### 6.2.2.3. Wave 3

##### *Wave 3 interview priorities and the implications for the method employed*

As with the wave 2 interview, the wave 3 interviews followed a semi-structured approach in which I followed the same interview schedule with each participant (see appendix B.14). A priority which was specific to the wave 3 interviews was to elicit explicit opinions from the participants on their ability to enjoy the different aspects of life, the barriers they faced when doing so and how they tried to overcome any barriers they faced. These explicit questions were asked concerning the domains indicated in the wave 2 interviews as likely being of particular importance to the wider sample of young people interviewed.

As outlined in Figure 5-1 in 5.2, in order to integrate the qualitative and quantitative strands of the research, I aimed to use the aspects of life identified by the sample as being of particular importance via the wave 2 material to: (i) inform my selection of domains for the quantitative model; and (ii) where gaps emerged in the quantitative data available concerning specific domains, prioritise their discussion in the wave 3 interviews.

However, given constraints in the time available to do the research project, the wave 3 interviews were undertaken before either the wave 2 material could be comprehensively analysed or the quantitative analysis could be completed. The focus of the wave 3 interviews was therefore informed by a *provisional* analysis of the wave 2 data and a conceptual design of the quantitative model which accounted for the data available.

I broadly took two approaches in order to increase my access to the domains prioritised following a provisional analysis of the wave 2 data. Consistent with my approach in wave 2, these approaches combined: (i) seeking to facilitate the individual implicitly communicating the emic knowledge I needed to access; and (ii) explicitly seeking the information of interest.

As will be discussed in greater detail below in line with the former, I noted on my research schedule the domains for which there are no corresponding variables in the LSYPE1. When asking follow-up questions based on the participant's initial narrative, I particularly prioritised asking follow-up questions relevant to these domains. To achieve the latter, after the biographically orientated questions, I asked explicit questions relating to each of the different aspects of life indicated by a provisional analysis of the wave 2 material as likely being of particular importance.

### *Overview of the wave 3 interview*

As shown by the wave 3 interview schedule in appendix B.14, similarly to the wave 2 interview, the interview started with an abridged BNIM question. As in the wave 2 interview, the aim of this question was to gain an overview of the individual's narrative since the last interview. Following their responses to the initial question, I again asked a limited number of follow-up questions based on their narrative, with the aim of initiating detailed narratives of particular events. As noted above, where possible, I intentionally chose to ask follow-up questions concerning the aspects of life for which there are no corresponding variables in the LSYPE1.

As with the wave 2 interviews, the emphasis then switched to focussing on questions relating to the cards that represented each of the valued aspects of life. As indicated above, I chose to only ask detailed questions concerning the domains which the provisional analysis of the wave 2 data had indicated as likely being of particular importance to individuals. The content of the wave 2 interviews also influenced the content of the cards presented. The cards used in wave 2 were edited to help the card for each retained domain reflect the emphases given across the cohort in the wave 2 interviews (appendix B.15 provides a summary of how these cards were adapted for the wave 3 interviews).

I presented the participant with each card one at a time and for each domain I asked: (i) the extent to which they were able to enjoy the specific aspect of life; (ii) what barriers got in the way of their enjoyment of that domain; and (iii) their approach for navigating the barriers they faced. These questions were asked in a discursive rather than a structured manner. I would at times follow-up their responses with different related questions in order to further explore the substantive issues of interest and elicit particular incidents where the individual had faced and sought to navigate a barrier they faced.

In a manner similar to the second wave interview, questions concerning the cards were followed by four questions that were taken from the LSYPE1 relating to the participant's sense of agency, their self-assessed life satisfaction and their self-assessed health (see the interview schedule in appendix B.14, each question permits responses to a limited number of categories). As in the second wave interview, the primary purpose of including these questions was to further my understanding of how young people approached answering these questions. Specifically, as elicited by further follow-up questions, I

wished to further understand the underlying rationale behind their decision to select a given category for each of the questions.

By the third wave of interviews, the participants were either in their final year of schooling prior to taking their GCSE examinations, or had recently taken the examinations, and I was interested in further exploring this time of educational transition. If in their narrative earlier in the wave 3 interview the individual had not extensively discussed this aspect of their life, then if they were in year 11 (the final year of schooling prior to taking GCSE examination), I explicitly asked them about their experience of preparing for their GCSEs and their subsequent plans. If they were in year 12 at the time of the interview, I asked the questions required to ensure I had responses concerning their experiences of preparing for their GCSEs, taking their examinations and receiving their results. If they had not already told me about their plans during their response to the narrative question, I also enquired about the vocational option they had since taken and tried to identify explicitly or implicitly if it was the option they desired prior to taking their examinations.

### 6.2.3. Data Analysis

#### 6.2.3.1. *Overview of approach*

Prior to undertaking the formal analysis, I listened to and checked the interview transcripts. Immersing myself in the data was the start of the analytical process. The analysis of the material generated from each of three waves of interviews was undertaken firstly at the level of the individual and then at the level of the cohort. By initially analysing the material at the level of the individual, it becomes possible to develop a theory of that individual, including their approach to telling their story within the interview. As discussed in 4.3.3, intentionally developing a theory of the individual and their approach to telling their story within the interview has a number of advantages.

Firstly, it allows the researcher to understand the meanings individuals give to particular events and circumstances in the context of their biography. This allows the researcher to develop a fuller understanding of the meaning imbued within each statement than if the accounts of specific incidents are coded, extracted from their individual biography and in their extracted form compared with similar accounts from that have been taken from other individuals (Hollway and Jefferson, 2000a; Wengraf, 2001a).

Secondly, developing a theory of the individual and the approach they have adopted for telling their story allows the researcher to explicitly consider how the individual's

defended subjectivity may have influenced both their telling of their biography as a whole and specific incidents within their biography. As discussed in 2.3, an individual may have motives to exaggerate, underplay or omit a specific event. Analysing their biography in its entirety therefore allowed me to critically consider statements and events that are contained (or omitted) in the transcript (Hollway and Jefferson, 2000c; Wengraf, 2001b).

Finally, considering each individual's biography and context allowed me to consider the interplay between: (i) the obstacles an individual has faced during their life; (ii) the resources they have had available to surmount these obstacles; and (iii) the consequences of surmounting (or failing to surmount) any one of these obstacles on their later life (Breckner and Rupp, 2002).

As discussed below, the approach taken to analysing the narrative interview material allows an analysis of not only the "causal" relationships between life events that are ascribed by the participant, but it also allows me to separately consider the events and draw my own hypotheses (Breckner and Rupp, 2002).

Having undertaken analysis at the level of the individual, I then switched to making contrasts and comparisons across the cohort. Making comparisons at the level of the cohort is particularly useful both for developing theory and for further understanding each of the individuals. Drawing contrasts and comparisons between individuals supported me in generating hypotheses that I hoped might hold at a more general level. For example, comparing the future aspirations of three boys with different health statuses might enable me to generate a hypothesis of how health status can affect the aspirations of boys. The generated hypotheses were then tested by re-particularising them for specific individuals (Wengraf, 2002). The hypotheses that emerged were therefore tested by assessing their fit across a range of individuals within the cohort. They were then adjusted as different individuals illustrated where the original hypotheses required a greater level of nuance. Theory developed using this approach should not only hold across a number of individuals, but it should also improve the researcher's understanding of each individual's biography (Wengraf, 2002).

As with any research endeavour, there were time constraints to consider when undertaking the analysis of the qualitative material generated by the different interview waves. This was particularly the case given: (i) the size of the study sample, which was larger than the typical number of 6-12 for BNIM based PhD theses (Wengraf, 2013) ; (ii) the desire to re-interview individuals over time; and (iii) the thesis as a whole taking a

mixed methods approach (meaning time had to also be found for the quantitative research outlined in chapter 0). While the BNIM analytical approach works best when a substantive amount of analytical effort is devoted to analysing the material from individual interviews, it would be unfeasible to invest a consistently high level of time in analysing each individual's interview material. Indeed, this approach would be inconsistent with Wengraf's suggested approach, summarised in 6.2.1.1., of distinguishing between contrastive and focal cases. A limited number of participants, based on the richness of their interview data, are selected to be focal cases. A larger amount of time invested in analysing the material that comes from these participants relative to that spent analysing the data of the contrastive cases. It is the focal cases who therefore become particularly central to the generation and illustration of the study findings (Wengraf, 2013).

A further complication when planning my analytical approach was that I could not be confident about which individuals would agree to be re-interviewed; nor could I be confident of how rich individual's interviews in later waves would turn out to be. Similarly, I could not avoid analysing individual interview material from prior waves before undertaking the later interviews as I needed the early analysis of the initial interview material to inform both the approach to the latter interviews and the decision as to whom to re-interview. To guide my decisions as to the level of depth with which to analyse each individual's material, I adopted an approach similar to that described on the training course led by Wengraf and eventually categorised each individual's material as either: gold (focal), gold (non-focal), silver "a", silver "b" or bronze. In many ways this is an extension of the conceptualisation of cases as being either focal or contrastive, which was previously touched on in 6.2.1.1. Table 6-3 below illustrates the number of individuals interviewed at each wave and at what stage the decision was taken as to the depth with which to analyse each individual's interview material.

Table 6-3: Schematic of the approach to analysis across the interview waves

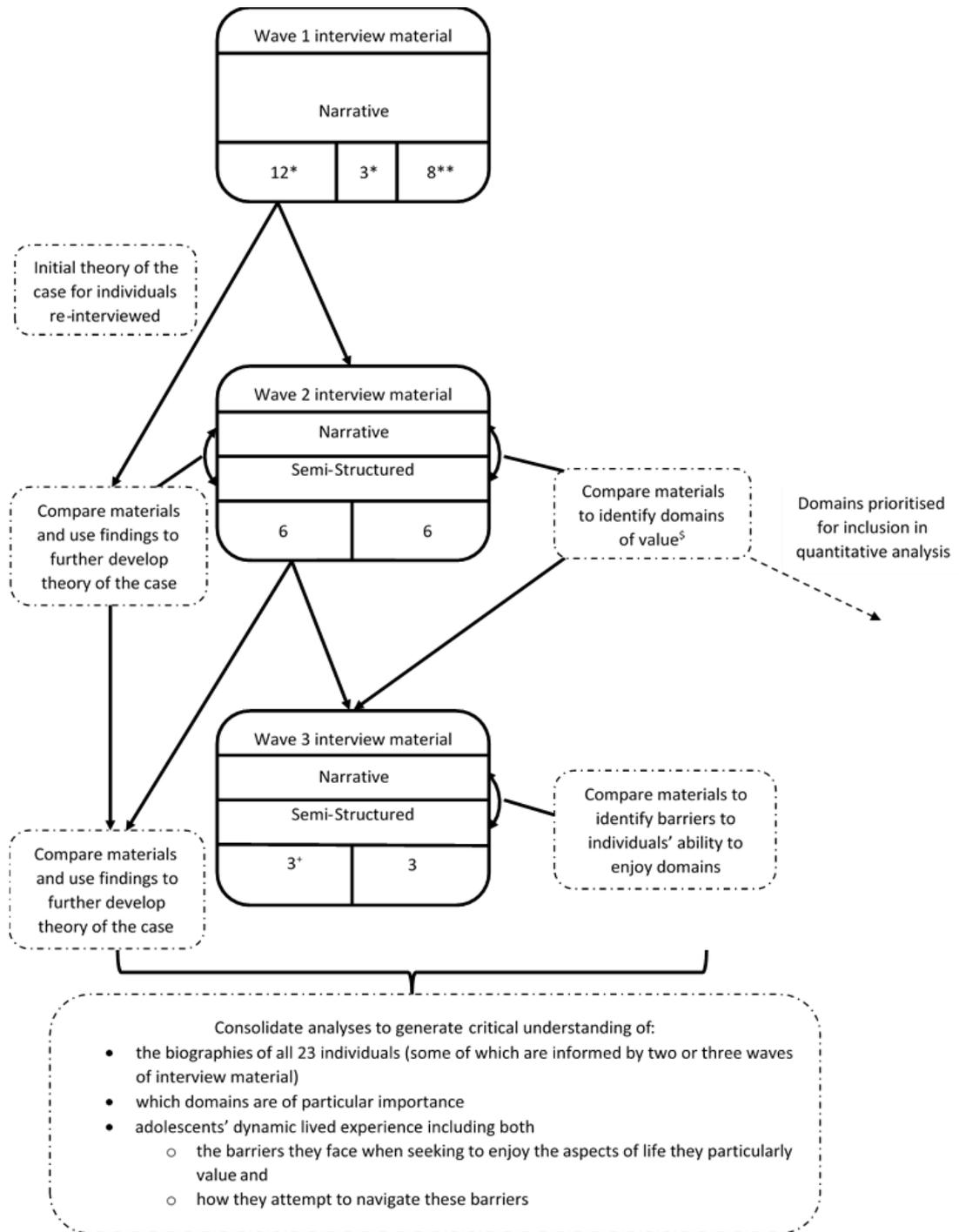
	Initial Analysis of wave 1	Wave 2 interviews	Initial Analysis of Wave 2	Wave 3 interviews	In depth re-analysis of wave 1-2	Analysis of wave 3	Final level of analysis
Gold*				6	6 (3 focal)	6 (3 focal)	6 (3 focal <sup>&amp;</sup> )
Silver+	15	12	12				9 (6 "a")
Bronze	8						8

**Notes:** \*Of the gold cases, 3 were focal and 3 were contrastive (all of the silver and bronze cases can be considered contrastive). & The material of the three focal cases was also analysed in group discussions with my two supervisors. A senior doctor who worked the hospital from which I recruited participants with CF and severe asthma attended one of these discussions (this senior doctor was involved in supervising me during the qualitative data collection). + For the initial analysis of the wave 1 interviews, a consistent level of analytical effort was invested into "a"s and "b"s. The main difference is that for Silver "a"s I also undertook wave 2 interviews whereas for silver "b"s I did not.

Figure 6-1 below provides a visual overview of the approach I adopted to undertaking and consolidating the different qualitative analyses. In accordance with the study plan outlined in 6.2.1.1, I ensured I maintained balance with regards the number of individuals in each of the six health status/gender strata. While not fully indicated by the figure below, it is worth noting that, as will be discussed in 7.4.1.1, the biographies of the 11 individuals interviewed once and the six individuals interviewed twice were used to test the generalisability of the main qualitative study findings (as summarised in 7.4.2).



Figure 6-1: Overview of the approach to undertaking the qualitative data analysis



**Notes:** \*The wave 1 material of all 15 (12+3) was analysed to a similar level of depth. \*\*A similar approach was adopted to analyse the eight "bronze cases" as to the other 15 individuals but the analysis was undertaken more rapidly. \$ The approach to contrasting the responses from the narrative and semi-structured questions is visually illustrated in greater detail in Figure 6-2 below. + As indicated in the figure and in Table 6-3, the material of three of the six wave 3 participants was also analysed in group discussions with my two supervisors. A senior doctor who worked in the hospital from which I recruited participants with CF and severe asthma attended one of these discussions (this senior doctor was involved in supervising me during the qualitative data collection).

The wave specific text below outlines in greater detail the analytical tasks undertaken for each of the groups at each stage of the analysis. For brevity, the approach is outlined below as a linear process; in practice the work was more iterative.

#### 6.2.3.2. *Wave 1*

As outlined in Table 6-3 above, prior to analysing the wave 1 data in detail, I selected the 15 individuals whose data I wanted to analyse in greater depth. Informed by discussions with my supervisors, I based this decision firstly on how likely I was to want to re-interview the individual. I both needed to have at least two individuals for each health/sex group and aimed to ensure over time the socioeconomic composition of the different health strata became increasingly similar. Secondly, the individual's stated willingness to take part in a subsequent interview. Thirdly, the ability of the individual to actively take part in the interview. Fourthly, the richness of each individual's interview material. Finally, the contribution of each of the individuals to a cohort across which there would be the possibility of drawing informative comparisons and contrasts. I analysed the data for these 15 individuals using methods in line with the BNIM approach<sup>26</sup>. In line with the BNIM approach outlined in 4.3.3, each transcript was analysed from two different perspectives, where initially each perspective was considered independently. The first perspective focused on attempting to understand the pattern in how an individual has chosen to date to live their life. The second perspective focused on trying to understand the pattern in how they have told their story of that life during the interview (Breckner and Rupp, 2002; Wengraf, 2001b).

In order to investigate further how a person has chosen to live their life for each participants' transcript, I took the following steps. Firstly, I reviewed their transcript in order to identify all uncontroversial data about the 'objective events' of their life. Secondly, having removed from the descriptions of these events all adjectives and causal explanations, the events were ordered chronologically. Thirdly, in order to try and hypothesise how the individual made decisions when living their life to date, I considered each of the objective events in their chronological order and sought to identify hypotheses as to what guided the participant's pattern of decision making (Breckner and Rupp, 2002; Wengraf, 2001b).

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<sup>26</sup> As outlined in Table 6-3, I chose not to analyse in depth the wave 1 interview data which came from eight individuals. Of these, three struggled to actively take part in the interview, two seemed unlikely to agree to be re-interviewed, and three provided interview material which did not seem as informative as other individuals in their health/sex group.

In line with the approach outlined in 4.3.3 in order to investigate further how the individual had chosen to tell the story of their life, I re-reviewed the individual's transcript and ordered it into stages. A new stage started every time either: the speaker changed, the topic changed or the manner in which the topic was being talked about changed. I then analysed the way the stages had come together in the interview in order to come to a view on how the participant had told their story (Breckner and Rupp, 2002; Rosenthal, 1993; Wengraf, 2001b).

To develop an initial theory of the individual, I noted the manner in which they had lived their life, the way they had told their story, and the connections between how the individual told their story and lived their life. The method of considering the individual's lived life and told story, both in isolation and in comparison, therefore allowed me to be critically aware of how the individual had chosen to present themselves in the interview. As such, the method equipped me to explicitly consider how the participant's defended subjectivity may have affected their responses within the interview (Breckner and Rupp, 2002; Wengraf, 2001b).

Having analysed each of the participants separately, I then sought to make comparisons and contrasts across the cohort. Hypotheses were initially developed by contrasting the first six individuals for whom I had undertaken in depth analysis at the level of the individual. Three of these individuals were placed in a triad in which I populated tables similar to those outlined in Table 6-4 below (Wengraf, 2013).

*Table 6-4: Shell table for undertaking comparisons using triads*

Aspects in common between both individual A and individual B	How this aspect is different for individual C
1	1
2	2
N	N
Aspects in common between both individual A and individual C	How this aspect is different for individual B
1	1
2	2
N	N
Aspects in common between both individual B and individual C	How this aspect is different for individual A
1	1
2	2
N	N

I adopted this approach as I had found it stimulated ideas well when using it on the BNIM training course led by Wengraf. Using this approach both helps to restrict the number of differences you identify between individuals and supports making links between commonalities and differences between individuals across the different aspects.

As I undertook the contrasts, I noted down different hypotheses generated from the tables. In order to further explore a given set of hypotheses, a different individual within the original six might be of relevance. I continued to undertake triads across the different individuals to explore, refine and develop new hypotheses<sup>27</sup>. Having iteratively moved between the individuals, I noted a number of theoretical observations that appeared to hold across the group. After I had finished analysing the interview material of the 17 additional individuals, I tested and refined these observations so they held well across the cohort.

My initial findings at the level of the individual and the cohort informed: (i) my ongoing qualitative data collection efforts; (ii) my initial analysis of the wave 2 interview data; and therefore (iii) my approach to specifying the quantitative model (reported in chapter 0). Consequently, I could not wait to complete the three waves of interviews before drawing findings from the wave 1 interview data. However, once I had completed the three waves of interview collection, I was in a position to decide who would be my focal cases. I then returned to these individuals' wave 1 interview data in greater depth.

#### 6.2.3.3. *Wave 2*

As discussed in 6.2.2.2, I endeavoured to use the material from the wave 2 interviews to not only further my understanding of the dynamic role of health in individuals' lived experience but also to understand which aspects of life they considered to be of particular importance.

#### *Further developing my critical understanding of the biographies of those re-interviewed*

As discussed in 6.1.1, I deliberately undertook more than one wave of interviews in order to obtain qualitative data that was particularly appropriate for investigating the dynamic impact of health difficulties on valued abilities and well-being. While the wave 1 narrative material necessarily contained dynamics, it primarily did so from the perspective held by the individual at the time of the first interview. Re-interviewing a number of the

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<sup>27</sup> A brief illustration of the use of triads to undertake this provisional comparative analysis can be found in appendix B.16.

individuals allowed me to obtain material that not only related to a slightly later period in their life, but that was recalled from a different perspective.

To investigate change in each individual's life, prior to analysing their wave 2 biographical material, I derived a number of hypotheses about the manner in which they would both live their life (including the obstacles they would face) and their approach in the wave 2 interview to telling their story. For each individual, I then analysed their wave 2 material in a manner similar to the approach adopted with the wave 1 narrative material, separately analysing the 'objective events' in their life and their approach to telling their story. When undertaking analysis at the level of the individual with the primary purpose of furthering my understanding of the individual's biography, I not only considered their responses to the biographical questions but also considered their contextualised responses to the question concerning the cards and the direct questions concerning the life satisfaction and self-assessed health.

Having analysed the individual's wave 2 material, I contrasted my findings with my earlier hypotheses that had been informed by their wave 1 material. I then explicitly considered the changes and continuities in my theory of the individual. Concerning any modifications to my understanding of the individual, I considered for each one which of three explanations was likely to be the most plausible. Firstly, I considered whether the modification was less likely a result of change in the individual's life and more likely a result of my greater exposure to the individual resulting in more being revealed (either as a result of greater trust or purely because an additional interview means more formal and informal information has been communicated). Secondly, I considered whether the change I believed I had observed was likely just a result of the individual aging: i.e. there was evidence of evolution in their self but in a manner that was to be expected given: (i) my theory of them as an individual in wave 1; and (ii) the transitions experienced as an individual moves through adolescence (as outlined in 2.5). Finally, I considered whether there was indication of a substantive change in the individual's sense of self – i.e. change which was beyond that which would readily be anticipated as a result of either of the two explanations above.

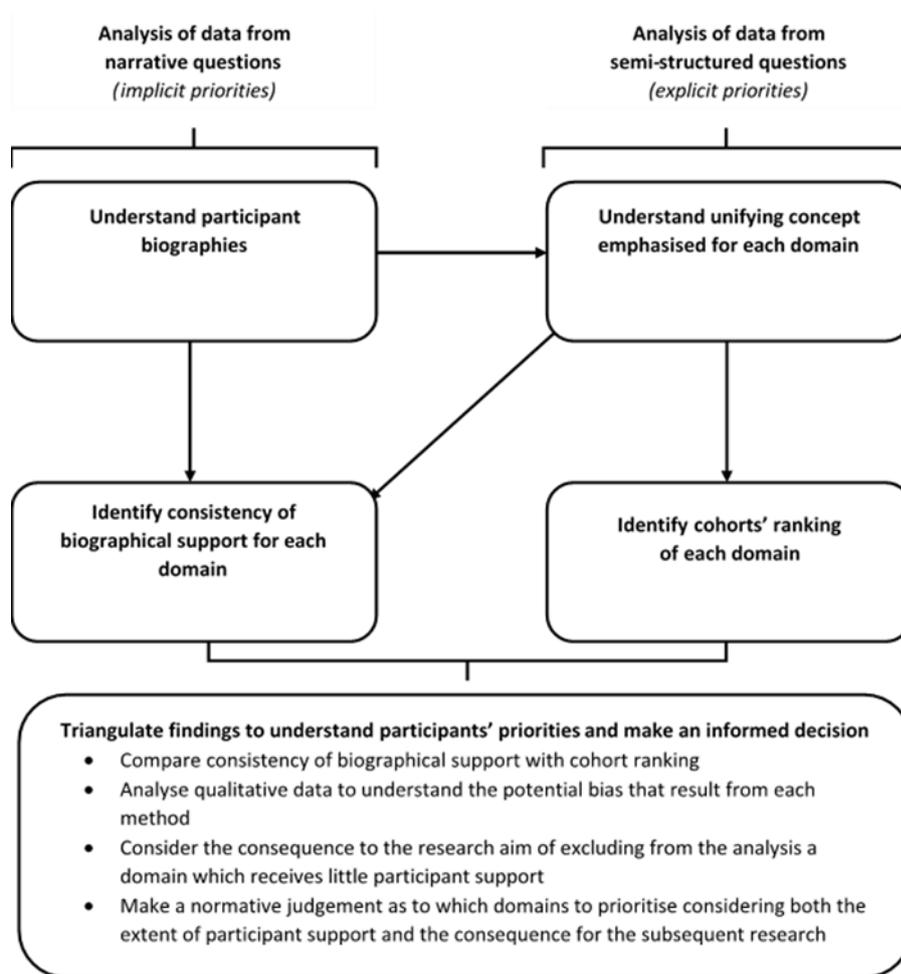
For each of the participants, having undertaken the above analyses, I updated my theory of them as an individual in a manner which attempted to capture my best understanding of them following an analysis of the wave 2 material and how this understanding had developed since my analysis of their wave 1 material. These findings were not only of

direct value for seeking to understand health's role in their lived experiences but, in conjunction with my analysis of the "bronze cases" wave 1 narrative material, also provided the context with which to investigate which domains were experienced as being of particular importance to young people.

*Identifying the domains of particular importance to the participants*

As discussed in 4.3, in order to undertake a dynamic analysis of health's role in the formation of valued abilities, it is necessary to restrict the number of different domains included in the analysis. This has parallels with forming a "pragmatic list" (Robeyns, 2003). In order to derive my pragmatic list in a participatory and transparent manner, I sought to elicit young peoples' priorities from amongst a more expansive, or "ideal", list. The theoretically informed list I aimed to further reduce was that developed by Burchardt and Vizard (2009) on behalf of the EHRC (as outlined in 4.3.1). As discussed in 4.3.3, because of their and my defended subjectivity, the approach likely to be most robust would be to elicit the young people's priorities both by: (i) explicitly asking about the importance of different aspects of life (domains); and (ii) by attempting to analyse their implicit views via an analysis of their narratives. Figure 6-2 below provides an overview of the approach I adopted.

Figure 6-2: Approach for combining qualitative methods to identify a prioritised list



Having undertaken analysis to understand the participants' biographies (as outlined above), I first sought to understand the meaning given by the individuals to the different valued abilities using framework analysis (Richie and Spencer, 2002). For each domain, using material from the wave 2 interview in which the participants discussed the different cards, I identified themes that emerged across the cohort. Informed by the framework analysis methodology, I then charted the thematic data on a matrix. For each aspect of life, I was then in a position to analyse the sub themes that emerged and to see which individuals raised them. Being able to interpret the statements with my wider knowledge of the individual based on our analysis of their narrative, I then noted the themes which were frequently emphasised for each aspect of life and a unifying concept which encapsulated these frequently emphasised themes.

For each aspect of life, having identified a unifying concept which encapsulated the themes that were given explicit emphasis by the 12 individuals interviewed in wave 2, I then investigated the consistency with which each of the 23 participants' biographies

supported the importance of the domain. I first re-considered each individual's biography and noted if it offered clear support for the domain's importance to the individual's lived experience. For the cohort as a whole, I summarised the consistency of biographical support for the experienced importance of each aspect of life by recording the proportion of biographies that clearly supported its importance. I then allocated each aspect of life a tentative ranking based on the consistency of biographical support across the cohort.

In addition to recording the consistency of support for each aspect of life's importance, I used data from the wave 2 ordering exercise to obtain an indication of the priority given across the cohort to each aspect of life in terms of its importance for "helping someone live a really good life". For each individual, I recorded the points allocated to each aspect of life using the Borda count method (Borda, 1953). I then allocated each aspect of life an additional ranking based on the cohort's explicit rating as indicated by its average Borda point score ("average voting score").

Given the small purposively recruited sample and the approximate nature of the derived summary measures, I treated the initial rankings derived from both approaches with caution. I used both purely to provide a simple, summary of the data to prompt further qualitative investigation.

In order to triangulate between findings derived from the biographical and semi-structured questions, I began by comparing the ranking derived from the "consistency of biographical support" with the ranking derived from the domain's average voting score. I noted: (i) which domains were strongly supported by both methods; (ii) which were strongly supported by only one of the two methods; and (iii) when neither method indicated a domain was a priority for the participants (Farmer et al., 2006). As a starting point, I considered a domain to be "strongly supported" if less than half of the alternative domains were above it (i.e. its rank was at the median or higher). I then returned to the qualitative data to understand why a domain's ranking might differ both according to the method used and the health status of the participant.

Having more fully understood both the cohort's narrative and ordering data, I analysed each with the purpose of further understanding the potential biases that might emerge from the other. I then considered the consequences for my research aim of dropping the aspects of life which received little support from the cohort's data and made an



empirically grounded decision as to the priority that should be given to incorporating each aspect of life in my pragmatic list.

#### 6.2.3.4. *Wave 3*

As outlined in 6.2.2.3, in addition to furthering my understanding of the dynamic lived experience of the participants, a specific priority of the wave 3 interviews and analysis was to further explore the extent to which individuals felt they were able to enjoy different valued abilities, the barriers they sometimes faced, and the approaches they adopted to navigate these barriers.

#### *Developing a dynamic case evolution for the six wave 3 participants*

Before undertaking the wave 3 interviews, using the findings of my wave 2 analysis, I developed hypotheses concerning how their lives and manner of talking about their lives would evolve. This had parallels with the approach I adopted for investigating change between wave 1 and wave 2. The slight modification was to record these hypotheses before the wave 3 interview rather than before the wave 3 analysis (so as to further ensure that recollections from the wave 3 interview did not subconsciously influence my hypotheses).

After analysing each participant's wave 3 material at the level of the individual using the approach adopted for their wave 1 and wave 2 material, I then considered the changes I observed in the individual using the same approach adopted when analysing change following the analysis of the wave 2 data. For my six wave 3 participants, I was then in a position to develop a dynamic profile of my theory of them as an individual. I used an approach I learned while on the BNIM training course which was led by Wengraf (as outlined in 6.2.1.4). For each individual, I condensed onto one sheet of A4 their transitions in three columns which related to: (i) the events recorded in their biographical data; (ii) the topics discussed in the interviews; and (iii) using the former two columns transitions concerning their successive states of subjectivity (transitions in their inner, experienced world). The A4 sheet was not only separated into the three columns but horizontally the table was split according to whether the life events/states of subjectivity proceeded a given interview. This method is visually illustrated in Table 6-5 below (it is worth noting that to preserve the participant's anonymity I have removed a substantial amount of detail which originally supported and illustrated the summary statements in each of the three columns).

Table 6-5: Example of three column summary of the evolution of a case

Analysis of biographical data	Successive States of Subjectivity	Analysis of approach to sequencing narrative
First interview (June 2014)		
<p><u>Junior school: enthusiastically involved in the everyday of school life (age 7-11)</u></p> <p><u>Secondary school: engaged yet different (11-14)</u></p> <p><u>Initial preparations for GCSEs (14-15)</u></p>	<ol style="list-style-type: none"> <li><b>1. Enjoying getting involved at school</b></li> <li><b>2. Cautiously experiencing the wider world</b></li> <li><b>3. Starting to step up for GCSEs</b></li> </ol>	<p><u>Starting school which was enjoyable, switching to junior school and then going on a family trip to America</u></p> <p><u>Experiences which have helped him grow up: going on a school trip without parents; transitioning to secondary school and going on a school trip to France</u></p> <p><u>Starting his GCSEs – noting that these dictate what you can later do in life</u></p> <p><u>He now enjoys going out with friends a lot more: school is now harder but he can have more fun outside of it</u></p>
Second interview (March 2015)		
<p><u>A summer of trips with friends and family (15)</u></p> <p><u>Mock exams: doing well but room for improvement (15)</u></p> <p><u>Christmas with his wider family including the older cousin who has done well for himself (16)</u></p>	<ol style="list-style-type: none"> <li><b>4. Stepping out from his parent’s sphere</b></li> <li><b>5. Preparing to step up to the measuring stick and meeting a role model</b></li> </ol>	<p><u>School trip to [removed to preserve anonymity]</u></p> <p><u>Family holiday to [removed to preserve anonymity]</u></p> <p><u>Seeing his wider family at Christmas</u></p>
Third interview (November 2015)		
<p><u>Intensive preparation and then taking exams (16)</u></p> <p><u>Last prom with school friends and holiday with parents (16)</u></p> <p><u>Starting at the new college (16)</u></p>	<ol style="list-style-type: none"> <li><b>6. Focussing on work to “do well”</b></li> <li><b>7. End of an era (prom and potentially last family holiday)</b></li> <li><b>8. Starting anew with academic confidence but no established networks</b></li> </ol>	<p><u>Working hard and doing well in exams</u></p> <p><u>School prom and family holiday</u></p> <p><u>Results day</u></p> <p><u>Starting at college: starting to make new friends and enjoying the study</u></p>

Having created a three column summary for each individual, I then created a visualised representation of their transitions through time in which I noted each of the hypothesised “states of subjectivity” in the order I hypothesised they occurred and illustrated each with a picture. I created these visual summaries so that when I subsequently undertook analysis at the level of the cohort I could rapidly recollect each of the individual’s transitions and therefore effectively compare and contrast the role of health in individuals’ lived experience.

In order to complete my analysis at the level of the individual, for each of my three focal cases, I undertook a group discussion, or “panel” with my supervisors. Wengraf (2013) discusses the advantages of gaining the insights of others when analysing interview transcripts. This perspective is consistent with my epistemological perspective as outlined in 1.3. As a subtle realist, I recognise that my own perspective is limited and that it is advantageous to learn from the perspectives of others<sup>28</sup>. The interview material of the three focal gold star cases was therefore also reviewed by academic supervisors. We did this together using a discussion group format. We reviewed for each of the individuals the pattern of their lived life and the pattern of their told story. We analysed the material of one participant per meeting<sup>29</sup> and followed a similar format to when I had previously undertaken the analysis. When analysing the pattern of the lived life, each life event was considered one at a time in chronological order; my supervisors raised numerous hypotheses at each stage and did so while not being able to see the subsequent life events of the individual. In contrast to when I adopted a similar analytical approach, my supervisors did so with truly no knowledge of the subsequent life events (whereas I had a suppressed memory of the individual’s biography as a result of undertaking the interviews and preparing the materials for analysis). A similar approach was undertaken for analysing the how the individual had told their story. Each stage was analysed and hypothesised on sequentially without my supervisors knowing what was to come within

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<sup>28</sup> Given practical constraints, including the need to comply with the guidance of the NHS ethics process, I only included individuals in the panel if they were involved in my supervisory team (either the team supervising the qualitative project or supervising my PhD as a whole). The panellists were all professional, middle aged women. Two were born in the UK, one was born outside of the UK. One of the panellists has no children, one has two adult children and the other has two step children who were in primary school at the time of undertaking the panel.

<sup>29</sup> A senior doctor who worked the hospital from which I recruited participants with CF and severe asthma attended one of these meetings (this senior doctor was involved in supervising me during the qualitative data collection) as the third member of the panel. I deliberately invited the doctor to attend a meeting in which the participant whose material was being analysed was not one of the doctor’s patients.

the transcript. During the discussion, I presented the data, answered factual questions and took notes. I attempted to limit my involvement in the discussions to avoid my perspective and knowledge influencing those of my supervisors.

Having reviewed the cases with my supervisors, I re-considered my theories about each individual and then considered how any insights offered by my supervisors might carry over to my analysis of other participants. In general, for each of the three focal cases, my supervisors came to a similar “theory of the individual”. Predominantly, the panel contributed to my analysis by confirming my own emerging view of the different individuals. However, for two of the three focal cases, the panel’s theory of the individual did contain informative supplements that I had not considered. For one of the participants, the panellists noted the greater than expected absence of their mother from the individuals’ narrative. For the second participant, the panellists noted signals within the participant’s phraseology that intimated the burden of managing their health difficulty had undermined the individual’s enjoyment of specific events. A subsequent retrospective analysis of these individuals’ data supported the panellists’ suggestions. I therefore took forward these modifications when using my understanding of each individual to identify the role of health in the participants’ lived experience.

#### *Investigating the role of health in the participants’ lived experience*

Having undertaken in-depth analysis at the level of the individual wave 3 participants, I was in a strong position to consider the dynamic interaction between health, the capacity to enjoy valued abilities and individuals’ lived experience. Initially, I undertook this analysis by explicitly considering the biographies of the six individuals whom I had interviewed through to wave 3. For each aspect of life emphasised as being of particular importance to the young people, I asked myself: (i) what is the dynamic through time I observe concerning this aspect of life (i.e. how does the manner in which individuals engage with this aspect of life seem to change through time?); (ii) to what extent are the participants able to flourish in this aspect of life, and is there any evidence of this changing over time?; (iii) what barriers tend to get in the way of them enjoying this aspect of life; (iv) if a health difficulty emerges as being a potential barrier to enjoying this aspect of life, *how* does it impair individuals’ ability to enjoy this aspect of life?; and (v) how have the participants sought to navigate these barriers? When considering these questions, informed by the biographies of the six participants (each from a different health status and gender stratum), I explicitly considered how my responses would differ according to the health status of the participants. Specifically, I considered whether the biographies

indicated differences between those recruited with no severe health difficulty, severe asthma and CF. This helped me identify health's role in an individual's ability to enjoy the other valued aspects of life.

Having reviewed the participants' biographies in order to inform my responses to these structured questions, I then visually mapped out for each aspect of life the trends in its dynamic and the manner in which it interacted with the other aspects of life. While I made these observations at the level of the cohort, for each observation, I would list the individuals whose biographies supported it. The analytical process continued through the process of writing up my results. Deeper engagement with the biographical data that illustrated each observation led to me further nuancing my position. Having completed a first draft of 7.3, I then listed the findings of central relevance to my research objectives, tested them against the biographies of all 23 individuals interviewed, and then further nuanced my observations to ensure the derived findings accorded with biographical data from across the interviewed cohort.

### **6.3. Conclusion**

As discussed in 6.1.1, combining both narrative and semi-structured methods should allow me to draw on the strengths of each approach. In 6.2, I have outlined in greater detail how these two approaches can be combined over multiple interview waves to robustly explore: (i) the aspects of life of particular importance to young people; and (ii) the role health (and health difficulties) play in the lived experience of young people. In chapter 7, I present the findings that relate to these two objectives of the qualitative research.

## 7. The findings of the qualitative research

### 7.1. Introduction

In this chapter, I present the findings of the qualitative research. In 7.2, I identify the aspects of life that are supported as being of particular importance to the young people interviewed. As outlined in 6.2.3.3, I evaluate the support each aspect of life receives by considering both: (i) the participants' stated orderings; and (ii) the extent to which each aspect of life is consistently supported as being of experienced importance by the cohorts' biographical data. When presenting the findings of this exercise in 7.2.1, I review for each aspect of life the concepts that were emphasised as being of particular relevance. This provides the context for my initial findings based on the two ordering approaches (as presented in 7.2.2). Having presented my initial findings, I triangulate between the participants' biographical data and their explicit orderings. Doing so enables me to first consider the influence of methods on the different rankings obtained (as summarised in 7.2.3). Second, I am able, via this process of triangulation, to consider the influence of health on the participants' priorities (as summarised in 7.2.4). In 7.2.5, informed by the perspectives of the participants, I reach a judgement as to which aspects of life to prioritise for inclusion in the subsequent research.

Having come to a judgement on which aspects of life to prioritise, in 7.3, I further investigate health's role in the lived experience of young people. As is outlined in greater detail at the start of 7.3, I exemplify my findings using the biographies of six participants (the final findings, however, receive support from the interviewed cohort as a whole). Doing so enables me to make inferences from their biographical data concerning: (i) the dynamic formation of each of the differing aspects of life during adolescence (as summarised in 7.3.2); and (ii) how these differing strands are entwined in the embodied life of the individual (as summarised in 7.3.3). In 7.4, I first critically review the strengths and limitations of the qualitative research as a whole before summarising the main findings of the qualitative study.

The novel contribution of this chapter is that it presents findings from the analysis of longitudinally collected narrative data, in order to provide a rich description of the effect of poor health on the formation of adolescents' wider valued abilities (capabilities). This is the first analysis of its kind, in this field, of which I am aware.

## 7.2. The aspects of life of particular importance to young people

7.2.1. The concepts emphasised as being of importance for each aspect of life

To identify the support for the importance of each aspect of life, both through the participants' explicit ordering of the domains and the consistency of biographical support, it is necessary to first ascertain the meaning(s) attributed to each aspect of life when discussing the cards. These were diverse but there was a degree of consistency with respect to which subdomains within each aspect of life were frequently indicated as being of importance relative to the others. To some extent, the themes raised by the participants were influenced by the content on each card (as presented in appendix B.13). Therefore, for each aspect of life in the italicised heading, I list both the title given by Burchardt and Vizard (2009) and the shortened title that I attributed to the domain in order to make the concept more accessible to the participants. Additionally, under the heading, for each of the different aspects of life, I list the three concrete examples of the aspect of life that I listed on the card. As outlined above, these were taken from the spontaneous responses of the participants who took part in the research reported by Burchardt and Vizard (2009). For each of the different aspects of life, having summarised the contents of the representative card I will then: (i) critically consider the themes that frequently emerged; and (ii) the unifying concept I attribute to the aspect of life which unifies and encapsulates those which were repeatedly emphasised as being of importance. Throughout, when referring to a participant, I use a pseudonym.

### 7.2.1.1. *The capability to live in physical security (Physical safety)*

The three examples of "physical safety" included on the card were: (i) not being bullied by people your own age; (ii) not being hurt by adults and; (iii) feeling safe inside and outside the home. When discussing this aspect of life the participants primarily focussed on the issue of bullying by peers. In their conceptualisation of this domain, the adolescents placed less emphasis on "not being hurt by adults". The quote below from Joseph, a participant with severe asthma, indicates this trend:

*"I used to be bullied a bit when I was younger when I, kind of, went in, when I started secondary school I didn't know anyone and it was, kind of, um, kind of like, a scary experience...as time went on and I started to build friendships and they, um, they helped me err and, kind of, like, I'd say protect me. Um, I wouldn't say being hurt by adults, I do' [sic], I'm not hurt by any adults"*

The participants often linked bullying to social isolation: social isolation could result from bullying, whereas having a network of friends was perceived to help reduce the risk that one would be bullied.

From the participants' quotes, it is difficult to be precise as to the exact nature of the bullying they referred to. Indeed, some seemed primarily to be indicating the importance of freedom from domestic abuse or violent assault. While not entirely distinct from bullying, they were perhaps commenting on a facet of life that had less relevance to school yard interactions and more to do with the life stage they were about to enter. Thea, a participant with no severe health difficulty who subsequently allocated this aspect of life a very high position in the ordering exercise, recollected the following when first discussing the physical safety card:

*"I was talking to my cousin who knows somebody else who had, um, been abused by her husband and it, it's just like it ruins people's lives almost because they can't enjoy what they're doing and usually the physical abuse is because of, um, because of, like, like them wanting authority over the other person and then wanting to make themselves feel better".*

When looking for a unifying concept, it would appear the "the freedom of being physically safe" is suitable as it has broader implications than might be commonly inferred from bullying.

#### 7.2.1.2. *The capability to be healthy (Good health)*

The three examples of "good health" included on the card were: (i) feeling healthy; (ii) getting enough sleep; and (iii) being able to see the doctor when you are ill. When discussing the card the participants with and without health difficulties frequently emphasised health's role as an enabler of other valued aspects of life (capability domains). Specifically, they discussed how health difficulties could both interrupt their ability to see friends and do activities with them. When discussing the card, Abbie, a participant with CF, recalled:

*"today I had to come home from school because I weren't very well and I didn't want to learn, I was like that, because it's school it's boring but it [good health] just gives you that chance to do quite, quite a few stuff. Like, so there's rock climbing. And if you didn't have good health then you wouldn't be able to do it".*

Both those with and without severe health difficulties also emphasised their perception of an interconnection between physical health and their state of mind. David, a participant with severe asthma, when discussing the importance of being able to see the doctor when ill, indicated that health difficulties would disrupt his "normal self":



*“say, I’ve got, like, a chest infection or something, it would take weeks to go away. But then I can just go to the doctor’s and be over with it in a few days or so and I can get back to being, like, my normal self and I don’t have to worry about anything”.*

Perhaps unsurprisingly, although the importance of being able to see a doctor when ill was rarely raised by the participants, when raised it was by three participants who had each experienced poor health (David and two of the participants who have CF).

When applying a unifying concept to the domain to capture the meaning generally attributed by the cohort, in line with the capability approach, I seek to adopt one which emphasises the aspect of life’s inherent rather than instrumental value. While recognising the support offered by the participants to my thesis’ underlying hypothesis, that poor health disrupts other valued aspects of life, I conceptualise the domain as “the ability to enjoy good health”. When subsequently using this term, I am implicitly referring to health as both physical and mental, recognising the interconnections raised by the participants between the physical and mental dimensions of health.

*7.2.1.3. The capability to be knowledgeable, to understand and reason and to have the skills to participate in society (Knowledge and skills)*

The three examples of “knowledge and skills” included on the card were: (i) able to learn new things; (ii) being creative with music and art and; (iii) space to consider what you think is important in life. Generally, the participants did not place much importance on the capacity to be creative with music and art. The response of Joseph, a participant with severe asthma, illustrates what seemed frequently to be a relative ambivalence:

*“Be creative with music, I wouldn’t say, well, I’m not a very arty person, so, if you ask me to draw a person I’d probably draw a stick man, er, but, um, but I’m quite, I’m quite musical, so, I, kind of, get that aspect”*

A few emphasised the importance of being able to consider what was important in life or similarly being able to learn more about the world as an end in itself. However, neither of these subdomains, which have similarity to Nussbaum’s domains of “practical reason” and “senses, imagination and thought”, respectively, received widespread support from the participants.

The facet which was repeatedly emphasised was that of accumulating the skills associated with employability. The participants appeared to emphasise the importance of the capacity they were currently forming to undertake desirable work in the future. A statement by Olivia, a participant with severe asthma, succinctly articulates what appeared to be a conviction held by many in the group:

*“You need this [Knowledge and Skills] because you need to get into a good school and you need to learn new skills so you can, like, do well in life and learn new things...You need knowledge and skills to get a good job and education”*

Given the repeated emphasis on the importance of skills which aided a desirable education and employment, I conceptualise the domain as “the ability to get a good job and be successful”.

#### *7.2.1.4. The capability to enjoy a comfortable standard of living with independence and security (Safe space to be independent)*

The three examples of “safe space to be independent” included on the card were: (i) enough money to do activities with friends; (ii) able to easily visit friends or go into town and; (iii) safe space to be on your own at home.

The latter, potentially because of its later positioning on the card, was only infrequently raised as being of experienced importance. When discussing the card, a number of participants emphasised the importance of having the resources required to take part in activities with friends. Emily, a participant recruited with no severe health difficulties, raised this as an important issue:

*“especially with the first, sort of, thing enough money to do activities. Like, not, like, if all your friends went or were going somewhere and you really want to go but you don't have the money. It's, like, well, y'you will feel, like, quite like you've missed out. And especially, like, a lot, everything costs, like, a lot of money now.”*

Similarly, several participants emphasised the importance of having the resources required to do activities and make decisions without having to turn to their parents for resources and in doing so implicitly require their permission to do the activity. Ben, a participant with CF, when first discussing the card highlighted this perspective:

*“It's just like you've got to have enough money to be able to lead your own things, you've got to, like, say you wanted to go somewhere, you don't have to ask your mum or your parent/carer for permission because you've got the money yourself. Y'you can do what you want with that money”*

As might be expected given their life stage, the participants therefore appeared to highlight the desire to have the resources required to take part actively in their friendship networks. Furthermore, they preferred that the resources required now be under their control rather than in the gift of their parents. A concept which unifies the two emphasised facets of this aspect of life is “having the resources to live with independence”.

7.2.1.5. *The capability to engage in productive and valued activities (Opportunities to do the things you value)*

The three examples of “opportunities to do the things you value” included on the card were: (i) opportunities for fun; (ii) time for meeting up with friends and; (iii) able to find a part time job. A difficulty which emerged from this domain was the all-encompassing nature of the card’s title (Opportunities to do the things you value). While it has meaning, and the participants could fully engage with the card, its broad nature elicited numerous responses that were relatively general. A response from Thea, a participant recruited with no severe health difficulties, illustrates this issue:

*“Yeah, also again important because, well I suppose if you value something you’re going to want to spend time doing it so you’re going to want, like, opportunities to do that thing...I think to have, like, a good life, like, you need to be able to do things that you enjoy otherwise you can’t really have a good life.”*

While the sentiment is coherent, and the statement usefully underlines the importance of enjoyable activities, the card’s title encourages a statement of somewhat circular logic: because the activity is valued it must be important to be able to do it.

There was some indication that certain specific family work contexts could lead individuals to be more financially conscious and therefore place greater importance on obtaining a part time job<sup>30</sup>. Generally, however, there was a degree of ambivalence about the importance of part time work as illustrated by the response of Joseph, a participant recruited with severe asthma:

*“as it says on here, it allows you to find a part time job. Yeah. I don't know whether that's as relevant as some of the other things, like, opportunities to have fun. I guess that's quite important because it allows you to, like, if you're feeling down you can, kind of, have fun and it'll, like, make you happier”*

Usefully, participants would at times indicate the importance of meeting with friends. Additionally, to more fully conceptualise the domain, I reviewed the participants’ biographies to identify the leisure activities they valued. As a cohort their biographies supported the importance of both: (i) leisure activities that involved high levels of physical exertion; and (ii) for leisure activities that involved little physical exertion. Given the participants’ general ambivalence concerning the importance of part time jobs during education and the diverse leisure activities undertaken by participants, both physical and

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<sup>30</sup> This was of relevance to one individual and for the purposes of preserving their anonymity I give limited specific information about their family back ground or supporting quotes.

not, an appropriate unifying concept which reflects the facets of this aspect of life emphasised by the participants is “opportunities to enjoy valued leisure activities”.

7.2.1.6. *The capability to enjoy individual, family and social life (Ability to enjoy time on your own and with others)*

The three examples of the “ability to enjoy time on your own and with others” included on the card were: (i) having confidence; (ii) able to join in the activities of your family and; (iii) not feeling lonely when you’re on your own.

A challenge of the original domain label is that it inherently posed two related but arguably distinct domains: the ability to enjoy time with others *and* the ability to enjoy time on your own. Concerning the latter, the participants frequently did emphasise both: (i) the importance of being able to enjoy your own company and (ii) the interconnectedness of the two domains – a number indicated that social isolation could have consequences for an individual’s ability to enjoy time on their own. A response from Ben, a participant with CF, summarises this perception:

*“if you’re ever on your own for a long time you start feeling like you’re unwanted. You start feeling the full, well I’m never going to have friends, I’m never going to have anyone to be with and then you completely lose your confidence because you think no-one actually wants me anymore, no-one wants to be my friend, no-one wants to be related to me”*

Despite the interconnections, there is an analytical rationale to making the two domains distinct: doing so enables an investigation of the association between the two. For my research aim, this is particularly important given the similarities between being able to enjoy time on your own and mental health. Anxiety and a sense of being low, arguably facets of mental health difficulties, were offered as examples of not enjoying time on your own.

Concerning “the ability to enjoy time with others” it is worth noting that the responses indicated this included both: (i) enjoying the relaxed company of friends and family; and (ii) being able to engage in conversations with others to share emotions, confide and get advice (i.e. relatively intense conversations). I therefore implicitly refer to both these facets when I use the unifying concept of “the ability to enjoy relating to others”.

7.2.1.7. *The capability to participate in decision-making, have a voice and influence (Freedom to make the decisions that matter to you)*

The three examples of “freedom to make the decisions that matter to you” included on the card were: (i) being listened to; (ii) respected by parents and teachers and; (iii) having a say in any decisions that affect you. When discussing this card, there was a degree of overlap between the themes the participants emphasised as being of importance for this aspect of life and the themes they emphasised when discussing “freedom to express yourself” (which is summarised below). Specifically, when discussing the card “freedom to make the decisions that matter to you” the two themes most frequently emphasised as being of importance could be summarised as “being free to make the important decisions” and “the opportunity to express yourself and be heard”. While acknowledging the interconnectedness of these aspects of life, given the domain below, when considering “freedom to make the decisions that matter to you” I will primarily consider themes which predominantly relate to decision making rather than self-expression.

Even with this self-imposed restriction, it is worth highlighting two facets of this aspect of life that were generally perceived as being important across the cohort. Firstly, participants often emphasised the importance of being listened to – arguably, it is impossible to influence a group decision concerning an issue that matters to you if no one is listening to your point of view. David, a participant with severe asthma, not only reflects this in his statement but also indicates the frustration and sense of disempowerment felt if your own view on an issue is suppressed:

*“I’d want to get, like, my, sort of, like, point across and if people, like, sort of, like, suppress my view or something or, kind of, like, feel that, like, theirs is, like, sort of, better than mine or whatever, I would, it would, kind of, like, be a bit, like, deflating to me”*

The second facet of the domain that was generally emphasised was the ability to make decisions on issues of importance. It is worth noting that individuals appeared to emphasise the importance of being able to make decisions both because the option taken could have a longer-term effect on the way their life developed *and* because the very act of making these decisions meant the life that subsequently evolved was *theirs* rather than one imposed on them by authority figures. When discussing the card John, a participant with no severe health difficulties, recalled an anecdote which illustrates these sentiments:

*“I heard about one of my friends, goes to another school...she wants to be in a Drama group and do, like, drama and, like, they’re doing soon, like, one of her favourite, ah, plays, ah, musicals. But her parents have said that she’s not allowed to go and do it*

*because it's too close to, ah, exams, which personally I thought was stupid, I don't, I don't agree with that at all...if my parents like said, "oh, no, you can't do that", like, you, like, and it was a once in a lifetime thing, I'd just be, like – I'd be so angry...I mean, it's your life, like, you should decide on what you want to do"*

A unifying concept which would appear to capture the themes emphasised as being of relative importance is therefore "the ability to make decisions on the things that matter" (for the purpose of brevity, I deliberately do not extend the phrase further but it should be noted that this relates to issues that matter to the *young person*). As mentioned, generally, this will necessarily involve being listened to. This domain has parallels with agency, the "freedom to bring about achievements one values and attempts to produce" (Sen, 1992: 57).

7.2.1.8. *The capability of being and expressing yourself and having self-respect*  
(Freedom to express yourself)

The three examples of "freedom to express yourself" included on the card were: (i) free to listen to the music you want to; (ii) able to talk with friends; and (iii) treated fairly compared to other students at school. Several interesting and interconnected facets to this aspect of life emerged as the participants discussed the card, some of which, while relating to the label, went substantively beyond the initial examples listed on the card. In summary, the four interconnected facets that were generally emphasised as being of importance were: (i) the ability to project one's individuality and identity; (ii) the necessity of "i" (the ability to project one's individuality and identity) to be and, through time, become who one truly is; (iii) the interconnections between the former two facets and relating to others; and (iv) the interconnections between all three and mental health/happiness. The reflections of David, a participant recruited with severe asthma, draws on all four of these facets:

*"if you can't really express yourself ["i"] then you're not being yourself ["ii"]...if you can't really do that you're, like, like, shut up, like shut out from, shut out because you can't really, sort of, do stuff. And, like, people don't let you be yourself ["ii"/"iii"] then you're like, it's just, like, [sigh] not really pleasant...if people stop you from being yourself ["ii"] you can't really, like, do the things that, like, you want to do and do the things that you make, you want to do and do the stuff that makes you happy ["iv"]".*

A unifying concept which summarises these different interconnected facets is "the freedom to express and discover one's identity". As outlined in 2.1.3, Sen defines functionings as valued "doings and beings" (Sen, 1990: 43); flourishing in this domain could be seen as the master "being". Developing a strong, liked self-identity is arguably the epitome of valued being – the individual has become who they want to be.

7.2.1.9. *The capability of knowing you will be protected and treated fairly by the law (Confidence that you will be protected and treated fairly by the law)*

The three examples of “confidence that you will be protected and treated fairly by the law” included on the card were: (i) trust the police won’t bully you; (ii) trust the police will protect you from others and; (iii) have the right to a fair trial. As will be outlined below few of the participants emphasised this aspect of life as one they experienced as being of importance. Nevertheless, for consistency, it is worth summarising the participants’ conceptualising of the domain.

Perhaps as a result of their lack of enthusiasm, the participants rarely went beyond the concrete examples listed on the card. Frequently, they acknowledged being able to trust the police and judiciary was in a counterfactual sense important but summarised that in their lived experience they took the benefits of this for granted. Additionally, those living in contexts where there likely was a greater need for police protection doubted whether the police could truly offer this. The facet which did receive support was having the right to a fair trial. The reflection of Ben, a participant recruited with CF, captures the general sentiment:

*“I disagree with that because you can never trust that, you can never be protected. Not everybody can be protected by the police. I mean it’s not fair to say oh, you have to protect everybody because there’s just simply not enough of them... Have the right to a fair trial; I can understand that bit. Like if I were caught, they don’t just arrest you, you actually have the, well, they do have to do that I guess but they can’t just arrest you for nothing”*

The facet of this aspect of life that was supported as being of importance by a number of the participants can therefore be summarised as “the freedom of knowing you will be treated fairly by the law”.

7.2.2. Initial findings based on the two ordering approaches

I now turn to considering the indications from the participants’ data as to the experienced importance of each aspect of life relative to the other. In Table 7-1 below, I report for each aspect of life: (i) the title allocated by Burchardt and Vizard (2009)<sup>31</sup>; (ii) the central label used on the representative card during the wave 2 interview; (iii) the overarching

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<sup>31</sup> In Table 7-1 I place each domain in the order allocated by Burchardt and Vizard (2009) – there is no indication from their work that the ordering is related to the relative importance of each domain.

concept which unifies the themes emphasised; (iv) it's position if ordered by consistency of biographical support; or (v) if ordered by voting score.

As discussed in 6.2.3.3, given the nature of the sample, the numerical data are to be interpreted with caution.

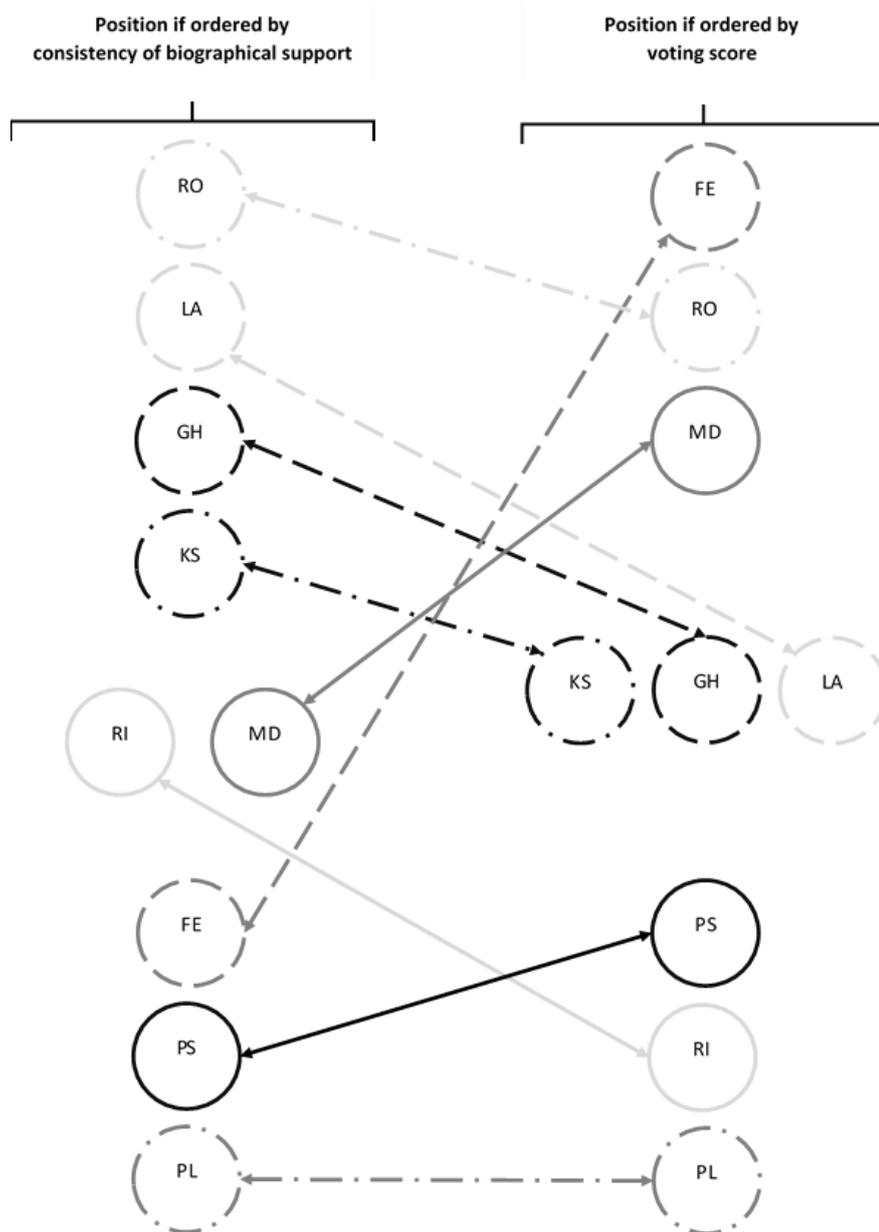


Table 7-1: Summary of the support for the importance of each aspect of life

Title allocated by Burchardt and Vizard (2009)	Term used in card for the aspect of life*	Overarching concept emphasised by participants	Position if ordered by consistency of biographical support (% biographies supporting importance)	Position if ordered by voting score (Average points from Borda count)
The capability to live in physical security	Physical safety	The freedom of being physically safe	8 <sup>th</sup> (13%)	7 <sup>th</sup> (4.7)
The capability to be healthy	Good health	The ability to enjoy good health	3 <sup>rd</sup> (70%)	4 <sup>th</sup> (5.5)
The capability to be knowledgeable, to understand and reason and to have the skills to participate in society	Knowledge and skills	The ability to get a good job and be successful	4 <sup>th</sup> (61%)	4 <sup>th</sup> (5.5)
The capability to enjoy a comfortable standard of living with independence and security	Safe space to be independent	Having the resources to live with independence	6 <sup>th</sup> (52%)	8 <sup>th</sup> (3.7)
The capability to engage in productive and valued activities	Opportunities to do the things you value	Opportunities to enjoy valued leisure activities	2 <sup>nd</sup> (83%)	4 <sup>th</sup> (5.5)
The capability to enjoy individual, family and social life	Ability to enjoy time on your own and with others	The ability to enjoy relating to others	1 <sup>st</sup> (100%)	2 <sup>nd</sup> (5.7)
The capability to participate in decision-making, have a voice and influence	Freedom to make the decisions that matter to you	The ability to make decisions on the things that matter	5 <sup>th</sup> (57%)	3 <sup>rd</sup> (5.6)
The capability of being and expressing yourself and having self-respect	Freedom to express yourself	The freedom to express and discover one's identity	7 <sup>th</sup> (43%)	1 <sup>st</sup> (6.3)
The capability of knowing you will be protected and treated fairly by the law	Confidence that you will be protected and treated fairly by the law	The freedom of knowing you will be treated fairly by the law	9 <sup>th</sup> (0%)	9 <sup>th</sup> (2.6)

**Notes:** \*In addition to the label shown in the column each card contained a background picture intended to visually represent the aspect of life and three concrete examples listed in bullet point form. These examples were drawn from the spontaneous comments which emerged from Burchardt and Vizard's (2009) participatory exercise. Pictures of the cards used are shown in appendix B.13.

Figure 7-1: Comparison of ordering according to the method used



**Notes:** PS = Physical safety (The freedom of being physically safe); GH = Good health (The ability to enjoy good health); KS = Knowledge and Skills (The ability to get a good job and be successful); RI = Resources for Independence (Having the resources to live with independence); LA= Leisure Activities (Opportunities to enjoy valued leisure activities); RO = Relating to Others (The ability to enjoy relating to others); MD = Make Decisions (The ability to make decisions on the things that matter); FE = Freedom of Expression (The freedom to express and discover one’s identity); TL = Treated fairly by the Law (The freedom of knowing you will be treated fairly by the law).

As can be seen in Figure 7-1, a number of aspects of life are supported as being of particular importance by both methods. These include: “the ability to enjoy relating to others”, “opportunities to enjoy valued leisure activities”, “the ability to get a good job and be successful”, “the ability to enjoy good health” and “the ability to make decisions on the things that matter”. In contrast, in the context of the need to reduce the domains included in the dynamic analyses of health’s role on the formation of valued abilities,

neither method supports either “the freedom of being physically safe” or “the freedom of knowing you will be treated fairly by the law” as being aspects of life which should be allocated a high priority for inclusion.

For two domains, the methods differ in the extent to which they indicate the aspect of life is likely *experienced* as being of particular importance. In relative terms, the importance of “the freedom to express and discover one’s identity” receives stronger support from the voting exercise than it clearly receives from the biographical material. Conversely, “having the resources to live with independence” receives somewhat stronger support from biographical material than the participants’ explicit orderings<sup>32</sup>.

I now turn to the qualitative data to investigate these divergences and the potential biases relating to each method. I report the responses from a limited number of participants to ensure it is possible for the reader to readily contrast the participants’ responses to explicit questions about the importance of the different aspects of life with their individual biographies.

### 7.2.3. Investigating the influence of method on the orderings

When discussing their approach to ordering the different cards, there was often a relatively ambivalent level of support for the domain “safe space to be independent” (conceptualised as having the resources to live with independence). Ben, a participant with CF, preferred to give this aspect of life a low ranking as he believed it was down to the individual to rectify any difficulties they faced in this regard, *“safe space to be independent, that’s like, that’s down to you so that’s not really as important”*.

Interestingly, this contrasted strongly with the ranking he gave to a similar domain; he spontaneously added “Roof over head, clothes, food and water”.

*“Everyone needs, like, a roof over their heads, they need food and water, whether it is, literally the smallest amount that you can get. Everyone needs food and water, no matter what the cost.... That’s why there’s so many food stores get robbed and they’re*

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<sup>32</sup> Strictly speaking if I adopted my initial guide, outlined in 6.2.3.3, of considering an aspect of life to be “strongly supported” as being of experienced importance if its rank was at the median or higher, then “having the resources to live with independence” would not be strongly supported by either method. However, given both the arbitrary nature of this threshold, the nature of the sample and the imprecision of the summary measures (and therefore ranks) it is worth explicitly considering the differences in the rankings received by method and whether or not this aspect of life should be prioritised for inclusion in the subsequent analyses.

*all like why do we get robbed? Well people that can't afford food and people that can't afford clothes, what, what are they meant to do?"*

Ben's biographical data is both useful for understanding this tension and supporting the experienced importance of the former domain. Ben's family lives in an economically deprived locality. Additionally, it appears his mother, working in a low paying occupation, is the sole earner in the family. Perhaps the financial hardship around Ben's life reinforces the importance of having the essentials while leading him to argue that material resources above the essentials are of relatively low importance.

While the biographical material offers an explanation of his argued position, it also provides evidence of discordance between his stated position and his reported lived experience. An analysis of Ben's narrative indicates an important, positive turning point in both his psychological well-being and his willingness to comply with an intensive medical regimen was when he and his wider family went away for a holiday together. This experience was one that required material resources above the level required for the essentials of a roof over one's head, clothes, food and water. Therefore, despite Ben's stated position, his own biography supports the importance of resources that go beyond the essentials required for survival.

In contrast to "having the resources to live with independence", the aspect of life conceptualised as "freedom to express and discover one's identity" received high average voting scores but relatively infrequent, *clear* support from the biographical data. This is likely a result of: (i) the abstract nature of the domain; and (ii) indications that, within individuals' biographical data, it was difficult to distinguish between this domain and "the ability to make decisions on the things that matter". Within the narrative material, it was more common to hear of the decision that was made, than either the prerequisite of being able to express one's view or even arguably one of the goals of being able to independently make decisions – that the individual could increasingly *become* an autonomous individual with a recognised, unique identity. This potentially represents a limitation of using the biographical consistency approach in isolation when investigating the degree of support within the participants' biographical data for the more abstract aspects of life. When reviewing the biographical data, I chose to only record where there was *clear* biographic support knowing that the alternative method would allow me to address this limitation.

#### 7.2.4. Investigating the influence of health on the participants' priorities

I now consider the influence of health on participants' priorities. Perhaps unsurprisingly, five out of eight individuals with severe health difficulties placed "the ability to enjoy good health" within the top two rows when undertaking the card exercise. None of the individuals without a severe health difficulty considered the aspect of life of sufficient relative importance to allocate it this position. Similarly, half of the individuals with a severe health difficulty explicitly considered "the ability to get a good job and be successful" important enough to place it in the top two rows, while none of those without a severe difficulty did so. In contrast, the responses indicated that those with severe health difficulties attached less explicit importance to "opportunities to enjoy valued leisure activities" than those without a severe health difficulty. Half of those with a severe health difficulty still placed this domain in their top two rows. However, *all* of those without a health difficulty allocated the domain this degree of importance.

Ben, the participant with CF previously mentioned, considered "opportunities to do the things you value", along with "safe space to be independent", to be an aspect of life which with sufficient effort any individual could flourish. It was therefore the individual's "problem" if they were currently not doing activities that they valued:

*"Opportunities to do the things you value; the same as safe space to be independent. It's down to you. Like if you want them opportunities and you deserve them opportunities or have enough money then go ahead and do it but if you don't deserve the opportunity, and you don't have the money then that's your thing, that's your own problem"*

Ben appeared to consider the extent to which individuals could secure knowledge and skills (the ability to get a good job and be successful) and good health to be more contingent on luck:

*"...knowledge and skills gets you through life in total but that gets you the through the rest of your life [sic.]. Obviously for the less, for the less fortunate people knowledge and skills is a really hard thing to do like to have, sorry, knowledge and skills. But for them that are lucky enough and are knowledgeable enough to have skills and obviously having [sic.] the ability to do stuff, they should cherish that ability...Third I put good health because you definitely [sic.] good health to get through a good life. Because if you have bad health all your life then you're just going to get, you're going to start feeling really bad about life and you're going to start thinking I wish I didn't have it and stuff and you just don't want that."*

Emily, a participant with no severe health difficulty, gave a relatively low position both to the importance of good health and to knowledge and skills:

*“You can have a little amount of skills and still be happy and stuff...um, and then, I don't really know where to put this one [Good health] because, like, people have really bad health but they're still really positive and have, like, really good lives and things”*

In contrast, she considered the opportunity to do valued activities to be amongst the most important aspects of life:

*“I think the freedom to express yourself and opportunities are the most important because if you can't do what you value, what's important to you and be hap', like, you're not going to be happy really because you're constantly, kind of, being made to do stuff you don't really like.”*

While Emily may have explicitly argued that the ability to get a good job and be successful was not of great importance, her biographical material, as outlined in greater detail in 7.3.2, appeared to contradict this. Though she may wish to argue that those without skills could still have a good life, her biographical data indicated she seemed very eager to avoid actualising this experience.

The responses of a number of participants supported the notion that those who experience an impaired ability to enjoy a given aspect of life, in this specific case health, tend to allocate that aspect of life a *higher* level of importance. Additionally, those who experience constraints in aspects of life they consider as foundational to their current and future ability to flourish as an individual, may allocate a lower relative importance to those aspects of life they perceive as being within their capacity. In addition to Ben, two of the participants, who at the time of recruitment had severe asthma, made explicit statements which support this hypothesis. When explaining his approach to ordering the cards, Joseph explicitly stated that his reason for putting some of the cards at the bottom was that he experienced no difficulties in those domains:

*“I put physical safety down there because I'm not, I don't really feel that I'm being bullied or, I feel quite safe, um, and confident, so, I put that down there. Um, I've put ability to enjoy time on your own and with others down there, again because I think, I don't think it's as important as err all the rest of them, um, because I do, I do have quite a bit of confidence um, I do, I do, [a chuckle] I, I can, like, join in activities with the family”*

Similarly, Olivia placed two of the cards at the bottom because she considered these aspects of life ones in which she could be confident she would not encounter difficulties:

*“And then opportunities to do the right things you value and safe space to be independent and ability, enjoy time on your own, with others, are least important because you know you’ve always got friends to go out with. Like, you’ve always got time to be with yourself and then you’ve always got time to just do what you want in life, that you can always do that.”*

If individuals prioritise more highly the domains in which they experience constraints, it would explain why those with health difficulties, who because of disrupted school attendance also experienced constraints in their ability to accumulate skills for employment, appeared to place a lower value on valued leisure activities (which was ranked lowly by those who also spontaneously indicated it was an aspect of life in which they experienced little constraint).

As discussed in 4.3 and 6.2, one reason for recruiting a sample which included those with severe health difficulties *and* those without is the concern in the literature about the role adaptation might play in influencing individuals’ evaluation of their own ability to enjoy inherently valued aspects of life (Biggeri and Libanora, 2011; Brazier et al., 2005; Sen, 1985). When considering the influence of adaptation on individuals’ valuation of different domains, it is therefore important to distinguish between their within-domain evaluation and their evaluation of the importance of each domain relative to the other (the latter being more relevant to this sub-study). Concerning within-domain evaluation, because of adaptation, individuals experiencing a constraint in a given domain may have lowered expectations regarding the extent to which they should be able to flourish in that aspect of life (Menzel et al., 2002). Prolonged difficulties may reduce expectations and cause them to consider their current ability to flourish in that domain to be high when an external observer might judge that same individual’s ability to flourish within that domain to be substantively inhibited (Brazier et al., 2005). While not presented here in depth, I found evidence of this psychological *within*-domain adaptation. Possibly as a result of comparisons with their previous experienced health, all eight participants with health difficulties interviewed in wave 2 self-assessed their own health over the last 12 months as being fairly good or very good. This included the four participants with CF, one of whom had only three months previously been admitted as an inpatient because of difficulties with her bowels (she subsequently required extended time off school to recover). However, a comparison of the orderings given by those who did and did not have severe health difficulties indicates that prolonged difficulties in a domain have the *opposite* effect on an individual’s evaluation of the importance of that domain relative to others. Living with the difficulty may cause an individual’s expectations concerning their

ability to flourish within that domain to *decrease* but their assessment of the relative value of that domain compared to the others to *increase*.

#### 7.2.5. Reaching a judgment concerning the “pragmatic “list”

Having qualitatively considered the participants’ data and the extent to which they provide evidence for the experienced importance of each domain, I now turn to explicitly considering which aspects of life to prioritise (and de-prioritise) for my “pragmatic list” (Robeyns, 2003). While doing so, I consider: (i) the relative support available for each aspect of life; (ii) the potential for bias associated with each of the methods used to identify the participants’ priorities; and (iii) the implications for my subsequent analyses of deciding to omit a domain.

Two domains, “freedom of knowing you will be treated fairly by the law” and “freedom of being physically safe”, received a relatively low-ranking score from the two ordering approaches. I plan to omit both from the planned dynamic analyses. I reached this decision because of the lack of empirical data from the participants to indicate that the importance of these aspects of life is actively experienced. While it is entirely possible that health difficulties do affect individuals’ ability to flourish in these inherently valued aspects of life, the participants’ data would suggest that without a specifically targeted sample it will be very difficult to identify: (i) variation in individuals’ flourishing as concerns these aspects of life; and (ii) how this variation is associated with differing health statuses.

Both “the freedom to express and discover one’s identity” and “having the resources to live with independence” received support from only one of the ordering approaches. I plan to include the former in my subsequent analyses. The voting scores indicate “the freedom to express and discover one’s identity” is of experienced importance. Though this aspect of life only receives strong support from one of the methods this is sufficient because the “biographical consistency” approach, at least in terms of providing an initial ordering score, is likely to have been biased against the more abstract aspects of life.

I plan, however, to exclude “having the resources to live with independence” as an explicit inherently valued aspect of life in the analysis. The reasons for this relate to my anticipated approach to the dynamic analyses. In short capability, sociological and welfare economic theory would indicate that some indicator of the financial resources available to the individual will need to be explicitly considered as an enabler of an individual’s



ability to enjoy the other aspects of life (i.e. in the terminology of the capability approach, material resources will need to be included as a *commodity*). Particularly for the quantitative analysis, there would be substantive difficulties involved in including this domain as an additional *outcome* given: (i) the anticipated requirement to control for resources as an enabling commodity; and (ii) the anticipated requirement to investigate the very correlated domain of work (“the ability to get a good job and be successful”). Including “having the resources to live with independence” as a separate domain would risk both an overly complex analysis and the inclusion of potentially overlapping concepts. Because of these issues, and the limited support from the participants’ responses for the domain’s inherent importance, I choose to not to include it in the pragmatic list.

The six inherently valued aspects of life I include in my reduced list are therefore: (i) the ability to enjoy good health; (ii) the ability to get a good job and be successful; (iii) opportunities to enjoy valued leisure activities; (iv) the ability to enjoy relating to others; (v) the ability to make decisions on the things that matter; and (vi) the freedom to express and discover one’s identity.

As will subsequently be discussed further in 8.2, the data available to analyse the role of health in the formation of these valued abilities differs for the qualitative and quantitative analyses (the LSYPE1, the secondary dataset used for the quantitative analysis, does not consistently collect data for all the domains in my “reduced list”). However, wherever feasible, I will aim to investigate health’s role in the formation of each of these inherently valued aspects of life.

### 7.3. Learning from the participants’ biographies

Having identified the aspects of life of particular importance to the participants, I am now in a position, via their biographical data, to investigate the influence of health difficulties on their lived experience. This will necessarily involve a consideration of the dynamic interaction between the different facets of individuals’ lives, including the role health plays in enabling individuals to enjoy the aspects of life they consider to be of inherent value.

As indicated in 6.2.3.4, the findings reported below have been reviewed against the biographical data of all 23 participants. However, to illustrate the findings in depth, I focus on the biographies of the six individuals interviewed through to wave 3.

I considered two separate approaches to illustrating the findings: (i) presenting the data thematically; or (ii) presenting abbreviated narratives for a number of the participants and contrasting these to illustrate health's dynamic role. The former readily facilitates me to draw material from across the six participants. The latter, while potentially confusing unless a further restricted number of biographies is drawn on, has the potential to provide a richer picture of how the different facets of life interconnect within the biography of the individual.

Below, I will attempt to draw on the strengths of both approaches. The findings below are therefore reported in the following format. Firstly, I report short biographies, covering life events that occurred up to approximately the time of the first interview, for my three focal cases: Emily (no severe health difficulties), David (severe asthma) and Emma (CF). Secondly, using the biographical data for all six participants from wave 3, I thematically present findings from the data. I sequentially switch focus with regards the inherently valued aspects of life (capability domains) I am considering in greatest depth. Thirdly, I return to considering solely the three focal participants. I simultaneously consider the way each biography to date illustrates: (i) the role health (and health difficulties) play in their ongoing lived experience; (ii) the dynamic interconnectedness of the different valued aspects of life; and therefore (iii) the role health (and health difficulties) play in their developing identity.

### 7.3.1. The start of three stories

Emily's recollection of childhood was characterised by fun and harmonious memories: family trips to Scotland to see her grandma during which her father introduced her to a love of nature by helping her spot deer while walking in the woods and showing her how to catch crabs while sitting at the end of the pier. Similarly, Emily remembered primary school with fondness – science was fun and involved working in teams, and her year would unite while playing mass games of "British Bulldog". Just how "rose tinted" these early memories are is difficult to say (indeed Emily literally reported having different colours associated with these early memories). However, as we met for later interviews, it subsequently became clear, through both her statements and her silences that, relative to her earlier childhood, Emily's early adolescence was a turbulent time. School suddenly involved much more work, *"when I started secondary school I didn't, I didn't like it as much really...it's actually just because I found primary school quite a lot easier than secondary school. In secondary school you have to like work like a lot more"*. Emily remained comparatively silent about another change: her father leaving the family home

and her family moving to a poorer part of the city where none of her school friends live. Tracing through her story, it seems clear that this event occurred in early adolescence, prior to the first interview. However, Emily never raised the issue for discussion in the interviews, in spite of questions intended to help her segue into this topic if she so wished. As Emily approached the time of the first interview, we see a life which, while starting very happily, has since encountered disruptions and trauma. As we further consider her transition from child to adult, Emily provides an example of an individual who, while having no severe health difficulties to manage, nevertheless was exposed to the instability and change that many individuals encounter.

As with Emily, stories from David's early life indicated fond memories of his early school experience: playing football with friends, learning to play the recorder and exercising his perfectionist streak when using the computers available to digitally manipulate images. While he recalled the odd misdemeanour, the overarching impression is of a young boy who rarely looked for trouble and was easily cowed when the threat of discipline came close to becoming a reality. While much of David's childhood seems very ordinary, there is evidence that he was already encountering some of the challenges which came with having allergies and poorly controlled asthma. The precautions he had to take already marked him out as somewhat different from his peers. For example, early in secondary school, on a school trip to France, David was involved but different. While his friends were eating food from a French bakery, David had to eat food brought from home – there was a heightened risk that information on allergy-related ingredients would not be fully labelled. David also recalled the awkwardness he would feel from the visual markers that emerged due to the need to keep his medicine to hand: *"I had this this bag that I'd wear for my epi pens, like it w', it's like a bum bag kind of a thing that I'd wear and I'd just remember like, like people 'd, loads of people were making like comments about it and that. I'd, like there, there w' wasn't like bad comments but it was just like being kind of noticed and feeling different kind of thing"*. However, health difficulties, and the associated precautions, were not David's only distinctive experience. As the interviews continued, it slowly emerged that prior to starting secondary school David had been identified as "gifted and talented". While appearing too diffident to explicitly raise this, it appears David drew confidence from the recognition of his academic talent. As David approached the period of the first interview, we see an individual endeavouring to learn to manage his health difficulty while minimising the distance it places between him and his peers. He appears to be an individual doing his best in some aspects of life to be

“normal” while experiencing differences which both add to and detract from his confidence.

From the very beginning, Emma’s health difficulty, CF, brought uncertainty and disruption to her life. Shortly after birth, Emma required numerous operations to address complications which she recalled as resulting from CF. In the later years of primary school, her health difficulty, and the related requirements for travel insurance, led to the cancellation of a much-anticipated holiday to Disneyland. Emma recalled a sense of injustice that she could not easily access the opportunities her friends were able to enjoy. A charity eventually helped her and her family surmount this obstacle. However, a nagging sense of powerlessness remained. This was heightened when she later found out that an exacerbation had nearly caused her to miss a subsequent holiday: *“I found out the day afterwards that they almost admitted me in before I went to [holiday location: omitted to preserve anonymity] I was just really upset and everything and I just, I just had a really bad tantrum... when I found out about the cystic fibro’, about me having to go back in, I was just, I was just broken”*. Through the periods of normalcy and the exacerbations, Emma clung closely to her parents and immediate friends. At one birthday party, Emma and her parents asked the guests to donate to a charity that had previously supported her rather than give presents. Emma spoke with passion about how a close friend was sponsored to take a relatively dramatic step in order to increase the funds that were raised [further detail omitted to preserve anonymity]. As Emma approached the period of the first interview, we see an individual rocked by the severe health difficulty she faces, along with the effort required to manage it. While seeing an adolescent frustrated by the injustice she daily experiences, we also see an individual embracing the support she receives from significant others and, with a degree of trepidation, seeking to seize the opportunities available to savour transient moments of joy that emerge.

### 7.3.2. Exploring transition in the aspects of life of particular importance

I now turn to considering the lived experience of the participants by giving particular emphasis sequentially to each of the aspects of life included in my prioritised list. As outlined above, the participants below include Emily, David and Emma as well as three more of their fellow participants: John (no severe health difficulties), Olivia (severe asthma) and Ben (CF).

### 7.3.2.1. *Fluctuating health*

The experienced health of the participants seemed to vary substantively from one interview wave to the next. Therefore, while each individual may have been recruited as either having “no severe health difficulties”, “severe asthma” or “CF”, the extent to which their experienced health reflected these labels, particularly in the case of the former two, could vary considerably.

Over the period, in which I undertook the three waves of interviews, there often appeared to be an improvement in the experienced health of those recruited as having severe asthma. David’s biography indicates that over time he learned to adapt to his health difficulty, working in collaboration with health care workers to reorder his external world so that his health difficulty caused less disruption to his lived experience. In part, as will be discussed later, this involved changes in the leisure activities he engaged with. While episodes of poor health were rarely raised in response to the narrative questions, David’s responses to the questions concerning his self-assessed health indicated his experienced health was on an upward trajectory:

*“I have, I have been, sort of, like, there have been times, like with my health, like, where I have been, sort of, like, a heck of a lot worse, like, especially when I was, like, younger, like especially with my, like, asthma in particular... and, sort of, like, like, the past 12 months it just has got a lot better” (wave 2)*

It would appear this was a result of him “learning”, in conjunction with his family and health care workers, how to more effectively manage his asthma and allergies:

*“Just probably health-wise, it’s probably the best 12 months I’ve had that I can remember. I mean, I think I’ve been going to doctors that long now that I finally got, like, the medication for me that’s right, and I’m, my health has been a heck of a lot better over the past year” (wave 3)*

For Olivia, another participant with severe asthma, the improvement in her experienced health was much more dramatic. At the time of the first interview Olivia reported being caught in a negative sequence of asthma exacerbations, leading to a need for treatment with steroids which she in turn believed to be the cause of her weight gain. Olivia seemed to view herself as overweight; as might be expected for a girl in early adolescence, this caused her great distress. Understandably, Olivia wanted to resolve her health difficulties – largely so that she could avoid treatment with steroids:

*“The main thing I’ve [sic] like want to change is like my weight and stop like taking the steroids and trying to get better and someone just to help me like not cure it but make it, my asthma, a lot better than it is.” (wave 1)*

The perceived impact of steroids upon their body shape was important for many of the girls with severe asthma. Including Olivia, three of the four girls raised this topic – emphasising how the need to take steroids had resulted in weight gain that was noticeable to their peers.

By the time of the second interview, much of the change Olivia desired in her first interview was in the process of occurring. Between the interviews, Olivia’s external world had been substantively re-ordered in a manner that had a dramatic impact on her experienced health. A machine had been fitted into her bedroom; this machine filtered out the allergens and brought about a big improvement in her experienced health:

*‘I’ve got this new machine in my bedroom that the hospital gave me, [omitted to preserve anonymity], and it’s worked wonders because I’ve been sleeping through the night and I haven’t been on any steroids since I got the machine.’ (wave 2)*

In the third interview, Olivia’s experienced health had improved to the extent that, in collaboration with her parents and the doctors, Olivia had decided she was ready to stop receiving omalizumab injections (a medication judged suitable for those with severe, persistent asthma (NICE, 2013b)). Olivia believed she received the new machine through a process of trial and error:

*“they were just trying to try anything that they could to help me with my asthma. So I think they tried the inhalers and the medications, and then the omalizumab and I think they got to the end of it where they thought, I might just have to have this machine to help me”*

Though it would seem this process of learning by the healthcare workers was not entirely linear, nor premeditated, it changed the trajectory of Olivia’s experienced health. As we will see below, this improvement also had implications for her self-image and ability to confidently engage in activities with friends.

Unfortunately, those participants who had CF did not experience the upward trajectory often observed amongst the participants with asthma. While there was no clear improvement over time in their health, the experienced health of those with CF was far from stable. In the period immediately before her first interview, Emma’s health had been relatively consistent, but between the first and second interviews her experienced health deteriorated:

*“In November I was admitted into hospital...I had something wrong with my stomach and I was admitted in for a couple of days and then they put me on some new medication and I’ve been taking it ever since...I may have to have surgery yet.”*

(wave 2)

As I will discuss in greater detail below, the deterioration in Emma's health had implications for her school attendance and, therefore, her ability to prepare for her mock GCSE examinations. Prior to the third interview, because of her experienced health between the first and second waves, and her narrative in wave one, which included numerous disruptions, I hypothesised that her experienced health would be poor. Additionally, I anticipated this would result in her continuing to remain close to sources of security (particularly her parents) but "change" was again evident. As will be outlined below, though with a degree of nerves and trepidation, Emma's experienced health was such that, prior to the third interview, she could travel a substantial distance to take part in an exchange programme with a school located in another continent [country name omitted to preserve anonymity]. However, Emma experienced no sustained improvement in her health. In her third interview, she reported:

*"recently when I, since I've come back from [distant country], there has been a case of me not being well, and I've been put on medication, and if medication doesn't work, I'm in for, I'm in hospital. And I don't want that, especially because I've, year 11 is a very important year for me."*

For those with CF, even when their experienced health was relatively good, it could rapidly deteriorate. Perhaps because of this uncertainty, it is amongst these participants that the interconnections between physical and mental health can be most clearly identified. For example, there are several episodes in Ben's biography when he seems to have had substantial difficulties with his mental health. Ben's health difficulty, and its associated medical regimen, seems to have played a substantial role in undermining his emotional well-being. In his first interview, Ben recalled when, approximately three years prior to the interview, he was diagnosed with another substantial comorbidity [omitted to preserve anonymity]. Ben recalls that when he received the diagnosis:

*"I walked out of room. I remember hearing about it and I really didn't want to know and erm because I knew what it were because my granddad has it so I just stood up and walked out of room and let my mum talk to them because I didn't want to talk to them"*

Ben recalled a period following the diagnosis of being emotionally low:

*"it were a period where I just didn't really feel like doing anything. I stayed in house more often. I really didn't want to do any medication for CF or obviously [additional health difficulty] but I'd only just started doing that but I was just determined I weren't going to do anything. I just sat in house on Xbox or whatever I were doing and I didn't get out much because I just really didn't feel like it."*

Ben subsequently received support from a hospital psychologist. At the time of the third interview, it seemed that Ben's emotional difficulties were still not fully resolved. Ben said little to this effect but prior to arranging the interview different hospital staff, many of whom – because of the intensive monitoring required for CF – have strong involvement in the patient's lives, intimated that he was going through a difficult period and might well refuse to be interviewed.

Even those enrolled as having “no severe health difficulties” appeared to experience fluctuating health. The narratives of many of these participants either explicitly or implicitly indicate variation in their experienced mental health. Their experienced difficulties were often communicated subtly. Perhaps this was a result of the stigma surrounding mental health difficulties (Jamison, 2006; Patel et al., 2007), or maybe the lack of familiarity between me and the participants resulted in this topic being judged by some as too intense to explicitly raise and dwell on. Additionally, many of the participants seemed more willing to divulge their difficulties retrospectively – after their struggles had largely been resolved.

As outlined above, Emily's life appears to have entered a turbulent period as she entered adolescence. Not only did her father leave the home but her family appears to have relocated to a notably more deprived location than those lived in by her school peers. Possibly the ramifications of this period of turbulence continued to influence her life at the time of the second interview. When explaining her response to the life satisfaction question she stated, “...*some stuff, kind of, that has happened, like, I don't know, would make me feel, makes me like, like, it's not exactly fair and stuff*”. When I subsequently asked her to expand on her response to the self-assessed health question Emily emphasised her good physical health bar a period in the past when she missed school, “*well, I've been, like, pretty well physically, like, there was a period where I was quite ill and I missed a bit of school then*”. Having summarised her *physical* health, she then changed her delivery. Speaking slowly, slightly more quietly and with a degree of caution in her tone, she then said, “*I haven't been, like, completely healthy and stuff recently*”.

Emily then swiftly changed tack, perhaps to distance this experience from her current reality, and chose instead to emphasise the relative improvement in what is likely her experienced mental health, “*well, not recently but a while ago, as to probably why it's not, like, very good. But then a lot more recently it's been a lot more good. So, it's not bad.*”



Arguably Emily's defended subjectivity leaves unclear the exact nature of her experienced health difficulty, its severity and its distance from the present at the time of the wave 2 interview. However, her broader biography, as well as her tone and speech patterns in the interview, indicate the likelihood that at the time of the second interview she had recently experienced a low point in her mental health and was currently recovering from it.

In contrast to Emily's relatively guarded and opaque statements, John, another participant enrolled as having no severe health difficulty, was more open about his struggles. In his first interview, John indicated he had recently sought support for difficulties with his mental health:

*"I've been meaning to go to the GP for quite a while erm and I went on my own which was weird because I've not really been on, been to the GP on my own before erm and then I went in and it was one of the first times that I had to describe something in my head with kind of clear and erm concise language and when I kind of rattled it off it (slight pause) it still seemed kind of over-exaggerated to me and like I'd blown it out of proportion erm and I said that to her and she said like lots of people often feel like that"*

While John appears to have appreciated the opportunity to talk to the general practitioner (GP), perhaps as a result of restricted resources for the treatment of mental health difficulties (NHS England, 2014; Smith and Wessely, 2015), he was unable to promptly obtain further support:

*"I was kind of happy with the result but it wasn't ideal because basically all she said was is we can't really do anything we have to put you down, your name down for a therapist thing and that's got like a four month waiting list so you're not gonna get a letter for ages and if you start to feel worse come back."*

Many of the participants, including those with "no severe health difficulties", therefore experienced impaired health. We will now turn to consider the dynamic interaction between their fluctuating experienced health and their efforts to successfully pursue their aspirations during this pivotal educational period.

#### 7.3.2.2. Pursuing aspirations

For many of the young people interviewed, perhaps unsurprisingly considering their educational stage, study and preparation for exams emerged as areas of stress within their narratives.

When John raised revision for exams in his initial narrative during the first interview, it immediately preceded the first time he discussed having had mental health difficulties. This possibly indicates that the pressure of the exams and the mental difficulties he had experienced are consciously or subconsciously connected:

*“it’s got to the point now where I’m comfortable with doing tests and it’s quite a weird thing ‘cause it kind of makes you feel more adult and erm like kind of aware of where your life’s going when you’re taking your GCSEs and you’re having to choose your GCSEs and all this and it’s quite strange to have that around so yeah and then erm err recently I’ve been to erm go to a GP about like mental issues and things and I’ve been signed up for erm a therapy interview”*

For those with no severe health difficulties, there appeared at times to be a discrepancy between individuals’ narrative accounts and their statements in response to explicit questions about the importance of education. Perhaps one approach to dealing with exam stress was to tell themselves, and anyone listening, that the importance of educational success was exaggerated. For instance, on the one hand, in his initial narrative at the start of the second interview, John stated:

*“I had my err mock tests for my GCSEs, um, and a few of my actual tests for GCSEs. And, ah, that was quite a big thing, ah, because it was the first, it’s the first, um, instance I’ve had of where what I do in, like, that hour-and-a-half, two hours, would impact on, like, my rest, the rest of my life”*

On the other hand, when asked in the same interview to explicitly state how important he thought knowledge and skills were for living a good life, John responded:

*“I don’t think it’s necessary for living a good life, um, but that’s, depends on how you define a good life, whether you define a good life ...I think for having a nice house and, like, having money and stuff, knowledge and skills is very important because it gets you places and it gets, gets you good jobs and it gets you, um, connections and things um, but I think for being happy, I don’t think necessarily knowledge and skills are something that you te’ [sic], really need, like.”*

Interestingly, this is in many ways a very thoughtful response. However, some part of John must consider being ‘successful’ of importance to living a good life. If happiness alone was of importance, and if knowledge and skills are not required for this, there would be little reason for him to find doing his GCSEs scary.

Similarly, as outlined in 7.2, when Emily was asked explicitly to consider the importance of knowledge and skills, she replied:

*“I think if you had a lot of knowledge and a lot of skills I don’t, I don’t think that matters on whether you have a better life or not. Like, in some ways it might affect it, like, if you have a lot, if you’re a lot more clever [sic] and you have a lot more skills*

*you'd probably get better jobs and things. But that doesn't mean you're going to be happier and stuff.” (wave 2)*

Despite the balanced and detached statement offered above, by the time of her GCSEs, Emily showed signs that she felt the exams to be of substantive importance:

*“Um, I remember when it was the first day of my, like... the first exam of the GCSEs. I'm like, I felt fine, but then I was sick in the morning. And it was like, after that I just, sort of, doubted whether [laughs] I was okay or not, because I thought I was alright, but then my body decided I wasn't... I can just remember the anxiety, sort of, around the time. You know, it was, kind of, like, they're important, but they're not the most important thing ever. But obviously just really important, and I just felt weird.”*

As might be expected, it appeared that during this period there was a gradual ratchetting up of the pressure felt by the young people, with the notable exception of the summer holidays when they were able to unwind and spend extended time with friends.

There was some indication from the young peoples' biographies that the effort they invested into their studies increased as their education progressed into these more pivotal and pressured phases. However, they sometimes also appeared anxious about the manner in which subjects they had previously enjoyed and found accessible became more difficult. For example, John in his third interview, recalled how after the summer holiday following his GCSEs he went back to school and started his A-levels:

*“I didn't really expect it to be as hard as it was. Like, especially, like, some of the other things, like English, I've always been, kind of, good at English, and it's been really hard. So that was quite surprising, I guess, and obviously that makes you think about well, like, I'm going to do university and, like, what I'm going to do for revision and stuff like that”*

Emily, in her third interview, like John in his first, connected study and mental health. By this time, she did so more explicitly in response to an enquiry about the extent to which she was able to enjoy good health:

*“like, I don't know, like, mentally healthy, like, you can feel quite stressful with sixth form. Uh, in having to do, like, it's, like, a really large mountain of work wide [sic]. See, sometimes it can be a bit overloading.”*

Given my suspicions from the previous interview that Emily at times struggled with her mental health, I then asked:

*“and in terms of that whole, sort of, mental area, is it, would that be, like, the main thing that you, it's like something to wrestle with? The, sort of, stress from work? [an affirmative non-verbal response from Emily] Yeah? And, um, when, what do you find are your best ways for managing that stress and getting on and, sort of, coping with it, would you say?”*

Far from indicating that she chooses to go out and do something fun to distract herself, Emily indicated her preferred coping mechanism was to press on in an effort to complete the work:

*"I'm always thinking about having to do it. So, kind of, have to just go and, I have to do it. But, I'm, it could be quite bad because I could probably, like, it's probably not very good just to spend, I don't know, one evening completely doing loads of work. But, I feel like I have to do it"*

Those with severe health difficulties had to handle the same pressures but with the added complexity of a health difficulty that could at times disrupt their ability to attend school.

During the period of particularly bad health between her first and second interviews, Emma defensively recalls how:

*"The bad thing was I was missing a lot of work off and some of the tests, um, I didn't get grades, that weren't up to my expectations in the, anyways, but apart from that my, the levels have, I, I have done really well to, in myself, I think, to say I was off for a long time. And even though my attendance is quite, my attendance was quite low."*  
(wave 2)

Possibly as a result of the pressure surrounding this period of study, Emma appeared to feel the need to justify missing school to real or imagined critics:

*"I can't help if I'm off school and if, and if, like, anyone has a problem with that then they, they can deal with it because if you, because it's, like, with cystic fibrosis, if you're, if you had to be admitted in you've got to be off for a couple of weeks of school because of all the medication and everything that you have to go through."*

The clear possibility that their health difficulty might disrupt their ability to 'keep up' may explain why those with a severe health difficulty, unlike those with no severe health difficulties, frequently emphasised the importance of knowledge and skills. When explicitly asked how important knowledge and skills were, Ben, a boy with CF responded:

*"You do need knowledge and skills to, a, lead a good life because a life without a job and without money is a bad life because it's going to be boring because you've got nothing to do."*

When he was younger, his father had left the family home. It would appear he left Ben's mother with much of the responsibility of providing for the family. Ben lived with his mother in a relatively deprived area. Potentially because of the family's difficult material position in the third interview, when discussing knowledge and skills, Ben emphasised a strong aspiration, which he thought would be difficult to accomplish, was to become:

*"the person in the family that provides for everyone instead of just certain people. So I'd like for all my family to have, like, easy, easy ways and stuff, and, and all that's pretty hard"*

David, like Ben, placed substantial emphasis on the importance of developing his knowledge and skills. In his narrative during the first interview, similarly to Emily and John, he made explicit the stress that accompanied preparing for the exams:

*“probably like the next big thing wa’ probably like the start of this year, like the start of my GCSEs and that’s like a really big thing because obviously I’ll want to do well in them you know and they do, kind of, they are important, they dictate like what I can do like later on in life. Like, like the stress that goes with it and that like is really difficult but it’s one of them things that you’ve kind of got to put up with”*

By the third interview, as discussed above, David’s health had stabilised, enabling him to apply a level of effort to his exam preparation that he reports his friends sometimes commented upon. When preparing for his GCSEs David recalled:

*“They’d be, like, I’d, I’d say to my friend like, “oh, I’ve done, sort of, six hours’ revision, I’ve got this many pages of notes on it all”, and then they’d, sort of, be like, “why have you done that much, sort of thing. You don’t really need to do that much.””*

For David, the perceived significance of the exams seemed again to lead to both stress and focus. When remembering his revision for his chemistry GCSE, he describes how when reading his chemistry revision guide:

*“I’d keep going through it and it just wasn’t sticking. Like, I couldn’t remember it very well, like, the actual information, what I was reading, and I just remember, like, keep practising and practising and practising it for hours and I wasn’t, sort of, like, getting sort of, stressing out slightly about it because I didn’t get it and it was, like, quite important.”*

The extra work, however, appeared to pay off, concerning the chemistry exam David stated:

*“eventually I did get there in the end, and then it came up in my exam the next day, and it clearly must have sunk in because I did well, it was my best exam”.*

At the time of his third interview, David’s strong exam performance, supported by his improved health, seems to have put him in a position of confidence about his future.

When talking about studying his A-levels, he mentions:

*“I’m doing maths, chemistry, physics and further maths, so it was like a new chapter in my life. Like now it’s, sort of, I’m doing this to, sort of, plan out what I want to do... to do for uni and I can do what I want for the rest of my life.”*

Of course, much was important to the young people outside of pursuing their educational and work aspirations. Below, we consider the role of leisure activities in their lived experience.

### 7.3.2.3. *Selecting activities to enjoy and identify with*

Valued leisure activities played several roles in the participants' lives. Their narratives indicated they not only engaged in these activities for the fun inherent within them but also to both project a positive self-identity and facilitate friendships.

One of Emily's favourite pastimes was dance. In her first interview Emily recalled attending dance classes from an early age, joining in with dance competitions and admiring the accomplishments of the older girls in the dance class:

*"the thing that sort of sticks out is when I was younger and you saw the older girls and err there was this one girl at my dance class whose gone on and done like loads of really good stuff but, and there's this other, and this other girl who, they were kind', they were the same age so they kind of like they were friends but they kind of had this like competition all the time... they just seemed so cool."*

There were indications within Emily's biography that she at times struggled to confidently relate to others as a result of shyness. However, it appears that on a school trip to Spain, her skill at dance gave her an opportunity to take centre stage in a game that was part of the evening's social activities:

*"They played this piece of music and you ha', everyone had to dance to it and whoever like danced the best to it got asked the question of what song it was and then if you got that you got like the point otherwise it get passed to the other team and then like so forth I just remember that because like I dance as a hobby and then like I just remember doing it and I just kind of enjoyed it because you were able to like actually dance [laughter] and that was, it was fun."* (wave 1)

Olivia, a participant with severe asthma, by contrast struggled in childhood and early adolescence to confidently engage in a number of socially-orientated leisure activities. In her first interview Olivia recalled:

*"I started dancing at the age of seven or eight and it was really, really nice and I met new friends and my family were supportive and I really, really enjoyed it. I went to shows and everything but then my asthma started getting worse and I had to stop the dancing which was a bit annoying because I liked it but I just had to stop it because of my asthma."*

The asthma not only directly affected her ability to undertake activities, but, as mentioned above, also disrupted her body image as a consequence of the weight gain she attributed to the need to take steroids.

*"I used to be really, really, really fat. Fatter than I am now and it was a bit annoying because I couldn't do a lot of the activities like go swimming or anything and I felt a bit like nervous when I put a swimsuit on, on holiday"* (wave 1)

The biographies of the participants with health difficulties indicated that one way they frequently adapted was in their selection of leisure activities. Many of the participants appeared to identify and select activities which were physically undemanding. Doing so enabled them to prevent the limitations imposed on their bodies by their health difficulties being projected to their peers. For example, while Olivia's health and body self-image may have disrupted her ability to confidently undertake activities such as swimming, she found she could still enjoy playing rounders:

*"all my friends and I have always done rounders since year seven and we've always won like certificates and medals for it at school and we've always just been a good team together and we've always supported each other in the game and we've always communicating outside of school as well" (wave 1)*

For Olivia, rounders seems to have not only been a fun activity but also an activity through which she has cemented lasting friendships at secondary school and gained recognition for her sporting ability. After her experienced health improved, Olivia's confidence to engage in physical leisure activities increased. In her second interview, Olivia mentioned that she was now able to regularly go to a gym with a friend:

*"I go nearly every week and every weekend, um. I'm just doing – we go on the weights, we go on the treadmill, I go on the cross training, the bike, and I just do exercising and I don't need my inhaler before or after."*

Similarly to Olivia, David appears to have followed this pattern of adjusting his leisure activities over time so that they were a good fit to his physical capacities. At primary school, David used to frequently play football with his friends. In the first interview, he recalled vivid memories of engaging in end of year school tournaments. However, in the third interview, when reflecting upon whether or not his health ever prevented him from doing the activities he wanted, David stated that:

*"Like, I could play a full game of football and be fine, sort of thing, and then I took a few years off it and played badminton instead, and then went back to football and my asthma got progressively worse, and then I just couldn't do it anymore. But I wanted to do it because I had done it before."*

David recalled an incident where he actively experienced his asthma constraining his ability to physically compete. Concerning a game of football he played a couple of years prior to the wave 3 interview, he recalled:

*"my asthma, like, physically wouldn't let me. Like, I'd be ten minutes, and then having to come off, and, like, pump myself silly with inhalers, because I'd push myself that much."*

Many of the boys with asthma placed greater emphasis on activities at which it was possible to demonstrate excellence without needing a high level of physical fitness. In addition to badminton, David took up eSports, a competitive form of video gaming. In his second interview David recalled:

*“me and my friend went down to London to this, kind of, like, this video games event down in London called Gfinity. It was, sort of, like, because me and my friend were like, quite, like, big, kind of, fans of, like, this, sort of, like, eSports”*

eSports has a large following. However, David had never been to a live event before. It made a strong impression on him:

*“I think it was, like, like, 3 or 4 thousand fans just sat watching this one thing. And it was just like unb’, it was just crazy, like, I’ve never really been to, like, any, like, anything like it ever” (wave 2)*

Emma, possibly because of her substantial health difficulties since birth, showed no indication of undertaking physically demanding leisure activities. Instead her passion was music:

*“with ma music I’m pretty much dedicated to it. If I said I get up at six o’, six or seven o clock in the morning and play the piano and just, just play, play it or sing and I do sing a lot” (wave 1)*

By the third interview, having largely recovered from the disruptions to her health reported during her second interview, Emma had the opportunity to express her talent to a wider audience. Emma went to a large summer camp, hosted an hour or so from her home. During the camp, a large event was held:

*“it was kind of a “Britain’s got talent” based thing, so you went to go and audition, and they put you through on the night. And only about five people were to perform on that night, on like a big concert stage...They also got me to perform on the Friday of um, like the last Friday of the camp. Um, they chose five people to perform again, and I was one of those five people. And both nights I performed to [a large audience] which I’d only done about 250 people before, and [performing to a large audience] was a big step, but it was a really good step to take, because I, it really gave me some courage to, and confidence, which was really good to be honest”*

Emma continued to take bold steps. As mentioned above, she took the opportunity to travel to [distant country] as part of a school exchange trip. This not only involved travelling a substantial distance from her parents to experience a different culture, but also gave Emma an opportunity to perform to a wider audience again:

*“I sang [name of song], in [distant country’s language] for her school and I also sang [name of song], when [the exchange pupil] was here, because [the exchange pupil] taught me [name of song], in [distant country’s language]. And I taught her, [name of song], in English. So we helped each other out there quite a lot. (wave 3)*



Emma's talent for singing gave her an opportunity to present a different facet of her identity to her peers. Below, we consider how individuals renegotiated their relationships as they transitioned through adolescence and the additional complications those with health difficulties faced in doing so.

#### 7.3.2.4. *Renegotiating relationships*

Over the course of the interviews, it was possible to observe that the participants increasingly wanted to spend time with peers and away from adult supervision. Peer interactions therefore seemed to become increasingly prominent and important in the individuals' narratives. As mentioned earlier, Emily's responses indicate that at times she struggled in social situations as a result of shyness. However, implicit within Emily's wave 2 narrative was a steady growth in her confidence in making new friends – this facet of life was discussed much more in her second interview than the first. The summer holiday following the first interview provided an opportunity for her to spend a large amount of time in a relaxed environment with her peers. In her second interview, Emily recalled time spent at the park with her friendship group:

*“it was just really relaxing and obviously, like, you became a lot closer with the people you were with because you saw them a lot of the time, you spent just most of your time just chatting with people”*

Emily's wave 2 biography illustrated a journey of progress in which, with some success, she learned to develop closer friendships and make friends with individuals outside of her established relational networks:

*“on New Year's Eve, er, I went to a party and I made friends with these girls from my school who, like, I already kind of knew but I wasn't that close with. And ever since then we've been quite close...I've made quite a few new friends because they were in the year above and I've made quite a few new friends and that, that's just been fun.”*

By the third interview, Emily's independence had increased to the point where she was going away on a holiday with her boyfriend and going to a pub where her friends performed as DJ's (and which appeared as an institution to be somewhat relaxed about checking the age of potential customers). However, as we will see below, when considering the young people's agency, Emily's transition to increasingly spending time with friends, independent of adult supervision, was contested by her mother.

For Emma, her health difficulty, and her real or imagined perception of how others saw her as a result, had a substantive influence on her capacity to comfortably spend time with peers. As outlined in the initial biography, for a birthday party prior to her first

interview, Emma was prepared to put her health difficulty centre stage by asking the friends who attended her birthday party to donate money to two charities that support children with CF instead of giving her presents:

*“Loads of people donated and by the end of it we raised around 500 pound for [the two charities] so 250 to each and I was just, I was just overwhelmed”*

As mentioned previously, in order to raise funds, one of her friends took a dramatic step in order to increase the amount of money raised [further detail omitted to preserved anonymity].

While with some people Emma appears to have been very comfortable to disclose her health difficulty and proactively seek support, with others she seems to have been much less comfortable:

*“some people um, they do really, they don’t really understand me from some point of view, because yeah, I may have um some kind of condition that um, that like makes me just, that makes me different from everybody else... I mean sometimes like some people don’t want me to express myself too much and sometimes I just keep quiet in front of them” (wave 3)*

This perception of not being understood, along with the very real need for continuing support with managing her health difficulty, may have led to Emma at times being uncomfortable to leave her parent’s company and spend time developing relationships with new individuals:

*“I can get a bit anxious, because like I’m away from my mum and dad, and I’m with people that might not accept me for who I am. But, because of my condition of course” (wave 3)*

It may be because of her health difficulty that Emma predominantly spent her time in situations where adults were available to supervise and support her. In contrast to Emily, when the opportunity availed itself to make new acquaintances, adult supervision seemed at times to prevent Emma from exploring encounters that had a degree of greater risk. After her performance at the summer camp, she recalls her camp leaders pulling her away from an encounter with a potential admirer:

*“the Tuesday’s performance I remember that um, afterwards an Irish guy, I went to the bar, and they were like “no”, and the [camp name] leaders were like “no”... [laughter].” (wave 3)*

David, with his improving experienced health, seemed in a stronger position to re-orientate his time away from being with his family. In his second interview, he recalled

separate visits to the same picturesque location. The first visit, organised by his school and with many of his school friends, he recalled in depth with a large degree of enthusiasm. David seems to have particularly enjoyed the opportunity to spend long periods of unstructured time relaxing with friends on the trip:

*“it was like, like, the majority of people that went on the school trip are luckily, it’s kind of, like, in my friend group, kind of thing and it was just, like, nicer spending, like, that time with everyone. And then, later that night after we’ve had our barbeque, we were located in, like, an area that when, there, there’s, like, a small, like, little stream, it was like a little stream or whatever ran near us so we, like, a group of us, about 20 of us trekked down there and just, just went into, like, the lake, like, paddled round in it for a good while.”*

His recollection of the second visit to the area with his family was more muted. Indeed, by the third interview, when discussing a holiday he had recently been on with his family, David was actively anticipating that he had now transitioned out of family holidays:

*“It’s good, yeah. Like, even though we may not get on all the time, sort of thing, it’s still nice, always, like, everyone gets along and everyone’s always having fun and stuff, and obviously it is, like, sort of, one of the probably last holidays I’ll go on with them... I’m at that, sort of, age now where I’m going to be moving on, doing things”*

Transitioning one’s role in the family appeared more complex for those whose poor experienced health resulted in a high medication burden. Past needs for support, and the current burden of regular medication and hospital visits, meant that parents often maintained a greater level of supervision, reinforcing the young person’s identity, within their shared relationship, as one who is vulnerable and in need of protection. Ben’s biographical material indicated that, to an extent, the continuing burden of CF led to this dynamic. Changes in his family context, however, appeared to have provided him with the opportunity to press for a new family “role”. The happy event of a new niece and nephew arriving, and the increased pressures on the wider family that resulted from his maternal grandparents’ health deteriorating, meant that there was an opportunity and expectation that he would increasingly care for himself and for others. He described his sense of moving from one who is nurtured to one who nurtures:

*“Yeah, I’ve got a nephew. And that, again was great because now we’ve got two things, like two new relatives that we can all be close to and we can all help grow up to be whatever they’re going to be in the future and that’s going to be like a new experience for me because I never really had to help anyone grow up except for my cousin... since last time I think my grandparents have been ill a lot more than last time. They’ve become really ill so we’ve got to start looking after them and stuff.”*  
(wave 2)

In Ben's initial narrative, there was evidence of a substantial level of emotional interdependence between Ben and his mother. Tracing through the biographical data, it was evident that Ben's emotional well-being would regularly rise and fall alongside his mother's. The struggles of one had a substantial impact on the other's ability to handle the significant burdens they faced together. Ben's experienced health appeared to stabilise between the first and second interview. This improvement, along with renewed determination to actively manage his health difficulty, gave him a platform on which to adjust to the changing dynamics within his wider family. As his mother's attention became increasingly focussed on caring for her parents, there was a change in the intergenerational relationships which, to some extent, constrained Ben's autonomy. A complex, dynamic interaction can therefore be seen between Ben's improving health, his grandparents' deteriorating health and his mother's choices as to where to focus her efforts to care and in Ben's case supervise.

I now turn to consider the biographies of the other participants to further investigate how their freedom to make decisions on the issues that mattered to them developed through time.

#### *7.3.2.5. Exploring increasing autonomy and its consequences*

An analysis of the participants' biographical data often indicated a steadily increasing ability to influence their inner and outer worlds. Their detailed narrative responses about particular incidents often indicated they were aware of the changes they wanted to bring about in their external environment and, maybe subconsciously, of the internal efforts they needed to make in order to actualise these. During this period, a number of individuals therefore appeared to be increasing their own self-mastery in order to increase their experienced agency. As might be expected, this evolution in both their self-mastery and their experienced external agency was embedded in their engagement in the other inherently valuable aspects of life. When attempting to further explore the individuals' inner world below, I therefore return to some topics I have previously raised. However, I switch the focus from being primarily on the aspect of life the individual is aiming to influence (i.e. a social dynamic they are aiming to re-balance) and instead attempt to glimpse facets of the individual's inner world, their underlying motivations and struggles, as they do so.

As discussed above, Emily's narrative material indicated that she struggled with shyness in social situations. In her third interview, Emily made explicit the difficulties she sometimes faced when attempting to confidently relate to others:

*"in some social situations, because, uh, I don't, don't know, like, I don't think I'm particularly good at being quite social. So sometimes, like, I don't feel very comfortable to, like, talk to people... I get a bit funny about when I can, like, talk to people about things. In those situations I don't feel very easy about expressing myself."*

Emily did not just accept this as a difficulty she could do nothing about. When asked about how she aimed to overcome this difficulty, she replied:

*"in the, like, moment of the situation, I probably wait until the situation has passed. But, like, I don't know, I think if you just, like, if sometimes I try and put, like, break, not feeling like that by saying something, I'd probably feel better in the long term. So, I try and do that."*

Her stated approach, that from time to time she attempted to break her fear by saying something, is supported by her wave 2 interview narrative in which, as discussed above, she reported a gradually increasing friendship network which included girls in the school year above her.

Emily not only attempted to master her internal world in order to change, through time, her confidence in being able to relate to peers but also took steps to increase the autonomy she experienced in her relationship with her mother. Dynamic interactions across the different facets of life are clearly evidenced in Emily's statements and biographical data, specifically: (i) an evolution in the activities she and her friends desire to engage with through time; (ii) a felt need to join in these activities both for their inherent value and their facilitative role in friendship and self-expression; (iii) Emily's perception of her mother's discomfort with the direction of change in these social activities and; (iv) a desire to become increasingly autonomous from her mother and also increasingly engage with her peers. To illustrate this, when asked how able she felt to make important decisions, she replied:

*"I think I'm allowed to do something, but my mum thinks I'm not. I think there's probably things that she doesn't like that I do. But, for me, I feel like it's okay because I keep, I have, like, healthy friendships and stuff. And like, I work hard at school, and like, that's, sort of, the main focus of my life at the minute."* (wave 3)

When asked about how she negotiates the disagreement with her mother, Emily replies that they *"kind of just snap at each other for a bit. And then probably just go out anyway [laughs]."* Emily appears to cite her hard work at school as a reason for why she should

be trusted with exerting her autonomy. Here, she may be seeing the freedom to go out as a reward for her hard work, or may be implying that her ability to make responsible decisions in one aspect of her life indicated she should be trusted with being able to have the final decision in other areas.

An analysis of the participants' biographical data indicates that this journey to increasing self-mastery and autonomy was not always one of continual progress. At times, it appeared that some of the young people overstated their influence over their outer world, potentially attempting to mask to themselves and others a troubling vulnerability. Emma provides an example of the protective claim to agency. In her first interview, Emma starts to consider a television documentary about a girl with CF who was terminally ill and could not be cured:

*"I watched this one where it was about this girl and she and she was terminally ill and they had to try and find a match for cystic fibrosis but they couldn't erm they just couldn't find out what it really [sort of disturbed giggle] like it was just hard for her to get a match pair of lungs for a lung transplant and she almost died with the condition and it's made me realise that if I keep myself erm if I keep myself healthy then I can live longer"*

At first reading, the implication of every effort being made to save the girl with terminal CF, yet there being little that could be done to help her, would seem to contradict the notion that if Emma keeps herself healthy she can live longer. Perhaps, however, the disturbing documentary prompted her to increased compliance both out of an attempt to distract herself from the eventual powerlessness she will likely experience and to attempt to prolong the period before this occurs. Seeing the powerlessness of another in a similar position possibly prompted Emma to use the agency she has to prolong the period for which she will be able to enjoy it.

Emma showed this determination to push on and make the most of life in other areas. Furthermore, she has done so while clearly being aware of the risks involved. She appears to have disciplined herself to take more adventurous steps despite the risks and her associated nerves. As discussed earlier, being away from her parents' emotional and practical support led to a degree of distress. When camping she recalled:

*"one of the nights when I were there, like I just, it just kicked in that, my mum and dad weren't there, and I just, I didn't go out, and I did cry, I did cry a bit. And I do miss them, and sometimes like going camping, it's a bit scary, because like with my medication and everything" (wave 3)*

As indicated above, the distress didn't stop her from persisting through the trip and taking the bold step of performing in front of a large audience, nor did it stop her taking the opportunity to go to on the school exchange trip to a distant country even with the continuing nerves:

*"I was a bit nervous about going through security, about what they'll say, and they'll take my medication off me, and a bit like going halfway across the world, that was a bit scary"*

Emma appears to have developed a pattern of behaviour which involves acknowledging the risks involved in a planned action, acknowledging the anxieties this ferments and then *deciding* to embrace the opportunities available to her and, as a necessary requirement for this, to master her own inner world.

Like Emma, at the time of the third interview, Olivia had decided to live with a degree of risk in order to achieve her desired outcome. Despite her allergies, Olivia reported a longstanding desire to be a veterinary nurse:

*"Since I were little I've always wanted to be, a veterinary nurse. I've always liked looking after animals or I've always like nature and outdoors and animals so I think I've grown up to be a veterinary nurse" (wave 3)*

Olivia's decision to attend the course was not made without careful consideration. The third interview occurred shortly after she had visited the college she would likely attend to assess her options:

*"I was a bit worried about starting college on the animal care course because of my asthma and my allergies. But they've persuaded me that I can wear gloves and I'll be safe with it, and if I do have an asthma attack, then they will help me overcome it, and they're quite supportive".*

Olivia therefore decided to pursue her reported long standing ambition, given her belief that the precautions and potential additional support made the risk of an asthmatic attack manageable.

David appeared to use his agency to attempt to determine the identity he will develop as an individual. As mentioned earlier with regards his studies, he reported continually acting and operating in a manner that he believed gave him the best chance of achieving his goals. He overcame the potential for his friends' statements and actions to influence him into making choices which fit better with their priorities than his own. Not only did he report persisting in his revision to a level that prompted his friends to comment but he also chose to prioritise attending the college he deemed most suitable, even though many of his friends were not going to go with him.

For many of the participants, the decision to employ their agency and take active control was clearly not without strain or consequence. As mentioned above, both Emma and Olivia had to take risks, sometimes with a degree of stress, to reach towards their objectives. For example, Emily emphasised in her third interview that she could choose how hard she worked in order to get the grades she desired. Emily's narrative implies she worked diligently. However, her attempts to take control of her future grades through evenings of applying herself to school work appeared to lead to stress, particularly given her further desire to employ her agency to balance study with dance and a number of relationships:

*"I probably do have a bit more time to see them [friends]. It's just [laughs] I'm not, I, I, I, like, prioritise my school work over it. So, sometimes I feel like I don't have enough time in, like, in the week, because I've got, like, I've got to do, like on Wednesdays I have, I don't have any time to do any work because I go dancing, to a dance class. So that's like one day out. And then, like, on another day I'll see my boyfriend. And then, I only have three days itself, like, I need to do work after school."* (wave 3)

Similarly, David's decision to go to a college few of his school friends had chosen also had the obvious consequence of initially leaving him surrounded by individuals he didn't know. At least initially he therefore had a very limited social network at his new place of study.

Given the consequences that sometimes occurred from employing their agency, it is maybe unsurprising that some, like John, oscillated in the degree to which they chose to forcefully do so. As discussed earlier, in his second interview, John stressed the importance of being able to make his own decisions. He illustrated its importance with the following scenario:

*"Say my mum picked all my choices for me for A Level and picked all my choices for G'err GCSE. Um, I would feel like that's my – those are my choices and that's not what I want to do. So inherently, I think, if my mum picked my choices, even if they were subjects that I enjoyed, I think I'd inherently dislike them just because they weren't my choice."*

Unfortunately, this abstract scenario became very real by the third interview. As mentioned above, John found English Literature much more difficult when taking it at A-level. Prior to the time of the third interview, John's school had asked his year group to sign a "contract" which would indicate they were committed to completing the subject to AS-Level (the first year of the A-Level). In the run up to signing the contract, John recalled:

*"I wanted to drop English lit, because after, when that move was coming up, I was, kind of, getting really worried that I wouldn't, if I wasn't able to drop English lit, then I*



*wouldn't do well in my other subjects, because I found English lit really hard um, but, you know, my mum said that I wasn't really allowed to drop it"*

Later in the third interview, when discussing the extent to which John felt free to make important decisions, the disagreement about whether or not John should drop English Literature re-emerged. John argued that he could drop it if he wished:

*"I'm not confident that I'll do well in it and I don't feel it's worth doing, and my mum just says that I can't drop it, so, and the problem is, is that I could, I could drop it anyway... like, I don't need my mum's approval or anything, but I just can't be arsed with having an argument afterwards"*

At least according to his argued position, John could have exerted his autonomy and taken the option which he viewed as being best. In contrast to Emily, however, John did not judge the difference in the outcomes, and the opportunity to show himself as autonomous, to be worth the likely ensuing argument with his mother.

The ability to increasingly influence one's outer world seemed to be considered of both inherent value and instrumental value by participants. However, while the increasing ability to exert their autonomy was perceived as desirable for a range of reasons, it was not without consequences. The participants appeared to show a substantial awareness of the potential implications of choosing to increasingly exert their agency. Their narratives and elicited responses indicate they were aware that increasing their experienced autonomy was not without risk. It is therefore unsurprising that they appeared to oscillate between either: (i) explicitly employing their autonomy with a degree of both persistence and anxiety or; (ii) *choosing* to go along with the preferred decisions of others to maintain a more harmonious state of affairs.

In the text below, I now return to considering the participants' freedom to express and discover their identity. Arguably, this is a continuing journey for everyone through life (Moshman, 2011d). Indeed, an analysis of the biographical data obtained from the interviews cannot not fully reveal the participants' inner world. Nevertheless, summarising the overarching narratives of the three focal cases may help illustrate the dynamic interplay between health and the other facets of the participants' lives; and how, whether consciously or subconsciously, through these different interacting facets of life, they express and explore who they are and therefore who they are becoming.

### 7.3.3. Health and the dynamic lived experience of the three focal cases

#### 7.3.3.1. *Emily*

Emily, having reportedly experienced an idyllic start to life, enters a time of unsettling transitions. At a time of adolescent transitions, she appears to simultaneously encounter disruption in family relationships, geographical relocation and a change in her educational environment. She transitions from being a girl to a young woman, loses the physical proximity of her father, moves to an economically deprived area and finds that school changes from being fun to increasingly serious. When retrospectively reviewing the narrative material concerning this period, she appears low in confidence, socially somewhat marginalised and struggling to an extent with her mental health. Nevertheless, we still see signals of a willingness to thrive and push for greater prominence when the opportunities present themselves – such as enjoying the opportunity to demonstrate her cultivated ability to dance when engaging in a competition on a school trip.

Despite the increasing pressures of school, Emily appears to gradually re-balance during the period of time covered by the three interviews. The summer holidays provide an opportunity for her to spend extended periods of time relaxing with friends in the park and despite her return to school in the year during which she will prepare for her GCSEs, she seems to increasingly enjoy spending time in the company of peers. As her confidence grows, she similarly demonstrates a determination to push through her social unease, establishing friendships with girls in the older school year after meeting them at a New Year's party.

As her examinations approach, Emily appears fully aware of the pressure placed on her by her surrounding context, to the extent it leads to her being sick. However, she seems to handle the pressure with a degree of success and appears to draw from this experience, amongst others, the need to attempt to manage that which cannot be fully controlled. Another summer brings the opportunity to camp with friends and holiday with her boyfriend. The last time we see her, she seems, to an extent, to have brought order out of turbulence: juggling school, friendships, a boyfriend and her dancing while learning to assert her right to make her own judgements. Perhaps this order comes at the cost of a degree of anxiety as she works late into the evenings in the attempt to assure herself the accomplishment of her future aspirations is within her control.

Emily appears to be increasing in her confidence to externally express an evolving identity as an independent, confident, sociable and talented individual. Within this seems at times to come at the cost of a persisting degree of stress and anxiety.

#### *7.3.3.2. Emma*

Emma's CF led to her having to negotiate more severe constraints on her body's capacities than Emily. As previously mentioned, from early childhood onwards, hospitalisations punctuated her recalled narrative, disrupting her ability to go on holidays and therefore to confidently anticipate upcoming events. As Emma progressed through secondary school, these periods of declining health also disrupted her ability to prepare for exams and therefore possibly because of this, and its impact on the wider facets of life, likely undermined her sense of agency.

Not only did CF undermine her body's capacity to pursue valued activities and aspirations, it also appears, in part because of this, to cause her to see herself as "different" – a felt identity she sometimes seems able to willingly embrace. As she transitions through adolescence, however, Emma seems increasingly determined to prevent her health difficulty defining either her actions or her external identity. Possibly with substantial encouragement from parents and support from teachers and other responsible adults, Emma chooses to demonstrate her musical talent in front of a very large audience on a summer camp and later when on a school trip to a distant country. For each of these excursions, Emma appears to have known well the additional complexities that could result from her health difficulty but with the support of responsible adults chose to explore, learn and perform.

Across the period covered by the interviews, we see Emma learning to negotiate living with her health difficulty and her perceived identity. We perhaps see someone learning to view themselves as able to manage their fears and embrace the opportunities for enjoyment, expression and development. By doing so, it would seem Emma is learning to present herself to those outside of her immediate support network primarily as a talented performer rather than as an individual with a with a severe health difficulty.

#### *7.3.3.3. David*

David's asthma and allergies initially appear to place visible restrictions on his ability to readily "fit in" with his peers. As mentioned previously, while seemingly having a network of close friends, early memories of secondary school often involved actions to accommodate the limitations imposed on him by his body: eating different foods in

France, being noticed for wearing a medicines bag and stopping football to instead play badminton. The material from David's first interview, and indeed some of his phraseology, indicates an individual ill at ease with his situation who finds events' potential for enjoyment marred by the felt need for caution.

By the second interview, David's confidence seems to be rapidly increasing. David appears to have identified contexts in which he can thrive and learned to present a more at ease persona to his peers. He talks at length about relaxed time with friends on school trips and travelling to London with a friend to attend a major eSports event. Perhaps David's increasing confidence comes from an increasing ability to manage his health difficulty, a maturing of his personality and the increasing centrality of study, a sphere in which he thrives, as he and his peers approach their GCSEs.

In the third interview, David's confidence seems to have developed further, possibly as a result of his success in his exams. David appears during this time to be forging quite an independent identity. Perhaps because of the importance he places on academic success, David is willing to opt for a college attended by few of his earlier friendship network. He also readily anticipates loosening his ties to family – stating it is likely that they will not go on another holiday together. However, despite his academic success and independent identity, health remains something of an issue. In his third interview, when asked about his life satisfaction, David explained that it was his health that stopped him being very satisfied. His response gives an indication of the way his health difficulty continues to affect his lived experience and felt identity:

*"It's probably just the general annoyance, sort of thing, of like, not being well and yet you know, like, everybody, like, a lot of other people you're around, like, when I was growing up, like, never have, like, the same stuff wrong with me, sort of thing, and, like, you don't want to be, sort of, different and have all this, like, that you're almost, like, special, like, different to them. You don't really want to be that." [emphasis added]*

Despite improvements in his lived experience, it would appear that health remains an issue – something that makes him *different*. David seems to pursue academic success not only for its direct benefits, in terms of the enjoyment of learning and the opportunities it opens up, but also to project an identity to others of being talented rather than "different".

The participants' biographical data indicate the dynamic interconnections between the different facets of their lives. As embodied individuals (Freund, 1990; Parsons, 1978;

Shilling, 2001), poor experienced health has implications for their ability to enjoy valued activities, renegotiate their relationships, pursue their aspirations and express and develop their desired identities (Bury, 2005c). Nevertheless, the participants, with the support of family, close friends and healthcare workers, often learn to positively adapt to their contexts. This process included using their agency to identify effective techniques for lessening the burden of their health difficulty, selecting activities which were less dependent on physical capacity and learning to embrace and project alternative, positive identities. However, the biographies of many of the individuals with health difficulties seemed to experience a continuing tension. Like David, some learned to adapt and increasingly project alternative identities while still seeming to experience a sense of “difference” in their inner identity (Boydell et al., 2008; Christian and D’Auria, 1997; Rhee et al., 2007; Woodgate, 2005, 1998).

#### 7.4. Concluding discussion

Given the mixed methods design of this thesis, I defer an *in-depth* discussion until after the comparison of the qualitative and quantitative research findings is reported in chapter 9 (and I am in a position to discuss the combined study). However, a brief discussion of both the qualitative study’s strengths and limitations; and its findings may be of value in order to facilitate both: (i) the subsequent comparison of findings; and (ii) the discussion concerning the reliability of any conclusions drawn from this process of triangulation.

##### 7.4.1. Strengths and limitations of the qualitative study

###### 7.4.1.1. *Strengths of the qualitative study*

As outlined in 6.2, my analytical efforts to identify the aspects of life of particular importance to individuals and investigate health’s role in individuals’ lived experience were highly interconnected. Because of this interdependence between the two components of the qualitative research, I predominantly consider these two study components’ strengths together (in contrast, some of the limitations are more specific to the individual components of the qualitative study).

The strengths of the qualitative study emanate from the approach of: (i) combining two different interview methods (each with different strengths); (ii) undertaking multiple interviews over time with a number of participants; and (iii) interviewing participants who both did and did not have a severe health difficulty. Combining both methods facilitated the dynamic within the interviews. As mentioned briefly in 6.2.2, adopting a narrative

approach allowed the structure and topics covered in the first wave of interviews to be heavily influenced by the participants themselves. Many seemed to enjoy the experience of being able to tell their story and recollect different life experiences. The wider life context they provided meant that, within the interview, I was able to anticipate where follow-up questions on a specific topic had the potential to cause distress and quickly withdraw from a line of questioning once there were signals the individual wished to move on from it. An additional advantage of the BNIM method was that I could do so with confidence, knowing their wider narrative would enable me to interpret these silences (Charmaz, 2002). In the subsequent waves, the use of both methods within a given interview helped facilitate a positive interview experience. The participants both had an opportunity to speak without interruption and engage in activities that differed in nature from those they had undertaken previously. Many seemed to enjoy the experience of engaging with the cards representing each of the domains, taking time to consider the relative priority they would allocate each during the ordering exercise.

In addition to facilitating the interview dynamic and therefore the range of experiences divulged, when undertaking an analysis of the data collected, the use of two interview methods allowed me to employ the data collected from each to develop a more robust understanding of the other's primary research objective. To illustrate, as reported previously in 6.2, the primary purpose of the semi-structured component of the wave 2 interviews was to identify the aspects of life of particular importance to young people. However, my understanding of individuals' responses to these questions was enriched by biographical data collected over two different waves of interviews. Furthermore, as reported in 6.2.3.3, I was able to use participants' biographical data as an additional criterion for examining whether there was clear support for the experienced importance of an aspect of life. Similarly, the responses to questions asked during the semi-structured phase of the second and third interviews helped me test and refine my understanding of each individual. As such, they informed my interpretation of their lived experience (and therefore health's role within it).

Undertaking up to three interviews with a number of the participants over a period of approximately 18 months enabled me to develop an improved understanding of them as an individual, gain a clearer view of change within their lives and observe a wider span of the adolescent period. Without repeat interviews, it would have been substantially harder to robustly investigate the *dynamic* role of health in individuals' lived experiences. Only after the interviews did I notice an unanticipated benefit; as reported above, the

experienced health of those recruited with health difficulties often fluctuated from one interview to the next. In my analysis, I was therefore able to make comparisons within and between individuals' biographical data to further investigate the influence of poor experienced health.

Combining within the design both repeat interviews with a number of individuals and a mixed sample enabled a final strength of the study – a consideration of the role of adaptation. To an extent, though a precise characterisation of the role played by adaptation was beyond the scope of the research (and the data I had available), I was able to explicitly consider how it may influence both individuals' lived experiences and the priority they placed on different domains. Repeated interviews with a number of individuals enabled me to observe how their activities and behaviour changed over time – their in-depth narratives helped me observe links between fluctuating health and modifications to their chosen activities. Similarly, I was able to contrast the behaviours of those with and without severe health difficulties to test whether these changes over time were common amongst healthy individuals of a similar age or seemingly of specific relevance to those with poor experienced health.

As reported above the mixed sample, and the two waves of biographical data, also enabled me to consider how the process of adaptation during this period of transition might influence individuals' prioritisation of the different aspects of life. I am able to ensure my prioritised list is of relevance to those with health difficulties while being in a position to confidently demonstrate my selection of domains is not influenced by any tendency amongst those with health difficulties to under-prioritise aspects of life in which they struggle due to reduced expectations.

For both components of the study, I was able to use data from my whole cohort to investigate the validity of hypotheses generated from an analysis of a more restrictive group. This enabled me to nuance my initial hypotheses and ensure the findings summarised in 7.4.2 are indicative of the data provided by cohort as a whole, rather than merely reflective of the cases that support a vibrant illustration (Silverman, 2014a).

With regards the contributions of the two components of the qualitative study, methodologically, this research is the first I am aware of to explicitly account for defended subjectivity when eliciting participant views on the aspects of life that should be prioritised for inclusion in a pragmatic list. With regards the substantive findings of the

qualitative research, I am aware of no other study that provides an in depth, dynamic description of health's role in the formation of valued abilities during adolescence.

#### 7.4.1.2. *Limitations of the qualitative study*

##### *Critically considering the qualitative study*

A limitation of the qualitative study was the existence of potential differences in the household socioeconomic composition of the different health status strata. As mentioned in 6.2.1.3, there is some indication that the participants recruited as having no severe health difficulties came from households that were generally more affluent than was the case for those recruited as having either severe asthma or CF. With small, purposively recruited samples, it is unlikely, indeed arguably impossible, to achieve balance between strata on all the characteristics of potential relevance. Given my approach of considering individuals' responses in the contexts of their wider biography, it could be argued that obtaining full balance is unnecessary (Silverman, 2014b). Nevertheless, as mentioned in 6.2.3.2, when deciding whom to re-interview, one of the factors I considered was their socioeconomic background. As such, I was able over time to ensure each stratum retained individuals from divergent socioeconomic backgrounds and therefore explicitly consider the extent to which differences in socioeconomic background rather than health status led to differences in, for example, either participants' selected leisure activities or the explicit prioritisations they gave to the differing aspects of life.

Returning to one of the strengths of the qualitative study, the use of both narrative and semi-structured methods, it is important to critically consider the extent to which they enable access to the phenomena of interest. The BNIM method provides a powerful approach for both eliciting narratives and critically considering a participant's approach to self-presentation (Wengraf, 2001a, 2001b). However, it can at best only enable a translucent (rather than transparent) view of their subjectivity and lived experience (Silverman, 2014a; Thomas, 2010). Combining both narrative and semi-structured questions did prompt responses that were complementary both with regards identifying the aspects of life that were of particular importance and in understanding health's role in the lived experience. It is important though to emphasise that an *enhanced* understanding can still be far from complete.

I now turn to considering the limitations of particular relevance to each of the separate components of the qualitative research.



*Limitations of the approach adopted to identifying the prioritised list*

The primary limitation of the methodology adopted for identifying which aspects of life are of particular value to young people is that the intensive interview approach adopted resulted in me only being able to interview and re-interview a relatively small number of participants. Alternative studies (Anich et al., 2011; Burchardt and Vizard, 2009), specifically aimed at identifying which capabilities to include in a list, have: (i) often only interviewed participants once; and (ii) not accessed the biography of the participant via adopting a narrative interview method. Other things being equal, adopting a more structured interview schedule and only interviewing individuals once enables a greater number of participants to be included in the research. However, when considering the limitation of a lower number of participants, it is also important to consider one's underlying assumptions concerning the behaviour of individuals in interviews. A larger number of participants adds little if there are reasons to believe that firstly the participant may select the statements they make in the interview to make a favourable impression on the interviewer (Thomas, 2010; Wengraf, 2001a), and secondly the method employed prevents their approach to presenting themselves (and therefore the domains they identify as being of particular importance) being explicitly analysed.

Individual components of the approach are also subject to limitations. For example, although the Borda count method provides a consistent way to allocate points to the different card orderings, there is no reason to believe the participants' preferences have ratio properties (Black, 1976) or are interpersonally comparable (Harrod, 1938; Kaldor, 1939; Robbins, 1938; Sen, 1985). Similarly, there is substantial subjectivity involved in the initial judgement as to whether an individual's biography does or does not offer support for the experienced importance of an aspect of life, particularly when that aspect of life is abstract in nature. In spite of the limitations of the individual components, it is arguable that triangulating the findings of each method minimises the relative weaknesses of each (Farmer et al., 2006). Using the qualitative data to undertake an in-depth investigation of any dissonance in the resulting findings provided me with the information required to make an informed judgement as to how to prioritise domains for the pragmatic list.

*Limitations of the investigation into health's role in individuals' lived experience*

In addition to the limited number of participants I had the capacity to interview and re-interview, a limitation of particular relevance to my efforts to identify how health difficulties influenced individuals' lived experience is my own defended subjectivity. In

comparison to the approach I adopted to identifying the prioritised list, my efforts to investigate health's role in adolescents' lived experience was disproportionately based on my own critical reflections regarding subtleties in individuals' narratives and biographical data (Thomas, 2010). Aware of this limitation I both: (i) undertook group analysis for the focal cases with my supervisors<sup>33</sup>; and (ii) endeavoured to remain reflexive while analysing the data and drawing up findings. However, my own perspective will have influenced my analysis of the participants' material. Because my perspective influenced both the manner in which I understood them as individuals and my critical interpretation of their narratives and argued positions, it is unavoidably the case that the qualitative study findings are both a result of their *and my* lived experience (Hollway, 2001; Mishler, 2007; Thomas, 2010). As such, the findings of the qualitative are constrained by the perspectives of both myself and those of the study participants. As discussed in chapter 5, it is in part because of this limitation that I believe there to be merit, where possible, in testing the findings which emerge from the qualitative research using quantitative data from a sample that is designed to reflect the age matched general population. To an extent, doing so will enable me to consider the degree to which the findings, in reduced form, that emerge from my and the participants' lived experience can be generalised to the wider adolescent population.

#### 7.4.2. Summary of the qualitative study's main findings

##### *Aspects of life of particular importance to young people*

The aspects of life I identified as being of particular importance to the adolescent participants were: (i) the ability to enjoy good health; (ii) the ability to get a good job and be successful; (iii) opportunities to enjoy valued leisure activities; (iv) the ability to enjoy relating to others; (v) the ability to make decisions on the things that matter; and (vi) the freedom to express and discover one's identity.

A second, perhaps supplementary finding, is that the participants' orderings and their explanation of their approach to ordering the domain cards indicated that the participants with health difficulties valued many of the same domains as those without health difficulties. The analyses indicate that the difficulties they face have not led them to devalue the domains in which they experience struggles. Indeed, there is an indication of the opposite effect – the constraints faced, including disrupted school attendance, may

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<sup>33</sup> As mentioned in 6.2.3.4 one of these analysis meetings was attended by a senior doctor who worked at the hospital from which I recruited the participants with CF and severe asthma.

have caused them to be more explicitly aware of the value of the aspects of life in which they have less ability to achieve the outcomes they desire (Maslow, 1943).

*Health's role in the formation of valued skills and abilities*

One of the substantive strengths of qualitative methods, as discussed in 4.4.1, is the rich, unreduced descriptions of individuals' lived experiences they enable. It is with a degree of hesitancy therefore that I provide below a reduced summary of the main findings to emerge concerning health's role in individuals lived experience and their opportunity to enjoy and develop valued abilities and skills. I therefore do not intend the summary below to displace or supplant the detailed findings reported in 7.3. However, given the mixed methods approach adopted in the thesis, it is important to succinctly record these findings. Doing so enables me to subsequently triangulate the qualitative and quantitative study findings in a transparent manner. Therefore, for each of the prioritised domains, in Table 7-2, below I briefly summarise my study findings with regards to the research questions that emerged following an initial analysis of the wave 2 transcripts. Given my research aims and objectives, I focus on summarising the findings that relate to *health's* role in the formation of valued abilities. Specifically, for each domain, I summarise observations firstly on the dynamic trend in how the particular aspect of life tends to evolve over the period of life in which I interviewed the participant. For the different prioritised aspects of life other than "the ability to enjoy good health", I then summarise: (i) the way a *health difficulty* tends to inhibit an individual flourishing in that aspect of life; and (ii) I summarise the approaches often employed by participants to surmount the barriers imposed by a *health difficulty*. When considering "the ability to enjoy good health" as the domain of primary interest. For "i" and "ii" (as listed directly above) I instead: consider the potential *wider barriers* that have the potential to prevent individuals being able to enjoy good physical and mental health; and the approaches individuals tend to employ to surmount these wider barriers.

Table 7-2: Summary of the qualitative findings

Category of finding	Summary of findings
<i>The ability to enjoy good health</i>	
Identified dynamic trends	Participants' experienced health tends to fluctuate over time
	Participants with asthma often experienced an improvement in experienced health over time
	Participants with CF did not experience a consistent upward trajectory in their experienced health
Barriers to flourishing in the domain	a) Having a diagnosed serious health difficulty often led to a substantial disruption of the participant's experienced health (e.g. CF or asthma)
	b) Participants, their parents and healthcare workers often experienced a prolonged period of time where they had not worked out the most effective way to manage the individual's health difficulty
	c) The demands of ongoing study and preparing for exams often led to periods of rising stress and anxiety for the participants
Approaches frequently adopted to surmount the barriers	Concerning "b": participants, especially those with asthma, appeared to learn over time in collaboration with parents and health care workers, which interventions were particularly effective in alleviating their health difficulty
	Concerning "c": some participants appeared to an extent to become accustomed to stress levels and pressure
	Concerning "c": some of the participants learned to become increasingly organised
<i>The ability to get a good job and be successful</i>	
Identified dynamic trends	For many participants, the pressure associated with study appeared to increase over time
Impact of poor experienced health on individuals' ability to flourish in the domain	The participants' ability to regularly attend school can be disrupted by health difficulties – sometimes this resulted in disrupted preparations for their exams
Approach frequently adopted to surmount difficulties imposed by a health difficulty	Some participants who missed school due to poor health reported trying to working harder on returning to school in an effort to catch up

Category of finding	Summary of findings
<i>Opportunities to enjoy valued leisure activities</i>	
Identified dynamic trend	The leisure activities the participants engaged in often appeared to become less structured and supervised by adults over time
Impact of poor experienced health on individuals' ability to flourish in the domain	Health difficulties sometimes resulted in the participants having to show greater caution when joining in leisure activities with their peers – this appeared at times to disrupt their enjoyment of the activity
Approach frequently adopted to surmount difficulties imposed by a health difficulty	The participants with a health difficulty often seemed to take up alternative activities for which their health difficulties imposed little or no constraint
<i>The ability to enjoy relating to others</i>	
Identified dynamic trend	Many of the participants seemed to increasingly want to spend time with peers and away from adult supervision
Impact of poor experienced health on individuals' ability to flourish in the domain	Participants' health difficulties seemed at time to undermine confidence in social settings
Approach frequently adopted to surmount difficulties imposed by a health difficulty	The participants with health difficulties appeared to gravitate towards peers who would accept these “different” behaviours and not draw attention to them
<i>The ability to make decisions on the things that matter</i>	
Identified dynamic trends	Participants often appeared to experience increasing freedom to make important decisions
	Participants often appeared to intentionally work on mastering areas of importance in which they struggled and learned to make progress in them
Impact of poor experienced health on individuals' ability to flourish in the domain	a) Difficulties with health seemed at times to constrain participants' ability to actualise desirable opportunities
	b) For those with health difficulties, particularly if it was CF, a legacy of being a recipient of care sometimes appeared to inhibit the ease with which they could redefine themselves as independent and autonomous individuals
Approaches frequently adopted to surmount difficulties imposed by a health difficulty	Concerning “a”: participants with health difficulties appeared to actively manage risks in order to make desirable activities and opportunities more feasible
	Concerning “a”: participants with health difficulties often learned to “push through” their fears and gather the courage required to enjoy valued opportunities that came with a degree of often well managed risk
	Concerning “b”: some of the participants became increasingly independent in managing their health difficulty – doing so enabled them to demonstrate to their parents they could be entrusted with independence in other aspects of life

Category of finding	Summary of findings
	<i>The freedom to express and discover one's identity</i>
Identified dynamic trend	The participants often appeared to consciously and subconsciously shape who they are becoming over time (often using other facets of life to do so)
Impact of poor experienced health on individuals' ability to flourish in the domain	Having a health difficulty which needed managing often led participants to a negative sense of being different. This included but was not limited to, girls frequently being concerned by their bodies as being visibly different and boys being concerned they may be perceived as frail.
Approach frequently adopted to surmount difficulties imposed by a health difficulty	As noted for "opportunities to enjoy valued leisure activities", the participants seemed to take up alternative activities which allowed them to feel and demonstrate a more positive identity.

The summary findings above are supported by the biographical data of both the girls and the boys who participated in the study. For some domains, the *specific* manner in which poor experienced health inhibited individuals' ability to enjoy an aspect of life tended to differ by gender. For example, poor health's disruption of the body often impeded girls' confidence as a result of inhibited physical appearance whereas it often inhibited boys' confidence via inhibited physical strength and fitness. Even in this example, the clearest identified differences observed by gender, the gender-specific findings cohere when considered at a more generalised level. Each specific finding supports the broader conclusion that a health difficulty can impede an individual's ability to meet society's expectation of their body's form and performance. This in turn can have consequences for their confidence when engaging in leisure activities and social relationships.

The participants' biographical data illustrate the interconnectedness of the different aspects of life within the lived experience of the individual. For example: (i) increasing educational pressures have implications for the participants' mental health; (ii) leisure activities often provide a context for individuals' social relationships to flourish; (iii) individuals often deploy their agency when selecting activities and renegotiating their relationships; and (iv) they arguably desire to flourish in their aspirations, leisure activities and relationships not only for the inherent value of each of these aspects of life but also to enable them as individuals to increasingly express and discover their desired identity.

The participants' biographies indicate that experienced poor health had the potential to disrupt all these interconnected facets of life. As outlined in 2.2.3, this in line with the expectations of a number of sociologists (Bury, 2005c; Freund, 1990; Parsons, 1978; Shilling, 2001). Poor experienced health disrupts the body's capacity (Bury, 2005c) and the body itself is central to individuals' ability to sense, understand, act and communicate with the world – the diverse capacities on which individuals draw in order to flourish (Freund, 1990; Parsons, 1978; Shilling, 2001). As reported in 7.3, and shown in Table 7-2, the participants with severe health difficulties could and did use their agency to navigate the additional difficulties they faced on their journey of transition from childhood to adulthood. However, their biographies indicate their experience of poor health continued to influence their ability to enjoy the different inherently valued aspects of their lives, including the identities they were learning to express and discover.

Having learned from the lived experiences of the participants and, using indicative reasoning, generated hypotheses about health's role in the formation of valued skills and

abilities, I shortly turn to testing these hypotheses using a wider analytic sample. In chapter 0, I report a quantitative investigation of the potential pathways via which health may disrupt the formation of valued abilities and therefore subsequent well-being. In chapter 9, I then triangulate between the qualitative and quantitative findings and explicitly consider, between the two studies, those findings that are supportive and discordant. In 9.4, having dialectically engaged with the discordant findings (Ó' Catháin et al., 2010), I then consider the findings of the study as a whole, its contribution to the literature and areas where further research may be of particular value.

*A brief stylistic note*

Though the thesis as a whole is a mixed methods study, I aim to ensure both the qualitative and quantitative strands individually accomplish the standards expected by practitioners from each strand's respective methodological area (O' Cathain et al., 2008). This has implications for the style with which the qualitative and quantitative studies are reported. Studies which report econometric analyses typically eschew a discursive self-reflective writing style and instead prioritise a relatively brief but precise report of the methods adopted and the results generated. Therefore, in chapter 0, I attempt to adopt a writing style which accords with the genre adopted for reporting econometric analyses. However, in chapter 9, when appropriate, I will return to making explicit how my individual background has shaped my perspective and therefore the analyses I have conducted.



## PART 3: A QUANTITATIVE INVESTIGATION



## 8. A quantitative analysis of the role of health in the development of valued abilities

### 8.1. Introduction

In this chapter I present the quantitative strand of the mixed methods study. In 8.1.1 I summarise the objectives of the quantitative study. I then review the theoretical literature that informs the analyses in 8.1.2. In 8.2 I provide an overview of the methods employed summarising: (i) which domains were included in the analyses; (ii) the models estimated; (iii) the variables incorporated in the analyses; and (iv) the approach adopted to testing the hypotheses that emerged from the qualitative study. In 8.3 I present the findings of the quantitative analyses including the degree of support they offer for the hypotheses that resulted from the qualitative research. The chapter concludes with a discussion of the strengths and limitations of the quantitative strand of the research and a summary of its findings. The novel contribution of this chapter is that it presents the first analyses I am aware of to estimate the dynamic associations between health difficulties in adolescence, the impaired formation of inherently valued abilities (capabilities) and reduced life satisfaction.

#### 8.1.1. Objectives of the quantitative study

In order to further the thesis' aim "to research the immediate and future impact of health difficulties during adolescence on the formation of valued abilities which foster well-being" the quantitative study has two related but distinct objectives<sup>34</sup>. The first objective of the quantitative study is to focus on the *thesis'* second objective by examining the pathways through which health difficulties impact the formation of valued abilities. As alluded to in 4.4 and chapter 5, the second objective of the quantitative study is to test hypotheses generated by the qualitative analysis concerning the impact of a health difficulty upon young people's lived experience.

#### 8.1.2. Theoretical literature of relevance to the quantitative analysis

In order to quantitatively investigate the impact of a health difficulty in adolescence on an individual's future well-being, I draw on three distinct but complementary theoretical frameworks which were outlined in chapter 2. Specifically, I draw on the theoretical literature concerning human capital, capabilities and SWB. Having briefly summarised the

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<sup>34</sup> This chapter builds on a previous analysis undertaken by Dr Popli, Professor Tsuchiya and myself (Gladwell et al., 2016).

relevance of each to the quantitative study, I outline an empirical investigation of the dynamic associations between health, valued abilities and SWB.

Human capital theory provides two useful insights for the quantitative study. Firstly, it is theorists from this background who have articulated that, as alluded to in chapter 1, good health is not only of inherent value to the individual but also both: (i) benefits the individual by enabling the individual to be productive in their tasks; and (ii) facilitates the accumulation of skills which will increase the individual's ability to produce valued outcomes over time (Grossman, 1972; Mushkin, 1962). As indicated by two of the empirical studies identified in the systematised review (De Ridder et al., 2013; Rees and Sabia, 2009), health has the potential to not only have the properties of a consumption good but also of capital. Secondly, as with financial capital, a reduction in the accumulated stock of human capital can have both immediate implications for the individual's productive potential and future consequences with respect to the quantity of capital accumulated over time (Cunha et al., 2010a; Cunha and Heckman, 2008; Heckman, 2006). However, for the purposes of the thesis, considering how health difficulties impact the individual's future *well-being*, human capital theory's primary focus on the production of economic outcomes is arguably too narrow. It risks focussing on the accumulation of wealth which is "...merely useful and for the sake of something else" (Aristotle, trans. 1980: 7).

As summarised in 2.1, well-being has historically been conceptualised eudaimonically and hedonically (Ryff et al., 2004). The capability approach, informed by a eudaimonic conceptualisation of well-being, considers the extent to which individuals are able to flourish (Nussbaum, 1988). The good life is one in which an individual has the opportunity to actualise valued "beings", such as being healthy and "doings", such as undertaking meaningful work (Sen, 1993, 1990). Conversely, SWB, informed by a hedonic conceptualisation of well-being, focuses on the extent to which individuals experience positive emotional affect and have a positive, cognitive, global evaluation of their lives (Diener et al., 1985). While these two approaches have critiqued the other's limitations, the two are arguably complementary (Dolan and White, 2006). Either approach in isolation has a substantial limitation, while combining them allows the limitations of each to be addressed. Specifically, it is debatable whether an achieved outcome (functioning), matters if it is rarely associated with improvements in the individual's life satisfaction (see 2.1.2 above). However, only considering individuals' life satisfaction, which is conceptualised within the wider literature as a component of SWB (Diener et al., 1985;

Diener et al., 1999), incurs the risk that some will underestimate the extent to which their ability to flourish within a given aspect of life is impaired. This is because over time, as discussed in 4.3.1 and 7.2, they may psychologically reconcile themselves to a harder existence and reduce their expectations (Sen, 1985). Empirically combining indicators informed as being of relevance to the two theoretical frameworks enables an investigation of the pathways via which a health difficulty not only impairs the achievement of valued outcomes (functionings) but also the consequences as regards their global assessment of life satisfaction (Stiglitz et al., 2010). Indeed, Anand et al. (2008) identified strong correlation between variables relating to different capability domains and life satisfaction using cross sectional data (see 4.4.2 above).

As discussed in 2.5 and observed in the biographies of the qualitative study participants, adolescence is a period of biological, psychological and social transition when individuals experience substantial change in their abilities and agency (Christie and Viner, 2005; Zimmermann and Cleary, 2006). It is also a period when key educational milestones are being reached and individuals are selecting and being selected for higher education or different vocational pathways. While the *qualitative* study above indicated potential pathways via which health difficulties may disrupt the formation of valued abilities these are, as yet, untested against an analytic population that is representative of the general adolescent population. As shown by the systematised review, the published literature to date has not investigated the dynamic relationship in the adolescent population between health, the formation of a range of valued abilities and the consequences for individuals' SWB. The published literature therefore leaves unclear the pathways via which health dynamically influences the formation of valued abilities in adolescence. While indicating a relationship between childhood *emotional* health and subsequent SWB (Layard et al., 2014), the literature fails to provide an estimate of the cumulative impact of health difficulties during adolescence on subsequent SWB. I therefore use a dynamic factor model to investigate: (i) the role of health in adolescence on the formation of valued abilities; (ii) the direct effect of health in adolescence on SWB in early adulthood; and (iii) the indirect effect of health in adolescence on later SWB via its role in the formation of valued abilities.

## 8.2. Methods

I use data from the LSYPE1 (Department for Education, 2011)<sup>35</sup>. The study, which aims to collate data on adolescents to inform UK government policy, follows a cohort of approximately 15,500 young people in English secondary schools. Individuals were aged 13-14 when the first wave of interviews was undertaken in 2004. The interviews were undertaken annually, and by the seventh wave, individuals were aged 19-20. The LSYPE1 is the first national dataset since the British Cohort Study to follow a cohort of English adolescents through most of their secondary education into adulthood (Chowdry et al., 2011, 2009)<sup>36</sup>.

### 8.2.1. Domains selected for inclusion in the analysis

As discussed in 4.3, in order to quantitatively model the dynamic association between health difficulties, the formation of valued abilities and SWB, it was necessary to identify which aspects of life should be prioritised for inclusion in the analysis. Identifying the aspects of life for inclusion in the analysis involved two steps. Firstly, as reported in 6.2.3.3 and 7.2, I identified the aspects of life which were explicitly and implicitly emphasised as being of importance by the 23 adolescents who were interviewed in the qualitative study. Secondly, having identified a reduced, pragmatic list (Robeyns, 2005b), I then reviewed the variables available in the LSYPE1 to assess whether the data were available in the LSYPE1 to include the aspect of life in my quantitative analysis. Given my interest in analysing the *dynamic* formation of these valued abilities, it was important that over the seven waves of the LSYPE1, variables relating to that aspect of life were included with relative consistency. Finally, when multiple conceptually related variables were available, I undertook exploratory factor analysis and confirmatory factor analysis to identify which variables should be incorporated in each valued ability's measurement model.

In my prioritised list, I have to omit "the freedom to express and discover one's identity" because no variables related to this domain were consistently included in the LSYPE1. Two aspects of life, "the ability to enjoy good health", and "the ability to make decisions on the things that matter" are incorporated in the analysis, but given: (i) the theoretical

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<sup>35</sup> I downloaded the data from the Economic and Social Data Service website on 9<sup>th</sup> August 2012.

<sup>36</sup> The Avon Longitudinal Study of Parents and Children (University of Bristol, 2013) does contain responses of participants of a similar age. However, it only contains the responses of young people and their parents who live in Bristol and the surrounding county. As such, it is questionable the extent to which it is nationally representative of an adolescent cohort.

explanatory power of both aspects of life as concerns flourishing in other aspects of life; (ii) the need for model simplicity; and (iii) concerning the former, the research prioritises of the thesis, they are included as potential *predictors* of flourishing in the other domains rather than as *outcomes* of interest (in 8.2.2, I briefly outline the steps taken to reduce the risk of bias occurring as a result of potential reverse causality between health and outcomes of interest).

The quantitative analysis therefore attempts to model the formation of three of the aspects of life included in the reduced list. These include: (i) “the ability to get a good job and be successful” (abbreviated for this chapter to “skills for employment”); (ii) “opportunities to enjoy valued leisure activities”; and (iii) the ability to enjoy relating to others (abbreviated for this chapter to “ability to enjoy social relationships”). Given the available data, as will be discussed further in 8.2.3, for this analysis, the labels of the second and third domains are altered to “opportunities to enjoy physical leisure activities” and “ability to enjoy social relationships”.

Concerning leisure activities, I make this alteration because the only variables consistently available which related to this aspect of life reported the extent to which the participant engaged in physical activities. While physical leisure activities were often emphasised in the qualitative interviews, other leisure activities were also valued. However, as discussed in 7.3, the interviews also indicated a substantial overlap between valued non-physical leisure activities and the ability to enjoy social relationships domain. As such, an individual’s ability to enjoy non-physical leisure activities is likely correlated with their ability to enjoy social relationships. I make the change to the label of the relationships domain to reflect this analysis’ focus on relationships with peers rather than family. This reduced focus is necessary because of the lack of data over time in the LSYPE1 concerning the relationship between the participant and either their parents or their siblings.

To derive a parsimonious model of the role of health in the formation of these valued abilities, I allocate variables from the LSYPE1 to three time periods. The three periods are: (i)  $t=0$ , when individuals were aged 13-15 (these are the initial two waves of the LSYPE1); (ii)  $t=1$  when individuals were aged 15-17 years (these are the school years immediately pre and post GCSE examinations and the end of compulsory education when the LSYPE1 data were collected); and (iii)  $t=2$  when individuals were aged 19-20, an age I categorise as “early adulthood” (this was the final wave of the LSYPE1 at the time I downloaded the data). Though in 8.2.3, I will describe the variables included in the analysis in greater

depth, I summarise the variables used from each wave of the LSYPE1, the model time period they are allocated to and the age of the participants at each time period in Table 8-1 below. I do so to enable a more concrete and clear explanation of the models and estimation approach in 8.2.2.



Table 8-1: Variables used across different waves of the LSYPE1

Time Age LSYPE1 wave	t = 0 13/14 to 14/15 years		t = 1 15/16 to 16/17 years		t = 2 19/20 years
	Wave 1	Wave 2	Wave 3	Wave 4	Wave 7
<b>Health Variables</b>	Mental health difficulty		Mental health difficulty		
	General health difficulty		General health difficulty		
<b>Valued abilities and skills modelled over time</b>	<b>Skills for employment</b>	KS3 (age 13/14) (NPD)	KS4-GCSE (age 15/16) (NPD)		NEET (age 19/20)
	<b>Valued physical activities</b>	No Sport		No Sport	Not Physically Active
	<b>Ability to enjoy social relationships</b>	Relational Exclusion		Relational Exclusion	Few close friends
<b>Subjective Well-being</b>					Not Satisfied with life
<b>Additional Covariates</b>	Gender	Educationally orientated aspirations*	Educationally orientated aspirations*		
	Ethnicity	Cannabis use		Cannabis use	
	Months younger than oldest in year	External locus of control		Either parent ill	External locus of control
	Either parent ill	Household SES		Household SES	Have own child
	Mother's education	Number of children in household		Single parent household	Not in relationship
	Parental rating of school	Local index of multiple deprivation	Local index of multiple deprivation		
		Single parent household			

**Notes:** SES = Socio economic Status; NPD = National Pupil Database; KS3 = Key Stage 3; KS4 = Key stage 4; GCSE = General Certificate of Secondary Education; NEET = Not in Education, Employment, or Training;

\*Covariate only used in regressions relating to skills for employment. + For the analytic sample this group is predominantly composed of individuals in a single person household however as value of 1 is also attributed to those in a household for whom no parental figure could be identified (in wave 1 this applies to 38 out of the 5,000 individuals and in wave 4 this applies to 76 of the 5,000 individuals).

## 8.2.2. Models and estimation approach

### 8.2.2.1. Overview of approach

I analyse data from the LSYPE1 using SEMs. As discussed in 4.4.2, adopting this approach has a number of benefits. Firstly, using SEMs allows me to incorporate measurement models within the analysis. As will be outlined in a formalised manner below, measurement models aim to estimate an underlying *latent* variable by estimating the shared covariance between several theoretically related *observed* variables. The shared covariance is hypothesised to be caused by the underlying latent variable. Concerning the measurement of the latent variable, the variance unique to each indicator is conceptualised as measurement error (Acock, 2013a). Using measurement models therefore allows me to address the issue of measurement error when estimating mental health difficulties and the valued abilities of skills for employment and the ability to enjoy social relationships (Cunha and Heckman, 2008). As discussed in 4.4.2, from the perspective of the capability approach, it has been argued previously that adopting a latent variable approach allows the researcher to go beyond the measurement of achieved outcomes and instead make inferences about individuals' underlying abilities from the observed measurement indicators (Anand et al., 2011; Krishnakumar and Ballon, 2008). Secondly, through the structural model, SEM allows me to jointly estimate both the measurement models and numerous structural regressions. This allows the joint estimation of correlations through time between: health and the formation of wider valued abilities; health and life-satisfaction; and the wider valued abilities and life-satisfaction. Finally, because the regressions are jointly estimated, the model is able to estimate the indirect correlation (or effect) between different variables (Beran and Violato, 2010). This enables an analysis of the pathways via which health difficulties in  $t=0$  *indirectly* impact valued abilities and SWB in  $t=2$  via their *direct* effect on valued abilities in  $t=1$ <sup>37</sup>.

From an analytical perspective, two beliefs about the nature of the formation of individual's valued abilities are in tension. Firstly, the systematised review in chapter 3 indicates that unobserved heterogeneity between individuals can confound the association between a health difficulty and impaired outcomes in a subsequent time period. However, as identified by the qualitative analysis, there is reason to believe the

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<sup>37</sup> For a detailed outline of the approach adopted to the estimation of indirect total effects see the article by Preacher and Hayes (2008).

different facets of an individual's life are highly interconnected. This poses analytical difficulties as, although it is possible to explicitly account for the potential influence of unobserved heterogeneity in a SEM, doing so with a complex analysis, which models the co-evolution of multiple valued abilities, is problematic. Below, I therefore: (i) outline my approach to jointly estimating the formation of the three inherently important aspects of life simultaneously (the "expanded structural model"); (ii) outline my approach to incorporating measurement models within the analysis; and (iii) outline my approach to explicitly incorporating unobserved heterogeneity in a structural model which is reduced such that it only models the *formation* of one of the inherently important aspect of life (the "reduced structural model").

#### 8.2.2.2. *Expanded structural model*

I model the formation of the valued ability/opportunity (ability) identified above with respect to prior valued ability, prior health and additional covariates. Equation (1) below algebraically presents the expanded structural model for the formation of valued abilities:

$$A_{i,j,t} = \sum_{j=1}^3 \beta_{j,t} A_{i,j,t-1} + \beta_{4,t} GHD_{i,t-1} + \beta_{5,t} MHD_{i,t-1} + \beta_6 X_i + \eta_{i,j,t} \text{ for } t= 1, 2 \quad (1)$$

Where, for the  $i=1, \dots, n$  individuals included in the analytic sample,  $A_{i,j,t}$  for  $j=1, 2, 3$  represents the three abilities. These three abilities can either be latent or observed variables (note from the perspective of the capability theory they can be interpreted as a capability when measured using a latent variable and as an achieved functioning when modelled using a single observed variable).  $\eta_{i,j,t}$  is the error term.  $GHD_{i,t-1}$  is the presence (or absence) of a General Health Difficulty for individual  $i$  at time period  $t-1$ . Similarly,  $MHD_{i,t-1}$  is the presence (or absence) of a Mental Health Difficulty for individual  $i$  at time period  $t-1$ .  $X_i$  represents the additional covariates included in the regressions per individual.

It is worth explicitly noting that, though of inherent value, I do not model the formation of the ability to enjoy good health within equation (1). General and mental health difficulties are included as predictor variables, or resources, within the expanded structural model but not as endogenous variables. There are four reasons for this approach. First, the focus of the thesis is health's role in the formation of the wider abilities of inherent value rather than the influence of these other abilities upon individuals' health. Second, as alluded to in 2.4.2, within the capability approach it is legitimate to conceptualise a characteristic of life such as health either in terms of its inherent value (when it is considered a capability or functioning) or in terms of its instrumental value (when it is

considered as a resource for the formation of other capabilities) (Binder and Coad, 2010). As such, in spite of its inherent value, given the focus of the research, it is theoretically coherent to incorporate health within the structural model as a resource for the formation of *other* valued abilities (instead of as an endogenous ability in its own right). Third, there is a need to maintain model parsimony. Fourth and finally, it is feasible to incorporate general and mental health difficulties as exogenous variables within equation (1) without risking endogeneity when estimating the associations between these variables and the impaired formation of the wider abilities of value. To limit the risk of endogeneity between experienced health difficulties and the impaired ability to enjoy one of the wider valued aspects of life, I take two steps in equation (1). Firstly, I lag both GHD and MHD. It is necessary to lag both because: (i) I wish to use reported GHD and MHD from the same time period; and (ii) the qualitative interviews indicate a mutually reinforcing dynamic between educational struggles and poor experienced mental health<sup>38</sup>. Secondly, within equation (1) I include respondents' lagged prior abilities. I do so not only because of their potential predictive value but also because their incorporation further reduces the risk of endogeneity in my estimates of the relationship between health and subsequent ability. For example, if there is the possibility that academic difficulties in  $t_0$  may be influencing  $MHD_{t_0}$ , then if I include  $MHD_{t_0}$  as a predictor of skills for employment $_{t_1}$  and omit to include skills for employment $_{t_0}$  there is a risk that the coefficient for  $MHD_{t_0}$  will be falsely inflated. This is because of the potential influence of the academic difficulties in  $t_0$  on both  $MHD_{t_0}$  and skills for employment $_{t_1}$ . The risk of endogeneity between mental health and skills for employment is, however, minimised by the inclusion of skills for employment $_{t_0}$  as an autoregressive predictor of skills for employment $_{t_1}$ .

SWB at  $t=2$  is modelled in terms of current abilities, prior health and additional covariates. Equation (2) below presents the structural regression used to estimate the predictors of SWB:

$$NSWL_{i,t} = \sum_{j=1}^3 \gamma_{j,t} A_{i,j,t} + \gamma_{4,t} GHD_{i,t-1} + \gamma_{5,t} MHD_{i,t-1} + \gamma_6 X_i + \zeta_{i,t} \quad \text{for } t=2 \quad (2)$$

where:  $NSWL_{i,t}$  is Not Satisfied With Life and  $\zeta_{i,t}$  is the error term. In  $t=2$ , all the variables for  $A_{i,j,t}$  are observed variables. From a theoretical perspective, they are therefore most accurately conceptualised as functionings (achieved outcomes).

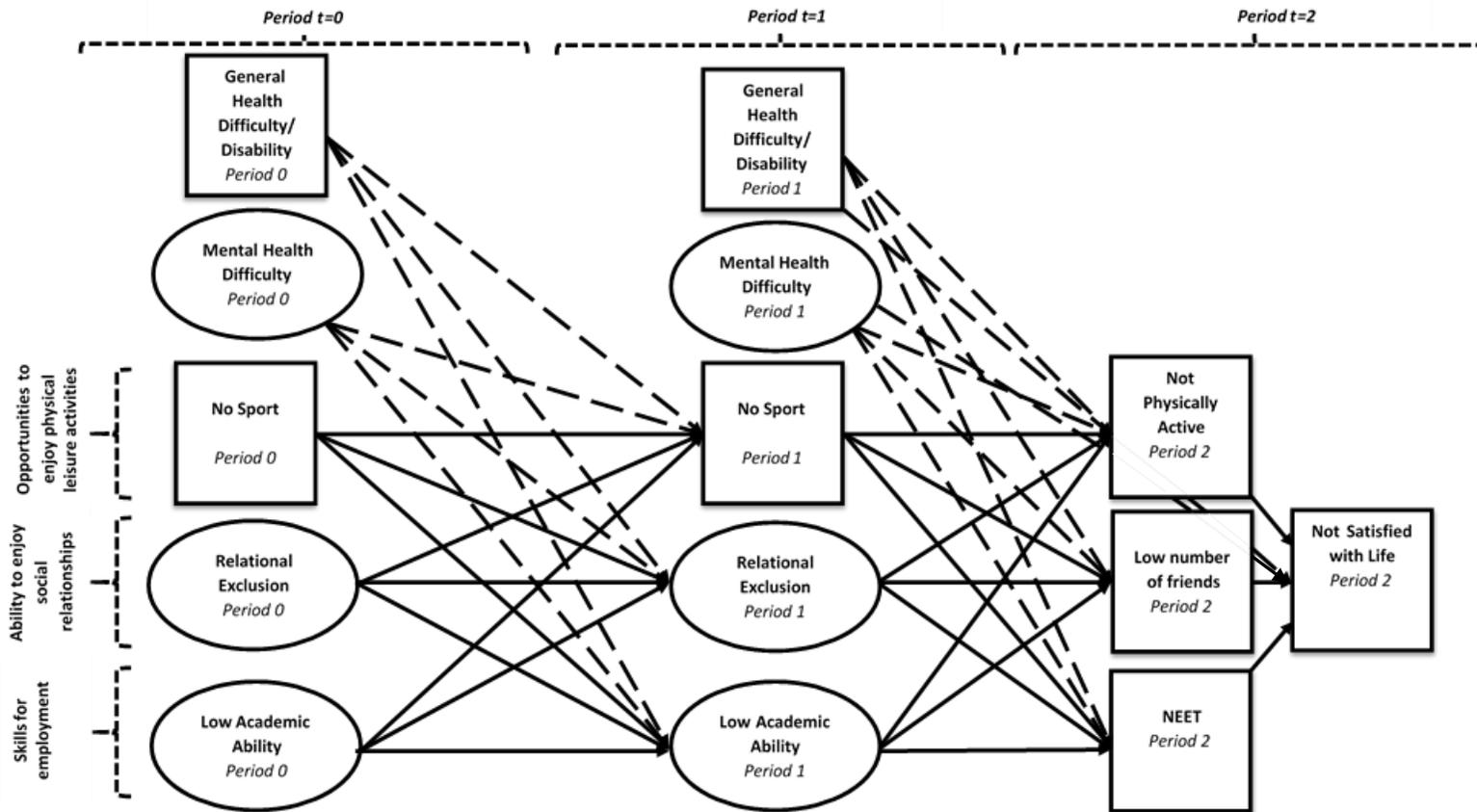
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<sup>38</sup> While not emphasised in the qualitative findings, a similar dynamic can be observed in the participant biographies between social isolation and poor mental health.

Similarly to equation (1), I lag both GHD and MHD. Doing so: (i) minimises the risk of endogeneity (as discussed previously); (ii) allows me to use reported GHD and MHD from the same period; and (iii) limits the risk of conflation between the related concepts of MHD and SWB. This approach is similar to that adopted by Layard et al. (2014) who lagged emotional health. As implicitly assumed by Layard et al., my approach to equation (2) implies a belief that the causal relationship between life satisfaction and achieved valued outcomes (degree of physical activity, number of close friends and employment status) can, as a simplified representation, be modelled as singular in direction. Hence the inclusion of these explanatory, outcome variables in the contemporaneous period to the dependent variable, life satisfaction.

Figure 8-1 below gives a diagrammatic representation of the expanded structural model. As is the convention, latent variables are shown in ovals and observed variables in square boxes. Arrows indicate the hypothesised pathways. Those of primary interest to the thesis' research aim are shown with dashed lines.

Figure 8-1: Diagrammatic representation of the expanded SEM



Note: For simplicity, covariates other than health are excluded from the diagram.

As shown in Figure 8-1, many of the dependent variables are represented using observed outcomes (being NEET in t=2, doing no sport in t=1, not being physically active in t=2, having few close friends in t=2). The singular observed variables used to represent these outcomes of interest are coded as binary variables. For each, I adopt the convention of modelling the observed outcome variable as:

$$A_{i,j,t} = 1 \text{ if } A_{i,j,t}^* > A_{j,t}$$

$$A_{i,j,t} = 0 \text{ otherwise}$$

where  $A_{i,j,t}^*$  can be interpreted as the continuous latent response variable for a specific individual  $i$  for the variable of interest in time period  $t$ , and  $A_{j,t}$  is the threshold for the variable (if the individual's latent response score is greater than the threshold, we observe "1", and if is less, we observe "0").

For each of the different binary variables, the outcome for the individual in time periods  $t=1$  and  $t=2$  can be modelled as:

$$\begin{aligned} & P(A_{i,j,t}=1 | \sum_{j=1}^3 \beta_{j,t}A_{i,j,t-1} + \beta_{4,t}GHD_{i,t-1} + \beta_{5,t}MHD_{i,t-1} + \beta_6X_i) & (3) \\ & = P(A_{i,j,t}^* > A_{j,t} | \sum_{j=1}^3 \beta_{j,t}A_{i,j,t-1} + \beta_{4,t}GHD_{i,t-1} + \beta_{5,t}MHD_{i,t-1} + \beta_6X_i) \\ & = 1 - P(A_{i,j,t}^* \leq A_{j,t} | \sum_{j=1}^3 \beta_{j,t}A_{i,j,t-1} + \beta_{4,t}GHD_{i,t-1} + \beta_{5,t}MHD_{i,t-1} + \beta_6X_i) \\ & = 1 - F(A_{j,t} - \sum_{j=1}^3 \beta_{j,t}A_{i,j,t-1} + \beta_{4,t}GHD_{i,t-1} + \beta_{5,t}MHD_{i,t-1} + \beta_6X_i) & t=1,2 \end{aligned}$$

where  $F(\cdot)$  is the cumulative distribution function for the error  $\eta_{i,j,t}$ . I assume  $\eta_{i,j,t}$  has a standard normal distribution, and estimate a probit model (Muthen, 2004).

A similar approach is adopted for the binary outcome variable of not being satisfied with life<sup>39</sup>. This approach is also adopted for the binary outcome variables included in the reduced structural model summarised in 8.2.2.4.

<sup>39</sup> For brevity, I do not specify in detail the differences. However, equation (3) would be altered such that: (i)  $NSWL_{i,t}$  would replace  $A_{i,j,t}$ ; (ii)  $NSWL_{i,t}^*$  would replace  $A_{i,j,t}^*$ ; and  $NSWL_t$  would replace  $A_{j,t}$ . Concerning the conditioning set, terms from the right of equation (2) would replace those which are currently drawn from the right of equation (1).

### 8.2.2.3. Measurement models

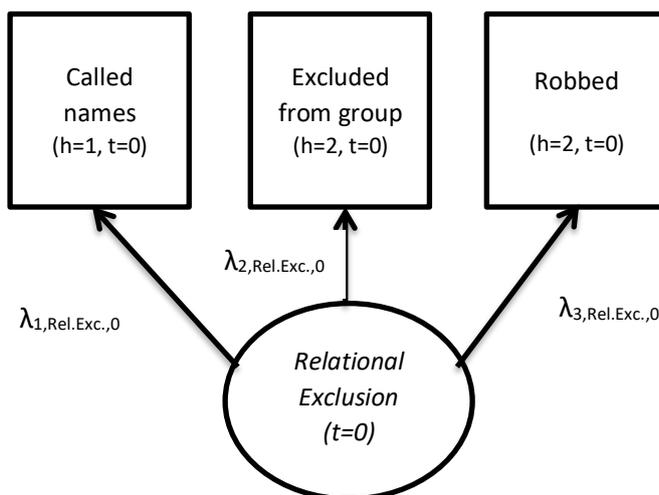
As discussed above, the latent variables incorporated in the SEMs are estimated using measurement models. A generalised summary of these models is presented in equation (4) below.

$$Z_{i,h,k,t} = \mu_{h,k,t} + \lambda_{h,k,t}\theta_{i,k,t} + \varepsilon_{i,h,k,t} \text{ for } t = 0, 1, 2 \quad (4)$$

where  $Z_{i,h,k,t}$  for  $h = 1, \dots, m_t$  represents the measures available at period  $t$  for the latent variable  $\theta_{i,k,t}$ .  $k=1,2,3,4$  and represents each of the four constructs measured as latent variables in the expanded SEM<sup>40</sup>.  $\lambda_{h,k,t}$  represents the factor loadings which can be interpreted as the amount of information the measures  $Z_{i,h,k,t}$  contain about the latent variable  $\theta_{i,k,t}$ .  $\varepsilon_{i,h,k,t}$  represents the measurement errors, which capture the difference between the observed measures and the unobserved latent variables.  $\mu_{h,k,t}$  is the intercept.

To clarify the concept in Figure 8-2 below, I present a schematic of the measurement model used to identify the hypothesised latent variable for relational exclusion in  $t=0$  (full descriptions of the observed variables can be found in the variables definition table in D1). As discussed in 4.4.2, the arrows represent the hypothesised causal relationship *from* the latent variable to the observed variables. The degree of association between the latent variable and the observed variables is represented by  $\lambda_{h,k,t}$  (which varies by observed variable).

Figure 8-2: Diagrammatic representation of  $t=0$  relational exclusion measurement model



<sup>40</sup> In the expanded SEM, the four constructs measured as latent variables are: (i) locus of control ( $t=0, t=2$ ); (ii) low academic ability ( $t=0, t=1$ ); (iii) relational exclusion ( $t=0, t=1$ ); and (iv) mental health difficulties ( $t=0, t=1$ ). The variables used in these measurement models are summarised within table C-1 (in appendix C.2) – to aid identification, these variables are underlined.



#### 8.2.2.4. *Reduced structural model*

As discussed above, given the potential for unobserved heterogeneity to confound the model estimates, I also explicitly specify a model which allows for time in-invariant unobserved heterogeneity. As discussed in 8.2.2.1, my ideal would have been to incorporate the estimation of the influence of latent (unobserved) heterogeneity in the expanded SEM; however, this poses computational difficulties. I therefore specify a “reduced model” which only estimates the formation of any one of the aspects of life. If health difficulties in t=0 had influenced the outcomes of inherent importance in t=2 via impairing the dynamic formation of each of the separate domains, I would have repeated the reduced model for each of the three aspects of life. However, as we will see subsequently in the quantitative findings, the quantitative analysis undertaken using the expanded SEM suggests the predominant pathway via which health difficulties are associated with a persistent, detrimental impact is via the impaired formation of skills for employment. The reduced model is therefore only specified for the formation of this aspect of life and its association with SWB. I adopt the approach presented by Bollen and Brand (2010) by incorporating unobserved heterogeneity as a latent variable via the use of a measurement model.

It is worth noting the similarities and differences between the approach adopted by Bollen and Brand (2010) and the conventional fixed effect panel data approach to accounting for time invariant unobserved heterogeneity. The latter controls for unobserved heterogeneity by *empirically* removing the influence of individuals’ time invariant characteristics from the estimated coefficients of the parameters of interest (Cameron and Trivedi, 2005). In contrast, when using the latent variable approach outlined by Bollen and Brand (2010), the potential influence of unobserved heterogeneity is explicitly accounted for during the model estimation process. However, this time invariant heterogeneity is not empirically “partialled out” (Bollen and Brand, 2010; Cameron and Trivedi, 2005).

A summary of the reduced model is specified in equation (5) below:

$$SFE_{i,t} = \sum_{j=1}^3 \beta_{j,t} A_{i,j,t-1} + \beta_{4,t} GHD_{i,t-1} + \beta_{5,t} MHD_{i,t-1} + \beta_6 X_i + UH_i + \eta_{i,t} \text{ for } t= 1, 2 \quad (5)$$

where  $SFE_{i,t}$  = Skills for Employment which, as mentioned above, varies between being latent (in  $t=0$  and  $t=1$ ) and observed (in  $t=2$ )<sup>41</sup>.  $UH_i$  is unobserved (latent) heterogeneity. In order for the model to be identifiable, it is necessary to assume time invariant unobserved heterogeneity equally effects the latent variable for low academic ability at  $t=1$  and the continuous latent response variable under the NEET binary variable. This is of course a relatively strong assumption as the two variables are conceptually related but not identical.

Figure 8-3 below gives a diagrammatic representation of the reduced SEM, where I adopt the same approach to specifying the structural regression for life satisfaction as is adopted for the expanded structural model – i.e. I still use equation (2) above<sup>42</sup>.

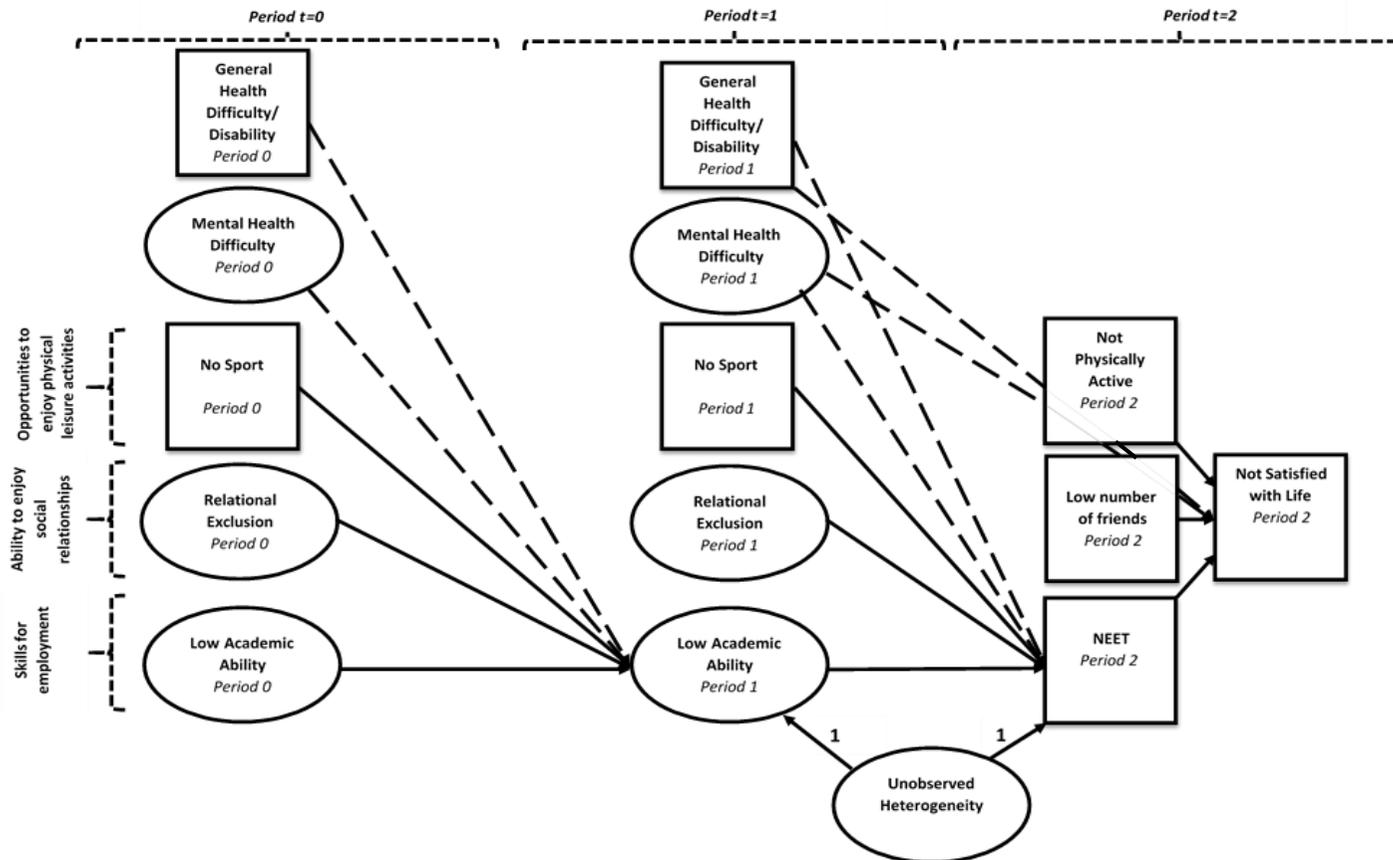
Of course, when estimating the reduced structural model which attempts to explicitly account for the influence of unobserved heterogeneity, I make two substantive changes to expanded structural model. I first reduce the model to having one autoregressive path and second explicitly account for unobserved heterogeneity. In order to support a comparison of the results derived from both models, I therefore also estimate an intermediate SEM where I include only one autoregressive path but do not attempt to explicitly account for unobserved heterogeneity. In the main body of the text, I only report the results for the expanded structural model and the reduced structural model that accounts for unobserved heterogeneity. However, Table C-3 in appendix C.3 reports the results of primary interest for these two models (labelled model 1 and model 3 respectively) alongside the intermediate SEM (labelled as model 2).

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<sup>41</sup> I adopt the same general approach to modelling the binary outcomes of being NEET and NSWL in the reduced SEM as outlined for the expanded SEM in equation (4) above.

<sup>42</sup>To minimise the risk of bias, in the two equations where NEET and NSWL were the dependent variable, I allow the two error terms of each to covary. It was possible to adopt this approach in the reduced structural model given its comparative simplicity in relation to the expanded structural model. However, perhaps as a result of the extensive covariates included in both equations, the correlation between the two error terms was insignificant.

Figure 8-3: Diagrammatic representation of the reduced SEM



**Note:** UH=unobserved heterogeneity. For simplicity, the only covariates included in the diagram are: health, the variables relating to the valued aspects of life included in the expanded SEM and modelled unobserved heterogeneity.

#### 8.2.2.5. Identification

##### *Assumptions required to identify both the expanded and the reduced SEM*

To enable the identification of the parameters in equations (1) to (5), I need to make the following assumptions. Firstly, with two categories of exceptions, the error terms for the measurement regressions summarised in equation (4) are assumed independent across individuals through time. I allow this assumption to be relaxed for the errors of the regressions relating to equivalent indicators asked over two waves of the LSYPE1<sup>43</sup>.

Additionally, in line with the findings of Hankins (2008), per wave I allow the error terms for the negatively phrased items of the 12-item General Health Questionnaire (GHQ-12) to be correlated.

Secondly, I assume that the error terms for the measurement regressions are independent of the underlying ability being measured and the variables included in the structural regressions (variables included in equations (1), (2) and (5)). Thirdly, I assume that individuals' baseline ability in each of the three aspects of life ( $A_0$ ) is assumed to be predetermined and is permitted to be correlated with the additional covariates ( $X$ ). The third assumption is required to incorporate the lagged dependent variables in equations (1) and (5) (Cunha et al., 2010b). Additionally, to aid computation, I assume that the error terms in the structural regressions and measurement regressions have a normal distribution, though this is not required for identification.

Because the factor loading in (4) can only be identified up to a scale, they need to be normalised. I can achieve this by either normalising one of the factor loadings in the measurement model to one or standardising the variance of the underlying latent variable; I take the former approach.

##### *Additional assumptions for the expanded SEM*

In line with the suggestions of Bollen and Brand (2010), I allow the error terms in equation (1) to be correlated through each domain's autoregressive path. For equation (1), I also allow the error term for each domain within a given period to be correlated. These steps allow for the possibility that unobserved variables may be affecting the process of ability formation (Acock, 2013). However, it is still necessary for me to assume the error terms for the regressions summarised in equation (1) are independent when the regressions are both for different domains and in different time periods. Additionally, for

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<sup>43</sup> As an example, I allow the error term specific to whether an individual was excluded from a friendship group in  $t=0$  to be correlated with the error term for the equivalent indicator in  $t=1$ .

the expanded SEM, I must assume the error terms for the regressions summarised in equation (1) are uncorrelated with the error term in equation (2). This assumption is arguably the strongest. However, as shown in Table 8-1, to minimise the risk that the error term in (1) is correlated with that in (2), I incorporate numerous covariates including the orientation of individuals' locus of control<sup>44</sup>.

*Additional assumptions for the reduced SEM*

Two assumptions are specifically required for the reduced SEM. Firstly, I must assume there are no time-invariant covariates in X (Bollen and Brand, 2010). Secondly, I must assume that unobserved heterogeneity is uncorrelated with the error terms in equations (2), (4) and (5). Given the first of these assumptions would likely be very strong, and given the time invariant covariates are not of primary interest to the research aim of the thesis, I remove the time invariant covariates from vector  $X_i$  in both equations (2) and (5)<sup>45</sup>. It is worth noting that removing the time in-invariant covariates should not result in omitted variable bias as the independent impact of each of the time in-variant covariates should be incorporated via the unobserved heterogeneity latent variable and its factor loadings (Bollen and Brand, 2010).

Both the expanded SEM and the reduced SEM require a number of different assumptions to enable model identification; neither model is without its limitations. When considering the findings of the two models, I will therefore have greatest confidence in those supported by *both* the expanded and the reduced SEMs. As concerns my research aim and objectives, the expanded SEM is of greatest relevance given its broader scope. The findings of the reduced SEM will therefore be used in a supportive manner. Specifically, I will use the findings of the reduced SEM to test whether associations concerning health and the formation of valued abilities remain significant once unobserved heterogeneity is incorporated into the analysis.

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<sup>44</sup> As noted in footnote 42, in the reduced SEM, I am able to allow the error term from one of the equations in (5) to correlate with the error term in equation (2). Perhaps as a result of the numerous covariates included in both equations, the error terms are not significantly correlated.

<sup>45</sup> The time invariant covariates dropped include variables relating to: young person's gender, young person's ethnicity, young person's age relative to the cohort, mother's education, number of dependent children in the household, parent's rating of the young person's school (which I interpret as an imperfect indicator of the quality of the secondary school education received by the young person), the deprivation of the local area, whether they are in a relationship in t=2 (as this covariate is only included once) and whether they have a child in t=2 (as this covariate is also only included once).

### 8.2.2.6. Estimation and diagnostic statistics

#### *Estimator*

Because many of my dependent variables are dichotomous rather than continuous, I choose the asymptotically distribution-free weighted least squares (WLS) approach (Finney and DiStefano, 2013). For the expanded SEM, equations (1) to (4) are estimated simultaneously (for the reduced SEM, equations (2) to (5) are estimated simultaneously). The WLS estimation process for categorical endogenous variables – the categorical dependent variables in equations (1), (2), (3) and (5) and the categorical indicator variables in equation (4) – is undertaken in three stages (Asparouhov and Muthén, 2010a). In the first stage, the thresholds for each of the categorical indicators are estimated. This is achieved by running probit regressions for each of the categorical indicators and then bivariate probit regressions for each pair. In the second stage, the correlations between the latent variables are estimated (the estimated thresholds, conditional means of the latent variables and the conditional variance-covariance matrix are then used to form the weighting matrix  $W$ ). Finally, the weighting matrix is used to estimate the model using the WLS method (Asparouhov and Muthén, 2010a; Finney and DiStefano, 2013). The following function is minimised:

$$F(\xi) = \sum (\sigma(\xi) - \hat{\sigma}) W^{-1} (\sigma(\xi) - \hat{\sigma})' \quad (6)$$

where  $\xi$  represents the parameters of the structural equation model,  $\sigma(\xi)$  represents the sample correlations and thresholds,  $\hat{\sigma}$  represents the correlations and thresholds as estimated by the model, and  $W$  is the diagonal of the weight matrix (the variances of the sample correlations and thresholds). When minimising the function  $F(\xi)$ , for each element, the discrepancy between the sample value and the model implied value  $\sigma(\xi) - \hat{\sigma}$  is therefore weighted according to that element's variance. For further details on the estimation approach, see Asparouhov and Muthen (2010a) and Finney and DiStefano (2013). The structural equation models are estimated using the weighted least squares mean and variance adjusted (WLSMV) estimator in Mplus v7.3 (Muthen and Muthen, 2012).

#### *Estimation of confidence intervals*

To account for the possibility that the distribution of the indirect effects may not be normally distributed, I use the bias corrected bootstrap method to generate empirical confidence intervals (Preacher and Hayes, 2008; Williams and Mackinnon, 2008). I adopt an approach which allows the technique to account for the complex sample data

(Asparouhov and Muthén, 2010b; Stapleton, 2008). For both the expanded and reduced SEM, I estimate the empirical confidence intervals using a minimum of 2,500 bootstrap samples<sup>46</sup>.

*Attrition, item non-response and the estimation method*

I use sampling weights from wave 7 to support the validity of inferences from the analytic sample to the general population. These weights take into account both the sample design and attrition bias, given that by wave 7 only 8,682 of the original 15,770 remained in the study (Anders, 2012). Individuals are also dropped from the analysis if they: (i) are missing observed variables from the structural regressions outlined in equations (1) and (2) above; (ii) are missing all the indicator variables for any single measurement model that is incorporated into the SEMs; or (iii) are from an independent school in wave 1<sup>47</sup>. The majority of the sub-sample of the individuals who attended an independent school did not have their examination data recorded in the national pupil data base, leaving open the possibility that the independent schools that did so are unrepresentative of the broader sub-sample. Table 8-2 summarises the impact of attrition and non-response on the availability of participants with the data required for inclusion in the analytic sample.

*Table 8-2: Attrition and missing variables in the LSYPE1*

Wave (year)	Age of YP	Total Number of YP Interviewed at each Wave	Number of YP who are present in all of the required waves*	Number of YP at each Wave with the Required Data for Inclusion*
1 (2004)	13/14 years	15,770	15,770	13,288
2 (2005)	14/15 years	13,539	13,539	8,390
3 (2006)	15/16 years	12,439	12,437	7,771
4 (2007)	16/17 years	11,801	11,425	6,791
7 (2010)	19/20 years	8,682	8,471	5,000

**Notes:** \*The number of young people (YP) interviewed in a specific wave who were also present for all of the previous required waves; + The number of young people present in a given wave and in each of the previous waves, with no missing data.

Excluding individuals who attrit, do not respond to required items or attended an independent school reduces the analytic sample to 5,000 individuals. Appendix C.4 reports a descriptive comparison of my analytic sample relative to my best estimate of the characteristics of the age matched general population. There is evidence of

<sup>46</sup> Mplus only allows the user to request the number of bootstrap samples to be generated rather than completed. When estimating the SEMs, for a small percentage of the bootstrap samples, the model estimation process did not complete. For each, I therefore generated 2,750 bootstrap samples so that the completion would be reached for more than 2,500 of them. For the expanded SEM, the model estimation process completes in 2,745 of the 2,750 samples (completion rate of 99.8%). For the reduced SEM, which accounts for unobserved heterogeneity, the model estimation process completes in 2,736 of the 2,750 samples (completion rate of 99.5%). Mplus only uses the completed bootstrap samples to estimate the empirical confidence intervals.

<sup>47</sup> For the reduced SEM, I use the same analytic sample as for the expanded SEM.

differences between the analytic sample and the age matched general population. However, as I use the WLSMV estimator, my estimates will be unbiased under the assumption that data are missing only as a result of variables included as covariates in the analysis (missing at random with respect to X [MARX]) (Asparouhov and Muthén, 2010a).

*Missing responses, their influence on my analytical strategy and robustness checks*

In my base case analysis, I avoid demarcating “don’t know” responses as “missing” if there is a clear rationale for considering the responses to be informative. I do so to reduce the level of item non-response, given its consequences for both missing data patterns and analytic sample size. In the base case analysis, I consider the “don’t know” responses to have potential meaning for three categories of variables – those relating to: educationally orientated aspirations, locus of control and relational exclusion. The assumptions I adopt in the base case are discussed in greater detail in appendix C.5. In order to assess the robustness of my base case results, I also undertake analyses in which I treat all “don’t know” responses as missing and drop individuals who did not have the required responses for inclusion in the analysis (as reported in appendix C.5). As can be seen by comparing Table C-7 with Table 8-4, varying the approach adopted to “don’t know” responses for the aspiration, locus of control and relational exclusion variables generally has little impact on the substantive findings of the analyses<sup>48</sup>.

I have not undertaken multiple imputation methods to estimate the missing data values. This is firstly because there is cause to believe that the MARX assumption, required for robust estimation, is reasonable. This is both because of the large number of covariates included in the analysis; and because when running the robustness check listed above, in spite of changes to the composition of the analytic sample, there is consistency in the results of the different analyses. Secondly, any additional accuracy with regards the estimated coefficients would do nothing to address a more important limitation of the quantitative analysis within the context of the mixed methods study. That is the imprecise fit between the variables available within LSYPE1 and the qualitative participants’ conceptualisations of the aspects of life they considered to be of particular importance.

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<sup>48</sup> Assuming a significance threshold of 5% of all the coefficients reported only two of substantive interest to the analysis change with regards their statistical significance. In both cases, my base case specification provides more conservative results. Every coefficient of primary interest to the study which is significant in the base case analysis is also significant in the analysis undertaken as a robustness check.



I estimate the model with a pooled gender sample because of: (i) the lack of impetuosity to fit the models separately by gender given the qualitative analyses did not indicate gender specific hypotheses which required testing; (ii) the complexity of the models estimated (which results from the need to investigate the differing pathways via which health difficulties may dynamically impact valued abilities); (iii) my desire to include individuals with missing responses where possible (in order to maximise the generalisability of my findings to the general population); and (iv) the need to derive empirical confidence intervals generated from numerous bootstrap samples in order to robustly estimate the significance of indirect effects. As indicated by Table 8-1, gender is included within the additional covariates  $X_i$  for the expanded SEM.

#### *Assessment of model fit*

Model fit is assessed using two diagnostic statistics, the comparative fit index (CFI) and the root mean square error of approximation (RMSEA) (Bentler, 1990; Steiger and Lind, 1980). I follow the recommendation of Hu and Bentler (1999) that for a model to be considered to have adequate fit to the data it must have a value *close to* 0.95 for CFI (for which a higher value is indicative of better fit) and 0.06 for RMSEA (for which a lower value is indicative of better fit).

#### 8.2.3. Summary of variables

Table C-1 in appendix C.2 provides the definitions of all the variables used in the study. For the analyses, I use variables from waves 1-4 and 7 of the LSYPE1. During waves 1-4, individual interviews were conducted with both the young person and their parents or guardians (and I use variables from both the interviews with the young person and with their parent/guardian). In wave 7, interviews were only undertaken with the young person.

##### 8.2.3.1. *Health*

General health difficulties are captured using self-report measures. To capture whether an individual has a general health difficulty in  $t=0$  (encompassing waves 1 and 2) I create a derived variable. In wave 2, individuals were asked to state whether their health in the last 12 months had been “very good”, “fairly good”, “not very good” or “not good at all”. Individuals were attributed as having a general health difficulty if they responded with either of the negative answers. While undertaking the qualitative research reported in chapters 6 and 7, it became apparent that adolescents with severe health difficulties had a tendency to give a positive self-assessment of their health if they experienced health

had been on an upward trajectory. Therefore, in this analysis, to reduce the risk of falsely attributing a positive health status to individuals with a health difficulty, I also attributed to the individual a general health difficulty if: (i) their parent reported they had a longstanding illness or disability in wave 1 which they expected to last for 24 months or longer; *and* (ii) in wave 4, the young person reported having a longstanding illness or disability. Individuals were therefore categorised as having a general health difficulty in  $t=0$  if they reported a negative assessment of their health in wave 2 or there was evidence of a continuing longstanding illness or disability in both wave 1 and wave 4<sup>49</sup>. Individuals were categorised as having a general health difficulty in  $t=1$  if they reported having a longstanding illness or disability in wave 4.

I measure whether the individual has a mental health difficulty using the GHQ-12 (Goldberg and Williams, 1988). The LSYPE1 includes the GHQ-12 when the individuals were aged 14/15 (LSYPE1 wave 2) and also when they were aged 16/17 (LSYPE1 wave 4). As outlined above, I adopt a latent variable approach to modelling mental health. In line with the study by Hankins (2008), confirmatory factor analyses supported modelling mental health as a single latent variable while explicitly accounting for measurement error that likely results from response bias on the negatively phrased items of the GHQ-12. Confirmatory factor analyses supported the interpretation of the GHQ-12 items as binary rather than Likert variables. This is consistent with the findings of Goldberg et al. (1997). Each indicator variable in the GHQ-12 was therefore coded as 0 if the individual provided either of the two possible emotionally positive responses and 1 if they provided either of the two possible emotionally negative responses.

#### 8.2.3.2. *Skills for employment*

I use measurement models to capture skills for employment in  $t=0$  and  $t=1$  using exam results from the National Pupil Database (NPD). The LSYPE1 sample (unless attending an independent school) is linked to the NPD, an administrative database which contains information on national examination results. As show in Table 8-1, in  $t=0$  and  $t=1$ , I use the individuals' national exam results to measure their cognitive ability, conceptualised as a component of their skills for employment. As such, the measurement models for

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<sup>49</sup> When labelling this derived variable as a “general health difficulty”, I have conceptualised disability in accordance with the definition attributed by World Health Organization, “Disability is the interaction between individuals with a *health condition* (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports). [emphasis added]” (World Health Organization, 2016).

employability primarily capture cognitive skills. The literature documents the importance of both cognitive skills and socioemotional (non-cognitive) skills (Cunha et al., 2010a) as predictors of employment outcomes. However, given their value beyond increasing employability, as outlined below, I incorporate socioemotional skills separately into the structural model via the measurement models relating to the ability to enjoy social relationships. Similarly, as indicated below, given locus of control's potential relevance to domains other than employability, I include it in all the structural regression equations as a covariate. For the skills, for employment autoregressive path, in  $t=0$ , I construct a measurement model for low academic ability. As indicator variables, I separately include English, Science and Maths test scores from the Key Stage 3 exams taken when individuals are aged 13-14. In  $t=1$ , I use the individual's GCSE exam results (the last exams taken during compulsory education by this cohort) when aged 15-16. The three indicators included in this measurement model for low academic ability are: the total GCSE points score, whether or not the individual passed their GCSE English exam, whether they passed their GCSE Maths exam<sup>50</sup>. For consistency with the measures of health difficulties and to ease the interpretation of results, negative results were attributed a higher value and positive results a lower value to form a measure of deficit in employability. A positive correlation between a health difficulty and this valued ability therefore indicates impaired health is correlated with the impaired formation of this valued ability. In  $t=2$ , I measure the outcome related to the individual's skills for employment – their NEET status (whether or not the individual is in education, employment or training). Individuals' NEET value is 1 if they are NEET and 0 otherwise.

### *8.2.3.3. Opportunities to enjoy physical leisure activities*

In any given wave, the LSYPE1 has a restricted number of variables relating to the ability to enjoy valued physical activities. As such, I cannot attempt to measure this valued ability as a latent variable, since doing so requires at least two indicators. Instead, per period, I use one variable relating to the frequency with which the individual has been physically active. In  $t=0$  (wave 2) and  $t=1$  (wave 4), the individual is asked, "how often do you do sports like football, aerobics, dance classes or swimming?" (Department for Education, 2013). In  $t=2$  (wave 7), perhaps to reflect the less structured nature of individuals' leisure activities as they transition from compulsory to post-compulsory education, the examples broaden. In wave 7, individuals were instead asked "how often do you do any kind of

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<sup>50</sup> The publicly available LSYPE1 data does not include whether individuals did or did not achieve a C at GCSE Science.

physical exercise? This could include things like cycling, going to the gym, going for long walks, dance classes, playing football or any other kind of sports?”. To reflect the different emphases in the questions, I label the variable in t=0 and t=1 “No sport” and in t=2 “No physical activity”. In each period, a value of 1 is given to the variable if the individual indicates they have not undertaken one of these activities within the last week. While the variables relating to the ability to enjoy valued physical activities are somewhat limited, I have kept this domain in the analysis because the qualitative interviews indicated both that it was of inherent value and that it played a role in facilitating social interactions.

#### *8.2.3.4. Ability to enjoy social relationships*

As with skills for employment, I use measurement models to capture the ability to enjoy social relationships in t=0 and t=1. I use variables relating to whether the individual reports being excluded from a friendship group, or bullied by either being called names or made to hand over money, to measure whether they are relationally excluded. In addition to the friendship exclusion question, I include the two bullying variables as measurement indicators because previous research has identified low friendship quality as a risk factor for subsequent victimisation (Crawford and Manassis, 2011; Goldbaum et al., 2003). It is therefore reasonable to believe the shared variance between the *three* indicators results from relational exclusion. In wave 7, individuals reported how many close friends they have. In t=2, I measure the achieved outcome related to the individual’s ability to enjoy social relationships. The variable, few close friends, has a value of 1 if the individual reports having fewer than the median number of close friends (less than four close friends) and 0 otherwise.

As can be seen above, the variables available for the different domains vary through time. This is particularly the case for the domains “ability to enjoy social relationships” and “skills for employment”. To an extent, this is a limitation of the data available. However, it also reflects that as individuals transition to early adulthood, different facets of a domain, and therefore different questions, become of greater relevance (Biggeri and Mehrotra, 2011).

#### *8.2.3.5. Subjective well-being*

As mentioned in 2.1.2 and 8.1.2 one component of SWB is life-satisfaction (Diener et al., 1999). In wave 7, individuals were asked how satisfied they were with their life so far and could respond either “very satisfied”, “fairly satisfied”, “neither dissatisfied nor satisfied”,

“fairly dissatisfied” or “very satisfied”. I create an outcome variable Not Satisfied With Life in  $t=2$ , which has a value of 1 if individuals give any of the three least positive answers and 0 if they state they are satisfied or very satisfied. While the variable only relates to one component of SWB, the others being positive and negative emotional affect, it is the component that is likely most stable. This is because the question attempts to prompt the individual into providing a global assessment of their lives rather than seeking to elicit answers around their current emotional state or mood (Diener et al., 1999).

When asked about their satisfaction with life one would of course expect an individual’s response to be shaped by their lived experience. This is supported by the research undertaken by Layard et al. (2014) who found there was a significant association between having lower life satisfaction and being unemployed or not having a partner (experiences which might be typically seen as undesirable).

#### 8.2.3.6. *Additional covariates*

As shown in Table 8-1, a broad range of covariates were included in the analysis to minimise the risk of confounding in my estimates. Covariates were incorporated that related specifically to: (i) the individual, such as the extent to which they had external or internal locus of control (Rotter, 1966); (ii) their household, such as the household socioeconomic group<sup>51</sup>; and (iii) to the local area, such as the local area’s index of multiple deprivation.

#### 8.2.4. Approach to testing hypotheses informed by the qualitative analysis

As discussed in 4.4, chapter 5 and 8.1, with respect to the thesis as a whole, I use a quantitative analysis of the LSYPE1 data to deductively test hypotheses informed by an inductive analysis of the qualitative interview data. As anticipated in 4.4, it is necessary to construct simplified hypotheses for testing – this results from the nature of the data available in the LSYPE1. Specifically, given the LSYPE only provide responses to singular questions asked annually, it is unfeasible to model within the expanded and reduced SEMs the actions individuals take to navigate the difficulties that are potentially imposed on them by a general or mental health difficulty. Ideally, I would explicitly undertake distinct tests for: (i) whether a health difficulty can impair the enjoyment of one of the three domains incorporated; and (ii) the actions individuals and their families take to

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<sup>51</sup> Household income is not included in the analyses. The related variable has a large number of missing responses. If it were to be included the analytic sample would fall to being approximately 2,700 individuals. I therefore instead included variables likely to be correlated with household income such as household socioeconomic group and mothers’ education.

surmount the difficulty imposed by a health difficulty. Instead, because of the data available, for each ability, I test the hypothesis that poor health imposes a sufficiently large constraint upon the accumulation of the ability that, even with efforts to navigate the constraint, poor health is associated with later reduced achievement in that valued aspect of life compared to others in the subsequent periods<sup>52</sup>. In this chapter, in contrast to chapters 7 and 9, I therefore do not formally consider the role of individual agency and therefore individuals' ability to adapt to changes in either their health or wider context.

A limitation of this necessary simplifying step is that in the event that no significant correlation is identified, it leaves open one of two possibilities: (i) that the health difficulty imposed no meaningful constraint on the formation of that ability; or (ii) that individuals and their families tended to find effective ways to navigate the constraint imposed by a health difficulty. Nevertheless, this approach still allows me to test for the pathways via which a health difficulty imposes such a constraint on the formation of a health difficulty that individuals and their families struggle to fully negate the health difficulty's negative influence. As will be discussed in chapter 9, an additional limitation imposed by the data available in the LSYPE1 is that I am not able to formulate, and therefore test, hypotheses relating to the dynamic trend observed for the differing domains from a comparison of the participants' biographies.

It is perhaps worth noting that when hypothesis testing, I will consider significance at a threshold of five percent or lower to lead to rejection of the "null hypothesis" – that there is no association between a health difficulty and subsequent achievement in the valued ability of relevance. Given its wider scope, the expanded SEM is the quantitative analysis via which I predominantly test the hypotheses generated from qualitative study findings.

#### 8.2.5. Descriptive Statistics

For brevity, I only present the results relating to gender and the variables of primary interest in Table 8-3, Table 8-4 and Table 8-6 below. Equivalent tables populated with the results for all the variables included in the analyses are available in appendix C, (tables C-

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<sup>52</sup> Of course, in a more formalised sense, I test the support for my null hypothesis ( $H_0$ ): that the correlation between a health difficulty and subsequent impairment in that domain is zero (there is no association). Formally, my alternative hypothesis,  $H_1$ , is that there is an association between a health difficulty and subsequent impairment in the domain of relevance. If the empirical confidence interval does not cross zero then I find against the null hypothesis and reject it. If instead the empirical confidence interval does cross zero then there is no reason to reject the null hypothesis and I therefore accept it.

2, C-8 and C-10, respectively). Table 8-3 below presents weighted descriptive statistics for the variables of primary interest to the study.

Table 8-3: Descriptive statistics

Variable	Observed	Mean	S.D.*	Minimum	Maximum
<b>Health Variables</b>					
<b>t=0 (Age 13-15)</b>					
General health difficulty	5,000	0.06	-	0	1
Mental health difficulty (GHQ-12)+					
Recently lost sleep	4,877	0.19	-	0	1
Recently under strain	4,785	0.27	-	0	1
Recent difficulties	4,741	0.19	-	0	1
Recently felt unhappy	4,870	0.24	-	0	1
Recently losing confidence	4,891	0.19	-	0	1
Recently felt worthless	4,873	0.12	-	0	1
Recently able to concentrate	4,903	0.14	-	0	1
Recently not useful	4,526	0.09	-	0	1
Recently made decisions	4,840	0.06	-	0	1
Recently enjoyed activities	4,916	0.10	-	0	1
Recently faced up to problems	4,894	0.08	-	0	1
Recently felt happy	4,792	0.11	-	0	1
<b>t=1 (Age 15-17)</b>					
General health difficulty	5,000	0.07	-	0	1
Mental health difficulty (GHQ-12)+					
Recently lost sleep	4,958	0.24	-	0	1
Recently under strain	4,957	0.33	-	0	1
Recent difficulties	4,945	0.22	-	0	1
Recently felt unhappy	4,944	0.27	-	0	1
Recently losing confidence	4,969	0.19	-	0	1
Recently felt worthless	4,961	0.12	-	0	1
Recently able to concentrate	4,984	0.15	-	0	1
Recently not useful	4,913	0.11	-	0	1
Recently made decisions	4,977	0.07	-	0	1
Recently enjoyed activities	4,986	0.14	-	0	1
Recently faced up to problems	4,976	0.10	-	0	1
Recently felt happy	4,959	0.12	-	0	1
<b>Variables for valued abilities and skills</b>					
<b>t=0 (Age 13-15)</b>					
English SATs score++,^	4,913	-11.38	1.97	-15.70	-7.00
Maths SATs score++,^	4,959	-12.24	2.51	-17.72	-5.00
Science SATs score++,^	4,954	-11.40	2.12	-15.82	-5.00
No sport	5,000	0.19	-	0	1
Called names	4,939	0.31	-	0	1
Excluded from group	4,969	0.16	-	0	1
Robbed	4,983	0.03	-	0	1
<b>t=1 (Age 15-17)</b>					
GCSE points++,^	5,000	-3.94	1.49	-10.64	0.00
GCSE English fail	5,000	0.36	-	0	1
GCSE Maths fail	5,000	0.40	-	0	1
No sport	5,000	0.45	-	0	1
Called names	4,977	0.15	-	0	1
Excluded from group	4,980	0.11	-	0	1
Robbed	4,994	0.01	-	0	1
<b>t=2 (Age 19-20)</b>					
NEET <sup>§</sup>	5,000	0.14	-	0	1
No physical activity	5,000	0.19	-	0	1
Few close friends	5,000	0.32	-	0	1
<b>Subjective well-being (Age 19-20)</b>					
Not satisfied with life	5,000	0.21	-	0	1
<b>Gender</b>					
Gender: Male	5,000	0.50	-	0	1

**Notes:** § "Not in Education, Employment or Training"; \*Standard deviations are only reported for continuous variables; + As summarised in 8.2.3.1, consistent with the findings of Goldberg et al. (1997) the GHQ-12 items are coded as binary rather than Likert variables. Each indicator variable in the GHQ-12 was therefore coded as 0 if the individual provided either of the

two possible emotionally positive responses per question and 1 if they provided either of the two possible emotionally negative responses. ++ These test scores have been multiplied by minus one so that worse tests results are given higher values (see 8.2.3.2); ^ The values reported here have been scaled. As mentioned below the variable description table in appendix C, Table C-1, to aid convergence, the raw SATs scores are divided by 3 and the total GCSE points score is divided by 100, bringing each variable's variance to within the range of 1-10 as recommended to aid convergence (Muthen, 2010).

### 8.3. Findings

#### 8.3.1. Results of the expanded structural equation model

##### 8.3.1.1. Direct associations

Table 8-4 presents the direct associations estimated using the expanded SEM. I consider: firstly, the associations over time between the valued abilities whose formation is modelled by the SEM; secondly, the association in t=2 between achieved outcomes in these domains and SWB; thirdly, the direct associations between health difficulties and the formation of these valued abilities over time; and finally, the direct associations between health difficulties at t=1 and SWB at t=2<sup>53</sup>.

Table 8-4: Structural results – expanded model

<b>Dependent Variable (latent variables italicised)<sup>+</sup></b>	<b>Explanatory Variable (latent variables italicised)</b>	<b>Association<sup>++</sup></b>
<i>Low academic ability</i> t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.75***
	No sport (t=0)	0.19***
	<i>Relational exclusion (t=0)</i>	0.03
	General health difficulty (t=0)	0.45***
	<i>Mental health difficulty (t=0)</i>	0.01
	Gender: male	0.07*
No sport t=1 (Age 16-17)	<i>Low academic ability (t=0)</i>	-0.03
	No sport (t=0)	0.68***
	<i>Relational exclusion (t=0)</i>	0.09**
	General health difficulty (t=0)	0.11
	<i>Mental health difficulty (t=0)</i>	0.01
	Gender: male	-0.67***
<i>Relational exclusion</i> t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.03
	No sport (t=0)	0.21***
	<i>Relational exclusion (t=0)</i>	0.50***
	General health difficulty (t=0)	0.25*
	<i>Mental health difficulty (t=0)</i>	0.33***
	Gender: male	-0.37***
NEET t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.25***
	No sport (t=1)	0.04
	<i>Relational exclusion (t=1)</i>	0.24***
	General health difficulty (t=1)	0.10
	<i>Mental health difficulty (t=1)</i>	-0.05
	Gender: male	0.15**

<sup>53</sup> For brevity, I do not report the factor loadings for the different measurement models in the main body of the text. These can be found in appendix C.6, Table C-9.



Dependent Variable (latent variables italicised)*	Explanatory Variable (latent variables italicised)	Association**
No physical activity t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	-0.04
	No sport (t=1)	0.42***
	<i>Relational exclusion (t=1)</i>	-0.05
	General health difficulty (t=1)	-0.21*
	<i>Mental health difficulty (t=1)</i>	0.05
	Gender: male	-0.30***
Few close friends t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.06**
	No sport (t=1)	0.13***
	<i>Relational exclusion (t=1)</i>	0.06
	General health difficulty (t=1)	0.00
	<i>Mental health difficulty (t=1)</i>	0.08***
	Gender: male	-0.13**
Not satisfied with life t=2 (Age 19-20)	NEET (t=2)	0.34***
	No physical activity (t=2)	0.08**
	Few close friends (t=2)	0.18***
	General health difficulty (t=1)	0.04
	<i>Mental health difficulty (t=1)</i>	0.18***
	Gender: male	0.12**
<b>Model Fit Statistics</b>		
CFI		0.93
RMSEA		0.02

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. For the continuous variables, the coefficient represents the change in the dependent variable associated with a 1-SD change in the variable. For the binary variables, the coefficient represents the change associated with a shift in the variable from 0 to 1. +The age ranges provided are specific to each dependent variable. For the T = 1 dependent variables they therefore vary as though in the same model time period the "No physical activity variable is from wave 4 of the LSYPE1 rather than wave 3; ++ As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,745 completed bootstraps for this model (out of a requested 2,750).

The direct effects reported in Table 8-4 generally support the hypothesis that skills accumulated in a prior period facilitate subsequent skill formation (Cunha and Heckman, 2008). There is a positive correlation between impaired skills for employment aged 13-14, 15-16 and being NEET aged 19-20. Similarly, there is a positive correlation between a lack of physical activity aged 13-14, 16-17 and 19-20. The relationship is somewhat more complex for relational inclusion. In the periods that parallel compulsory education (t=0 and t=1), there is a significant positive association along the domain's autoregressive path; however, the association between being relationally isolated at the end of compulsory education (aged 15-16) and having few close friends when aged 19-20 is statistically insignificant.

The results also indicate associations through time between the three domains of skills for employment, ability to undertake physical leisure activities and the ability to enjoy social relationships. Individuals are at a greater risk of being NEET not only if they have

impaired formation of cognitive skills (which I have termed “low academic ability”) but also, perhaps unsurprisingly, if they have impaired non-cognitive skills (or “relational exclusion”). Similarly, individuals are more likely to have few close friends aged 19-20 if previously they were not physically active or had low academic ability (cognitive skills). The model results therefore support the notion of cross-productivity between the different valued abilities (Cunha and Heckman, 2007).

Being NEET, not being physically active and having few close friends all independently increase the probability the individual will not be satisfied with life aged 19-20.

Having outlined the interrelationships between each of the three different domains and life satisfaction, I now turn to consider the role of health. Table 8-4 indicates that a general health difficulty has the potential to impair the formation of skills for employment (cognitive skills) whereas a mental health difficulty tends to impair the formation of relational skills. The model results suggest that a mental health difficulty continues to have a significant direct association through the time periods incorporated in the model. In contrast, the results only indicate a significant direct association between a general health difficulty and impaired skill formation during the period of preparation for the GCSE examinations. Perhaps surprisingly, the model indicates a weak association between a general health difficulty aged 16-17 and being physically active aged 19-20. This association, insignificant at a five percent threshold, may be spurious. Alternatively, it may provide a degree of support for the notion that those with a health difficulty prioritise exercise as an investment for improving their health (Grossman, 1972).

Finally, there is no significant direct association between a general health difficulty aged 16-17 and life satisfaction aged 19-20. However, in accordance with the findings of Layard et al. (2014), a mental health difficulty aged 16-17 is significantly associated with not being satisfied in life aged 19-20.

The expanded SEM meets the criteria for indicating it has an adequate fit to the data. For both CFI and RMSEA, the values are *close to* the values suggested by Hu and Bentler (1999)<sup>54</sup>. Additionally, the model parameter estimates appear to have face validity. Many of the significant coefficients reported above have the sign that might be anticipated in

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<sup>54</sup> For both indices, the values are close to the values suggested by Hu and Bentler (1999) for CFI the score; however, for CFI, the score suggests slightly worse fit than would be indicated by a score of 0.95. Conversely, for RMSEA, the score of 0.02 suggests a substantively better fit than would be indicated by a score of 0.06.

advance. Where this is not the case, they are corroborated by an analysis of the descriptive data.

### 8.3.1.2. Total association between health difficulties and adult outcomes

I now turn to considering the total association between a health difficulty in adolescence and the achieved outcome aged 19-20 for each of the three inherently valued abilities incorporated in the expanded SEM. Additionally, I report the total association between a health difficulty in adolescence and reduced SWB aged 19-20. For the purpose of brevity, I only report the indirect pathways that are significant at a threshold of 5% or lower. The results of relevance are summarised in Table 8-5 below.

Table 8-5: Total effect of health difficulties on outcomes aged 19-20 (expanded model)

Variable (latent variables italicised)	Total effect	Direct effect	Sum of indirect effects
<i>The ability to get a good job and be successful</i>			
<b>General Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.18***	-	0.18***
Statistically significant indirect pathway(s) <sup>+</sup>	GHD <sub>t0</sub> → LAA <sub>t1</sub> → NEET <sub>t2</sub>		
<b>General Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.10	0.10	-
Statistically significant indirect pathway(s)	N.A.		
<b>Mental Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.08***	-	0.08***
Statistically significant indirect pathway(s)	MHD <sub>t0</sub> → RE <sub>t1</sub> → NEET <sub>t2</sub>		
<b>Mental Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	-0.05	-0.05	-
Statistically significant indirect pathway(s)	N.A.		
<i>Opportunities to enjoy valued physical leisure activities</i>			
<b>General Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.02	-	0.02
Statistically significant indirect pathway(s)	-		
<b>General Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	-0.21*	-0.21*	-
Statistically significant indirect pathway(s)	N.A.		
<b>Mental Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	-0.01	-	-0.01
Statistically significant indirect pathway(s)	-		
<b>Mental Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.05	0.05	-
Statistically significant indirect pathway(s)	N.A.		
<i>The ability to enjoy relating to others</i>			

Variable (latent variables italicised)	Total effect	Direct effect	Sum of indirect effects
<b>General Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.06**	-	0.06**
Statistically significant indirect pathway(s)	-		
<b>General Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.00	0.00	-
Statistically significant indirect pathway(s) <sup>+</sup>	N.A.		
<b>Mental Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.02	-	0.02
Statistically significant indirect pathway(s)	-		
<b>Mental Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.08***	0.08***	-
Statistically significant indirect pathway(s)	N.A.		
<i>Subjective well-being</i>			
<b>General Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.07***	-	0.07***
Statistically significant indirect pathway(s)	GHD <sub>t0</sub> → LAA <sub>t1</sub> → NEET <sub>t2</sub> → NSWL <sub>t2</sub>		
<b>General Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.06	0.04	0.02
Statistically significant indirect pathway(s)	-		
<b>Mental Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.03***	-	0.03***
Statistically significant indirect pathway(s)	MHD <sub>t0</sub> → RE <sub>t1</sub> → NEET <sub>t2</sub> → NSWL <sub>t2</sub>		
<b>Mental Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.18***	0.18***	0.00
Statistically significant indirect pathway(s)	MHD <sub>t1</sub> → FCF <sub>t2</sub> → NSWL <sub>t2</sub>		

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. GHD "General Health Difficulty"; FCF "Few Close Friends"; LAA "Low Academic Ability"; MHD "Mental Health Difficulty"; NEET "Not in Education, Employment or Training"; NSWL "Not Satisfied with Life"; RE "Relational Exclusion".

As noted above, there appears an association through time between skills for employment and the ability to enjoy social relationships. Both of these domains are also strongly associated with life satisfaction. Given: (i) the significant association between a general health difficulty aged 14-15 and reduced skills for employment aged 15-16; and (ii) the continued interdependence between skills for employment and the ability to enjoy social relationships, it is perhaps unsurprising that a general health difficulty aged 14-15 is significantly associated with both an increased likelihood of both being NEET *and* having few close friends aged 19-20.

A mental health difficulty aged 14-15 is significantly associated with an increased risk of being NEET aged 19-20 via its impact on the ability to enjoy social relationships, which in

turn is a predictor of subsequent NEET status aged 15-16. Perhaps predictably, a mental health difficulty aged 14-15 is therefore also significantly associated with reduced life satisfaction in early adulthood. A mental health difficulty aged 16-17 is associated with having few close friends aged 19-20, which in turn leads to the significant indirect pathway to reduced life-satisfaction. The model results are therefore supportive of the notion that mental health difficulties aged 16-17 have both a direct and an indirect effect on subsequent life satisfaction.

Before considering the results of the reduced SEM, it is perhaps first worth noting some summary findings from the expanded SEM. Firstly, only for two of the three aspects of life, skills for employment and the ability to enjoy social relationships, is the impaired outcome significantly associated with a health difficulty in the previous period (perhaps, as will be discussed in chapter 9, because the impact of a health difficulty on physical activity may be contemporaneous). Secondly, of these two aspects of life, only skills for employment consistently has a statistically significant autoregressive path (perhaps because changing vocational settings disrupt individuals' relational contexts between  $t=1$  and  $t=2$ ). Finally, every significant pathway from a health difficulty *aged 14-15* to reduced life satisfaction at some point includes an association with reduced skills for employment.

### 8.3.2. Results of the reduced structural equation model

I now turn to reporting the results of the reduced SEM which attempts to incorporate the influence of unobserved heterogeneity. As discussed in 8.2, it is only feasible to adopt this approach for an SEM that has one autoregressive path. In practice, I only fit the reduced SEM to skill for employment's autoregressive path because this is the only path indicated by the expanded SEM to *both*: (i) have a statistically significant autoregressive path; and (ii) have a significant negative association with a health difficulty in the prior period.

Prior to summarising the results of the reduced SEM, it is worth noting that as summarised in greater detail in appendix C.3, there is consistency in the sign and significance of the coefficients of primary interest to the research that are estimated in the expanded SEM, the intermediate SEM (as outlined in 8.2.2.4) and the reduced SEM. Any meaningful differences in these estimated coefficients fit the pattern of being significant in the expanded SEM and the intermediate model (neither of which attempt to account for time-invariant heterogeneity) and insignificant in the reduced SEM (which does attempt to control for the influence of time-invariant heterogeneity).

Table 8-6 presents the direct associations estimated using the reduced SEM<sup>55</sup>.

Table 8-6: Structural results: reduced model

Dependent Variable (latent variables italicised)	Explanatory Variable (latent variables italicised)	Association <sup>+</sup>
<i>Low academic ability</i> t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.81***
	No sport (t=0)	0.18***
	<i>Relational exclusion (t=0)</i>	0.01
	General health difficulty (t=0)	0.44***
	<i>Mental health difficulty (t=0)</i>	-0.04
NEET t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.40***
	No sport (t=1)	0.09
	<i>Relational exclusion (t=1)</i>	0.11
	General health difficulty (t=1)	0.07
	<i>Mental health difficulty (t=1)</i>	-0.02
Not satisfied with life t=2 (Age 19-20)	NEET (t=2)	0.26***
	No physical activity (t=2)	0.11*
	Few close friends (t=2)	0.38***
	General health difficulty (t=1)	0.07
	<i>Mental health difficulty (t=1)</i>	0.16***
<b>Model Fit Statistics</b>		
CFI		0.94
RMSEA		0.02

**Notes:**\*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. For the continuous variables, the coefficient represents the change in the dependent variable associated with a 1-SD change in the variable. For the binary variables, the coefficient represents the change associated with a shift in the variable from 0 to 1. +As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,736 completed bootstraps for this model (out of a requested 2,750).

As discussed above, my intent is to use the findings of the reduced SEM, which accounts for the influence of unobserved heterogeneity, to *support* the findings of the expanded SEM, which because of its increased scope is, in design, more aligned with my research aim and objectives. For brevity, I therefore limit my summary of the results in Table 8-6 to those relating to health’s association with the formation of valued abilities and SWB.

As can be seen by comparing Table 8-6 with Table 8-4, both analyses indicate: (i) a general health difficulty aged 14-15 is associated with impaired skills for employment aged 15-16; (ii) low academic ability aged 15-16 is significantly associated with a higher risk of being NEET aged 19-20; and (iii) being NEET aged 19-20 is significantly associated with a higher risk of not being satisfied with life in the contemporaneous period. As might therefore be expected, Table 8-7 below indicates, in accordance with the results for the

<sup>55</sup> As with the expanded SEM for brevity, I do not report factor loadings for the different measurement models in the main body of the text. These can be found in appendix C.6, Table C-11.

expanded SEM, a general health difficulty aged 14-15 is indirectly associated with a higher risk of being NEET aged 19-20. Additionally, the results of both models indicate that a general health difficulty aged 14-15 is not only associated with impaired achievement of an inherently valued ability aged 19-20, but also significantly associated with an increased risk of not being satisfied with life.

The reduced SEM is unable to offer support for the influence of a mental health difficulty on the formation of valued abilities and life-satisfaction given: (i) the need to restrict the reduced SEM to including one autoregressive path; (ii) the lack of significant association through the ability to enjoy social relationships' autoregressive path; and (iii) that it is solely with respect to the formation of this domain that a mental health difficulty has a significant *direct* association. This does not negate the findings of the expanded SEM relevant to the potential influence of a mental health difficulty. However, still greater caution is required when drawing causal inferences about mental health's influence due to my inability to explicitly account for the potentially confounding role of time invariant heterogeneity.

Table 8-7: Total effect of health difficulties on outcomes aged 19-20 (reduced model)

Variable (latent variables italicised)	Total effect	Direct effect	Sum of indirect effects
<i>The ability to get a good job and be successful</i>			
<b>General Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.17***	-	0.17***
Statistically significant indirect pathway(s) <sup>+</sup>	GHD <sub>t0</sub> → LAA <sub>t1</sub> → NEET <sub>t2</sub>		
<b>General Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.07	0.07	-
Statistically significant indirect pathway(s) <sup>+</sup>	N.A.		
<b>Mental Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	-0.02	-	-0.02
Statistically significant indirect pathway(s) <sup>+</sup>	-		
<b>Mental Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	-0.02	-0.02	-
Statistically significant indirect pathway(s) <sup>+</sup>	N.A.		
<i>Subjective well-being</i>			
<b>General Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.05**	-	0.05**
Statistically significant indirect pathway(s) <sup>+</sup>	GHD <sub>t0</sub> → LAA <sub>t1</sub> → NEET <sub>t2</sub> → NSWL <sub>t2</sub>		
<b>General Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.09	0.07	0.02
Statistically significant indirect pathway(s) <sup>+</sup>	-		
<b>Mental Health Difficulty t=0 (Age 14-15)</b>			
Coefficients	0.00	-	0.00
Statistically significant indirect pathway(s) <sup>+</sup>	-		
<b>Mental Health Difficulty t=1 (Age 16-17)</b>			
Coefficients	0.15***	0.16***	0.00
Statistically significant indirect pathway(s)	-		

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. GHD "General Health Difficulty"; FCF "Few Close Friends"; LAA "Low Academic Ability"; MHD "Mental Health Difficulty"; NEET "Not in Education, Employment or Training"; NSWL "Not Satisfied with Life".

### 8.3.3. Support for the hypotheses that emerge from the qualitative study

In Table 8-8 below, I note whether the quantitative analyses support the hypotheses derived from findings of the qualitative study. It is perhaps worth noting, firstly, that with respect to *meaning*, I intend the statements reported in column "summary of qualitative findings" to be identical to the equivalent statements reported in the findings column of Table 7-2 in 7.4.2 (for the purposes of saving space in the table below, I have abbreviated some of the phraseology). Secondly, the list of domains included in Table 8-8 is of course



shorter than that included in Table 7-2 given the inability to include all the prioritised domains in the quantitative analysis (as discussed in 8.2.1).

Table 8-8: Level of support from the quantitative analysis for the qualitative hypotheses

Category of finding	Summary of qualitative findings	Related hypothesis tested in the quantitative study	Support for hypothesis (expanded SEM – considering both estimated direct and indirect effects)	
	<i>The ability to get a good job and be successful</i>			
Barrier	The participants' ability to regularly attend school can be disrupted by health difficulties – sometimes this resulted in disrupted preparations for their exams	Poor health imposes sufficiently large constraints upon the accumulation of this ability/skill that even with [unobserved] efforts to navigate the constraints poor health is associated with reduced achievement compared to others in the subsequent periods	GH <sub>t0</sub>	✓
			MH <sub>t0</sub>	×/✓
Observed approach to navigating barrier	Some participants who missed school due to poor health reported trying to working harder on returning to school in an effort to catch up		GH <sub>t1</sub>	×
			MH <sub>t1</sub>	×
	<i>Opportunities to enjoy valued leisure activities</i> (N.B. for quantitative study only concerns physical leisure activities)			
Barrier	Health difficulties sometimes resulted in the participants showing greater caution when joining in leisure activities with their peers – this appeared at times to disrupt their enjoyment of the activity	Poor health imposes sufficiently large constraints upon the accumulation of this ability/skill that even with [unobserved] efforts to navigate the constraints poor health is	GH <sub>t0</sub>	×
			MH <sub>t0</sub>	×
			GH <sub>t1</sub>	×

Category of finding	Summary of qualitative findings	Related hypothesis tested in the quantitative study	Support for hypothesis (expanded SEM – considering both estimated direct and indirect effects)	
Observed approach to navigating barrier	The participants with a health difficulty often seemed to take up alternative activities for which their health difficulties imposed little or no constraint	associated with reduced achievement compared to others in the subsequent periods	MH <sub>t1</sub>	×
	<i>The ability to enjoy relating to others</i>			
Barrier	Participants' health difficulties could undermine confidence in social settings	Poor health imposes sufficiently large constraints upon the accumulation of this ability/skill that even with [unobserved] efforts to navigate the constraints poor health is associated with reduced achievement compared to others in the subsequent periods	GH <sub>t0</sub>	×/✓
Observed approach to navigating barrier	Those with health difficulties appeared to gravitate towards peers who would accept these "different" behaviours and not draw attention to them		MH <sub>t0</sub>	✓
			GH <sub>t1</sub>	×
			MH <sub>t1</sub>	✓

In the subsequent chapter, I undertake a formal comparison of the qualitative and quantitative study findings. This includes a discussion of potential reasons for any disparities. Here, I briefly summarise a number of observations based on the table above. Firstly, there is little support for the initial hypotheses when testing the association between a health difficulty aged 16-17 and outcomes aged 19-20. To an extent, this is unsurprising given the hypotheses were formed from biographical data that do not extend to this period. Secondly, the hypotheses relating to the influence of a health difficulty on individuals' opportunities to enjoy valued physical leisure activities received no support from the formalised quantitative analysis (and potential reasons for this will be explored in chapter 9). Thirdly, in the equivalent age range to those included in the qualitative study, there was moderately strong support from the formalised quantitative analysis for the hypotheses concerning the influence of both a general and a mental health difficulty upon individuals' ability to get a good job and be successful. The mixed support indicated for the influence of a mental health difficulty aged 14-15 on subsequent employment outcomes represents the: (i) insignificant direct association to low academic ability aged 15-16; and (ii) the significant indirect association to NEET status aged 19-20 (predominantly via the association with relational exclusion aged 15-16). Finally, with regards the ability to enjoy relating to others, there is support for the influence of a mental health difficulty. In a manner that has parallels with the influence of a mental health difficulty on individuals' ability to get a job and be successful the mixed support for the influence of a general health difficulty aged 14-15 on *the ability to enjoy relating to others is a result of*: (i) the insignificant direct association to relational exclusion aged 15-16; and (ii) the significant indirect association to having few close friends aged (19-20) (predominantly via the association with impaired academic ability aged 15-16).

#### 8.4. Concluding discussion

I defer an extended consideration of the quantitative study findings until the subsequent chapter both to minimise duplication and because this is consistent with my epistemological position: to best understand complex phenomena it is valuable to draw on as many perspectives as possible (Seale, 1999; Tashakkori and Teddlie, 2010). However, before moving on, it is worth noting the strengths and limitations of the quantitative analysis. Directly below I attempt to do so according to the standards expected by practitioners of econometrics (I will therefore defer to the subsequent chapters any critique of the *quantitative* study that might more commonly be proposed

by *qualitative* or mixed methods practitioners). In 8.4.2, I then briefly summarise the main findings of the quantitative study.

#### 8.4.1. Strengths and limitations of the quantitative study

##### 8.4.1.1. *Strengths of the quantitative study*

As mentioned at the beginning of the chapter this is the first study I am aware of to jointly estimate the dynamic associations between health difficulties in adolescence, the impaired formation of inherently valued abilities and reduced SWB. The use of SEM as a methodology not only allows the analysis to make inferences about individuals' unobserved abilities but also allows an explicit, formal analysis of the pathways which mediate health's role in the formation of valued abilities and the consequences as regards SWB (Muthen and Asparouhov, 2015).

Even considering only those findings relating to education and employment, the ability to explicitly test mediating pathways arguably allows the study to move beyond the related literature reviewed in Chapter 3. The implicit empirical support offered for impaired formation of academic ability being the mediator via which a health difficulty impairs subsequent employment and educational outcomes (Brekke, 2015; De Ridder et al., 2013; Rees and Sabia, 2009) can therefore be explicitly tested. The combined findings of the expanded SEM and the reduced SEM confirm this mediational pathway and indicate the association is unlikely a result of unobserved heterogeneity confounding the relationship. Indeed, as concerns health's role in the formation of human capital, this study further supersedes the literature by allowing me to not only explicitly test this mediational pathway but also: (i) do so while explicitly accounting for health status in the subsequent period (which I find to be a redundant predictor); and (ii) estimate an additional mediating pathway, namely via health's association with impaired social as well as cognitive skills.

Using both an expanded SEM (with a scope substantively beyond the previous models reviewed) and a reduced SEM (that formally incorporates unobserved heterogeneity) allows the quantitative study to contribute to the literature by: (i) identifying strong empirical support for general health's role during adolescence in facilitating the formation of cognitive skills for employment; and (ii) indicating that as concerns the formation of wider valued abilities the predominant consequence of having a mental health difficulty is

its association with a reduced ability to enjoy social relationships (though this in turn may also have consequences as concerns employability). Additionally, by integrating SWB into the analyses, the study is able to identify that a general health difficulty is *indirectly* associated with reduced SWB because of its association with impaired skills for employment. In contrast, a mental health difficulty: (i) has a direct association with reduced life satisfaction in the subsequent period (as identified by Layard et al. (2014)); and (ii) there is evidence of an indirect association via impaired social relationships.

#### 8.4.1.2. *Limitations of the quantitative study*

I aimed to quantitatively investigate the pathways through which negative health dynamically impacts valued abilities. However, when taking the quantitative study in isolation, caution is required before interpreting the associations reported above as being reflective of causation. In the expanded SEM, the numerous domains incorporated in the analysis meant I was unable to control for unobserved heterogeneity between individuals, and was instead only able to minimise the risk of confounding through the incorporation of a broad range of covariates. In the reduced SEM, a number of assumptions are required in order to model the single autoregressive path while attempting to formally incorporate the influence of unobserved heterogeneity. Of particular pertinence is the need to assume time invariant heterogeneity has an equal influence on the latent variable for low academic ability at  $t=1$  and the continuous latent response variable under the NEET binary variable. This is a strong assumption both because the influence of unobserved heterogeneity on skills for employment may vary over time (Bollen and Brand, 2010) and because, as mentioned in 8.2.2.4, the two variables are conceptually related but not identical. The results from both the expanded and reduced SEM must therefore be treated with caution. It is nevertheless notable that with their *differing* limitations each suggests an association between: (i) a general health difficulty aged 14-15; (ii) impaired formation of skills for employment; and (iii) reduced SWB aged 19-20. However, as concerns *causality*, the models at best can provide a useful framework to assess the extent to which the data in the LSYPE1 cohere with hypotheses that emerge from the qualitative study.

#### *Limitations in the variables available*

My reliance on a secondary dataset to investigate complex phenomena in a manner that draws on a heterodox theoretical framework (the capability approach) results in the analyses relying on indicators that are arguably often relevant but not ideal. Other than

the large number of adolescents interviewed for an extended number of waves, a strength of the LSYPE1 is its broad scope with regards the number of aspects of an individual's life for which there are responses. Unfortunately, perhaps because it is managed by the Department for Education (Department for Education, 2011), and therefore has an educational focus, it contains relatively little detail as concerns the health difficulties individuals face. For my broad aim of investigating the influence of a health difficulty, in general, this is not a substantive limitation. However, some readers, particularly those from a health care background, may consider it of value if future research focussed on the impact of specific difficulties upon the formation of valued abilities.

As concerns the incorporation of "the ability to enjoy social relationships", a brief review of the psychological literature on social relationships and networks (Kawachi and Berkman, 2001; Parker et al., 2006; Smith and Christakis, 2008) indicates the use of specifically designed indicators which may capture the concepts of interest more precisely than those variables used on this analysis. Psychologists might understandably consider those variables available in the LSYPE1 limited. Nevertheless, it is arguable that the number of close friends an individual reports having during this period of high peer social orientation (Parker et al., 2006) is likely to be strongly associated with the individual's confidence in their social relationships. Additionally, it is worth noting that in both the reduced and the expanded SEM, having few close friends is a highly significant predictor of not being satisfied with life, further supporting the variable's validity as an indicator of impaired social relationships (which one would expect to be associated with life satisfaction).

As already discussed in 8.2.1, data availability resulted in limitations as concerned the variables used to incorporate "opportunities to enjoy valued leisure activities". The diverse nature of activities individuals could potentially enjoy means that, unless it was a particular focus of those designing the data collection efforts, there would likely be analytical difficulties in optimally measuring individuals' ability to enjoy this facet of life. My results indicate that, in part, the limited variables available still allowed an exploration of a dynamic I anticipated from the qualitative analysis: (i) the role of physical activities as a context for developing friendships; and (ii) the potential mediating role this aspect of life might have between a health difficulty, which I hypothesised would undermine an

individual's capacity to undertake physical leisure activities, and social relationships. The expanded SEM strongly supports the first part of this dynamic. As will be discussed in greater detail in 9.3.2.2, the lack of association identified in the expanded SEM between a general health difficulty and a lack of physical activity in part likely results from the conservative specification of the structural equations which precludes the estimation of the contemporaneous impact of a health difficulty on individuals' valued abilities. This in a more general sense is an additional limitation worth noting. As discussed in 8.2.2, I adopted this approach given my desire to: (i) maintain a consistent model specification approach; while (ii) reducing the risk of endogeneity between health difficulties (particularly as concerns mental health) and an individual's ability to enjoy the other inherently valued aspects of life.

#### *Attrition and item non-response*

The substantial proportion of individuals who were dropped from the analytic sample through attrition and item non-response is a limitation of the analysis. To an extent, this is a common issue faced when undertaking longitudinal analyses. While the use of survey weights and a robust estimator increases the validity of any inferences made with respect to the state educated general adolescent population, it is possible that there are differences on unobservable characteristics between my analytic sample and the wider population that could lead to bias in the estimates<sup>56</sup>.

As mentioned in 8.2.2.6, I could have used multiple imputation methods to minimise attrition due to item non-response and therefore further reduce the risk of bias. By using auxiliary covariates in addition to those included in my analysis, I would be in a stronger position to assume data were missing at random (MAR) rather than MARX (missing at random once conditioned on X – the covariates included in my analysis) (Asparouhov and Muthén, 2010; Holder, 2015). However, as mentioned in 8.2.2.6, I did not undertake

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<sup>56</sup> Table C-4 (in appendix C.4) illustrates the differences in the summary statistics of the analytic sample compared to the age matched general population. Having re-weighted my analytic sample, they are still less likely to: be male, be from an ethnic minority, have a mother with lower or no educational qualifications, be from a single parent family, attend a school which their parent does not rate positively, themselves have a longstanding illness or disability, have lower educational aspirations or have a parent who unemployed rather than having a managerial or professional occupation. Additionally, there are generally more dependent children in the households of those who dropped out and the year 9 test scores of those who dropped out are lower. As these, or equivalent covariates are included in the structural regressions these specific observed differences should not bias the results. However, particularly with regards the expanded SEM which does not attempt to control for unobserved heterogeneity, there is the possibility that differences between the analytic sample and the age matched general population might lead to differences in unobserved characteristics that could bias the results.



multiple imputation for two reasons. Firstly, MARX assumption required for robust estimation receives support from both: (i) the large number of covariates included in the analyses; and (ii) the consistency in the substantive findings of the analyses across the base case analyses and the robustness check to explore the impact of attributing all “don’t know” responses as missing (which compared to the base case approach leads to an analytic sample with: an increased number of missing responses; a reduced number of observations being included in the analysis; and significantly lower test scores). Secondly, the context of this quantitative analysis, as a strand of a wider mixed methods study, influenced my decision to not implement the complex imputation methods required when dealing with stratified survey data (Drechsler, 2015; Holder, 2015). For the mixed methods study as a whole, the need to assume individuals were MARX (rather than MAR) is arguably of relatively low importance compared to the limitations previously mentioned concerning the variables available in the LSYPE1. Undertaking multiple imputation would have no impact on my ability within the quantitative analyses to incorporate concepts that were entirely aligned with the valued abilities emphasised as being of importance by the participants who took part in the qualitative study. When considering this quantitative study as a component of the mixed methods study as a whole, it is therefore arguable that undertaking multiple imputation would likely have little impact on the substantive findings and limitations of the quantitative analysis.

#### *Interpretability*

A final limitation of the analyses undertaken relates to the interpretability of the coefficients. A disadvantage of using a SEM (with latent explanatory variables, indirect coefficients and binary variables in wave 7) is that the estimated coefficients have no interpretable meaning beyond their sign, significance and relative size. Though, other things equal, interpretable coefficients are preferable, this limitation is arguably not crucial given the role of the quantitative analyses in the overall mixed methods study. My objective with these analyses is not to derive a precise, causal estimate of the difference a health difficulty, or health care intervention, makes to individuals’ ability to enjoy valued aspects of life (though future research on this topic would be of value as discussed in 9.4.3.2). Instead, as mentioned in 8.1.1, they are to: (i) identify the pathways via which health difficulties are associated with the impaired formation of valued abilities; and (ii) test the generalisability of hypotheses derived from the qualitative research. Though my

adopted method *inhibits* the estimation of interpretable coefficients, it *enables* me to achieve the objectives for the quantitative analyses in the context of the wider study.

#### 8.4.2. Summary of the quantitative study's main findings

The quantitative analyses indicate support for the hypothesis that a health difficulty in adolescence can disrupt the ongoing formation of valued abilities. The analyses indicate, however, that the extent to which this disruption *persists* can vary. The analyses support the following observations. First, a general health difficulty in the period prior to GCSE examinations is associated with the impaired formation of the ability to get a good job and be successful. Second, a mental health difficulty is associated with an impaired ability to enjoy relating to others. Third, there is interdependence between the ability to get a good job and be successful and the ability to enjoy social relationships. Therefore, fourth, a general health difficulty aged 14-15 is associated with both the impaired formation of both the formation of the ability to get a good job and be successful and the ability to enjoy relating to others. Fifth, there is a significant direct association between a mental health difficulty aged 16-17 and not being satisfied with life aged 19-20. Finally, because a general health difficulty aged 14-15, a mental health difficulty at the same age and a mental health difficulty aged 16-17 are associated with the impaired formation of valued abilities that predict of life satisfaction, each also has a significant indirect association with not being satisfied with life aged 19-20.

I now turn to integrating the findings of the qualitative and quantitative strands of the research in order to more fully assess the role health plays during adolescence in the formation of valued abilities.

## PART 4: COMBINING THE PERSPECTIVES



## 9. Integrating the findings of the qualitative and quantitative research

### 9.1. Introduction

This thesis aims to investigate the immediate and future impact of health difficulties during adolescence on the formation of valued abilities (capabilities). As discussed in chapters 1, 4 and 5, to achieve this aim there are substantial benefits in combining qualitative and quantitative methods. Using narrative methods to access the emic knowledge of those with the lived experience of a health difficulty in adolescence is not only of inherent value but, by informing an inductive process of reasoning, enables the generation of hypotheses which can be deductively tested – leading to the development of etic knowledge. As discussed in chapters 4 and 5, the analysis of both qualitative and quantitative data is arguably an effective way to combine: (i) emic and etic knowledge; and similarly, (ii) inductive and deductive reasoning.

As discussed in chapter 5, in order to enable the research yield of the combined methods to be maximised, the *study designs* of the qualitative and quantitative strands need to be carefully integrated (Ó’Catháin et al., 2010). Doing so is a necessary precursor for allowing the *findings* of the two studies to be rigorously triangulated. As outlined in greater detail in chapters 5-8: (i) the qualitative study influenced the domains selected for incorporation in the quantitative study and consequently the hypotheses which could be tested; and (ii) my awareness of the limitations of the quantitative data enabled me to be aware of relevant research areas which would be particularly reliant on the qualitative analysis (allowing me to remain cognisant of any opportunities to elicit in-depth responses concerning these areas in the third wave of interviews).

My focus now turns to integrating the findings of the qualitative and quantitative studies in order to more fully address the research aim and objectives. In 9.2, I summarise the methods employed to triangulate between the findings of the qualitative and quantitative strands of the research. The integrated findings of the mixed methods study are presented in 9.3. Finally, in 9.4, I discuss the mixed methods study’s strengths and limitations, contribution to the literature and implications for policy and future research. The novel contribution of this chapter is to present findings on the role of health in the formation of valued abilities that are informed by an integrated consideration of *both* the longitudinal qualitative and longitudinal quantitative research strands. This is the first study I am aware of to combine both longitudinal qualitative and quantitative research

methods when investigating the role of health in the formation of the wider valued abilities.

## 9.2. Methods

As discussed in chapter 5, I adopt a triangulation protocol, a formalised approach to comparing the findings of my qualitative and quantitative studies, which is informed by the triangulation protocol employed by Farmer et al. (2006). Before outlining the specific approach I adopt, it is worth noting two substantive differences between their studies and mine which led to me to adapting their suggested approach.

The first difference concerns the size of the research team undertaking the combined methods project. It is likely that in the study undertaken by Farmer et al. (2006) separate individuals analysed the two different datasets. Therefore, at the time of their initial analysis, the emergent findings from one strand of the study were unlikely to have influenced the emergent findings of the other. The possibility of generating independent, initial findings for each strand arguably increases the confidence one can have in findings which are subsequently supported by both. In my research project, this was not a plausible option. As required for a Doctoral Thesis, the research reported in thesis was undertaken by me, a singular individual. An advantage of my need to undertake both the qualitative and the quantitative aspects of the project is that it is easier for the two strands, and their findings, to be coherently integrated. A disadvantage is that it diminishes the ability of one study's findings to truly validate the other – the two sets of findings were not generated independently and then compared. I will therefore employ greater caution in the extent to which I consider any agreement in findings between the two strands to offer support for their validity.

A second important difference between my study and that undertaken by Farmer et al. (2006) is that I am comparing the findings that emerge from analysing *both* qualitative and quantitative data. In both components of Farmer et al.'s research, the data analysed is reported as primarily being of a qualitative nature. As discussed in 4.4, the nature of the data used in the quantitative analysis makes it unfeasible to truly test hypotheses that are fully equivalent to the inductive findings generated by the analysis of the qualitative data. Firstly, as mentioned in 8.2.4, the hypotheses tested in the quantitative analysis involved a degree of process reductionism – specifically, I could not investigate both: (i) the extent to which a health difficulty caused disruption; and (ii) the extent to which individuals and their families were able to adapt and eventually deal with the difficulty it caused. Instead,

I could only hypothesise that it would cause a difficulty too large to be fully resolved. Secondly, a degree of conceptual reductionism is often required (e.g. as discussed in chapter 0 the ability underlying covariance in an individual's exam scores is not conceptually identical to "the ability to get a good job and be successful"). The qualitative and quantitative studies therefore do not investigate identical facets of the same phenomena but instead approach it from different perspectives (Moffatt et al., 2006).

Differences in the methods employed, the complexity of the hypotheses tested and the degree to which the domains of interest have required simplification likely result in one of Farmer et al.'s convergence coding categories being misleading. For my study, given the differences mentioned above, it is unlikely that findings from my qualitative and quantitative studies can ever be in "full agreement". Instead, concerning a specific valued aspect of life (capability domain), when there is consistent coherence between the findings of the two sub-studies, I will instead use "agreement". I will use the term "partial agreement" where there is a degree of agreement but also some discordance between qualitative and quantitative findings. Table 9-1 below presents my adapted triangulation protocol.

Table 9-1: Triangulation protocol (adapted from Farmer et al. (2006))

Step	Activity
1. Sorting	Identify the primary findings of each sub-study and categorise them according to: (i) the valued aspect of life to which they relate; and (ii) the category of qualitative finding to which they relate (e.g. “trend”, “barrier”, etc.) <sup>+</sup> .
2. Convergence coding	<p>Within each category compare the findings from each strand of mixed method research study to assess the degree of convergence. Characterise the degree of convergence using the following classifications of agreement.</p> <p><i>Convergence coding scheme</i></p> <p><b>Agreement</b> Consistent coherence in the findings of the two sub-studies (as they relate to the specific valued aspect of life).</p> <p><b>Partial agreement</b> A degree of agreement but also some discordance between the findings of the two sub-studies (as they relate to the specific valued aspect of life).</p> <p><b>Silence</b> The findings of one study cover an issue on which the other study has no directly relevant results. In this event, given the restricted scope of the quantitative study, consider whether there are any informal analyses of the quantitative data which might offer further support from a different data source for inductively driven qualitative findings.</p> <p><b>Dissonance</b> There is disagreement between the findings of the qualitative and the quantitative studies. Employ a dialectical approach to identify if an alternative perspective on the seemingly dissonant findings that emerge from each sub-study can be resolved with a fuller understanding of the underlying phenomena in a manner which then makes sense of the data in each study and resolves the dissonance in the initial findings*.</p>
3. Convergence assessment	Review the convergence coding for each of the valued aspects of life to provide an assessment of the degree of convergence by: (i) aspect of life; and (ii) a global assessment of the level of convergence.
4. Completeness assessment	Compare the scope of findings for each of the separate sub-studies to enhance the completeness of the combined set of findings and identify important differences in the two sub-studies’ coverage.
5. Feedback	Feedback triangulated results to my supervisory team for review and clarification.

**Notes:** <sup>+</sup> In effect, I have already undertaken this step in order to test hypotheses informed by the qualitative findings in the quantitative study; \*See O’Cathain et al. (2010).

It is worth re-stating that the participants in the qualitative study could at a maximum be aged 17 at the time of the last wave of interviews. Though the findings of the qualitative study can be used to inform hypotheses regarding the influence of a health difficulty aged 16-17 (t1) on individuals’ abilities to enjoy the other valued aspects of life in the subsequent period (t2: aged 19-20), this latter period was not directly observed in the qualitative study.



### 9.3. Findings

#### 9.3.1. Summarising the level of agreement between the two study strands

Table 9-2 below summarises the degree of convergence between the findings of the qualitative and quantitative strands of the mixed methods study. As with the quantitative study, in accordance with the aim of the thesis, I focus on the findings concerning how health difficulties affect the other inherently valued aspects of life. Below I therefore *do not* separately consider how an individual's ability to enjoy good health is affected by the other inherently valued aspects of life. The table is similar to Table 8-8 in the previous chapter. The substantive changes made to the tables include: (i) incorporating the paraphrased qualitative findings of relevance to "the ability to make decisions on the things that matter" and "the freedom to express and discover one's identity" (which were not included in the quantitative analysis); and (ii) explicitly noting the level of agreement between the qualitative and quantitative studies in the final column (including if there is "silence"). When reviewing Table 9-2, it is notable that there is often partial agreement between the qualitative and quantitative findings in the period covered by both studies and dissonance in the subsequent period.

Table 9-2: Convergence coding matrix

Category of finding	Summary of qualitative findings	Related hypothesis tested in the quantitative study	Support for hypothesis (from direct and indirect effects)		Level of agreement between studies
	<i>The ability to get a good job and be successful</i>				
Trends	For many the pressure associated with study appeared to increase over time	No directly equivalent hypothesis is tested	N.A.		Silence
Barrier	The participants' ability to regularly attend school can be disrupted by health difficulties – sometimes this resulted in disrupted preparations for their exams	Poor health imposes sufficiently large constraints upon the accumulation of this ability/skill that even with [unobserved] efforts to navigate the constraints poor health is associated with reduced achievement compared to others in the subsequent periods	GH <sub>t0</sub>	✓	Partial agreement  (Differs between agreement and dissonance by time period and dimension of health)
			MH <sub>t0</sub>	×/✓	
Observed approach to navigating barrier	Some participants who missed school due to poor health reported trying to working harder on returning to school in an effort to catch up		GH <sub>t1</sub>	×	
			MH <sub>t1</sub>	×	
	<i>Opportunities to enjoy valued leisure activities</i> (N.B. for quantitative study only concerns physical leisure activities)				
Trend	Leisure activities often became less structured and supervised by adults	No directly equivalent hypothesis is tested	N.A.		Silence
Barrier	Health difficulties sometimes resulted in the participants showing greater caution when joining in leisure activities with their peers – this appeared at times to disrupt their enjoyment of the activity	Poor health imposes sufficiently large constraints upon the accumulation of this ability/skill that even with [unobserved] efforts to navigate the constraints poor health is associated	GH <sub>t0</sub>	×	Dissonance
			MH <sub>t0</sub>	×	
			GH <sub>t1</sub>	×	

Category of finding	Summary of qualitative findings	Related hypothesis tested in the quantitative study	Support for hypothesis (from direct and indirect effects)		Level of agreement between studies
Observed approach to navigating barrier	The participants with a health difficulty often seemed to take up alternative activities for which their health difficulties imposed little or no constraint	with reduced achievement compared to others in the subsequent periods	MH <sub>t1</sub>	×	
<i>The ability to enjoy relating to others</i>					
Trend	Many increasingly spent time with peers, away from adult supervision	No directly equivalent hypothesis is tested	N.A.		Silence
Barrier	Participants' health difficulties could undermine confidence in social settings	Poor health imposes sufficiently large constraints upon the accumulation of this ability/skill that even with [unobserved] efforts to navigate the constraints poor health is associated with reduced achievement compared to others in the subsequent periods	GH <sub>t0</sub>	×/✓	Partial agreement  (Differs between agreement and dissonance by time period and dimension of health)
Observed approach to navigating barrier	Those with health difficulties appeared to gravitate towards peers who would accept these "different" behaviours and not draw attention to them		MH <sub>t0</sub>	✓	
			GH <sub>t1</sub>	×	
			MH <sub>t1</sub>	✓	
<i>The ability to make decisions on the things that matter</i>					
Trends	Many experienced increasing freedom to make important decisions	No hypothesis because not included as an endogenous variable	N.A.		Silence
	Participants often appeared to intentionally work on mastering areas of importance in which they struggled and learned to make progress in them				

Category of finding	Summary of qualitative findings	Related hypothesis tested in the quantitative study	Support for hypothesis (from direct and indirect effects)	Level of agreement between studies
Barriers	a) Difficulties with health seemed at times to constrain participants' ability to actualise desirable opportunities			
	b) For those with health difficulties, particularly if it was CF, a legacy of being a recipient of care could inhibit their freedom to redefine themselves as independent and autonomous individuals			
Observed approaches to navigating barrier	Concerning "a": participants with health difficulties actively managed risks in order to make desirable activities and opportunities more feasible			
	Concerning "a": participants with health difficulties often learned to "push through" their fears and gather the courage required to enjoy valued opportunities that came with a degree of often well managed risk			
	Concerning "b": some of the participants became increasingly independent in managing their health difficulty – this enabled them to demonstrate to their parents they could be entrusted with independence in other aspects of life			

Category of finding	Summary of qualitative findings	Related hypothesis tested in the quantitative study	Support for hypothesis (from direct and indirect effects)	Level of agreement between studies
<i>The freedom to express and discover one's identity</i>				
Trend	The participants often appeared to shape who they are becoming over time	No hypothesis because not included as an endogenous variable	N.A.	Silence
Barrier	Having a health difficulty often led participants to a negative sense of being different.			
Approach frequently adopted to surmount barrier	As noted for "opportunities to enjoy valued leisure activities", the participants seemed to take up alternative activities which allowed them to feel and demonstrate a more positive identity.			

### 9.3.2. Investigating health's role using the findings of both study strands

As discussed in chapters 1 and 5, my purpose in combining qualitative and quantitative methods is to reduce the extent to which either approach constrains my perspective on how negative health in adolescence affects the wider abilities individuals value. Below, where possible, for each of the prioritised valued aspects of life (other than “good health”), I first compare the findings of the qualitative and quantitative strands. Then, when both strands of the study report findings of relevance to the valued aspect of life, I endeavour to encapsulate my understanding of health's influence on individuals' ability to enjoy that aspect of life in a manner that implicitly *synthesises* the findings of both strands of the mixed methods study.

#### 9.3.2.1. *The ability to get a good job and be successful*

##### *Investigation of the degree of convergence between the two strands' findings*

Using the formalised quantitative models reported in chapter 0, I am not able to test the trend, observed in the biographical data, that the pressure of study increases over time. It is perhaps interesting to note that a descriptive investigation of the data available in the LSYPE1 indicates that when they are aged 16-17, a significantly higher proportion of individuals have a GHQ-12 score above the threshold that indicates they are at risk of a mental health difficulty than when aged 14-15. Caution is required before interpreting this as demonstrating that exam stresses are increasing over time as: (i) not all the LSYPE1 participants are still in a study environment aged 16-17; and (ii) numerous other factors change over time and could also contribute to an increasing proportion at risk (Mezulis et al., 2009). Nevertheless, the descriptive analysis of the quantitative data is not inconsistent with the dynamic trend identified in the qualitative biographies. However, it is important to note that the participants' biographies do not always illustrate this increased pressure as a negative trend. For some, the extra pressure seemed to result in a switch from having a relatively low level of focus on their studies to a level of application that many might consider being of value. For others though, the increased pressure did seem detrimental, impairing their ability to enjoy other facets of life (Denscombe, 2000).

As can be seen in Table 9-2, there is substantial agreement between the qualitative and quantitative strands of the research with respect to the age period covered by both sub-studies. The quantitative analysis supports the hypothesis that a general health difficulty aged 14-15 impairs individuals' ability to accumulate the skills required get a good job and be successful. Indeed, due to the longer period for which participants were followed in

the LSYPE1 relative to the qualitative study, the quantitative findings in one sense go beyond those of the qualitative study. The quantitative findings indicate that the consequence of a general health difficulty on the accumulation of skills for employment persists into early adulthood. Concerning the influence of a mental health difficulty at the same stage, the degree of agreement between the studies is somewhat more nuanced. It would appear that independent of general health, a mental health difficulty has little direct influence on individuals' ability to successfully accumulate academic knowledge. However, the quantitative analysis indicates a significant indirect association between a mental health difficulty and future NEET status via its association with increased relational exclusion aged 15-16, which could be conceptualised as related to "non-cognitive skills" (Heckman, 2006).

As concerns the influence of both a general and a mental health difficulty aged 16-17 on the ability to get a good job and be successful, there is dissonance between the two study strands. Given the absence of qualitative data when individuals are aged 19-20 (the age for the quantitative outcome measure), it is difficult to fully investigate the reasons for this. One possible explanation, of particular relevance to the limited impact of a general health difficulty, is that by age 16-17, individuals' trajectories are more established, having had their academic ability formally recognised via their GCSEs. Potentially, a setback in their ongoing ability to acquire skills for employment after these exams is of less importance than any setback experienced in the prior period. Another possible explanation is that by age 16-17, individuals may have learned to more effectively navigate the difficulties imposed on their abilities to study or work. As an example, they may have selected an option following compulsory education which matches their body's capacities.

#### *Integrated mixed methods study findings*

Given the differing pathways via which mental and general health appear to influence the formation of the ability to get a good job and be successful, it is perhaps worth maintaining that distinction when drawing integrated findings for the mixed methods study. To avoid duplication, given the quantitative findings, indicate the importance of relational exclusion to the indirect association between the mental dimension of health and the ability to get a good job and be successful, I postpone further consideration of this dynamic until 9.3.2.3 (where I will eventually consider both the influence of a mental health difficulty on social relationships and the additional associated consequence with regards employment).

Turning to the influence of a general health difficulty in adolescence on the formation of individuals' ability to get a good job and be successful, it would appear that it is of substantive importance in the period immediately prior to the GCSE exams. As outlined in chapter 7, the participants' biographical data illustrate the impact poor experienced health can have on school attendance. Some missed school for prolonged periods. Others, while not missing school for long durations, seemed to have a school experience that was overshadowed by the possibility of an exacerbation that might result in humiliation in front of friends (Rhee et al., 2007) or hospitalisation. Taken together, it seems very plausible that a general health difficulty has the potential to disrupt the accumulation of knowledge in the period prior to GCSEs. As mentioned, the quantitative findings not only support this but also indicate the consequences of disrupted skill accumulation for subsequent educational and employment prospects.

The biographical data also illustrate the potential in the period after GCSEs for individuals to undertake largely positive adaptations to their health difficulty and minimise its subsequent impact. This potentially has two dimensions. Firstly, as mentioned in chapter 7, participants with asthma appeared to achieve an improvement in their experienced health over time (as mentioned in chapter 7, no such positive trend was observed for those with CF). For those with asthma, this improvement in experienced health seemed in part to result from identifying the most effective way to manage their health difficulty. If this trend of increased skill in adapting to one's health difficulty frequently occurs for a substantive proportion of other chronic health difficulties (Woodgate, 1998), then it is unsurprising that the degree to which a health difficulty causes disruption in the quantitative analysis appears to decrease. Secondly, the biographical data indicate that those with health difficulties actively considered which of the options available would be feasible given their level of experienced health. These would be conditional on their achieved GCSEs (and therefore their experienced prior health may have indirectly imposed restrictions via worsened GCSE results) but a greater diversity of options were now available compared to when younger. Importantly, given the diversity of options the individual could potentially access, "success" could not as readily be reduced to a single dimension (in contrast to previously when nearly all individuals were undertaking national level exams). Therefore, even if the individual chose to adopt a less demanding vocational pathway, the extent to which it could subsequently be judged inferior would be less objective and therefore perhaps less vigorously enforced. When considering these interconnected aspects of adaptation, the former, more effectively managing one's



health difficulty, seems entirely positive (Brazier et al., 2005; Menzel et al., 2002). The latter, selecting an activity for which one has sufficient experienced health, is eminently sensible, and to an extent, the increased flexibility at this stage of life, and the opportunity to adapt in this manner, is a positive development. However, this form of adaptation is not without cost. Compared to the individual with no substantive health difficulty, the adapting individual may have to forgo their hypothetically *preferred* option because of their body's capacity.

In summary, an analysis of the qualitative and quantitative data and findings indicate that the period prior to GCSE examinations is one in which a general health difficulty can substantively impair the formation of an individual's ability to get a good job and be successful. Post GCSE examinations, the additional effect of a health difficulty appears limited perhaps as a result of largely positive adaptations which result in: (i) improved management of their difficulty; and (ii) the selection of educational and training options that are within their body's capacity (enabled by the greater number of options that are available).

#### *9.3.2.2. Opportunities to enjoy valued leisure activities*

##### *Investigation of the degree of convergence between the two strands' findings*

As with the other inherently valued aspects of life, I am not able to use the formal quantitative analysis to test the dynamic trend observed from the biographical data – that over time activities become less structured and are less frequently supervised by adults. Indeed, it is difficult to even informally test a related hypothesis using data from the LSYPE1. The questions related to leisure activities that are asked both when individuals are aged 13-14 and aged 16-17 do not inquire as to whether a parent or adult was with the young person when they undertook the respective activity. However, the biographical data do offer very strong support for the trend. Additionally, the development psychology literature indicates that over time adolescents increasingly pursue autonomy from adults (Laible et al., 2004; Parker et al., 2006) and spend an increasing amount of time with peers (Parker et al., 2006). The absence of quantitative support for this trend therefore does not seem an important gap as concerns the mixed methods study. Indeed, explicitly making this observation would be unnecessary were it not for its potential pertinence when considering the influence of a health difficulty on the opportunities an individual has to enjoy valued leisure activities.

For both general and mental health at each time period, there is dissonance between the hypothesis generated from the qualitative sub-study and the findings of the quantitative analysis. Below, I consider potential reasons for this dissonance. First, the variables used in the quantitative analysis are not very nuanced. The importance of the indicators available as a plausible explanation is compounded by a second possible explanation, the adaptive behaviour observed in the biographical data. Particularly amongst the boys interviewed who had severe asthma, there seemed to be a trend towards dropping physically demanding activities in which they struggled to compete and instead focussing on activities in which they could flourish. Some of the activities they adopted were sedentary but others, like badminton or rounders, involved physical exertion while not exposing their body's lower capacity. This adaptive behaviour, consistent with the findings of empirical research previously undertaken by Rhee et al. (2007), compounds the potential importance of the crudeness of the LSYPE1 indicators used in the quantitative analysis. The indicators only ask the individual to indicate whether (or not) they have undertaken relatively physically strenuous activities (examples given in the questions include football, dance classes or swimming). They therefore preclude an assessment of the extent to which a health exacerbation results in individuals selecting activities which are less physically demanding than those they might have otherwise opted for (e.g. David choosing to take up badminton and to largely finish playing football with his friends).

A third potential explanation for the apparent dissonance between the qualitative and quantitative strands concerns the manner in which I specified the quantitative analysis. As discussed in chapter 0, in order to reduce the risk of endogeneity, I lagged health as an explanatory variable and included the lagged absence of physical activity as a covariate. Although this approach has advantages, it prevents the analysis capturing the contemporaneous impact of a health difficulty on the individual's ability to enjoy a specific aspect of life. It is likely the case that an individual's health difficulty in the present plays a substantive role in inhibiting their current ability to enjoy physical activity (in contrast, the impact of reduced physical activity on experienced physical health is likely to be lagged). The approach I have adopted to the quantitative analysis in effect attributes any contemporaneous impact of health on physical activity to the coefficient relating to the lagged absence of physical activity incorporated within the same structural regression. From first principles, as outlined above, there is good reason to believe the impact of a physical health difficulty on physical exercise will be contemporaneous.

Additionally, it is worth noting that a simple analysis of correlations, which must be interpreted with great caution given the potential of confounding underlying factors, shows that a general health difficulty aged 13-14 is significantly correlated with not being physically active at the same age. There is also a significant correlation between a health difficulty and the contemporaneous absence of physical activity when aged 16-17<sup>57</sup>. Interestingly there is no significant correlation between a general health difficulty at  $t=0$  and not being physically active in  $t=1$ . In contrast to the previously considered aspect of life, there is therefore no support from the quantitative analytic sample for an assumed effect of poor health on physical activity *persisting* into the subsequent time period.

#### *Integrated mixed methods study findings*

Having carefully considered: (i) the nature of the variables included in the quantitative analysis (of particular relevance given the possibility for individuals to adapt by changing their physical activity of choice); (ii) the implications of the approach to specifying the quantitative structural model; and (iii) the contemporaneous correlations within the LSYPE1 data, it would seem the quantitative strand does not in any substantive manner call into question the findings of the qualitative strand.

The dynamic trend observed in the biographical data, that activities become less structured and supervised by adults over time, potentially results in individuals increasingly having freedom to implement adaptive behaviour as they transition from being perceived as children to being perceived as adults. As they transition, instead of having to often undertake physical activities in a large *group* so they can be efficiently monitored by adults (for instance in physical education classes at school), they can instead increasingly take up activities as *individuals* (or alongside a limited number of peers). This allows those with health difficulties to customise their choice of activities to those that are a better fit with their bodies' capacities (Rhee et al., 2007). Here, there are perhaps parallels with the increased flexibility individuals experience post GCSE examinations to select an educational or training route that matches their physical

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<sup>57</sup> In addition to the analysis of bivariate correlations, I also undertook a probit regression in which no physical activity aged 16-17, the dependent variable, was regressed on *contemporaneous* general health and the covariates specified in equation (1) of 8.2.2.2 (other than no physical activity aged 13-14). The coefficient for contemporaneous general health was significant at the 10% threshold but not the 5% threshold. Strictly speaking, this analysis fails to support the importance of contemporaneous general health. It is important to remember, however, that this analysis is still beset by the limitation of the indicator used for exercise. As discussed, this limitation is likely compounded by trend observed in the biographical data for individuals to often adapt by adopting less strenuous physical activities rather than dropping these activities altogether.

capacity. While there is an advantage to being increasingly able to select activities that one is able to enjoy without inhibition, a health difficulty can still to an extent disrupt the individual's experience of this facet of life. The increased flexibility the individual experiences may enable them to identify an *alternative* activity that: (i) inherently provides enjoyment; (ii) provides a context for developing friendships; and (iii) helps them portray a positive identity. However, a health difficulty may still prevent an individual being able to enjoy what would have otherwise been their *favoured* option.

Non-physical leisure activities are *conceptually* somewhat difficult to distinguish from the ability to enjoy relating to others and very difficult to distinguish *empirically* with the data available in the LSYPE1. Instead of dwelling on my inability to quantitatively investigate the impact of a health difficulty on the formation of this sub-domain, I will instead now turn to considering the study findings concerning health's role in the formation of the conceptually related domain.

### 9.3.2.3. *The ability to enjoy relating to others*

#### *Investigation of the degree of convergence between the two strands' findings*

As with the two valued aspects of life previously reviewed, I am not able to use the LSYPE1 data to formally test the dynamic trend observed in the qualitative analysis – that many of the participants increasingly seemed to want to spend time with peers and away from adult supervision. To an extent this seems to be assumed by the designers of the LSYPE1. After the first wave of interviews they collect little data concerning the relationship between the parent and the young person. While this in no way proves the trend, it is perhaps supportive of there being a general notion that as individuals transition from childhood to adulthood they seek to increasingly relate to their peers (Laible et al., 2004; Parker et al., 2006). As with the previous domain, it can be helpful to remain cognisant of the manner in which this aspect of life often develops when investigating the extent to which a health difficulty in adolescence disrupts this valued aspect of life. While the absence of data in the LSYPE1 prevents me testing the validity of this view, it is not only supported by the biographical data I analysed but also the development psychology literature (Laible et al., 2004; Parker et al., 2006). I now turn to considering the extent to which the results of the quantitative analysis indicate that a health difficulty disrupts an individual's ability to enjoy social relationships with others.

In a manner that has parallels with the relationship between mental health and skills for employment, Table 9-2 indicates partial support for the hypothesis that a general health

difficulty aged 14-15 disrupts the ability to enjoy relating to others at later ages. There is dissonance with regards the direct association between a general health difficulty aged 14-15 and impaired social relationships aged 15-16. However, there is a significant indirect association between having a general health difficulty aged 14-15 and having few close friends aged 19-20. As mentioned in chapter 0, the pathway with the strongest association is via impaired skill for employment aged 15-16. The quantitative analysis and the wider literature support the notion that social networks are in a state of flux post compulsory education as individuals transition from one context to another (Parker et al., 2006). If one has previously experienced bullying at school, the opportunity therefore exists to identify a new friendship group, reducing the risk that the experienced isolation persists. However, low academic ability in  $t=1$ , modelled using test scores at GCSE, likely has an influence on the ease with which one can access institutions in which to continue one's education (and develop friendship networks). This interim step, accessing sixth-form colleges and training institutions post GCSE, was not explicitly included as it would have required more time periods to be added to the model. Nevertheless, one's academic ability is a strong predictor of not being in education, employment or training after compulsory education (Cornaglia et al., 2015). It is plausible that because a general health difficulty is associated with an increased risk of not getting high grades, it is also indirectly associated with not being able to access contexts conducive to developing friendship networks (Thompson et al., 2014).

Having a general health difficulty aged 16-17 is not associated with having fewer close friends aged 19-20 (this is the case when the model is fitted with genders combined and separately by gender). As mentioned above, in some respects, this does not contradict the narrative data as individuals in the qualitative sample were not interviewed through to the age of 19-20. Entering new contexts may again explain this lack of association. As individuals choose their educational, employment or training options after post-compulsory education, they likely develop new friendship groups and have quite possibly learned to adapt by finding networks who are accepting of their longstanding health difficulty (Boydell et al., 2008; Christian and D'Auria, 1997). Additionally, as previously mentioned with respect to the development of the ability to get a good job and be successful, if individuals are learning to manage their health difficulty more effectively over time (Woodgate, 1998), one would expect the association between a health difficulty and relational isolation to weaken.

As concerns the mental dimension of health, a difficulty aged 14-15 is associated with being relationally excluded aged 15-16, even having controlled for previous relational exclusion. This supports a dynamic that is observed, but hard to disentangle, in the biographical data, namely that it is not only plausible that social isolation can have a detrimental effect on an individual's mental health but also that mental health difficulties can exacerbate social isolation (Parker et al., 2006). Additionally, the quantitative data indicate that this dynamic continues in later adolescence and early adulthood as having a mental health difficulty aged 16-17 is significantly associated with having fewer close friends aged 19-20.

#### *Integrated mixed methods study findings*

Taken together, the qualitative and quantitative strands would indicate that in the period prior to the end of compulsory education a health difficulty often does undermine social confidence. As with the aspects of life discussed above, there is evidence of interaction between the individual, their changing context, their peer group and their often increased ability to manage the extent to which a health difficulty disrupts their experienced health.

As mentioned above (when considering the influence of health on the ability to get a good job and be successful) the interconnected nature of: (i) relationships; (ii) relational skills; (iii) educational/employment opportunities; and (iv) the contexts these provide for relationships broadens the potential ramifications of a health difficulty in adolescence. Not only can a mental health difficulty impair an individual's ability to enjoy social relationships, an aspect of life of substantive *inherent* importance, but additionally via the disruption of social relationships and social skill development, it can also further exacerbate later opportunities for education and employment. Similarly, the impact of a general health difficulty on skills for employment (and the consequence for one's subsequent context in which to build relationships) appears to indirectly affect individuals' subsequent friendship network. The quantitative data indicate that individuals with a general health difficulty aged 14-15 are both at a higher risk of having few close friends (impaired relational networks) and being NEET (economically marginalised). The individual who experiences both could be seen as *socially* marginalised (Silver, 1994). The analyses therefore indicate that a health difficulty may not only lead to ongoing consequences for the *individual* but also for *society* by increasing the risk that those with a health difficulty in adolescence will have a diminished ongoing ability to contribute relationally and economically.

#### *9.3.2.4. The ability to make decisions on the things that matter*

As previously discussed, and as shown in Table 9-2, it was not feasible to explore in the formal quantitative analysis the association between a health difficulty in adolescence and either: (i) impaired ability to make decisions on the things that matter; or (ii) impaired freedom to express and discover one's identity. As such, it is not possible to compare the qualitative findings with those of the quantitative analysis. However, the integrated findings reported so far support both the notion: (i) individuals are able to proactively make decisions which often enable them to adapt to their difficult circumstances with a degree of success; and (ii) that the differing aspects of life are enmeshed. This was a provisional finding of the qualitative study of particular relevance to both "the ability to make decisions on the things that matter" and "the freedom to express and discover one's identity". In 9.3.2.4 and 9.3.2.5, I now turn to briefly re-review the influence of a health difficulty on individuals' ability to enjoy these valued facets of life. When doing so, though I predominantly rely on the analysis of the individuals' biographical data, I also draw on the integrated findings concerning the other intertwined valued aspects of life.

The participants' biographical data led to the conclusion that over time many of the participants appeared to experience increasing freedom to make important decisions in the different aspects of life of importance to them. The narratives indicated this resulted from individuals often experiencing an increased ability to control their inner and outer worlds. This increased control enabled the pursuit of the second observed trend, that individuals often appeared to intentionally work to master the aspects of life in which they struggled and learn how to make progress in them. These trends may have particular pertinence for those who experience poor health in adolescence. Specifically, a synthesis of the findings of the two study strands indicates that, as individuals move towards adulthood, their family and societal contexts evolve in a manner that provides them with increased opportunity to customise their overlapping educational, leisure and relational spheres in a manner that is more suitable to their body's capacities (Brady et al., 2015). As mentioned previously, there appears to be a particularly marked change in their ability to customise these overlapping spheres post their GCSE examinations.

As discussed in chapter 7, individuals' ability to shape their outer worlds is not unbounded. Rather, it is shaped by one's socioeconomic contexts and access to bodily, social and material resources (Brady et al., 2015). The integrated study findings suggest that even after individuals have completed their GCSEs (and the employment related pathway becomes more diverse), individuals may experience constraints in the choices

they are able to actualise because of previously impaired skill formation. Specifically, as previously mentioned, the quantitative analysis indicates that poor health in the period prior to the GCSE examinations can impair the formation of relational and cognitive skills. Though the number of hypothetical opportunities may subsequently increase, the quantitative analysis indicates a persisting reduction in these individuals' ability to remain in institutions offering education, employment or training. This likely also explains the increased risk that they will have a smaller relational network. The quantitative analysis indicates that this impaired ability to actualise opportunities, that many value, has consequences for the extent to which those with health difficulties are satisfied with their lives in early adulthood.

In summary, the qualitative and quantitative strands support the notion that individuals are increasingly able to shape their outer worlds. However, the previous disruptions caused by poor health can leave a persisting legacy, imposing additional constraints on their ability to employ their agency to actualise valued opportunities (Brady et al., 2015).

#### *9.3.2.5. The freedom to express and discover one's identity*

As with the ability to make important decisions, this aspect of life is highly enmeshed with those others *through which* one expresses and discovers their identity. Indeed, for brevity, I avoid repeating the integrated findings concerning the persisting manner in which health may constrain an individual being able to become whom they intend with respect to their relational and occupational spheres of life. In 7.3.3, I considered the intertwined nature of life in order to explore how health dynamically influenced the formation of individuals' identities. There and in this chapter, I have explored the manner in which individuals increasingly appear to be able to adapt, often positively, to the constraints imposed upon their bodies by a health difficulty. However, as discussed above, adaptation may often involve an individual with a health difficulty selecting an option which, though more suitable given their experienced constraint, would otherwise not have been their favoured choice. Additionally, the adaptive opportunities available may already be restricted as a result of earlier impaired cognitive and relational skill formation. There were signals in the qualitative study that though individuals were able to adapt and forge a positive identity that accounted for, but was not dominated by, their body's limitations, doing so was not without cost. For David, the actions required to adapt to his body's limitations also led to a sense of being "different". In a number of other empirical studies investigating the lived experience of adolescents with a long-term



health difficulty, this disturbing sense of “difference” has also been identified (Boydell et al., 2008; Christian and D’Auria, 1997; Rhee et al., 2007; Woodgate, 2005, 1998).

David explicitly linked this sense of difference to why he had given a caveated response to the question concerning his life satisfaction. The quantitative analysis provides support for the relationship between: (i) impaired health; (ii) impaired subsequent ability to enjoy inherently valued aspects of life such as obtaining a good job and enjoying relationships with others; and (iii) satisfaction with one’s life (and perhaps therefore one’s emerging identity). While satisfaction with one’s life so far and satisfaction with one’s identity are conceptually distinct, it would seem that “a good life” would incorporate both. Indeed, it is hard to see how an individual could achieve one without the other. Jointly considering the findings of both strands therefore supports the conclusion that individuals are far from powerless to adapt to their health difficulty and that they often employ their agency with the implicit goal of developing a positive self-identity. However, the qualitative and quantitative data indicate these adaptive behaviours may fail to fully mitigate the constraints imposed by the body’s limitations. Similarly, while the individual may be able to increasingly shape their life and identity in a positive manner, the data indicate that these efforts, while laudable, often fail to fully negate the impact of a health difficulty on both one’s emergent identity and life-satisfaction.

## 9.4. Concluding discussion

### 9.4.1. Strengths and limitations of the mixed methods study

Before considering in depth the strengths and limitations of the mixed methods study, it is perhaps worth briefly recalling the study aim and objectives – it is primarily in reference to these that the study should be critically appraised.

As outlined in 1.2, the aim of this study is to research the immediate and future impact of health difficulties during adolescence on the formation of valued abilities which foster well-being. In order to do, so I aimed to achieve two objectives: (i) investigate the lived experience of adolescents, noting their accounts of how health affects their valued abilities; and (ii) examine the pathways through which health difficulties impact the formation of valued abilities.

#### 9.4.1.1. *Strengths of the mixed methods study*

As first indicated in 1.3, and then outlined in greater detail in chapters 4 and 5, to address the research aim it was necessary to intentionally *integrate* both qualitative and

quantitative methods. The major strength of the thesis is the complementary dynamic between the qualitative and quantitative strands of the research. As discussed previously, the qualitative study enables the research to be grounded in the emic knowledge of individuals experiencing health difficulties as they navigate adolescence. The quantitative analysis allows hypotheses, generated through inductive analysis, to be tested deductively using a representative data sample supporting the generation of etic knowledge. The “thick” descriptive analysis of the role of health in adolescence provided by the qualitative strand is complemented by the quantitative model’s estimation of the simplified pathways via which health difficulties are (and are not) found to be associatively linked with the impaired formation of valued abilities. Finally, the findings of both studies can be compared and contrasted. Via dialectic reasoning, this process of triangulation enables both a fuller and more robust perspective of health’s role than if either approach was adopted in isolation.

The longitudinal nature of the data used in both strands of the research and the methods selected for the analyses allowed the complementary synergy between emic and etic, indicative and deductive, “thick” and simplified, to occur *dynamically*. Both strands of the mixed methods study were therefore designed individually, and in combination, to enable an analysis of the interaction through time between health, the formation of valued abilities and well-being. Given the research aim, and the policy context alluded to in the introduction, this is of great importance. The dynamic aspect of this integrated mixed methods study allows this thesis to contribute to the wider literature both methodologically and substantively. However, before reviewing the thesis’ contributions in greater depth, it is first important to consider its limitations.

#### *9.4.1.2. Limitations of the mixed methods study*

To avoid duplication, below, I primarily focus on the limitations of relevance to the integrated mixed methods study as a whole. Where particularly relevant, I allude to limitations specific to either the qualitative or quantitative studies (these are of course discussed more comprehensively in chapters 7 and 0, respectively)<sup>58</sup>.

Many of the main limitations of the mixed methods study stem from my attempt to investigate a broad research question with the constrained resources of a PhD student.

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<sup>58</sup> To an extent, the limitations of each individual strand influence the limitations of the integrated study as a whole. However, it is worth noting the individual strands were designed and integrated with the intention of, where possible, minimising the weakness of the other (Nastasi et al., 2010).

Though I will argue below the approach adopted has allowed the thesis to provide a helpful exploration of health's role in the formation of valued abilities during adolescence, greater research resources would enable the findings to be established with greater specificity and therefore accuracy. The two main constraints, inherent to my research context, were: (i) the need to use a *secondary* longitudinal dataset in order to obtain data from a large sample over an extended period; and (ii) the need to undertake the mixed methods study as an individual, early career researcher.

The first of these constraints resulted in me being unable to influence the quantitative data collected. The latter has implications for: the degree of specialism I am able to bring to either method (Cathain et al., 2008; Johnson and Onwuegbuzie, 2009); my inability to generate findings from each method independently and only then compare them (as discussed in 9.2); and the number of participants I was able to interview in the qualitative study (which further constricted my ability to interview numerous individuals across a broad range of health difficulties). With greater resources, it would therefore have been possible to undertake an integrated study where there was limited dissonance between each strand with respect to: the coverage of each prioritised aspect of life; the duration of follow-up; the socioeconomic composition of those recruited as having no health difficulty; and the detail available on the health of the participants. Furthermore, by being able to interview a greater number of girls and boys, the qualitative data may have indicated clearer differences between the genders with regards health's role in the formation of valued abilities. Additionally, because the analysis of each strand would likely have been undertaken independently, the team could place still greater confidence in those findings that were supported by both the qualitative and quantitative strands of the study.

My study, with the resources available to me, by implication therefore has the following limitations. Firstly, the quantitative and qualitative studies differ in their coverage of the prioritised aspect of life. I am therefore unable to fully use both strands to investigate health's role in the formation of "the ability to make decisions on the things that matter" and "the freedom to express and discover one's identity". Secondly, differences in the duration for which individuals were followed between the qualitative and quantitative studies result in me being unable to use the qualitative data to fully explore and interpret the quantitative findings concerning the influence of health when aged 16-17 on individuals' achievement of outcomes of inherent importance when aged 19-20. Thirdly, though the qualitative data emerge from interviews with participants with very specific

health difficulties, the quantitative analyses rely on a very broad definition of a “general health difficulty”, which includes individuals who had either an illness or a disability<sup>59</sup>. Finally, I was unable to undertake an in-depth investigation of any differences between girls and boys with regards health’s role in the formation of valued abilities. As indicated in chapter 7, the participants’ biographical data did not indicate substantial differences. However, this may have resulted from the limited scope for inter-gender comparison once I had stratified by health status.

In spite of the resource constraints, the approach adopted to the integrated mixed methods study reduced the consequences imposed by the limitations in each strands’ data. Combining the methods allowed me to undertake a detailed investigation of health’s role in the formation of each of the prioritised aspects of life in at least one strand of the mixed methods study (indeed because “the ability to make decisions on the things that matter” and “the freedom to express and discover one’s identity” are enmeshed in the other aspects of life, my findings concerning these domains are also to an extent informed by the quantitative study). Similarly, despite my inability to continue to interview adolescents into early adulthood the duration of quantitative data available allowed me to assess the extent to which hypotheses generated from the qualitative analysis continued to be supported during this period. Additionally, though there is a dissonance as regards the specificity with which health is defined between the analysis, there is an argument that it is optimal to inductively generate hypotheses from a detailed understanding from a specific research context before testing their predictive power when applied more broadly (Glaser and Strauss, 1967b).

While some limitations are a result of scarce research resources, two are probably best conceptualised as the direct counterparts of specific *strengths* of the study. First, as a result of undertaking a longitudinal mixed methods study, there is a risk that data informing the qualitative and particularly the quantitative analyses omit individuals who do not “have a stable and coherent life” (Thompson, 2004: 251). Given that the duration

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<sup>59</sup> In 8.2.3, I provide a detailed outline of the approach taken to deriving my variables for a general health difficulty. The affirmative responses likely include some individuals who primarily saw themselves as having a disability rather than an illness. As outlined in footnote 49 in 8.2.3, I have conceptualised disability in accordance with the definition attributed by World Health Organization, “Disability is the interaction between individuals with a *health condition* (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports). [emphasis added]” (World Health Organization, 2016). As such, I conceptualise having a health condition, disability and general health difficulty as interconnected phenomena.

of the qualitative analysis was relatively short, that I was able to make efforts to increase the likelihood of participants agreeing to be re-interviewed, and that only two individuals refused to be re-interviewed<sup>60</sup>, this risk was largely mitigated for the qualitative analysis. With the quantitative analysis, there is reason to believe that over a seven year period, those with less stability in their lives are more likely to drop out and therefore be missing responses for the outcome variables in early adulthood. The longitudinal nature of my research question, and therefore data sources, may therefore indirectly have implications for the generalisability of my findings to those individuals who have unstable contexts.

Second, the dialectic approach adopted to consider the qualitative and quantitative findings necessarily results in some findings having a degree of disconnect from one or both of the two study strands. If, given my epistemological position, I wish to minimise the extent to which my perspective on reality is constrained, it is reasonable to adopt the perspective offered by both strands to inform a broader view of the phenomena. Where the two strands offer very similar findings, it should be clear how my integrated view is supported by the underlying analyses of the qualitative and quantitative data. However, where the findings of the two strands differ, the integrated finding, informed by a dialectic consideration of them both, may be anchored primarily in my own subjective view of the overall perspective offered by the mixed methods study (rather than being a direct result of the findings of *either* the qualitative or quantitative strands). In short, though there is merit in a dialectic approach, relatively less emphasis can be placed on those findings that are at least initially contradicted by one of the study strands.

#### 9.4.2. Contribution to the literature

As initially discussed in 2.1.4, during this thesis, I have attempted to navigate the tensions of both: (i) researching as an economist while drawing on the methods, practices and theories of other disciplines of relevance to my research aim; and (ii) using a vocabulary that is accessible to readers with a variety of backgrounds while not losing connection with the theoretical framework that sensitised me to this area of research. To appropriately assess the thesis' contribution to the literature, it is now necessary to

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<sup>60</sup> After each wave 1 interview, I enquired of every participant if they were willing to be re-interviewed (while also emphasising there was no pressure to do so). One participant stated at that point that they did not want to undertake a second interview. The second participant who refused to be re-interviewed initially stated they were happy to do so. When I later made contact with this participant via their school teacher (the participant had no severe health difficulty) to arrange the second interview, they declined the invitation.

contextualise my research within the discipline of economics and the literature of the capability approach.

#### 9.4.2.1. *Methodological contribution*

As discussed in 2.4, within the capability literature, there is a sparsity of empirical studies investigating the *formation* of capabilities. Within the wider literature of relevance to the thesis aim and objectives, the systematised review indicated an absence of longitudinal studies which integrate both qualitative and quantitative methods. The overarching methodological contribution of this study is therefore to integrate *longitudinal* qualitative and quantitative methods to investigate the formation of valued abilities and skills (capabilities); an area numerous researchers have noted is under researched (Ballet et al., 2011; Binder and Coad, 2010; Heckman and Corbin, 2016; Leßmann, 2009).

It is self-evident that longitudinal analysis, an approach rarely employed in the capability literature, is of value when investigating health's role in the *formation* of capabilities. It is perhaps worth a moment to summarise the contribution made by integrating qualitative and quantitative methods. As shown by the systematised review, the human capital literature has only employed quantitative methods to investigate health's role in the formation of valued abilities during adolescence. These are sufficient for investigating the impact of poor health on subsequent employment outcomes, a domain supported as being of importance by economic theory. However, in combination with a relatively restrictive theoretical perspective, the absence of qualitative methods contributes to analyses which neglect to investigate the role health plays in the formation of the numerous skills required for the "production" of a good life.

To investigate the broader role of health in the formation of the valued abilities which contribute to a good life (well-being), it is of value to both have a broader sensitising theoretical framework and the means to elicit the broader outcomes of value (Robeyns, 2005b). Qualitative methods would play an important role in an evaluation of health's role in the formation of valued abilities even if their contribution was solely to help specify a more comprehensive *quantitative* analysis. They contribute to the quantitative analysis by: (i) informing which domains should be prioritised for inclusion (via an approach that accounts for individuals' subjectivity – an additional methodological contribution of the thesis); and (ii) providing hypotheses for subsequent testing that are grounded in my understanding of the lived experience of adolescents. Additionally, in contrast to quantitative analyses which broaden from narrow economic outcomes by

focussing solely on SWB, incorporating a number of inherently valued achieved outcomes alongside life-satisfaction enables the analysis to indicate the *pathways* through which health difficulties are associated with impaired life-satisfaction. As will be discussed in further detail below, a clearer diagnosis of poor health's role in the dynamic impairment of well-being should enable a greater understanding regarding which interventions may have the potential to redress the difficulties affected individuals face.

The mixed methods approach is, however, of value beyond its ability to inform a more robust and comprehensive quantitative analysis. The qualitative findings themselves provide a description of health's influence on adolescents' lived experience, detailing the manner in which health difficulties impair individuals' abilities to enjoy the inherently valued aspects of life. Importantly, the "thick" descriptions provided by the qualitative data and analysis (Robeyns, 2005b) allow an investigation of the efforts made by young people and their families to mitigate the impact of a health difficulty. The perspective offered by the qualitative study is not only of direct value to the research aim and objectives but also heightens the value of the quantitative analysis. Integrating the two studies' findings enables a post-hoc consideration of the less intuitive quantitative results. Longitudinally combining methods, and therefore combining process and variance approaches to the understanding of causality, enables a deeper and more robust understanding of health's role in the *formation* of valued abilities.

#### 9.4.2.2. *Substantive contribution*

As discussed in chapter 1, two distinct bodies of literature provided separate but complementary findings which when inductively combined inspired the thesis' research aim. Specifically, the paediatric health literature suggests health difficulties during adolescence can place individuals at a greater risk of missing school and experiencing greater social isolation from peers (Snelgrove, 2015; Suris et al., 2004; Westborn, 1992). The human capital literature indicates that cognitive and socioemotional skills developed earlier in life both persist into future periods and increase the productivity of further investments in those skills (Cunha et al., 2010a; Cunha and Heckman, 2008; Heckman, 2006). If both these findings are true, inductive reasoning would indicate that a health difficulty in adolescence both impairs an individual's *immediate* and *future* accumulation of these inherently valued abilities (Alkire, 2008; Burchardt and Vizard, 2009; Nussbaum, 2001). This thesis' substantive contribution is to empirically investigate this hypothesis in an integrated study.

Starting with the immediate impact of a health difficulty, the participants' biographies demonstrate the importance of the body to individuals' lived experience. As outlined in chapter 7, those whose bodies' capacities were impaired as a result of poor experienced health struggled at times to maintain consistent attendance at school. Additionally, toll taken on the body from illness, and the side effects of required medications, often undermined the individual's self-image. Many of the girls with a health difficulty reported a lack of confidence concerning their physical appearance. Many of the boys with poor experienced health appeared conscious of their lower ability to compete physically with their peers. The thesis therefore provides *empirical* support for the embodiment literature (Freund, 1990; Parsons, 1978; Shilling, 2001).

The participants' biographical data enabled the thesis to contribute to the literature on capabilities, health and adaptation by exploring the approaches those with health difficulties took to adjust to their health difficulty. An integrated analysis of both biographical data collected longitudinally from a mixed sample, and the mixed sample's explicit prioritisation of differing aspects of life enabled me to distinctly consider two differing facets of adaptation. Firstly, as regards the importance individuals give to different domains, there is a concern within the capability literature that individuals may adjust over time to bad circumstances and begin to undervalue aspects of life in which they are constrained (Biggeri and Mehrotra, 2011; Nussbaum, 2001; Sen, 1985). However, though there is the possibility their within domain *expectations* were lowered, there was no indication that their experienced health led them to suppress the value of domains in which they experienced constraints such as good health and knowledge and skills. Indeed, as outlined in 7.2.4, those with health difficulties attributed a relatively *higher* priority to those domains in which they likely experienced constraints than the participants who had no severe health difficulties.

Secondly, I was able to investigate the approaches that individuals adopted in living with a severe health difficulty as they transitioned through adolescence. This is of course outlined in far greater detail in 7.3, but it is clear individuals both adopted behaviours which masked the exposure of their limitations (e.g. increasingly switching one's focus from physically demanding leisure activities to those that are less physically demanding) and behaviours which actively projected a positive identity (e.g. Emma's proactive approach to performing publicly when the opportunities to so emerged). Additionally, following individuals through an extended period of adolescence allowed me to identify that as individuals transitioned to adulthood the opportunities to customise their lives,



and therefore adjust their activities to fit with their bodies' capacities, increased. An analysis of the biographical data therefore indicates that adaptation not only occurs, but that the scope for adaptive behaviour *increases* as individuals transition from childhood to adulthood.

As mentioned above, a motivation for the thesis was the indication within the wider literature that not only did poor health impact individuals' current valued abilities, but that individuals' present abilities influenced their capacity for further developing these abilities over time. Both the qualitative and quantitative strands of the research empirically demonstrate the interdependence of the different facets of life. Furthermore, the quantitative analysis indicated an interdependence through time between relationships (non-cognitive skills), cognitive skills and employment. In accordance with the research by Cunha, Heckman and their colleagues (Cunha et al., 2010a; Cunha and Heckman, 2008; Heckman, 2006) cognitive skills and non-cognitive skills were predictive of employment. Additionally, I find that impaired cognitive skill aged 15-16 is predictive of having few close friends aged 19-20. The wider literature (Cornaglia et al., 2015; Thompson et al., 2014) supports the inference that this may be a result of individuals with impaired cognitive skill having reduced access to the educational, employment and training contexts conducive to supporting relational networks.

As mentioned in 8.4.1.1, the previous literature lacked robust analyses which explicitly investigated the association between both: (i) impaired general health; and (ii) the formation of a *range* of valued abilities. The previously mentioned research by Cunha, Heckman and colleagues maintained a degree of breadth by investigating the formation of both cognitive and non-cognitive skills. However, they did not investigate the role of *health* in the formation of these skills. Conversely, the studies reviewed in chapter 3 either: only related to health's effect on educational and employment outcomes; or were drawn from samples likely unrepresentative of the general population (undermining the validity of any inferences made back to the wider population). The quantitative analysis reported in chapter 0 therefore substantively contributes to the literature by empirically demonstrating through time the association between poor health and both: (i) the impaired formation of inherently valued abilities; and (ii) the estimated consequences in terms of a reduced probability of being satisfied with life. Additionally, the analysis enabled me to identify that a general health difficulty and a mental health difficulty appear to disrupt the formation of valued abilities via different pathways. A general health difficulty aged 14-15 was directly associated with the impaired formation of

academic ability. In contrast, a mental health difficulty when aged both 14-15 and 16-17 was directly associated with subsequent impaired ability to enjoy social relationships. Of course, as highlighted in 8.3.1.2, the interdependence between the relational and employment pathways through time leads to a general health difficulty aged 14-15 having an indirect association with an eventual impaired ability to enjoy social relationships. Similarly, a mental health difficulty when aged 14-15 has a significant indirect association with subsequently having a reduced ability to get a good job and be successful.

By integrating the qualitative and quantitative strands of the research, this mixed methods study therefore adds to the literature by *empirically* supporting the hypothesis that a health difficulty in adolescence impairs an individual's immediate and future accumulation of inherently valued abilities. Poor experienced health disrupts individuals' ability to flourish in many of the different, interdependent facets of life. The analyses of quantitative data indicate that disruptions at the age of 14-15 result in an impaired ability to actualise positive employment and relational outcomes both when aged 15-16 and when aged 19-20. As a consequence, although individuals employed their agency to adapt to their health difficulties, compared to their healthy counterparts they: (i) still faced greater constraints when seeking to make important decisions; (ii) were less likely to report being satisfied with their life in early adulthood; and (iii) reported a negative sense of "difference" with regards their developing identity (Boydell et al., 2008; Christian and D'Auria, 1997; Rhee et al., 2007; Woodgate, 2005, 1998).

#### 9.4.3. Implications of the thesis' findings

##### 9.4.3.1. *Implications for policy*

The empirical research reported in this thesis indicates that during the formative stage of adolescence, poor health disrupts the formation of relational and employment skills. My findings indicate the detrimental impact of a general health difficulty on employment skills persists into early adulthood. The wider literature suggests an impaired ability to participate in the workforce may have continuing consequences over the life course. Those who are unemployed and inactive after compulsory education experience lower participation in the labour market over the long term (Bell and Blanchflower, 2011). Clark et al. (2001) found spells of unemployment were associated with lower happiness two decades later. Bell and Blanchflower's analysis indicated that, "the longer the spell of unemployment before the age of 23, the lower is happiness nearly 30 years later at age 50" (Bell and Blanchflower, 2011: 263). The evidence in this thesis and the wider

literature therefore combine to indicate a persisting association between both: (i) a health difficulty in adolescence and impaired employment skills in early adulthood; and (ii) impaired employment skills in early adulthood and lower employment opportunities (and life-satisfaction) over the life course.

The empirical analyses in this study and the wider literature therefore suggest that health: (i) is of innate value to the individual; (ii) benefits the individual by enabling the individual to be productive in their tasks; and (iii) facilitates the accumulation of skills which will increase the individual's ability to produce valued outcomes over time (Grossman, 1972; Mushkin, 1962).

The aim of the thesis has been to undertake an initial empirical investigation of the role of health in the formation of valued abilities. Further research will be required in order to generate detailed, evidence based policy suggestions. The findings generated to date do, however, have implications for policy makers. Below, I summarise one specific illustrative example (of course my own work background, as a health economist involved in health technology assessment submissions, has influenced the policy area selected).

As discussed in chapter 1, when assessing new medical technologies, NICE considers the first two characteristics of health listed above but does not consider the impact of an improvement in health on an individual's *accumulation* of valued abilities and the benefits in terms of their improved ability to achieve valued outcomes over time (NICE, 2013a). The findings reported in this thesis and the wider literature combine to suggest that, at least for some younger age groups, an important facet of health is being omitted when considering the contribution improved health in the present makes to individuals' current and longer-term well-being.

For those age groups whose cognitive and socioemotional skills are still at a formative stage, a health care intervention may play a substantial role in reducing the extent to which the health difficulty disrupts the formation of valued abilities. Currently, the benefits accrued over time as a result of the enhanced formation of valued abilities are not included in the assessment of the health intervention. Other things equal, this will result in an inefficient allocation of health care resources *if* one were aiming to use government expenditure to maximise individuals' well-being over the life course – the maximand suggested by a number of leading economists (Bernanke, 2012; O'Donnell et al., 2014; Stiglitz et al., 2010). By contrast, considering this facet of health will enable the prioritisation of interventions which have a positive "return" over time. Further

considering health's role as "capital" would lead, other things equal, to a proportional increase in funding for interventions which, via improved health, enhance the *formation* of individuals' inherently valued abilities. In contrast to the disability-adjusted life year (Murray, 1994), this greater prioritisation of resources for the younger age groups therefore need not depend on the DALY's contentious judgement of younger people's social role relative to other age groups (Anand and Hanson, 1997). Instead, it can be justified on the grounds of the efficient maximisation of well-being. Of course, such an approach necessitates that the objectives specific to each department, e.g. population health in the case of the Department of Health, or education and skills for the Department of Education, are considered subordinate to their government's maximand. Though well-being consists of each of these different aspects of life (Stiglitz et al., 2010), for well-being to be maximised, each department must not only pursue its specific objectives but also remain mindful of their contribution to citizen's formative, multidimensional "well-becoming" (Austin, 2016; Stiglitz et al., 2010).

Investing in individuals' health during formative periods has the potential to facilitate the formation of inherently valued abilities which: (i) continue to benefit the individual over the life-course; and (ii) increase their continuing capacity to relationally and economically contribute to society. Such an approach would therefore not only lead to improvements in efficiency at the level of the individual but, by reducing social exclusion, also generate obvious spill over benefits for society as a whole (OECD, 2013). As mentioned, this finding is undoubtedly of relevance to numerous policy areas. Other examples include but are not limited to: (i) consideration of how best to support young people with prolonged absence from school as a result of poor experienced health; (ii) the need for collaborative efforts between schools and healthcare providers; and (iii) arrangements for young people as they transition from child to adult healthcare services.

#### *9.4.3.2. Implications for further research*

When making decisions, the policy maker(s) can of course: (i) be informed by an explicit mathematical estimation of a given benefit; or (ii) recognise the benefit's likely existence and, in a less formalised manner, allow this benefit to influence decisions at the margin. It will require substantial further research before it is viable to estimate the precise benefit a given health gain plays in the formation of the treated population's valued abilities and incorporate this benefit when prioritising resources. However, a greater understanding of health's role in facilitating the formation of valued abilities both enables the latter of the approaches listed above to be undertaken with greater confidence while contributing to

the knowledge eventually required for the former. Below, I outline two distinct but complementary areas that may be promising starting points for further research<sup>61</sup>.

First, it would be informative to broaden this area of research in order to develop a greater understanding of the role health plays in facilitating the formation of valued abilities over the life course. It would be informative both to: (i) know how a health difficulty at *different* life stages affects the formation of valued abilities; and (ii) gain a clearer understanding of how the impaired formation of valued abilities earlier in life influences one's ability to enjoy these abilities much later in the life course. A greater understanding of these two topics would enable a clearer understanding of the total impact of a health difficulty in a given period on the formation of individuals' valued abilities over the life-course (and therefore also enable an estimate of the benefit of reducing the health difficulty's impact). Additionally, it would enable the identification of the age groups where health's role in facilitating the ongoing formation valued abilities is of most importance.

In contrast to the first suggested area of research, the second would be to focus rather than broaden the research. Having identified the age groups where the current omission of health's role in the formation of valued abilities likely leads to the greatest allocational distortion, it would be informative to focus further on specific health difficulties that place a high burden on these age groups. As an example, if early childhood was found to be a period when poor health had a particularly detrimental effect on the long-term formation of valued abilities, a health difficulty of particular relevance to this age group could be investigated in greater detail. For this specific health difficulty<sup>62</sup>, it would then be possible to explore a number of research questions which include but are not limited to:

1. Which valued abilities are particularly impacted by the health difficulty?
2. By what pathways does the health difficulty affect these different valued abilities (i.e. if "the ability to enjoy relating to others" is affected, what are the specific ways in which this tends to happen?)?

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<sup>61</sup> I summarise two *descriptive* areas for further research. For the approach to be fully operationalised within the health technology assessment process, it would also be necessary to consider the equity implications of doing so. These considerations are beyond the remit of this thesis.

<sup>62</sup> If instead adolescence was identified as being a period of particular importance to investigate at the health difficulty specific level, given the findings of the current research, it might be of most value to focus on a health difficulty that causes particular disruption to the formation of skills for employment.

3. To what extent is there a gradient between the severity with which individuals have the health difficulty and the extent to which it impacts individuals' capacity to enjoy these different valued abilities?
4. Does the detrimental impact of the health difficulty on the different valued abilities appear to differ according to demographic characteristics such as household socioeconomic group, gender, ethnicity, etc.?
5. To what extent does the health difficulty's detrimental impact persist in affecting the formation of these valued abilities over time?

Once the above questions were answered in greater depth for a specific health difficulty, it would be viable both to hypothesise which interventions were most likely to minimise the impact of the health difficulty on the formation of valued abilities, and to subsequently design a study to investigate the extent to which the interventions did so.

#### 9.4.4. Conclusion

This thesis has investigated the immediate and future consequences of a health difficulty during adolescence on valued abilities and well-being. The mixed methods findings indicate that though individuals increasingly employ their constrained agency to adapt to their poor experienced health by disrupting their embodied capacities, a health difficulty still undermines their ongoing ability to: (i) pursue their educational and employment aspirations; and (ii) enjoy social relationships. Not only does this study suggest that a health difficulty impairs individuals' ongoing ability to enjoy these inherently valued aspects of life, it also indicates there are consequences with regards individuals' ability to be satisfied with the person they are becoming and their life as a whole.

Adolescence is a period when individuals' capacities and identities are in rapid transition (Christie and Viner, 2005; Moshman, 2011d). Good health plays an important role in supporting an individual's capacity to enjoy and continue to develop the valued abilities that both constitute and enable a good life. Further research is required to inform efficient investments in adolescents' health that equip the individuals themselves to increasingly flourish and enrich the societies they inhabit through their fuller participation (Mushkin, 1962; Nussbaum, 1988).

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## APPENDICES

### A. Appendices relating to systematic review methods

#### A.1. Search protocol for health, valued activities and well-being in adolescence

##### *Criteria for inclusion of studies for the systematised literature review*

I have adopted the PECOS (Population, Exposure, Control, Outcome, Study-type) framework to inform the inclusion/exclusion criteria. I have chosen the PECOS framework (Population, Exposure, Control, Outcome, Study-type) instead of the PICOS (Population, Intervention, Control, Outcome, Study-type) framework as the health changes experienced by the population are an exposure rather than an intentional intervention (Tomioka et al., 2014).

##### **Population**

- Adolescents as defined by the study itself – synonyms such as youth or young person will also be taken to refer to this population; and
- Individuals from societies which have advanced economies.

##### **Exposure**

- Exposure to a physical health difficulty; or
- Exposure to a mental health difficulty.

##### **Control/Comparison Group**

- Adolescent population who are not exposed to a physical or mental health difficulty.

##### **Outcome**

- Change in capabilities; or
- Change in functioning levels; or
- Change in abilities or skills judged conceptually similar to capabilities or functionings.

##### **Study Type**

- Quantitative analysis using longitudinal cohort data; or
- Qualitative analysis using longitudinal cohort data; or
- Studies reporting analyses of longitudinal qualitative and quantitative data (Longitudinal mixed methods studies).

### *Criteria for exclusion of studies*

I will exclude quantitative studies if they do not attempt to control for observable factors which might confound the correlation between the exposure and outcome variables. I will exclude qualitative studies if they do not contain a comparison group of individuals with a severe health difficulty. Additionally, I will only include studies if they are available in English. This final criterion is solely a result of my linguistic limitations.

### *Search strategy for the systematised literature review*

I will undertake the systematised review by searching the Web of Science database. I will use a search strategy of adolescent AND illness AND capability/functioning (or a term judged conceptually similar to capability/functioning) AND longitudinal study. The table below demonstrates the search strategy implemented in Web of Science. I will not restrict the search by document type. I will implement the search using the Topic filter<sup>63</sup>.

*Table A-1: Search Strategy used to identify articles through the Web of Science*

Number	Term
1	Topic=((("capabilit* approach") OR (capabilit* AND Sen) OR (capabilit* AND Nussbaum) OR ("capabilit* measure") OR ("capabilit* list*") OR ("capabilit* index*")) Timespan = All years Search language = Auto
2	Topic=((("psych* wellbeing") OR ("psych* well-being") OR ("human capital") OR (eudaimoni*) OR (narrative*) OR (biograph*) OR (agency)) Timespan = All years Search language = Auto
3	Topic=((longitudinal) OR (panel) OR (cohort)) Timespan = All years Search language = Auto
4	Topic=((Adolescen*) OR (youth*) OR ("young person") OR ("young people") OR (teen*)) Timespan = All years Search language = Auto
5	Topic=((health*) OR (ill*) OR (disease*) OR (infirm*) OR (sick*)) Timespan = All years Search language = Auto
6	1 OR 2
7	4 AND 5 AND 6 AND 3

The search will be undertaken during August 2015.

<sup>63</sup> The topic filter results in Web of Science searching the document title, abstract, author key words and "Key words Plus<sup>®</sup>" (key words attributed by the Thomson Reuters editors if they believe they have been omitted by the author or publisher) (Thomson Reuters, 2016, 2015) .

### *Selection of studies for the systematised review*

To determine whether a study should be included, I will read the title and abstract of all identified hits of the electronic bibliographical databases. I will decide the eligibility of the article according to the inclusion criteria. If there is any doubt, I will retrieve the full text article and review that.

### *Quality assessment procedure for the systematised review*

If the search identifies any longitudinal quantitative studies which meet the inclusion/exclusion criteria, I will use The BMJ Reader's Guide to critical appraisal of cohort studies to evaluate their quality.

If the search identifies any longitudinal qualitative studies which meet the inclusion/exclusion criteria, I will use the CASP tool "10 questions to help you make sense of qualitative research" (CASP, 2013) to evaluate their quality. If the search identifies any longitudinal mixed methods studies which meet the inclusion/exclusion criteria, I will use the questions in table 2 of the study by O'Cathain et al. (2008) to evaluate their quality.

The critical appraisal process will only be undertaken by one researcher due to the nature of the research project (a component of a PhD thesis)<sup>64</sup>.

### *Data extraction procedure for the systematised review*

I will extract data from quantitative studies, or the quantitative components of mixed methods studies, using a set data extraction form obtained from the Doctoral Development Programme training course in *Systematically Reviewing the Literature* undertaken at the University of Sheffield. If my search identifies one or more qualitative (or mixed methods) studies which meet the search criteria, I will: (i) critically assess the study(ies) using the checklists mentioned in the main text above; (ii) consider which summary information is most pertinent to record for each of the studies within a summary table for incorporation in the thesis; and (iii) populate this table directly from the relevant studies.

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<sup>64</sup> The critical appraisal tool and data extraction form which I subsequently used are outlined in appendix A.2. It was only necessary to use those designed for quantitative studies. I did not use the tools or forms designed for either qualitative or mixed methods studies. As discussed in 3.3, no studies using these methods met the inclusion/exclusion criteria.

## A.2. Forms used for critically assessing studies and extracting data

### *Quality assessment checklist: BMJ Reader's Guide to critical appraisal of cohort studies*

1. What comparison is being made?
2. Does the comparison make clinical sense?
3. What are the potential selection biases?
4. Has there been a systematic effort to identify and measure potential confounders?
5. Is there information on how the potential confounders are distributed between the comparison groups?
6. What methods are used to assess differences in the distribution of potential confounders?
7. Are the analytical strategies clearly described?
8. Do different analytical strategies used yield consistent results?
9. Are the results plausible?

### *Data extraction form*

General information	Date of data extraction
<b>Identification features of the study</b>	
<p><b>Author</b></p> <p><b>Article Title</b></p> <p><b>Source (eg Journal, Conference) Year / Volume / Pages / Country of Origin</b></p> <p><b>Institutional Affiliation (first author) and/or contact address</b></p> <p><b>Identification of the reviewer</b></p> <p><b>Notes</b></p>	
<b>Specific information</b>	
<p><b>Study characteristics</b></p> <p><b>Verification of study eligibility</b></p> <p><b>Population characteristics and setting</b></p> <p>1 <i>Target population (describe)</i></p> <p>2 <i>Inclusion criteria</i></p> <p>3 <i>Exclusion criteria</i></p> <p>4 <i>Recruitment procedures used (participation rates if available)</i></p> <p>5 <i>Characteristics of participants at intervention commencement</i></p> <ul style="list-style-type: none"> <li>• <b>Age</b></li> <li>• <b>Ethnicity</b></li> <li>• <b>Class</b></li> <li>• <b>Sex</b></li> <li>• <b>Other information</b></li> </ul>	

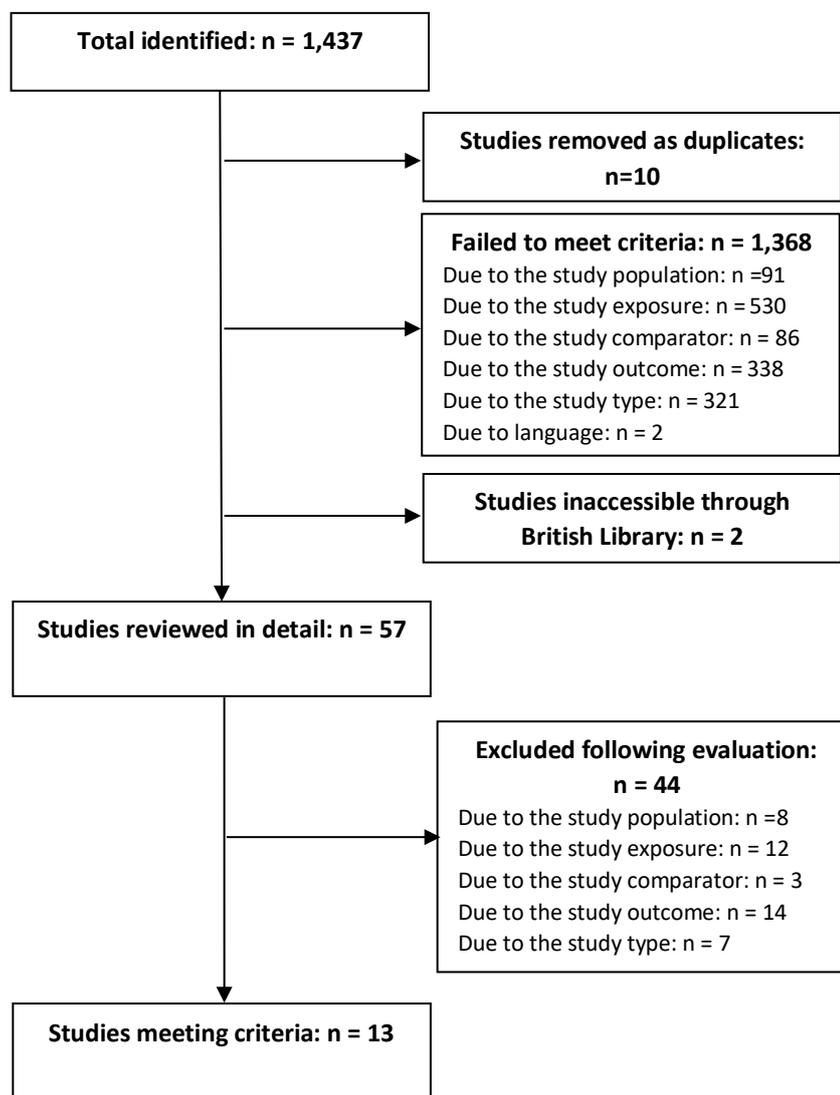
<p>6 <i>Number of participants</i></p> <p>7 <i>Were intervention and control groups comparable?</i></p>
<p><b>Methodological quality of the study</b></p>
<p><b>Exposure</b></p> <p>1 <i>Focus of exposure</i></p> <p>2 <i>Duration of exposure</i></p> <p>3 <i>Number of conditions</i></p>
<p><b>Outcomes, outcome measures</b></p>
<p>1 <i>What was measured at baseline?</i></p> <p>2 <i>What was measured after the exposure?</i></p> <p>3 <i>Who carried out the measurement?</i></p> <p>4 <i>What was the measurement tool?</i></p> <p>5 <i>How was the validity of self-reported behaviour maximised?</i></p> <p>6 <i>Time interval between measurements:</i></p> <p>7 <i>Duration of study:</i></p>
<p><b>Analysis</b></p>
<p>1 <i>Statistical techniques used</i></p> <p>2 <i>Does technique adjust for confounding?</i></p> <p>3 <i>Unit of analysis</i></p> <p>4 <i>Attrition rate (overall rates)</i></p> <p>5 <i>Was attrition adequately dealt with?</i></p> <p>6 <i>Number (or %) followed-up from each condition</i></p>
<p><b>Results</b></p>
<p>1 <i>Quantitative results (e.g. estimates of effect size)</i></p> <p>2 <i>Effect of the exposure on other mediating variables</i></p> <p>3 <i>Qualitative results</i></p>
<p><b>Notes</b></p>



### A.3. Expanded summary of the systematised search study selection process

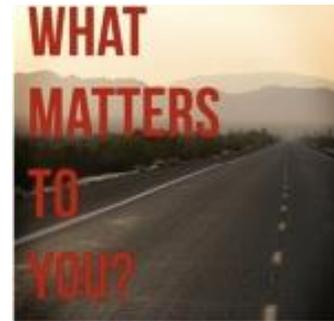
As discussed in 3.3, when reviewing studies identified through the systematised search, for the purposes of efficiency, having identified a study that failed to meet one of the criteria, the study was excluded. No further attempt was made to identify whether the study failed multiple criteria. Figure A-1 below provides an expanded summary of the study selection process, showing the number of studies which were excluded per criterion.

Figure A-1: Expanded flow diagram of the study selection process



## B. Appendices relating to qualitative study methods

### B.1. Participant information sheet (v0.3)



## **Participant Information Sheet**

### ***What Opportunities Matter to Young People?***

## ***What Opportunities Matter to Young People?***

We are inviting you to join in a research project to find the answer to the question "What Opportunities Matter to Young People?". Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, teacher, doctor or nurse if you want to.

### *What is the project's purpose?*

Everyone is different but everyone has something that matters to them. The opportunity to spend time with other people and join in with activities is part of what makes life enjoyable. The project aims to study:

- what opportunities matter most to young people
- what hurdles sometimes get in the way of these opportunities
- how young people and their families work to overcome these hurdles

The project is also interested in exploring how young people's views on what matters to them might change over time.

### *Why have I been chosen?*

You have been chosen because you are the right age to take part in the study and because you attend either:

- the Cystic Fibrosis Unit at the Sheffield Children's Hospital,
- the Respiratory Department at the Sheffield Children's Hospital or
- King Edward VII School.

The plan is to interview another twenty three young people. The project aims to recruit a broad range of young people so that it gets answers from people who see things differently.

### *Do I have to take part?*

No. It is up to you. We will ask you for your agreement and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

### *What will happen to me if I take part?*

If you and your parent agree that you can take part you will be interviewed. The interview should take around 1 hour. You may be invited for two more interviews. These won't happen until roughly six months and 1 year after the first interview. These extra interviews will explore how you and your family have helped make the most of the opportunities you value during the time since the last interview. The extra interviews are being done as the project is investigating how what is particularly important to young people can change over time.

The interviews will be lightly structured – this means that while the different interviews will cover similar topics there will be plenty of space for you to spend time talking about the things you want to emphasise.

*Is there anything else to be worried about if I take part?*

Due to the interview topics it may be the case that issues come up which make you emotional. However the interviewer will do everything they can to be sensitive during the discussion. During the interview you can stop the interview or take a break if you want to or need to. You also don't have to answer any questions that you do not feel comfortable with.

*What are the possible benefits of taking part?*

It is hoped that the interviews will provide you with an opportunity to talk about what matters to you. It is also hoped that the findings of this research will inform future efforts to help young people like you. In addition upon completion of the first interview you will receive gift vouchers worth £15.

*What if something goes wrong?*

If something goes wrong during an interview and you would like to make a complaint your first point of contact should be the person supervising the project, Dr Jenny Owen. However, if you feel your complaint has not been handled as well as you would like you can contact Sheffield University's Registrar and Secretary. You could also tell your parent or a school teacher, doctor or nurse. The contact details for Dr Jenny Owen and Sheffield University's Registrar and Secretary are given at the end of this sheet.

If during the interview you become particularly upset the interview will stop. A doctor or nurse (if you attend Sheffield Children's Hospital) or your head of year (if you attend King Edward VII School) will be contacted so that they can make sure you are provided with extra support.

*Will anyone else know I'm doing this?*

We will keep your information in confidence. This means we will only tell those who have a need or right to know. The only people who you will know you are taking part in the project are members of the research team and:

- your doctors and nurses (if you attend either the Cystic Fibrosis Unit or the Respiratory Department at the Sheffield Children's Hospital) or
- your teachers (if you attend King Edward VII School).

The only case in which the topics you discuss would not be kept confidential is if you raise an issue which suggests you are at a high risk of harm or have been harmed. If this was to occur only those people who are responsible for protecting you would be told about the issue you raised. If you attend Sheffield Children's Hospital this would be a doctor or nurse who is involved in your care at the hospital. If necessary, the individual at the hospital responsible for child protection would also be contacted. If you attend King Edward VII School the person who was contacted would be the head of your school year. If necessary, the individual at the school responsible for child protection would also be contacted.

*What will happen to the results of the research project?*

The results of this research project will inform a wider study which both investigates the opportunities that matter to young people and how they are affected by health problems during adolescence. The results of the research project will be shared with you and the other young people taking part.

*Who is organising and funding the research?*

The University of Sheffield are funding this research project. It is being organised by a post graduate student at the University (Daniel Gladwell) and two senior academic staff (Jenny Owen and Aki Tsuchiya). This research has been organised with help from Sheffield Children's Hospital and King Edward VII's School. No one is receiving extra payments for including you in this study.

*Will my interview be recorded?*

Your interview will be recorded using audio equipment. The recordings will be stored on encrypted devices which will be locked in secure cabinets. Two years after the research project has been completed all of the recordings from your interview will be deleted. Your confidentiality will be protected.

*Who has ethically reviewed the project?*

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, they make sure the research is fair. This project has been ethically reviewed and given a favourable opinion by the Camden and Islington Research Ethics Committee.

**Thank you for taking the time to read this information sheet.  
If you decide to take part in the study please keep this information  
sheet in a safe place in case you need to refer to it later.**

## **Contact Details**

### **Contact for further information or if interested in taking part:**

*Daniel Gladwell*

Email address: [d.gladwell@sheffield.ac.uk](mailto:d.gladwell@sheffield.ac.uk)  
Address: Health Economics and Decision Science  
School of Health and Related Research (SchARR)  
University of Sheffield  
Regent Court  
30 Regent Street  
Sheffield  
S1 4DA

Telephone Number: 07975945756

### **Contact details for making a complaint:**

*Jenny Owen*

Email address: [j.m.owen@sheffield.ac.uk](mailto:j.m.owen@sheffield.ac.uk)  
Address: Public Health Section  
School of Health and Related Research (SchARR)  
University of Sheffield  
Regent Court  
30 Regent Street  
Sheffield  
S1 4DA

Telephone Number: 0114 2220849

*Aki Tsuchiya*

Email address: [a.tsuchiya@sheffield.ac.uk](mailto:a.tsuchiya@sheffield.ac.uk)  
Address: Health Economics and Decision Science  
School of Health and Related Research (SchARR)  
University of Sheffield  
Regent Court  
30 Regent Street  
Sheffield  
S1 4DA

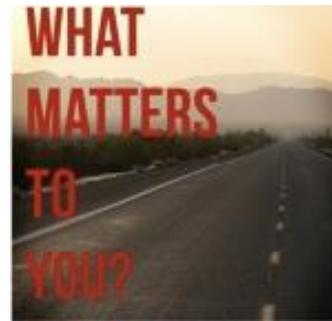
Telephone Number: 0114 2220710

*Sheffield University Registrar and Secretary*

Email address: [registrar@sheffield.ac.uk](mailto:registrar@sheffield.ac.uk)  
Address: Office of the Registrar and Secretary  
Firth Court  
Western Bank  
Sheffield  
S10 2TN

Telephone Number: 0114 2221100

B.2. Information about the research (v0.3)



**Information about the Research**

***What Opportunities Matter to Young People?***



## ***What Opportunities Matter to Young People?***

Your child is being invited to take part in a research project. Before you decide whether to consent to their participation it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish your child to take part. Thank you for reading this.

### *What is the project's purpose?*

Everyone is different but everyone has something that matters to them. The opportunity to engage with different people and activities is part of what makes life enjoyable. The project aims to research:

- what opportunities matter most to young people
- what hurdles sometimes get in the way of these opportunities
- how young people and their families work to overcome these hurdles

The project is also interested in exploring how what matters to young people changes over time.

### *Why has your child been invited?*

Your child has been invited because they are the right age to take part in the study and because they attend either:

- the Cystic Fibrosis Unit at the Sheffield Children's Hospital,
- the Respiratory Department at the Sheffield Children's Hospital or
- King Edward VII School.

The plan is to interview another twenty three young people. The project aims to recruit a broad range of people so that the research findings are informed by a broad range of perspectives.

### *Does my child have to take part?*

It is up to you to decide with your child whether or not they take part. If both of you decide that your child should take part you will be given this information sheet to keep (and be asked to sign a consent form). You can still withdraw your child's participation at any time. You do not have to give a reason.

*What will happen to my child if they child take part?*

If you and your child agree that they can take part your child will be interviewed. The interview should take around 1 hour. Your child may be invited for two more interviews. These will not occur until roughly six months and 1 year after the initial interview. The aim of these later interviews will be to explore how they and their family have helped make the most of the opportunities your child values during the time since the last interview. The extra interviews are being done as the project is interested in investigating how what is particularly important to young people can change over time.

The interviews will be lightly structured – this means that while the different interviews will cover similar topics there will be plenty of space for your child to spend time talking about the related issues they want to emphasise.

*What are the possible disadvantages and risks of taking part?*

Due to the interview topics it may be the case that issues come up which are emotive for your child. Every effort will be made by the interviewer to be sensitive during the discussion. During the interview your child can stop the interview or take a break if they want to or need to. They also don't have to answer any questions that they do not feel comfortable with.

*What are the possible benefits of taking part?*

It is hoped that the interviews will provide your child with an opportunity to talk about what matters to them. It is also hoped that the findings of this research will inform future efforts to help young people and their families enjoy life's opportunities and overcome hurdles to these opportunities such as bad health. In addition upon completion of the first interview your child will receive gift vouchers worth £15.

*What if something goes wrong?*

If something goes wrong during an interview and you would like to make a complaint your first point of contact should be the project supervisor, Dr Jenny Owen. However, if you feel your complaint has not been handled to your satisfaction you can contact Sheffield University's Registrar and Secretary. The contact details for Dr Jenny Owen and Sheffield University's Registrar and Secretary are given at the end of this sheet.

If during the interview your child becomes particularly distressed the interview will stop. As an additional precaution a member of a member of your child's direct care team (if your child attends Sheffield Children's Hospital) or your child's head of year (if your child attends King Edward VII School) will be notified so that they can ensure they are provided with extra support.

*Will my child's participation in this project be kept confidential?*

The only case in which the topics your child discusses will not be kept confidential is if an issue is raised which suggests they are at a high risk of harm or have been harmed. If your child discloses information which suggests they are at high risk of harm the interviewer would first contact a member of your child's direct care team (if your child attends Sheffield Children's Hospital) or your child's head of year (if they attend King Edward VII School) in order to work out the most appropriate way to reduce the high risk.

If your child discloses a past experience of having been harmed the interviewer will pause the interview and suggest to the young person that they have disclosed an experience of abuse or violence. The interviewer will then discuss with the young person the need to contact an appropriate source of support. If the young person was recruited through Sheffield Children's Hospital the researcher would then discuss the potential previous episode of abuse with a member of your child's direct care team (if your child attends Sheffield Children's Hospital) or your child's head of year (if your child attends King Edward VII School). If after this discussion further advice is needed the interviewer will contact the individual responsible for child protection at either Sheffield Children's Hospital or King Edward VII School, depending upon which institution your child attends.

Unless either of these highly unlikely situations occur, all the information that we collect about your child during the course of the research will be kept strictly confidential. Your child will not be able to be identified in any reports or publications'.

*Will my child's interview be recorded, and how will the recorded media be used?*

The interviews will be recorded using audio equipment. Future publications reporting the research may contain short anonymised quotes from your child's interview to illustrate the research's findings. It will not be possible for anyone to recognise any of the quotes that may be used. Apart from these short, anonymised quotations the

audio recordings of your child's interview made during this research will be used only for analysis. No other use will be made of them without your and your child's written permission, and no one outside the project will be allowed access to the original recordings. The recordings and transcripts will be stored on encrypted devices which will be locked in secure cabinets. Two years after the research project has been completed all of the recordings from the interviews will be deleted. Your child's confidentiality will be protected.

*What will happen to the results of the research project?*

The results of this research project will inform a wider study which both investigates the opportunities that matter to young people and how they are affected by health problems during adolescence. The results of the research project will be shared with all of the participants.

*Who is organising and funding the research?*

The University of Sheffield is funding this research project. It is being organised by a post graduate student at the University (Daniel Gladwell) and two senior academic staff (Dr Jenny Owen and Professor Aki Tsuchiya). This research has been organised in collaboration with Sheffield Children's Hospital and King Edward VII's School. No one is receiving extra payments for including your child in this study.

*Who has ethically reviewed the project?*

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your child's interests. This project has been ethically reviewed and given a favourable opinion by the Camden and Islington Research Ethics Committee.

**Thank you for taking the time to read this information sheet.  
If you consent to your child taking part in the study please keep this  
information sheet in a safe place in case you need to refer to it later.**

## **Contact Details**

### **Contact for further information or if interested in taking part:**

*Daniel Gladwell*

Email address: [d.gladwell@sheffield.ac.uk](mailto:d.gladwell@sheffield.ac.uk)  
Address: Health Economics and Decision Science  
School of Health and Related Research (SchARR)  
University of Sheffield  
Regent Court  
30 Regent Street  
Sheffield  
S1 4DA

Telephone Number: 07975945756

### **Contact details for making a complaint:**

*Jenny Owen*

Email address: [j.m.owen@sheffield.ac.uk](mailto:j.m.owen@sheffield.ac.uk)  
Address: Public Health Section  
School of Health and Related Research (SchARR)  
University of Sheffield  
Regent Court  
30 Regent Street  
Sheffield  
S1 4DA

Telephone Number: 0114 2220849

*Aki Tsuchiya*

Email address: [a.tsuchiya@sheffield.ac.uk](mailto:a.tsuchiya@sheffield.ac.uk)  
Address: Health Economics and Decision Science  
School of Health and Related Research (SchARR)  
University of Sheffield  
Regent Court  
30 Regent Street  
Sheffield  
S1 4DA

Telephone Number: 0114 2220710

*Sheffield University Registrar and Secretary*

Email address: [registrar@sheffield.ac.uk](mailto:registrar@sheffield.ac.uk)  
Address: Office of the Registrar and Secretary  
Firth Court  
Western Bank  
Sheffield  
S10 2TN

Telephone Number: 0114 2221100



## B.4. Parental consent form (v0.3)

University of Sheffield

### Parental Consent Form

Title of Research Project: What opportunities matter to young people?

Name of Researcher: Daniel Gladwell

**Participant Identification Number for this project:      Please initial box**

1. I confirm that I have read and understand the sheet giving information about the research dated 18<sup>th</sup> March 2014, version 0.3 which explains the above research project and I have had the opportunity to ask questions about the project.

2. I understand that the participation of my child is voluntary and that I am free to withdraw my consent for their participation at any time without giving any reason and without there being any negative consequences. In addition, should my child not wish to answer any particular question or questions, they are free to decline.  
*(To withdraw, please contact Daniel Gladwell on 07975945756 or d.gladwell@sheffield.ac.uk)*

3. I give permission for members of the research team to have access to the anonymised responses of my child. I understand that the name of my child will not be identified or identifiable in the report or reports that result from the research.

4. I agree to the data storage and disposal arrangements outlined in the sheet giving information about the research

5. I agree my child taking part in the above research project.

\_\_\_\_\_  
Name of Parent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Lead Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*To be signed and dated in presence of the parent*

Copies:

*Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form, information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the projects main record (e.g. a site file), which must be kept in a secure location.*

Version 0.3: 18<sup>th</sup> March 2014

## B.5. NHS ethics approval letter



**NRES Committee London - Camden & Islington**

North East REC Office  
Room 002  
TEDCO Business Centre  
Rolling Mill Road  
Jarrow  
Tyne & Wear  
NE32 3DT

Telephone: 0191 4283478

25 March 2014

Mr Daniel Gladwell  
School of Health and Related Research  
Regent Court  
Sheffield  
S1 4DA

Dear Mr Gladwell

<b>Study title:</b>	<b>What opportunities matter to young people and what abilities are needed in order to enjoy them?</b>
<b>REC reference:</b>	<b>14/LO/0497</b>
<b>Protocol number:</b>	<b>NA</b>
<b>IRAS project ID:</b>	<b>141103</b>

Thank you for your email correspondence responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager, Hayley Henderson. [nrescommittee.london-camdenandislington@nhs.net](mailto:nrescommittee.london-camdenandislington@nhs.net)

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

A Research Ethics Committee established by the Health Research Authority



#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host

A Research Ethics Committee established by the Health Research Authority

organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

#### Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Advertisement	Poster, V0.1	18 February 2014
Covering Letter	From Daniel Gladwell, V 0.1	27 February 2014
Covering Letter		18 March 2014
Evidence of insurance or indemnity	University of Sheffield, Start Date: 01/05/2014	22 January 2014
Evidence of insurance or indemnity	Zurich Municipal, NHE-03CA06-0013, Expiry: 28/09/2014	25 September 2013
Interview Schedules/Topic Guides	Wave 1, V0.1	25 February 2014
Interview Schedules/Topic Guides	Wave 2, V0.1	25 February 2014
Interview Schedules/Topic Guides	Wave 3, V0.1	25 February 2014
Investigator CV	Daniel Gladwell (CI)	19 February 2014
Investigator CV	Jenny Owen (Academic Supervisor)	14 February 2014
Investigator CV	Aki Tsuchiya	11 February 2014
Investigator CV	Noreen West CV	14 February 2014
Letter from Sponsor	Assessment Form for PhD Upgrade	14 November 2013
Letter from Sponsor	Transfer/Upgrade Report	
Other: Email Confirming Authorised Signatory for Sponsors Representative	From Mrs Lindsay Unwin	26 February 2014
Other: E-mail confirmation of Noreen West to be lead collaborator		17 March 2014
Participant Consent Form: Assent Form	V0.2	26 February 2014
Participant Consent Form: Parental Consent	0.3	18 March 2014
Participant Information Sheet: Information about the Research (Primary Carer)	0.3	18 March 2014
Participant Information Sheet: Participant	0.3	18 March 2014
Protocol	V0.2	25 February 2014
REC application	IRAS V3.5, 141103/575348/1/873	04 March 2014
Referees or other scientific critique report	Transfer Report from MPhil to PhD	18 October 2013
Response to Request for Further Information		18 March 2014

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/LO/0497	Please quote this number on all correspondence
------------	--

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



pp  
Rosie Glazebrook  
Chair

Email: [nrescommittee.london-camdenandislington@nhs.net](mailto:nrescommittee.london-camdenandislington@nhs.net)

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Dr Ravi Maheswaran,*  
*Ms Wendy Swann, Sheffield Children's NHS Foundation Trust*

A Research Ethics Committee established by the Health Research Authority

## B.6. Amendment approval letter



### Health Research Authority

#### NRES Committee London - Camden & Islington

North East REC Office  
Room 002  
Jarrow Business Centre  
Rolling Mill Road  
Jarrow  
Tyne & Wear  
NE32 3DT

Tel: 0191 4283476

28 April 2014

Mr Daniel Gladwell  
School of Health and Related Research  
Regent Court  
Sheffield  
S1 4DA

Dear Mr Gladwell

**Study title:** What opportunities matter to young people and what abilities are needed in order to enjoy them?  
**REC reference:** 14/LO/0497  
**Protocol number:** NA  
**Amendment number:** Amendment 1  
**Amendment date:** 10 April 2014  
**IRAS project ID:** 141103

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
REC Form - what opportunities marrer highlighted		05 March 2014
Protocol	Revised V0.3	10 April 2014
Covering Letter	E-mail correspondence	10 April 2014
Scientific Review of Amendment 1		10 April 2014
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	10 April 2014

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/LO/0497:	Please quote this number on all correspondence
-------------	--

Yours sincerely



pp

**Mrs Rosie Glazebrook**  
**Chair**

E-mail: [nrescommittee.london-camdenandislington@nhs.net](mailto:nrescommittee.london-camdenandislington@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Ms Wendy Swann, Sheffield Children's NHS Foundation Trust  
Dr Ravi Maheswaran*

**NRES Committee London - Camden & Islington**

**Attendance at Sub-Committee of the REC meeting on 28 April 2014**

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mrs Rosie Glazebrook	Consumer Marketing	Lay
Ms Eleni Yerolaki	Specialist Counsellor	Lay Plus

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Sally Dunn	REC Assistant

## B.7. University ethics approval



Kirsty Woodhead  
Ethics Committee Administrator

Regent Court  
30 Regent Street  
Sheffield S1 4DA  
Telephone: +44 (0) 114 2225403  
Fax: +44 (0) 114 272 4095 (non confidential)  
Email: k.woodhead@sheffield.ac.uk

Our ref: 0739KW

8 April 2014

Daniel Gladwell  
ScHARR

Dear Daniel

**What opportunities matter to young people and what abilities are needed in order to enjoy them?**

Thank you for submitting the above research project for approval by the ScHARR Research Ethics Committee. On behalf of the University Chair of Ethics who reviewed your project, I am pleased to inform you that on 08 April 2014 the project was approved on ethics grounds, on the basis that you will adhere to the documents that you submitted for ethics review.

The research must be conducted within the requirements of the hosting/employing organisation or the organisation where the research is being undertaken.

If during the course of the project you need to deviate significantly from the documents you submitted for review, please inform me since written approval will be required. Please also inform me should you decide to terminate the project prematurely.

Yours sincerely

A handwritten signature in black ink, appearing to read "K. Woodhead".

**Kirsty Woodhead**  
Ethics Committee Administrator



## B.8. Confirmation email from University of Sheffield ethics committee

From: Jennifer A Burr <[j.a.burr@sheffield.ac.uk](mailto:j.a.burr@sheffield.ac.uk)>  
Date: 28 April 2014 at 14:05  
Subject: Re: Research Ethics Approval  
To: Daniel J Gladwell <[d.gladwell@sheffield.ac.uk](mailto:d.gladwell@sheffield.ac.uk)>  
Cc: Kirsty Woodhead <[k.woodhead@sheffield.ac.uk](mailto:k.woodhead@sheffield.ac.uk)>, Jenny Owen <[j.m.owen@sheffield.ac.uk](mailto:j.m.owen@sheffield.ac.uk)>

Dear Daniel,  
Don't worry. You don't need approval from the NHS and from us too.  
Good luck  
Jennifer

On 28 April 2014 14:01, Daniel J Gladwell <[d.gladwell@sheffield.ac.uk](mailto:d.gladwell@sheffield.ac.uk)> wrote:

Dear Kirsty,

Following the approval of the research project with the reference number 0739KW (Project Title: What opportunities matter to young people and what abilities are needed in order to enjoy them?) I had to apply for a substantial amendment. Attached is the amendment form, an up to date protocol (this was the only study document that needed changing) and a letter from the REC confirming the accept the amendment. Please could you confirm that the SchARR Research Ethics Committee also accepts the amendment?

Best wishes

Dan

## B.9. Disclosure and barring service: enhanced certificate

<b>Enhanced Certificate</b>		 <b>Disclosure &amp; Barring Service</b>
<b>Page 1 of 2</b>		
<b>Certificate Number</b>	001427583678	
<b>Date of Issue:</b>	29 NOVEMBER 2013	
<b>Applicant Personal Details</b>		
Surname:	GLADWELL	
Forename(s):	DANIEL JONATHAN	
Other Names:	NONE DECLARED	
Date of Birth:	23 AUGUST 1985	
Place of Birth:	GLOUCESTER	
Gender:	MALE	
<b>Employment Details</b>		
Position applied for:	CHILD AND ADULT WORKFORCE HEALTHCARE RESEARCHER	
Name of Employer:	UNIVERSITY OF SHEFFIELD	
<b>Countersignatory Details</b>		
Registered Person/Body:	UNIVERSITY OF SHEFFIELD	
Countersignatory:	LISA BELL	
<b>Police Records of Convictions, Cautions, Reprimands and Warnings</b>		
NONE RECORDED		
<b>Information from the list held under Section 142 of the Education Act 2002</b>		
NONE RECORDED		
<b>DBS Children's Barred List information</b>		
NONE RECORDED		
<b>DBS Adults' Barred List information</b>		
NONE RECORDED		
<b>Other relevant information disclosed at the Chief Police Officer(s) discretion</b>		
NONE RECORDED		
<b>Enhanced Certificate</b>		
This document is an Enhanced Criminal Record Certificate within the meaning of sections 113B and 116 of the Police Act 1997.		
<b>THIS CERTIFICATE IS NOT EVIDENCE OF IDENTITY</b>		<b>Continued on page 2</b>
 Disclosure and Barring Service, PO Box 165, Liverpool, L69 3JD Helpline: 0870 90 90 811		© Crown Copyright

**Use of certificate information**

The information contained in this certificate is confidential and all recipients must keep it secure and protect it from loss or unauthorised access. This Certificate must only be used in accordance with the Disclosure and Barring Service's (DBS) Code of Practice and any other guidance issued by the DBS. Particular attention must be given to the guidance in the fair use of the information in respect of those whose Certificate reveals a conviction or similar information. The DBS will monitor the compliance of Registered Bodies with this Code of Practice and other guidance.

This Certificate is issued in accordance with Part V of the Police Act 1997, which creates a number of offences. These offences include forgery or alteration of Certificates, obtaining Certificates under false pretences, and using a Certificate issued to another person as if it was one's own.

This Certificate is not evidence of identity of the bearer, nor does it establish a person's entitlement to work in the UK.

**Certificate content**

The personal details contained in this Certificate are those supplied by or on behalf of the person to whom the Certificate relates at the time the application was made and that appear to match any conviction or other details linked to that identity.

The information contained in this Certificate is derived from police records, and from records held of those who are unsuitable to work with children and/or adults, where indicated. The police records are those held on the Police National Computer (PNC) that contains details of Convictions, Cautions, Reprimands and Warnings in England and Wales, and most of the relevant convictions in Scotland and Northern Ireland may also be included. The DBS reserves the right to add new data sources. For the most up to date list of data sources which are searched by the DBS please visit the DBS website.

The Other Relevant Information is disclosed at the discretion of the Chief Police Officers or those of an equivalent level in other policing agencies, who have been approached by the DBS, with due regard to the position sought by the person to whom the Certificate relates.

**Certificate accuracy**

The DBS is not responsible for the accuracy of police records.

If the person to whom this Certificate relates is aware of any inaccuracy in the information contained in the Certificate, he or she should contact the Countersignatory immediately, in order to prevent an inappropriate decision being made on their suitability. This Countersignatory will advise how to dispute that information, and if requested arrange for it to be referred to the DBS on their behalf. The information should be disputed within 3 months of the date of issue of the Certificate.

The DBS will seek to resolve the matter with the source of the record and the person to whom the Certificate relates. In some circumstances it may only be possible to resolve a dispute using fingerprints, for which consent of the person to whom the Certificate relates will be required.

If the DBS upholds the dispute a new Certificate will be issued free-of-charge. Details of the DBS's disputes and complaints procedure can be found on the DBS's website.

**Contact us**

Post:	Disclosure and Barring Service PO Box 165 Liverpool L69 3JD	Telephone:	Customer Services: 0870 90 90 811 Welsh line: 0870 90 90 223 Minicom: 0870 90 90 344
Web:	<a href="http://www.homeoffice.gov.uk/cbs">www.homeoffice.gov.uk/cbs</a>		
Email:	<a href="mailto:customerservices@cbs.gsi.gov.uk">customerservices@cbs.gsi.gov.uk</a>		

If you find this certificate and are not able to return it to the person to whom it relates, please return it to the DBS at the address above or hand it in at the nearest police station.

**End of Details**

disclosure disclosure disclosure disclosure disclosure

## B.10. Interview sample (detailed summary table)

Table B-1: Detailed summary of the participants included in the qualitative research

Pseudonym	Health status	Gender	School year*	Participated in wave 1 interview?	Participated in wave 2 interview?	Participated in wave 3 interview?	Index of Multiple Deprivation Decile+
Brendan	NSHD	Male	Year 10	Y	Y	N	8
Camilla	NSHD	Female	Year 9	Y	N	N	9
Emily	NSHD	Female	Year 9	Y	Y	Y	1
Jake	NSHD	Male	Year 10	Y	N	N	4
John	NSHD	Male	Year 10	Y	Y	Y	10
Samantha	NSHD	Female	Year 10	Y	N	N	4
Thea	NSHD	Female	Year 10	Y	Y	N	10
David	SAsth	Male	Year 10	Y	Y	Y	8
Ibrahim	SAsth	Male	Year 10	Y	N	N	2
Joseph	SAsth	Male	Year 9	Y	Y	N	8
Mohammed	SAsth	Male	Year 9	Y	N	N	1
Olivia	SAsth	Female	Year 9	Y	Y	Y	5
Sasha	SAsth	Female	Year 9	Y	N	N	1
Trisha	SAsth	Female	Year 10	Y	Y	N	2
Zaiada	SAsth	Female	Year 10	Y	N	N	8
Abbie	CF	Female	Year 9	Y	Y	N	3
Ben	CF	Male	Year 9	Y	Y	Y	4
Chloe	CF	Female	Year 10	Y	N	N	10
Emma	CF	Female	Year 10	Y	Y	Y	5
Jack	CF	Male	Year 10	Y	N	N	5
Joshua	CF	Male	Year 10	Y	N	N	1
Maria	CF	Female	Year 9	Y	N	N	6
Nathan	CF	Male	Year 9	Y	Y	N	8

**Notes:** **NHSD**, No severe Health Difficulty; **SAsth**, Severe Asthma (defined for the purpose of this study as having a BTS score of 3 or above and having required support from a respiratory consultant in the last two years); **CF**, Cystic Fibrosis; \*School year at the time of first interview (individuals in year 9 would be aged between 13-14 and those in year 10 would be aged 14-15); +These scores represent the deprivation decile of the Lower Layer Super Output Area in which the individual's household is located – a higher decile indicates a lower level of deprivation.

## B.11. Overview of the contribution of the pilot interviews

As discussed in 6.2.2, ahead of each wave of interviews, I undertook two pilot interviews with personal acquaintances of mine. One on the individuals who took part in the pilot interviews was a similar age to the study participants. Below, I briefly summarise what I learned from the pilot interviews and how they influenced my adopted approach.

### *Pilot interviews undertaken prior to wave 1*

My main conclusion from the pilot interviews taken prior to wave 1 was that the narrative approach was suitable for my intentions. I was reassured that the acquaintance of a similar age to the study participants was able to engage with the approach well (when on the training course I had only practiced it with academically orientated individuals of a similar age to myself). As discussed in 6.2.2.1, though I sensed the pilot interviewee was keen to give me the responses she believed I wanted, the BNIM style of interviewing (outlined in 6.2.2.1) encouraged me to ask follow-up questions on areas I believed to be *her* main topics of interest. Therefore, the interview likely stayed closer to her areas of interest than if I had asked her a series of direct questions (which would likely lead to me both setting the agenda of the discussion and eliciting responses to these pre-determined questions that she thought were “correct”). I also noted that the narrative approach helped me engage with the perspective of the interviewee. As such, it helped me more easily see the world from the perspective of a young person.

When reflecting on the pilot interviews, I did note some stylistic errors I had made (for example, asking the interviewee questions at the end of a sequence of speech that, according to the BNIM method, precluded me subsequently returning to topics that are covered earlier in that sequence). I therefore noted these errors and endeavoured to avoid them when undertaking the wave 1 interviews.

### *Pilot interviews undertaken prior to wave 2*

When re-interviewing the acquaintance of a similar age to my participants, I noted that the planned approach for the second wave built well upon the first interview. Although it did take her a little while to re-orientate her memory back to the time of the first interview (which was required in order to recall what had happened since), she was soon able to confidently engage with the BNIM question. The card exercises worked well but, when reflecting on the pilot interview later, I decided I needed to be careful just how much I enquired about their rationale for ordering the cards. If I asked questions that

were too probing in nature, I would risk accidentally leading them into my own way of thinking by highlighting any inconsistencies in their approach. If I inadvertently led them to thinking I thought their ordering was inconsistent, there was a risk that when I gave them space to reflect and change the order, they would do so not because their own thoughts had further developed but because they wanted to give me a “correct” ordering.

My pilot interview with an acquaintance of a similar age to myself was very helpful for conceptually engaging further with the questions I was asking (e.g. what do I mean by a “really good life and how might different individuals interpret this). I also took away some practical learnings from the interview (e.g. to make sure I had a pen and note pad in an accessible location so the interviewee could easily add any extra aspects of life they thought were omitted from the initial list).

#### *Pilot interviews undertaken prior to wave 3*

My planned approach generally worked well in the pilot interviews undertaken prior to wave 3. However, the pilot interviews usefully contributed by not only increasing my confidence ahead of the main interviews but also by highlighting places within the schedule where my planned phraseology of questions was unhelpful. Specifically, I realised: (i) that my approach to asking follow-up questions about the participant’s experience of the build up to the GCSE examinations was under developed; and (ii) my approach to asking the individual the extent to which they were able to enjoy the different aspects of life represented by the cards etc. was not accessible enough for young people of a range of academic abilities. Ahead of the wave 3 interviews, I therefore considered how to phrase these questions in a way that was more accessible for the participants.

## B.12. Wave 2 interview schedule

### Wave 2 Interview schedule

#### *Initial Question*

As you know I'm interested in what matters to young people. We did an interview in (May/June/July) last year. Please could you tell me about all the events and experiences that have been important to you personally that have happened since we last spoke? I'll listen first and I won't interrupt.

#### *Exercise using capabilities cards*

Some university researchers have suggested that there are certain opportunities and abilities that make living a really good life easier. One of the things I'm looking to find out about is what young people think about the list they've proposed. In many ways I'm more interested in what you think than what they think so please feel free to agree or disagree with what they suggest.

I've got some cards to show you that represent each aspect of life they think is important. Please don't be too concerned about either the picture or the bullet points – they are just meant to help you think through the main idea which is represented by the title.

1. First we are just going to look one at a time at each of the aspects of life they think are very important for making it possible to live a really good life [read each title aloud as it is given]:
  - a. Does the card make sense to you? Is it clear what that aspect of life is?
  - b. Do you or do you not agree that this aspect of life is very important for being able to live a really good life?
  - c. Could you explain why you think it is important (or why you don't think it's important)?
2. This is a bit trickier and you don't need to force it, but is there any aspect of life you think is really important that they have left off this list?
3. Now for the final exercise with these cards. There's no hurry with this but nor is there a "right answer" you must get to. Could you please order them in a way that shows which of these aspects of life are most important to least important for helping someone live a really good life. You may want to arrange them sort of like a Christmas tree, like this... (do it with them turned over...). There is no "right way" to do this -I'm interested in your opinion on this
  - a. (after they have done it) Thanks - could you just explain to me why you ordered them in the way you did? (take a picture of the cards before and after the discussion in case they change the order as we talk..)

#### *Subjective well-being*

How dissatisfied or satisfied are you about the way your life has turned out so far?

Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Fairly dissatisfied	Very dissatisfied

#### *Self-assessed health*

In the last 12 months would you say your health has been:

Very good	Fairly good	Not very good	Not good at all

[enquire as to why they have given the response they have if they don't immediately offer it]

*Clarifying questions on anything key that I have not got correct from first interview*

*Family Tree*

"in the last interview I asked about your whole life - obviously family is often quite important in people's lives. Could you write down your family tree for me - just as far back as your grandparents?".

*Parental occupations*



B.13. Cards representing aspects of life that may be of value (for wave 2)



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**Confidence that you will be protected and treated fairly by the law**

- Trust the police won't bully you
- Trust the police will protect you from others
- Have the right to a fair trial



Background image: "Acather96," Image Title: Bedfordshire Police ANPR Interceptor,

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### **Freedom to express yourself**

- **Free to listen to the music you want to**
- **Able to talk with friends**
- **Treated fairly compared to other students at school**

Background image: "magdaro," image Title: Colours, <http://www.freemages.com/photo/colors-1158808>, copied under Freemages.com Content License. Alterations made by Daniel Gladwell included lightening the background image and adding text based on Burchardt and Vizard (2009).

## **Freedom to make the decisions that matter to you**

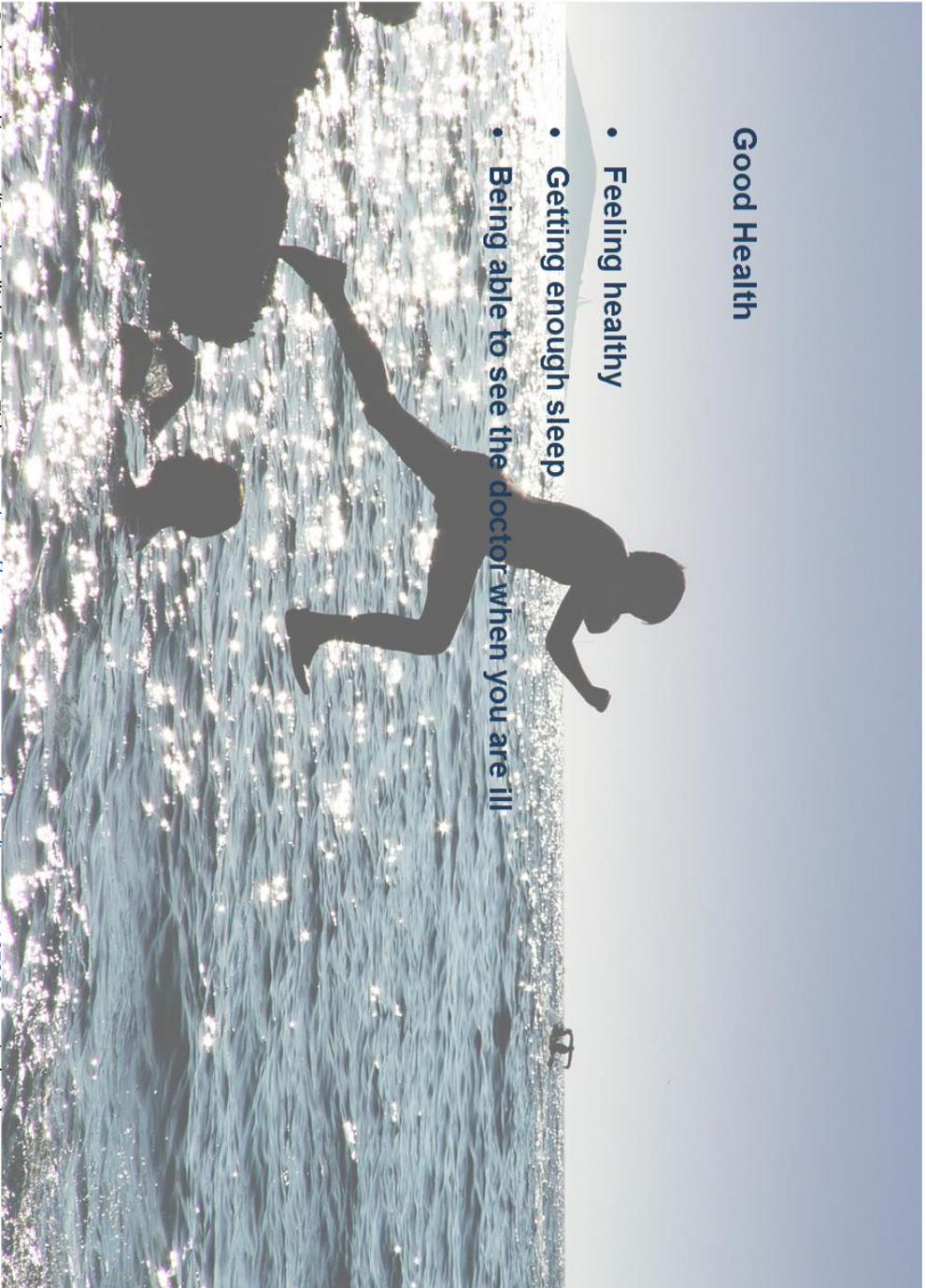
- **Being listened to**
- **Respected by parents and teachers**
- **Having a say in any decisions that affect you**



Background image: "killick1," image Title: Silhouette of signpost against a winter sky, <http://www.freemages.com/photo/silhouette-of-signpost-against-a-winter-sky-1157085> , copied under Freemages.com Content License Alterations made by Daniel Gladwell included  
Lightening the background image and adding text based on Burchardt and Vizard (2009).

## Good Health

- Feeling healthy
- Getting enough sleep
- Being able to see the doctor when you are ill



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## Knowledge and Skills

- Able to learn new things
- Being creative with music and art
- Space to consider what you think is important in life



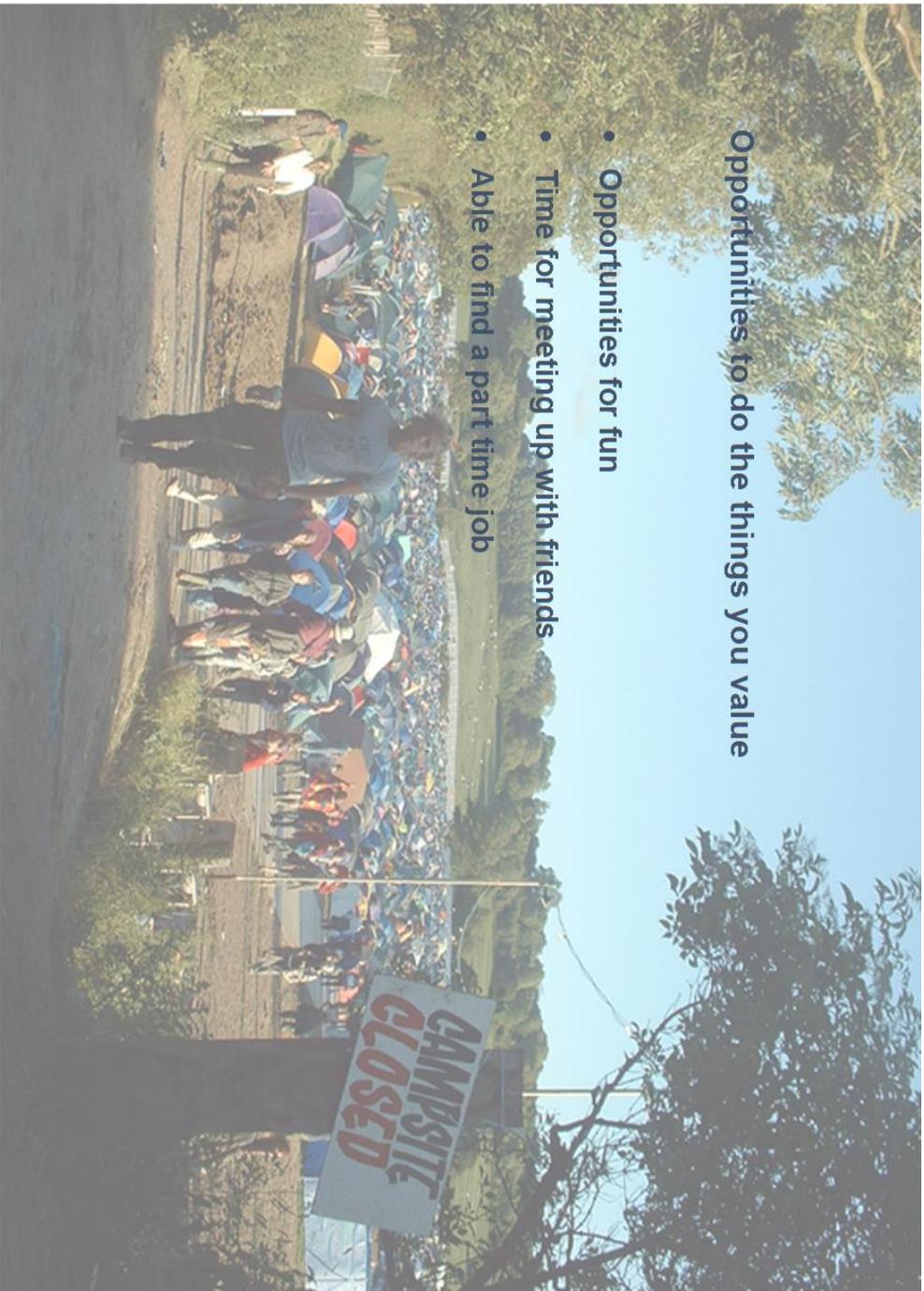
Background image: "Gözde Otman," Image Title: University life, <http://www.freemages.com/photo/university-life-1442115>, copied under Freemages.com Content License Alterations made by Daniel Gladwell included lightening the background image and adding text based on Burchardt and Vizard (2009).



Background image: "Stephen," Image Title: HandsonTop-3, <http://www.freemages.com/photo/1285834>, copied under Freemages.com Content License Alterations made by Daniel Gladwell included transforming the background image to being in black and white and adding text based on Burchardt and Vizard (2009).

## Opportunities to do the things you value

- Opportunities for fun
- Time for meeting up with friends
- Able to find a part time job

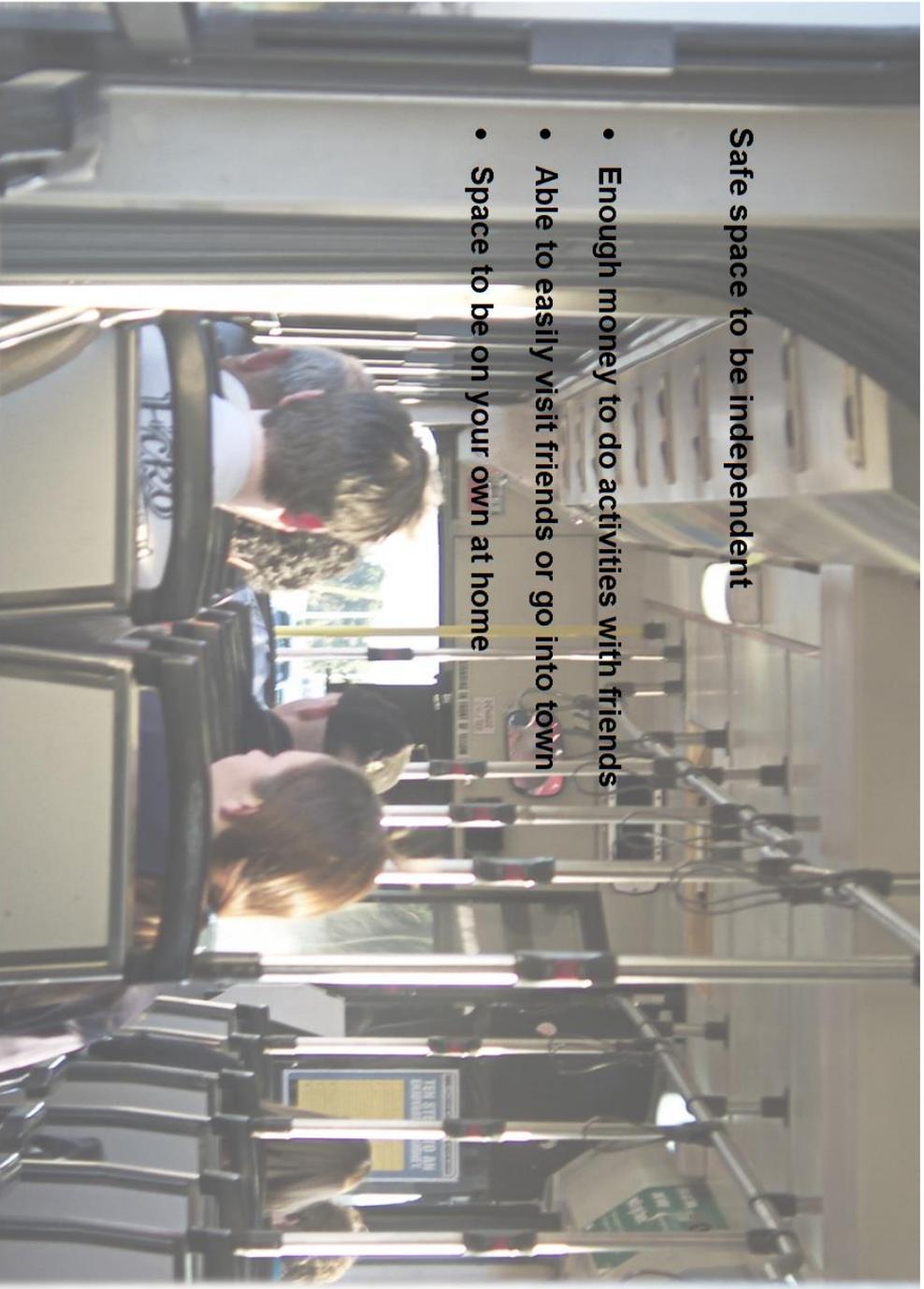


Background image: "Joe D," Image Title: Glold campsite friday, [https://commons.wikimedia.org/wiki/File:Glold\\_campsite\\_friday.jpg](https://commons.wikimedia.org/wiki/File:Glold_campsite_friday.jpg), copied under the creative commons Attribution-sharealike 1.0 Generic license: <https://creativecommons.org/licenses/by-sa/1.0/deed.en>  
Alterations made by Daniel Gladwell included lightening the background image and adding text based on Burchardt and Vizard (2009)



### **Safe space to be independent**

- **Enough money to do activities with friends**
- **Able to easily visit friends or go into town**
- **Space to be on your own at home**



Background image: "Nick Cowie," Image Title: Bus ride, <http://www.freeimages.com/photo/bus-ride-1469628>, copied under Freeimages.com Content License Alterations made by Daniel Gladwell included lightening the background image and adding text based on Burchardt and Vizard (2009).

## B.14. Wave 3 interview schedule

### Wave 2 Interview schedule

#### *Initial Question*

As you know I'm interested in what matters to young people. We last did an interview in November last year. Please could you tell me about all the events and experiences that have been important to you personally that have happened since we last spoke? I'll listen first and I won't interrupt.

#### *Exercise using capabilities cards*

Last time we did some exercises using cards that showed aspects of life people sometimes value. After interviewing people I have looked at people's responses and then changed some of the cards to reflect what was often particularly important. I have brought back the aspects of life that as a group you most often identified as being of value (though they may not contain all the cards you individually prioritised). In this interview I'm particularly interested to find out more about the extent you are able to enjoy these different aspects of life, and if relevant, find out more about what sometimes gets in the way of you being able to enjoy them.

Pass cards one at a time and for each individually explore:

#### **"How much would you say you are able to..."**

- enjoy these aspects of life (if helpful for thinking about this bring in comparison to peers)

#### **"If you were thinking a little more deeply about this/that..."**

- what barriers get in the way (for those with health difficulties explicitly ask about health after they have spontaneously raised any barriers)
- how much do family,(and family resources) help them get over these barriers (including health)
- whether there are any other sources of support which particularly help (friends, family friends, school teachers...)

#### *Subjective well-being*

- after each question ask them "just out of interest could you just talk to me a little about why you gave that answer" if they don't say

#### *Agency questions*

How much do you agree or disagree that: "I can pretty much decide what will happen in my life"?

Strongly agree	Agree	Disagree	Strongly disagree

How much do you agree or disagree that: "If you work hard at something you'll usually succeed"?

Strongly agree	Agree	Disagree	Strongly disagree

How dissatisfied or satisfied are you about the way your life has turned out so far?

Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Fairly dissatisfied	Very dissatisfied

*Self-assessed health*

In the last 12 months would you say your health has been:

Very good	Fairly good	Not very good	Not good at all

[enquire if they think their answer to any of the earlier questions influenced how they answered the later questions]

*Clarifying questions on anything key that I have not got correct from second interview*

- (if in year 12) So you finished your GCSE's last summer:
  - Can you tell me any more about the period preparing for your GCSE's (don't ask if BNIM covered this)?  
After response, **"you said...do you remember any time particularly vividly when that happened?"**
  - Can you tell me any more about doing the exams?
  - Can you tell me any more about getting your results?
    - probe for if happy with them
  - Can you tell me any more about what you are doing now you have finished your GCSE's?
    - probe on whether it is what they wanted to do before GCSE's, extent to which it is what they want to do now and how much they enjoy it
- if in year 11
  - Can you tell me any more about preparing for your GCSE's at the moment (don't ask if BNIM covered this)?  
After response, **"you said...do you remember any time particularly vividly when that happened?"**
  - what would you like to do after you've done your GCSE's?
    - could probe on if there is anything they think might stop them being able to do this
- I am asking everyone this:
  - have you always lived in the UK?
  - have your parents always lived in the UK?
- Any other questions of relevance from gaps in wave 2 responses

*Topics of particular interest during narrative section (and also during cards):*

- Areas of interest

- **Transitioning from being reliant on parents to increasingly spending time with friends (for all health groups but particularly those with health problems)**
  - **Particularly push stories relating to doing concrete activities with friends in order to explore transition to being more independent**
  - extent to which it is happening
  - what slows it down (burden of condition and need for support, parents not letting them go)?
- Freedom to express yourself/identity
- Relating to others:
  - relationships with family
  - both the more “positive” aspects of it (intimacy etc) and
  - the negative (social exclusion)
- Valued activities (both physical and not)
- Movement towards achieving aspirations (including education, exam grades)
- Freedom to make the decisions that matter to you
- For each interested in
  - barriers (including health) and
  - the extent to which they
    - have/haven’t been able to overcome the barriers and
    - achieve the functioning they want
  - how they have overcome barriers (individual agency, friends, family (parents), family friends, school teachers etc)

### B.15. Cards representing aspects of life that may be of value (for wave 3)

As discussed in 6.2.2.3, in wave 3 I used a reduced number of cards compared to in the wave 2 analysis. This was so I could have a more involved discussion about the aspects of life that I thought, based on a provisional analysis of the participants' wave 2 data, had the potential to eventually be identified as being of particular importance to young people. In addition to limiting the number of cards used, I also altered them based on the participants' discussion in the wave 2 interviews. Specifically, while other things equal aiming to maintain consistency between the interview waves, I ensured the three specific examples listed on each of the cards accorded with the concepts per domain that were frequently emphasised as being of importance. In order to minimise the risk of individuals only thinking about the first "concrete" example when considering the card, of the three examples that received support as being of importance, I deliberately put them in reverse order with respect to the frequency with which each aspect of life was emphasised by the participants.

My provisional analysis of the concepts emphasised for each aspect of life supported editing the overall heading for three of the cards. "Ability to enjoy time on your own and with others" was simplified (and re-orientated) to "Enjoying time with others". "Freedom to make the decisions that matter to you" was simplified to "Freedom to make important decisions". "Opportunities to do the things you value" was shortened to "Valued Activities". For a more detailed discussion of the concepts emphasised as being of importance per aspect of life, see 7.2.1.

For the purpose of restricting the file size of the appendix, I do not include the full pictures of the cards used in the wave 3 interviews (though they are available upon request). Instead, in Table B-2 below, per card, I list both: (i) the title used for the card in wave 2 and wave 3; and (ii) the concrete examples used (in the order they were presented on each of the cards). Note that each of the cards used in wave 3 adopted the same background image as was used for the equivalent card in wave 2.

Table B-2: Comparison of the text on the cards used in wave 2 and wave 3

	Text used in wave 2 version	Text used in wave 3 version
<i>Ability to enjoy time on your own and with others</i>		
Title	As directly above	Enjoying time with others
Examples	<ul style="list-style-type: none"> <li>• Having confidence</li> <li>• Able to join in the activities of your family</li> <li>• Not feeling lonely when you're on your own</li> </ul>	<ul style="list-style-type: none"> <li>• Having confidence</li> <li>• Able to join in the activities of your family</li> <li>• Not feeling lonely when you're on your own</li> </ul>
<i>Confidence that you will be protected and treated fairly by the law</i>		
Title	As directly above	Not applicable as the card was not used in the wave 3 interviews
Examples	<ul style="list-style-type: none"> <li>• Trust the police won't bully you</li> <li>• Trust the police will protect you from others</li> <li>• Have the right to a fair trial</li> </ul>	
<i>Freedom to express yourself</i>		
Title	As directly above	As directly above
Examples	<ul style="list-style-type: none"> <li>• Free to listen to the music you want to</li> <li>• Able to talk with friends</li> <li>• Treated fairly compared to other students at school</li> </ul>	<ul style="list-style-type: none"> <li>• Able to be yourself</li> <li>• Free to do creative activities</li> <li>• Able to talk confidently with friends</li> </ul>
<i>Freedom to make the decisions that matter to you</i>		
Title	As directly above	Freedom to make important decisions
Examples	<ul style="list-style-type: none"> <li>• Being listened to</li> <li>• Respected by parents and teachers</li> <li>• Having a say in any decisions that affect you</li> </ul>	<ul style="list-style-type: none"> <li>• Respected by parents and teachers</li> <li>• Free to say what you want and be listened to</li> <li>• Having a say in any decisions that affect you</li> </ul>
<i>Good Health</i>		
Title	As directly above	As directly above
Examples	<ul style="list-style-type: none"> <li>• Feeling healthy</li> <li>• Getting enough sleep</li> <li>• Being able to see the doctor when you are ill</li> </ul>	<ul style="list-style-type: none"> <li>• Feeling physically healthy</li> <li>• Feeling mentally healthy</li> <li>• Being well enough to do activities with friends</li> </ul>
<i>Knowledge and Skills</i>		
Title	As directly above	As directly above
Examples	<ul style="list-style-type: none"> <li>• Able to learn new things</li> <li>• Being creative with music and art</li> <li>• Space to consider what you think is important in life</li> </ul>	<ul style="list-style-type: none"> <li>• Space to consider what you think is important in life</li> <li>• Able to learn new things</li> <li>• Able to achieve your aspirations</li> </ul>
<i>Physical Safety</i>		
Title	As directly above	As directly above
Examples	<ul style="list-style-type: none"> <li>• Not being bullied by people your own age</li> <li>• Not being hurt by adults</li> <li>• Feeling safe inside and outside the home</li> </ul>	<ul style="list-style-type: none"> <li>• Not being hurt by adults</li> <li>• Feeling safe inside and outside the home</li> <li>• Not being bullied by people your own age</li> </ul>
<i>Opportunities to do the things you value</i>		
Title	As directly above	Valued Activities
Examples	<ul style="list-style-type: none"> <li>• Opportunities for fun</li> </ul>	<ul style="list-style-type: none"> <li>• Going on holiday</li> </ul>

	<b>Text used in wave 2 version</b>	<b>Text used in wave 3 version</b>
	<ul style="list-style-type: none"> <li>• Time for meeting up with friends</li> <li>• Able to find a part time job</li> </ul>	<ul style="list-style-type: none"> <li>• Able to do fun physical activities</li> <li>• Time for going out with friends</li> </ul>
	Safe space to be independent	
Title	As directly above	Not applicable as the card was not used in the wave 3 interviews
Examples	<ul style="list-style-type: none"> <li>• Enough money to do activities with friends</li> <li>• Able to easily visit friends or go into town</li> <li>• Space to be on your own at home</li> </ul>	

## B.16. Illustration of the approach to using triads to undertake comparisons

As mentioned in 6.2.3.2, after initially undertaking an analysis of the wave 1 interview material at the level of the individual I subsequently sought to make contrasts across the cohort. My primary purpose for doing so was to generate provisional findings which could inform my ongoing data collection efforts. Below is a brief illustration of the triad method I used to undertake the initial contrasts between individuals. This is summarised using the example of just three individuals. However, as mentioned in 6.2.3.2, I dynamically moved between six of the participants, contrasting different combinations of three to explore differences and identify hypotheses.

The participants contrasted below Thea (participant with no severe health difficulty) David (participant with severe asthma) and Ben (participant with CF)

*Table B-3: Table for undertaking comparisons using triads*

<b>Aspects in common between both David and Thea</b>	<b>How this aspect is different for individual Ben</b>
Both boys	A girl
No explicit mention of tiffs between friends*	Discussion of fallings out between friends
Holidays and trips play quite a prominent part in their stories	Holidays do not play a prominent part in Thea's story
Both have a health difficulty	Thea seems very healthy
There is no hobby or sport that they seem to take up with real passion	Thea seems very into her sport
<b>Aspects in common between both David and Ben</b>	<b>How this aspect is different for individual Thea</b>
Both from middle class families	Ben's family is not professional
Both mention education and university	I don't think Ben mentions education or university
Neither appear to have had mental health difficulties	Ben seems to have had quite a few difficulties
<b>Aspects in common between both individual Thea and Ben</b>	<b>How this aspect is different for David</b>
Singular similarity noted [not repeated here to preserve anonymity]	Singular distinctive noted [not repeated here to preserve anonymity]

\*Ben talks about two of his friends having a wrestle but it seems pretty good natured

Below I briefly list some initial theorisations that the above triad generated. These may well have later been undermined by wider contrasts between different participants or even further data collected on the above participants in subsequent interviews.

First, I noted that none of the boys I have explicitly looked at who have health problems seem to have a classic hobby/sport that they are passionate about. In all the interviews, the only hobby (excluding computer games) I could recollect as being of importance for a



boy with a health difficulty was Mohammed who seemed to enjoy drawing. Second, I noted the importance of relational and educational family resources for cushioning the impact of a very severe health difficulty. When observing the first rotation, across the different aspects, it was stark the degree of “capital” Thea and David have that Ben does not have (note in the above table for purposes of preserving anonymity I have not included all the information used in my provisional analysis using triad).

I then noted that within the above triad the two participants recruited as having a health difficulty had conditions that are arguably of different levels of severity. To further understand Ben’s distinctives (other than his health difficulty), I then constructed a new triad which included him, another participant recruited as having CF and David.

## C. Appendices relating to the quantitative study

### C.1. Ethical approval to use data from the LSYPE



Cheryl Oliver  
Ethics Committee Administrator

Regent Court  
30 Regent Street  
Sheffield S1 4DA

Telephone: +44 (0) 114 2220871  
Fax: +44 (0) 114 272 4095 (non confidential)  
Email: c.a.oliver@sheffield.ac.uk

30 April 2012

Daniel Galdwell  
SCHARR

Dear Daniel

#### **Analysing the development of capabilities using the LSYPE dataset**

I am pleased to inform you your supervisor has reviewed your project and classed it as 'low risk' so you can proceed with your research, *subject to you obtaining the relevant permission. Please note it is your responsibility to find what these are and to ensure that these are obtained.*

The research must be conducted within the requirements of the hosting/employing organisation or the organisation where the research is being undertaken.

I have received a hard copy of your student declaration together with your Supervisor's confirmation for research that does not involve human participants and that you will be undertaking research which involves analysis of already existing data ('secondary data').

Yours sincerely

**Cheryl Oliver**  
**Ethics Committee Administrator**

Copy: Aki Tsuchiya

## C.2. Summary tables for the quantitative analysis

Table C-1: Variable definitions

Variable (abbreviation)*	Time period (Wave)	Description
<b>Outcome Variables</b>		
Subjective well-being		
Not satisfied with life	2 (7)	Binary Variable (0-1). 1 = reply but don't affirm being satisfied with the way their life has turned out so far
<i>Low academic ability</i>		
English SATs score	0 (1)	Continuous variable (multiplied by -1). Raw values range from -53.16 to 0 (the higher the worse). To aid convergence the values for each test score are scaled by dividing by 3. **
Maths SATs score		
Science SATs score		
GCSE points	1 (3)	Continuous variable (multiplied by -1). Raw values range from -1064 to 0 (the higher the worse). To aid convergence the values for this variable are scaled by dividing by 100. **
GCSE English pass+	1 (3)	Binary Variable (0-1). 1 = if failed to get c or above
GCSE Maths pass+		
Not in Education Employment or Training (NEET)	7	Binary Variable (0-1). 1 = if not in education, employment or training.
Opportunities to undertake physical leisure activities		
No sport <sup>+++</sup>	0 (1); 1 (4)	Binary Variable (0-1). 1 = if haven't done any sport in the last week.
No physical activity <sup>+++</sup>	2 (7)	Binary Variable (0-1). 1 = if haven't done relatively strenuous physical activity in the last week.
<i>Relational exclusion</i>		
Called names	0 (1); 1 (3)	Binary Variable (0-1). 1 = if have been upset by name calling in last 12 months
Excluded from group	0 (1); 1 (3)	Binary Variable (0-1). 1 = if have been excluded from a group of friends in last 12 months
Robbed	0 (1); 1 (3)	Binary Variable (0-1). 1 = if have been made to hand over money in last 12 months
Few close friends	2 (7)	Binary Variable (0-1). 1 = if report less than the median number of close friends (3 or less).
<b>Health</b>		
General Health		
General health difficulty	0 (2)	Binary Variable (0-1). 1 = Poor self-assessed health or long-term illness or disability
General health difficulty	1 (4)	1 = Long-term illness or disability
Mental health difficulty	0 (2); 1 (4)	For all 12 questions below: Binary Variable (0-1). 1 = if provide one of the two more negative replies to the question
Whether recently been able to concentrate (Recently able to concentrate)		
Whether recently been able to enjoy day to day activities (Recently enjoyed activities)		
Whether recently been able to face up to problems (Recently faced up to problems)		
Whether recently been feeling reasonably happy (Recently felt happy)		

Variable (abbreviation)*	Time period (Wave)	Description
		Whether recently been losing confidence (Recently losing confidence)
		Whether recently been thinking of themselves as a worthless person (Recently felt worthless)
		Whether recently felt capable of making decisions about things (Recently made decisions)
		Whether recently felt constantly under strain (Recently under strain)
		Whether recently felt couldn't overcome difficulties (Recent difficulties)
		Whether recently felt they have played a useful part in things (Recently not useful)
		Whether recently felt unhappy and depressed (Recently felt unhappy)
		Whether recently lost sleep over worry (Recently lost sleep)
<b>Additional covariates</b>		
Either parent ill	0 (1); 1 (4)	Binary Variable (0-1). 1 = One or more of the young person's parents has a longstanding illness, disability or infirmity
Ethnicity: Not white	0 (1)	Binary Variable (0-1). 1 = Not white
Gender: Male	0 (1)	Binary Variable (0-1). 1 = Male
Base Category Household Socioeconomic Status: Managerial/Professional	0 (2); 1 (4)	
Household Socioeconomic Status: Intermediate (Household: Intermediate)	0 (2); 1 (4)	Binary Variable (0-1). 1 = household reference person has an occupation classified as Intermediate according to the National Statistics Socioeconomic Classification.
Household Socioeconomic Status: Routine/Manual (Household: Routine/Manual)	0 (2); 1 (4)	Binary Variable (0-1). 1 = household reference person has an occupation classified as Routine or Manual according to the National Statistics Socioeconomic Classification.
Household Socioeconomic Status: Unemployed (Household: Unemployed)	0 (2); 1 (4)	Binary Variable (0-1). 1 = household reference person is unemployed.
Local Index of Multiple Deprivation (as above)	0 (2); 1 (3)	Integer variable: Higher score indicates a higher level of local area deprivation. To aid convergence the values for this variable are scaled by dividing by 10 <sup>++</sup>
Months younger than oldest in year (as above)	0 (1)	Ordered integer variable (0-11). 0 is September 1989, 11 is August 1990
Base Category: Mother's Highest Qualification: A level or above	0 (1)	
Mother's Highest Qualification: GCSE or lower level qualification (Mother: GCSE/lower qualification)	0 (1)	Binary Variable (0-1). 1 = Mother's highest qualification are GCSE or lower qualifications
Mother's Highest Qualification: No Qualification (Mother: no qualification)	0 (1)	Binary Variable (0-1). 1 = Mother has no formal qualifications
Number of dependent children in same household as the	0 (2)	Ordered integer variable (1-10).

Variable (abbreviation)*	Time period (Wave)	Description
young person (Number of children in household)		
Parent's rating of the young person's school (Parental rating of school)	0 (1)	Binary Variable (0-1). 1= parent responds but neither affirms the school as "good" or "very good"
Single parent household (as above) ****	0 (1); 1 (4)	Binary Variable (0-1). 1 = do not have two parents in household
Likelihood of young person applying to university (University plans)	0 (2); 1 (3)	Binary Variable (0-1). 1 if the young person responds but does not affirm they think it "fairly likely" or "very likely" that they will apply to university.
What the parent thinks the young person will do after compulsory education (Parent thinks YP will do)	0 (2); 1 (3)	Binary Variable (0-1). 1 if the parent responds but does not affirm they think the young person will stay in education when they finish compulsory education.
Whether young person ever tried cannabis (Ever tried cannabis)	0 (2); 1 (4)	Binary Variable (0-1). 1 if the young person has ever tried cannabis.
Whether young person is in a relationship (Not in relationship)	2 (7)	Binary Variable (0-1). 1 if the young person is not in a relationship
Young person has own child (Have own child)	2 (7)	Binary Variable (0-1). 1 if the young person has their own child
<i>Locus of control</i>		
<u>Locus of control (LC): Decide what will happen in my life (LC: Decide what happens)</u>	0 (2); 2 (7)	Ordered categorical variable (0-4). Young person's agreement with statement "I can pretty much decide what will happen in my life" 0 if strongly agree, 4 if strongly disagree.
<u>Locus of control: If someone is not a success it's usually their fault (LC: Failure their fault)</u>	0 (2); 2 (7)	Ordered categorical variable (0-4). Young person's agreement with statement "If someone is not a success in life, it is usually their own fault" 0 if strongly agree, 4 if strongly disagree.
<u>Locus of control: If you work hard at something you'll usually succeed (LC: Work hard usually succeed)</u>	0 (2); 2 (7)	Ordered categorical variable (0-4). Young person's agreement with statement "If you work hard at something you'll usually succeed" 0 if strongly agree, 4 if strongly disagree.

**Notes:** \*Latent variables are italicised (indicator variables used in the measurement models are underlined); + The publicly available LSYPE1 data does not include whether individuals did or did not achieve a C at GCSE Science. ++ To aid convergence the Mplus designers recommend scaling variables of a continuous nature by a constant of sufficient magnitude to bring their variance to a value of between 1-10 (Muthen, 2010). \*\*\* The examples listed are the same in wave 1 and wave 4 "How often do you do sports like football, aerobics, dance classes or swimming". In the wave 7 questionnaire, the examples for the equivalent variable differ "How often do you do any kind of physical exercise? This could include things like cycling, going to the gym, going for long walks, dance classes, playing football or any other kind of sports?"; \*\*\*\* For the analytic sample, this group is disproportionately composed of individuals in a single parent household however to avoid losing from the analytic sample individuals with an unconventional family context a value of 1 is also attributed to those in a household where there was no mother or father (in wave 1 this applies to 38 out of the 5,000 individuals; in wave 4 it applies to 76 of the 5,000 individuals).

Table C-2: Descriptive statistics for all covariates included in the analyses

Variable	Observed	Mean	S.D.*	Minimum	Maximum
<b>Health Variables</b>					
<b>t=0 (Age 13-15)</b>					
General health difficulty	5,000	0.06	-	0	1
Mental health difficulty (GHQ-12)+					
Recently lost sleep	4,877	0.19	-	0	1
Recently under strain	4,785	0.27	-	0	1
Recent difficulties	4,741	0.19	-	0	1
Recently felt unhappy	4,870	0.24	-	0	1
Recently losing confidence	4,891	0.19	-	0	1
Recently felt worthless	4,873	0.12	-	0	1
Recently able to concentrate	4,903	0.14	-	0	1
Recently not useful	4,526	0.09	-	0	1
Recently made decisions	4,840	0.06	-	0	1
Recently enjoyed activities	4,916	0.10	-	0	1
Recently faced up to problems	4,894	0.08	-	0	1
Recently felt happy	4,792	0.11	-	0	1
<b>t=1 (Age 15-17)</b>					
General health difficulty	5,000	0.07	-	0	1
Mental health difficulty (GHQ-12)+					
Recently lost sleep	4,958	0.24	-	0	1
Recently under strain	4,957	0.33	-	0	1
Recent difficulties	4,945	0.22	-	0	1
Recently felt unhappy	4,944	0.27	-	0	1
Recently losing confidence	4,969	0.19	-	0	1
Recently felt worthless	4,961	0.12	-	0	1
Recently able to concentrate	4,984	0.15	-	0	1
Recently not useful	4,913	0.11	-	0	1
Recently made decisions	4,977	0.07	-	0	1
Recently enjoyed activities	4,986	0.14	-	0	1
Recently faced up to problems	4,976	0.10	-	0	1
Recently felt happy	4,959	0.12	-	0	1
<b>Variables for valued abilities and skills</b>					
<b>t=0 (Age 13-15)</b>					
English SATs score++,^	4,913	-11.38	1.97	-15.70	-7.00
Maths SATs score++,^	4,959	-12.24	2.51	-17.72	-5.00
Science SATs score++,^	4,954	-11.40	2.12	-15.82	-5.00
No sport	5,000	0.19	-	0	1
Called names	4,939	0.31	-	0	1
Excluded from group	4,969	0.16	-	0	1
Robbed	4,983	0.03	-	0	1
<b>t=1 (Age 15-17)</b>					
GCSE points++,^	5,000	-3.94	1.49	-10.64	0.00
GCSE English fail	5,000	0.36	-	0	1
GCSE Maths fail	5,000	0.40	-	0	1
No sport	5,000	0.45	-	0	1
Called names	4,977	0.15	-	0	1
Excluded from group	4,980	0.11	-	0	1
Robbed	4,994	0.01	-	0	1
<b>t=2 (Age 19-20)</b>					
NEET <sup>§</sup>	5,000	0.14	-	0	1
No physical activity	5,000	0.19	-	0	1
Few close friends	5,000	0.32	-	0	1

Variable	Observed	Mean	S.D.*	Minimum	Maximum
<b>Subjective well-being (Age 19-20)</b>					
Not satisfied with life	5,000	0.21	-	0	1
<b>Additional covariates</b>					
<b>t=0 (Age 13-15)</b>					
Either parent ill	5,000	0.31	-	0	1
Ethnicity: Not white	5,000	0.13	-	0	1
Gender: Male	5,000	0.50	-	0	1
Household: Intermediate	5,000	0.16	-	0	1
Household: Routine/Manual	5,000	0.38	-	0	1
Household: Unemployed	5,000	0.03	-	0	1
LC: Decide what happens	4,976	1.57	-	0	4
LC: Failure their fault	4,969	1.64	-	0	4
LC: Work hard usually succeed	4,992	0.77	-	0	4
Local Index of Multiple Deprivation^	5,000	2.13	1.59	0.1	8.0
Months younger than oldest in year	5,000	5.61	-	0	11
Mother: GCSE/lower qualification	5,000	0.43	-	0	1
Mother: no qualification	5,000	0.16	-	0	1
Number children in household	5,000	2.10	-	1	10
Parental rating of school	5,000	0.11	-	0	1
Single parent household	5,000	0.23	-	0	1
University plans	5,000	0.38	-	0	1
Parent thinks YP will do	5,000	0.27	-	0	1
Ever tried cannabis	5,000	0.18	-	0	1
<b>t=1 (Age 15-17)</b>					
Either parent ill	5,000	0.23	-	0	1
Household: Managerial/Professional	5,000	0.36	-	0	1
Household: Intermediate	5,000	0.20	-	0	1
Household: Routine/Manual	5,000	0.28	-	0	1
Household: Unemployed	5,000	0.16	-	0	1
Local Index of Multiple Deprivation^	5,000	2.13	1.59	0.10	8.00
Single parent household	5,000	0.26	-	0	1
University plans	5,000	0.40	-	0	1
Parent thinks YP will do	5,000	0.21	-	0	1
Ever tried cannabis	5,000	0.37		0	1
<b>t=2 (Age 19-20)</b>					
Have own child	5,000	0.05	-	0	1
LC: Decide what happens	4,996	1.67	-	0	4
LC: Failure their fault	4,994	2.07	-	0	4
LC: Work hard usually succeed	5,000	0.81	-	0	4
Not in relationship	5,000	0.47	-	0	1

**Notes:** \$ "Not in Education, Employment or Training"; \*Standard deviations are only reported for continuous variables; + As summarised in 8.2.3.1, consistent with the findings of Goldberg et al. (1997), the GHQ-12 items are coded as binary rather than Likert variables. Each indicator variable in the GHQ-12 was therefore coded as 0 if the individual provided either of the two possible emotionally positive responses per question and 1 if they provided either of the two possible emotionally negative responses. ++ These test scores have been multiplied by minus one so that worse tests results are given higher values (see 2.2); ^ The values reported here have been scaled. As mentioned below Table C-1, to aid convergence: (i) the raw SATs scores are divided by 3; (ii) the total GCSE points score is divided by 100; and (iii) the Local Index of Multiple Deprivation scores are divided by 10. Doing so brings each variable's variance to within the range of 1-10 as recommended to aid convergence (Muthen, 2010).

### C.3. Comparison of the results estimated by the three SEMs

As mentioned in 8.2.2.4, in order to estimate a SEM which explicitly attempts to account for unobserved heterogeneity (model 3), I make two substantive changes to the expanded SEM (model 1). I first reduce the model to having one autoregressive path, and second attempt to explicitly account for time invariant unobserved heterogeneity. While of limited intrinsic interest, I therefore also estimated an “intermediate SEM” (model 2) in which no attempt was made to explicitly incorporate time invariant heterogeneity but the SEM was reduced to having one rather than three autoregressive paths. In Table C-3, I present the coefficients of primary interest to the study that are estimated by all three SEMs (i.e. to aid the comparison I only present the coefficients relating to the “skills for employment” autoregressive path and the SWB regression).

Table C-3: Comparison of the results of primary interest as estimated by the three SEMs

Dependent variable (latent variables italicised)	Explanatory variable (latent variables italicised)	Model 1 <sup>+</sup> (expanded SEM)	Model 2 <sup>+</sup> (reduced SEM, no UH)	Model 3 <sup>+</sup> (reduced SEM with UH)
<i>Low academic ability</i> t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.75***	0.75***	0.81***
	No sport (t=0)	0.19***	0.17***	0.18***
	<i>Relational exclusion (t=0)</i>	0.03	0.04*	0.01
	General health difficulty (t=0)	0.45***	0.46***	0.44***
	<i>Mental health difficulty (t=0)</i>	0.01	0.00	-0.04
NEET t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.25***	0.24***	0.40***
	No sport (t=1)	0.04	0.09	0.09
	<i>Relational exclusion (t=1)</i>	0.24***	0.23***	0.11
	General health difficulty (t=1)	0.10	0.10	0.07
	<i>Mental health difficulty (t=1)</i>	-0.05	-0.07*	-0.02
Not satisfied with life t=2 (Age 19-20)	NEET (t=2)	0.34***	0.35***	0.26***
	No physical activity (t=2)	0.08**	0.11**	0.11*
	Few close friends (t=2)	0.18***	0.40***	0.38***
	General health difficulty (t=1)	0.04	0.02	0.07
	<i>Mental health difficulty (t=1)</i>	0.18***	0.19***	0.16***
<b>Model Fit Statistics</b>				
CFI		0.93	0.93	0.94
RMSEA		0.02	0.01	0.02

**Notes:** UH, unobserved heterogeneity; \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. For the continuous variables, the coefficient represents the change in the dependent variable associated with a 1-SD change in the variable. For the binary variables, the coefficient represents the change associated with a shift in the variable from 0 to 1. + As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2745, 2745 and 2736 completed bootstraps for model 1, model 2 and model 3, respectively (out of a requested 2750 for each).



As can be seen by reviewing the results presented in Table C-3, there is generally consistency in the results of primary interest to the study in terms of the coefficients' sign and significance. Concerning the coefficients estimated in all three models, the pattern that holds for any meaningful differences in the estimated coefficients is that those that are significant in model 1 or model 2 may not be when estimated in model 3. There is no meaningful difference in the coefficients for the explanatory variables of primary interest for low academic ability. Concerning the predictors of NEET status when aged 19-20, the one substantive difference is that relational exclusion is not a significant predictor of in model 3 (whereas it is a significant predictor in model 1 and 2). Concerning the predictors of not being satisfied with life, not being physically active is a significant in model 1 and model 2 but not in model 3 (assuming a 5% threshold).

#### C.4. Investigating the representativeness of the analytic sample

In Table C-4 below, I attempt to compare the representativeness of my analytic sample with my best estimate of the age matched general population. To undertake this comparison, I relied predominantly on wave 1 variables either used in the analysis (or the wave 1 equivalents of the wave 2 variables used in the analysis). I then estimated the sample mean and standard deviation of these variables for: (i) all enrolled in the LSYPE using the wave 1 survey weights (this acted as a proxy for the values that would be expected in the age matched general population); and (ii) my analytic sample using the wave 7 survey weights<sup>65</sup>.

In order to obtain an estimate of whether there was a significant difference between the populations, I then undertook a Chi-squared test between the "general population" and analytic samples' distributions for those variables what are dichotomous. For variables that were continuous or integers, I employed a two sample T-Test<sup>66</sup>.

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<sup>65</sup> The slight exception to this is mental health. Generally, for simplicity and consistency, I only included wave 1 variables for this exploratory exercise however given the importance of health to the analysis and the absence of wave 1 variables relating to mental health I drew on the wave 2 data to estimate the general population prevalence of mental health difficulties. For the purposes of simplicity, I did not use a latent variable approach but rather incorporated mental health in this analysis as a binary variable. Individuals were therefore either characterised as being at risk or not according to whether their total score was above the threshold of three. This threshold was based on the findings of the U.K. centre included in the study by Goldberg et al. (1997)

<sup>66</sup> Certain assumptions required for the T-Test are not strictly met by all the integer and continuous variables (particularly the assumption of normality). I did not undertake a Mann-Whitney U Test because: (i) the aim of this exploratory exercise was merely to gain an approximate sense of

Table C-4: Comparing the analytic sample with an estimate of the general population

Variable	Wave	Mean (estimate of general population)	Mean (base case analytic sample)	Significant difference
<b>Health Variables</b>				
General health difficulty <sup>^</sup>	1	0.15	0.13	***
Mental health difficulty (GHQ-12) <sup>^</sup>	2	0.18	0.18	
<b>Variables for valued abilities and skills</b>				
English SATs score <sup>+, ^^</sup>	1	-11.11	-11.38	***
Maths SATs score <sup>+, ^^</sup>	1	-11.94	-12.24	***
Science SATs score <sup>+, ^^</sup>	1	-11.11	-11.40	***
No sport	1	0.20	0.19	
Called names	1	0.30	0.31	*
Excluded from group	1	0.17	0.16	
Robbed	1	0.03	0.03	
<b>Additional covariates</b>				
Either parent ill	1	0.30	0.31	
Ethnicity: Not white	1	0.14	0.13	***
Gender: Male	1	0.52	0.50	**
Household: Intermediate <sup>^</sup>	1	0.20	0.20	
Household: Routine/Manual <sup>^</sup>	1	0.37	0.36	
Household: Unemployed <sup>^</sup>	1	0.04	0.03	***
Months younger than oldest in year	1	5.60	5.61	
Mother: GCSE/lower qualification	1	0.42	0.43	**
Mother: no qualification	1	0.19	0.16	***
Number of children in household	1	2.25	2.21	**
Parental rating of school	1	0.12	0.11	**
Single parent household	1	0.25	0.23	**
University plans <sup>^</sup>	1	0.35	0.32	***
Parent thinks YP will do <sup>^</sup>	1	0.31	0.29	***

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. <sup>^</sup> These variables are not identical to those employed in the quantitative analyses but instead are proxies that rely solely on wave 1 variables; <sup>^^</sup> This variable differs from the approach used in the analyses, see footnote 66 for further details; + these test scores have been multiplied by minus one so that worse tests results are given higher values (see 8.2.3.2). <sup>^^</sup> The values reported here have been scaled. As mentioned below Table C-1, to aid convergence the raw SATs scores are divided by 3. Doing so brings each variable's variance to within the range of 1-10 as recommended to aid convergence (Muthen, 2010).

As discussed in 8.4.1, the table above indicates that with respect to certain variables there are likely differences between the age matched general population and the analytic sample. This should not undermine the robustness of any inferences made as long as any differences are restricted to the observed variables included as covariates within the analyses.

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whether the analytic sample population was equivalent to the general population sample; and (ii) because there was no readily implementable way to undertake the Mann-Whitney U test with weighted survey data.

## C.5. Investigating the impact of varying the approach to “don’t know” responses

### *Summary of approach adopted in the base case analysis*

As mentioned briefly in 8.2.2.6, in my base case analysis, I avoid demarcating “don’t know” responses as “missing” if there is a clear rationale for considering the responses to be informative. I consider the “don’t know” responses to have potential meaning for variables relating to educationally orientated aspirations, locus of control and relational exclusion. Table C-5 below summarises the approach implemented in the base case for these variables.

*Table C-5: Base case approach to “don’t know” responses*

<b>Category of variable</b>	<b>Abbreviated name of variable*</b>	<b>Time period (Wave)</b>	<b>Approach adopted to “don’t know” response</b>	<b>Rationale</b>
Educationally orientated aspirations	Parent thinks YP will do	0 (2); 1 (3)	Coded as “1” (indicating no clear signal of aspiration)	Arguably the parent (for the first variable) and the young person (for the second variable) not knowing whether the young person will stay in education or apply to university indicates a potentially low level of (educationally orientated) aspiration. “1” is therefore interpreted as the absence of a clear signal of educationally orientated aspiration. “0” is interpreted as the presence of a clear signal of educationally orientated aspirations.
	University plans	0 (2); 1 (3)		
Locus of control	LC: Decide what happens	0 (2); 2 (7)	The variable as a whole has five categories; individuals who responded “don’t know” were allocated to the central category	Given the use of the Likert scale and the absence of a “neither agree or disagree” option for the respondents it is reasonable to assume those who responded “don’t know” were ambivalent between the responses aligned with having external and internal locus of control.
	LC: Failure their fault	0 (2); 2 (7)		
	LC: Work hard usually succeed	0 (2); 2 (7)		
Relational exclusion	Called names	0 (1); 1 (3)	Coded as “0” (indicating no clear signal of relational exclusion)	The individual responded to these questions in the “self-completion” portion of the interviews. They therefore knew the interviewer could not see their responses. As such, if the individual did not recall one of these events happening in the
	Excluded from group	0 (1); 1 (3)		
	Robbed	0 (1); 1 (3)		

Category of variable	Abbreviated name of variable*	Time period (Wave)	Approach adopted to “don’t know” response	Rationale
				last 12 months, there is reason to believe they are generally not experiencing the same level of relational exclusion as those that do affirm that one of these events has happened. “1” is therefore interpreted as a clear signal or the given form of relational exclusion. “0” is interpreted as the absence of a clear signal of the given form of relational exclusion.

Notes: \*See Table C-1 for a full description of the variable.

As a robustness check, I instead coded all the variables listed in Table C-5 as missing if the participant responded “don’t know” to the related question. Table C-6 below compares the analytic samples used in the base case analyses and the robustness check. The same methods were used to undertake the tests of statistical significance as were employed to populate Table C-4. However, in Table C-6, for both the base case analytic sample and the robustness check analytic sample, I use the wave 7 sampling weights<sup>67</sup>. The comparison below is undertaken for all the variables of primary interest to the base case analysis. The table indicates that there is a significant difference between the two samples at the 5% threshold for those variables relating to the accumulation of skills for employment (e.g. test scores and NEET status).

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<sup>67</sup> This is because, in contrast to the analysis reported in C.4, my purpose is no longer to estimate whether there are differences between my analytic sample and the general population (requiring where possible the use of wave 1 variables that are not effected by attrition) but rather to ascertain if changing my approach to the coding of “don’t know” responses substantively alters the composition of my analytic sample with regards the variables of primary interest to the analysis.

Table C-6: Comparison of the analytic samples

Variable	Base case sample		Robustness check sample		Significant difference
	Obs.	Mean	Obs.	Mean	
<b>Health Variables</b>					
<b>t=0 (Age 13-15)</b>					
General health difficulty	5,000	0.06	4,406	0.06	
Mental health difficulty (GHQ-12)+					
Recently lost sleep	4,877	0.19	4,307	0.19	
Recently under strain	4,785	0.27	4,234	0.27	
Recent difficulties	4,741	0.19	4,196	0.19	
Recently felt unhappy	4,870	0.24	4,301	0.24	
Recently losing confidence	4,891	0.19	4,319	0.19	
Recently felt worthless	4,873	0.12	4,296	0.12	
Recently able to concentrate	4,903	0.14	4,324	0.14	
Recently not useful	4,526	0.09	4,012	0.09	
Recently made decisions	4,840	0.06	4,278	0.06	
Recently enjoyed activities	4,916	0.10	4,338	0.10	
Recently faced up to problems	4,894	0.08	4,322	0.08	
Recently felt happy	4,792	0.11	4,243	0.10	
<b>t=1 (Age 15-17)</b>					
General health difficulty	5,000	0.07	4,406	0.07	
Mental health difficulty (GHQ-12)+					
Recently lost sleep	4,958	0.24	4,366	0.25	
Recently under strain	4,957	0.33	4,370	0.34	
Recent difficulties	4,945	0.22	4,358	0.22	
Recently felt unhappy	4,944	0.27	4,355	0.27	
Recently losing confidence	4,969	0.19	4,375	0.19	
Recently felt worthless	4,961	0.12	4,370	0.12	
Recently able to concentrate	4,984	0.15	4,391	0.16	
Recently not useful	4,913	0.11	4,332	0.10	
Recently made decisions	4,977	0.07	4,389	0.07	
Recently enjoyed activities	4,986	0.14	4,395	0.14	
Recently faced up to problems	4,976	0.10	4,384	0.10	
Recently felt happy	4,959	0.12	4,370	0.12	
<b>Variables for valued abilities and skills</b>					
<b>t=0 (Age 13-15)</b>					
English SATs score++,^	4,913	-11.38	4,332	-11.52	***
Maths SATs score++,^	4,959	-12.24	4,371	-12.40	***
Science SATs score++,^	4,954	-11.40	4,369	-11.54	***
No sport	5,000	0.19	4,406	0.18	
Called names	4,939	0.31	4,251	0.32	
Excluded from group	4,969	0.16	4,286	0.17	
Robbed	4,983	0.03	4,366	0.03	
<b>t=1 (Age 15-17)</b>					
GCSE points++,^	5,000	-3.94	4,406	-4.04	***
GCSE English fail	5,000	0.36	4,406	0.33	***
GCSE Maths fail	5,000	0.40	4,406	0.38	***
No sport	5,000	0.45	4,406	0.45	
Called names	4,977	0.15	4,387	0.16	
Excluded from group	4,980	0.11	4,391	0.10	
Robbed	4,994	0.01	4,403	0.01	
<b>t=2 (Age 19-20)</b>					
NEET <sup>§</sup>	5,000	0.14	4,406	0.12	**
No physical activity	5,000	0.19	4,406	0.19	
Few close friends	5,000	0.32	4,406	0.31	
<b>Subjective well-being (Age 19-20)</b>					
Not satisfied with life	5,000	0.21	4,381	0.20	*

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. Obs. is observations; \$ “Not in Education, Employment or Training”; + As summarised in 8.2.3.1, consistent with the findings of Goldberg et al. (1997), the GHQ-12 items are coded as binary rather than Likert variables. Each indicator variable in the GHQ-12 was therefore coded as 0 if the individual provided either of the two possible emotionally positive responses per question and 1 if they provided either of the two possible emotionally negative responses. ++ These test scores have been multiplied by minus one so that worse tests results are given higher values (see 8.2.3.2); ^ The values reported here have been scaled. As mentioned below the variable description table in appendix C, Table C-1, to aid convergence, the raw SATs scores are divided by 3 and the total GCSE points score is divided by 100 – doing so brings each variable’s variance to within the range of 1-10 as recommended to aid convergence (Muthen, 2010).

Table C-7 below reports the coefficients when the expanded SEM is estimated using the analytic sample generated by coding all “don’t know” responses as missing (Model 1: No “don’t know” responses). To facilitate the comparison, I also include the results of the base case expanded SEM (Model 1: base case approach). As reported in 8.2.2.6, a comparison of the base case results with those generated in the robustness check indicates that varying the approach adopted to coding “don’t know” responses to the variables listed in Table C-5 has little impact on the substantive findings of the analysis. Of all the coefficients of primary interest to the study the only differences are that in the analyses undertaken as a robustness check: (i) a general health difficulty aged 14-15 is predictive of increased relational exclusion aged 15-16; and (ii) a mental health difficulty aged 16-17 is predictive of undertaking no physical activity when aged 19-20. In the base case analysis, neither of these coefficients is significant at a 5% threshold.

Table C-7: Comparison of the direct associations of primary interest (expanded SEM)

<b>Dependent variable (latent variables italicised)</b>	<b>Explanatory variable (latent variables italicised)</b>	<b>Model 1: Base case approach<sup>+</sup></b>	<b>Model 1: No “don’t know” responses<sup>+</sup></b>
<i>Low academic ability</i> <i>t=1 (Age 15-16)</i>	<i>Low academic ability (t=0)</i>	0.75***	0.76***
	No sport (t=0)	0.19***	0.14**
	<i>Relational exclusion (t=0)</i>	0.03	0.04
	General health difficulty (t=0)	0.45***	0.44***
	<i>Mental health difficulty (t=0)</i>	0.01	0.00
	Gender: male	0.07*	0.05
<i>No sport</i> <i>t=1 (Age 16-17)</i>	<i>Low academic ability (t=0)</i>	-0.03	-0.04
	No sport (t=0)	0.68***	0.68***
	<i>Relational exclusion (t=0)</i>	0.09**	0.08**
	General health difficulty (t=0)	0.11	0.14
	<i>Mental health difficulty (t=0)</i>	0.01	0.02
	Gender: male	-0.67***	-0.67***
<i>Relational exclusion</i> <i>t=1 (Age 15-16)</i>	<i>Low academic ability (t=0)</i>	0.03	0.03
	No sport (t=0)	0.21***	0.25***
	<i>Relational exclusion (t=0)</i>	0.50***	0.51***
	General health difficulty (t=0)	0.25*	0.33**
	<i>Mental health difficulty (t=0)</i>	0.33***	0.33***
	Gender: male	-0.37***	-0.39***
NEET	<i>Low academic ability (t=1)</i>	0.25***	0.24***

Dependent variable (latent variables italicised)	Explanatory variable (latent variables italicised)	Model 1: Base case approach <sup>+</sup>	Model 1: No “don’t know” responses <sup>+</sup>
t=2 (Age 19-20)	No sport (t=1)	0.04	0.00
	<i>Relational exclusion (t=1)</i>	0.24***	0.28***
	General health difficulty (t=1)	0.10	0.04
	<i>Mental health difficulty (t=1)</i>	-0.05	-0.05
	Gender: male	0.15**	0.14*
No physical activity t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	-0.04	-0.03
	No sport (t=1)	0.42***	0.46***
	<i>Relational exclusion (t=1)</i>	-0.05	-0.07
	General health difficulty (t=1)	-0.21*	-0.14
	<i>Mental health difficulty (t=1)</i>	0.05	0.07**
	Gender: male	-0.30***	-0.26***
Few close friends t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.06**	0.08***
	No sport (t=1)	0.13***	0.12***
	<i>Relational exclusion (t=1)</i>	0.06	0.06
	General health difficulty (t=1)	0.00	-0.03
	<i>Mental health difficulty (t=1)</i>	0.08***	0.09**
	Gender: male	-0.13**	-0.14**
Not satisfied with life t=2 (Age 19-20)	NEET (t=2)	0.34***	0.38***
	No physical activity (t=2)	0.08**	0.08**
	Few close friends (t=2)	0.18***	0.19***
	General health difficulty (t=1)	0.04	0.07
	<i>Mental health difficulty (t=1)</i>	0.18***	0.15***
	Gender: male	0.12**	0.16***
<b>Model Fit Statistics</b>			
CFI		0.93	0.93
RMSEA		0.02	0.02

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. For the continuous variables, the coefficient represents the change in the dependent variable associated with a 1-SD change in the variable. For the binary variables, the coefficient represents the change associated with a shift in the variable from 0 to 1. + As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,745 and 2,730 completed bootstraps for the models adopting the “base case” and “No don’t know responses” approaches, respectively (out of a requested 2,750 for each).

## C.6. Full results for the base case analyses

Table C-8: Direct associations in the structural model (expanded SEM)

Dependent variable (latent variables italicised) <sup>+</sup>	Explanatory variable (latent variables italicised)	Association <sup>++</sup>
<i>Low academic ability</i> t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.75***
	No sport (t=0)	0.19***
	<i>Relational exclusion (t=0)</i>	0.03
	General health difficulty (t=0)	0.45***
	<i>Mental health difficulty (t=0)</i>	0.01
	Either parent ill (t=0)	0.05
	Ethnicity: Not white (t=0)	0.12**
	Gender: Male (t=0)	0.07*

Dependent variable (latent variables italicised) <sup>+</sup>	Explanatory variable (latent variables italicised)	Association <sup>++</sup>
	Household: Intermediate (t=0)	0.12**
	Household: Routine/Manual (t=0)	0.26***
	Household: Unemployed (t=0)	0.68***
	Local Index of Multiple Deprivation (t=0)	0.00
	<i>Locus of control (t=0)</i>	0.05**
	Months younger than oldest in year (t=0)	0.09***
	Mother: GCSE/lower qualification (t=0)	0.18***
	Mother: no qualification (t=0)	0.42***
	Number of children in household (t=0)	0.03
	Parental rating of school (t=0)	0.34***
	Single parent household (t=0)	0.15*
	University plans (t=0)	0.38***
	Parent thinks YP will do (t=0)	0.40***
	Ever tried cannabis (t=0)	0.08
	No sport t=1 (Age 16-17)	<i>Low academic ability (t=0)</i>
No sport (t=0)		0.68***
<i>Relational exclusion (t=0)</i>		0.09**
General health difficulty (t=0)		0.11
<i>Mental health difficulty (t=0)</i>		0.01
Either parent ill (t=0)		0.06
Ethnicity: Not white (t=0)		-0.10*
Gender: Male (t=0)		-0.67***
Household: Intermediate (t=0)		-0.09
Household: Routine/Manual (t=0)		-0.02
Household: Unemployed (t=0)		-0.02
Local Index of Multiple Deprivation (t=0)		-0.08
<i>Locus of control (t=0)</i>		0.10***
Months younger than oldest in year (t=0)		0.01
Mother: GCSE/lower qualification (t=0)		0.13***
Mother: no qualification (t=0)		0.14**
Number of children in household (t=0)		-0.03
Parental rating of school (t=0)		0.10
Single parent household (t=0)		-0.01
Ever tried cannabis (t=0)		-0.03



Dependent variable (latent variables italicised)*	Explanatory variable (latent variables italicised)	Association**
<i>Relational exclusion</i> t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.03
	No sport (t=0)	0.21***
	<i>Relational exclusion (t=0)</i>	0.50***
	General health difficulty (t=0)	0.25*
	<i>Mental health difficulty (t=0)</i>	0.33***
	Either parent ill (t=0)	0.03
	Ethnicity: Not white (t=0)	-0.09
	Gender: Male (t=0)	-0.37***
	Household: Intermediate (t=0)	0.02
	Household: Routine/Manual (t=0)	0.00
	Household: Unemployed (t=0)	-0.06
	Local Index of Multiple Deprivation (t=0)	-0.30
	<i>Locus of control (t=0)</i>	-0.09
	Months younger than oldest in year (t=0)	0.05*
	Mother: GCSE/lower qualification (t=0)	0.05
	Mother: no qualification (t=0)	0.07
	Number of children in household (t=0)	-0.01
	Parental rating of school (t=0)	0.06
	Single parent household (t=0)	-0.01
	Ever tried cannabis (t=0)	0.17*
NEET t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.25***
	No sport (t=1)	0.04
	<i>Relational exclusion (t=1)</i>	0.24***
	General health difficulty (t=1)	0.1
	<i>Mental health difficulty (t=1)</i>	-0.05
	Either parent ill (t=1)	0.00
	Ethnicity: Not white (t=0)	0.01
	Gender: Male (t=0)	0.15**
	Household: Intermediate (t=1)	-0.05
	Household: Routine/Manual (t=1)	-0.06
	Household: Unemployed (t=1)	0.18**
	Local Index of Multiple Deprivation (t=1)	0.39***
	<i>Locus of control (t=2)</i>	0.07**
	Single parent household (t=1)	0.29***
	University plans (t=1)	0.22***
	Parent thinks YP will do (t=1)	0.01
	Ever tried cannabis (t=1)	0.15**
	Not in relationship (t=2)	0.18***
	Have own child (t=2)	0.84***
	No physical activity t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>
No sport (t=1)		0.42***
<i>Relational exclusion (t=1)</i>		-0.05
General health difficulty (t=1)		-0.21*
<i>Mental health difficulty (t=1)</i>		0.05

	Either parent ill (t=1)	-0.04
	Ethnicity: Not white (t=0)	-0.02
	Gender: Male (t=0)	-0.30***
	Household: Intermediate (t=1)	-0.09
	Household: Routine/Manual (t=1)	-0.16**
	Household: Unemployed (t=1)	0.01
	Local Index of Multiple Deprivation (t=1)	0.05
	<i>Locus of control (t=2)</i>	0.08**
	Single parent household (t=1)	-0.11
	Ever tried cannabis (t=1)	0.16**
	Not in relationship (t=2)	0.02
	Have own child (t=2)	-0.34***
Few close friends t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.06**
	No sport (t=1)	0.13***
	<i>Relational exclusion (t=1)</i>	0.06
	General health difficulty (t=1)	0.00
	<i>Mental health difficulty (t=1)</i>	0.08***
	Either parent ill (t=1)	0.00
	Ethnicity: Not white (t=0)	0.04
	Gender: Male (t=0)	-0.13**
	Household: Intermediate (t=1)	0.02
	Household: Routine/Manual (t=1)	0.12**
	Household: Unemployed (t=1)	0.15**
	Local Index of Multiple Deprivation (t=1)	0.23*
	<i>Locus of control (t=2)</i>	0.07**
	Single parent household (t=1)	-0.10
	Ever tried cannabis (t=1)	-0.10*
	Not in relationship (t=2)	-0.01
Have own child (t=2)	0.43***	
Not satisfied with life t=2 (Age 19-20)	NEET (t=2)	0.34***
	No physical activity (t=2)	0.08**
	Few close friends (t=2)	0.18***
	General health difficulty (t=1)	0.04
	<i>Mental health difficulty (t=1)</i>	0.18***
	Either parent ill (t=1)	0.08
	Ethnicity: Not white (t=0)	0.06
	Gender: Male (t=0)	0.12**
	Household: Intermediate (t=1)	0.09
	Household: Routine/Manual (t=1)	-0.05
	Household: Unemployed (t=1)	0.12
	Local Index of Multiple Deprivation (t=1)	0.04
	<i>Locus of control (t=2)</i>	0.20***
	Single parent household (t=1)	0.12
	Ever tried cannabis (t=1)	0.14**
	Not in relationship (t=2)	0.23***
Have own child (t=2)	-0.70***	
<b>Model Fit Statistics</b>		
CFI		0.93

RMSEA	0.02
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**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. For the continuous variables, the coefficient represents the change in the dependent variable associated with a 1-SD change in the variable. For the binary variables, the coefficient represents the change associated with a shift in the variable from 0 to 1. + The age ranges provided are specific to each dependent variable. For the T = 1 dependent variables, they therefore vary as though in the same model time period the “No physical activity variable is from wave 4 of the LSYPE1 rather than wave 3. ++ As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,745 completed bootstraps for this model (out of a requested 2,750).

Table C-9: Coefficients for the measurement models (expanded SEM)

Latent variable	Indicator	Association <sup>+</sup>
<i>Low academic ability</i> <i>t=0 (Age 13-14)</i>	English SATs score	0.77***
	Maths SATs score <sup>++</sup>	0.86 <sup>(N.A.)</sup>
	Science SATs score	0.92***
<i>Relational exclusion t=0</i> <i>(Age 13-14)</i>	Called names <sup>++</sup>	0.74 <sup>(N.A.)</sup>
	Excluded from group	0.58***
	Robbed	0.54***
<i>Mental health difficulty t=0</i> <i>(Age 14-15)</i>	Recently able to concentrate	0.62***
	Recently enjoyed activities	0.77***
	Recently faced up to problems	0.78***
	Recently felt happy	0.87***
	Recently losing confidence	0.80***
	Recently felt worthless	0.80***
	Recently made decisions	0.67***
	Recently under strain	0.67***
	Recent difficulties	0.74***
	Recently not useful	0.61***
	Recently felt unhappy <sup>++</sup>	0.86 <sup>(N.A.)</sup>
	Recently lost sleep	0.69***
<i>Locus of control t=0</i> <i>(Age 14-15)</i>	LC: Decide what happens	0.29***
	LC: Failure their fault	0.44***
	LC: Work hard usually succeed <sup>++</sup>	0.53 <sup>(N.A.)</sup>
<i>Low academic ability t=1</i> <i>(Age 15-16)</i>	GCSE points <sup>++</sup>	0.87 <sup>(N.A.)</sup>
	GCSE English pass	0.84***
	GCSE Maths pass	0.89***
<i>Relational exclusion t=1</i> <i>(Age 15-16)</i>	Called names <sup>++</sup>	0.84 <sup>(N.A.)</sup>
	Excluded from group	0.69***
	Robbed	0.67***
<i>Mental health difficulty t=1</i> <i>(Age 16-17)</i>	Recently able to concentrate	0.62***
	Recently enjoyed activities	0.66***
	Recently faced up to problems	0.80***
	Recently felt happy	0.84***
	Recently losing confidence	0.80***
	Recently felt worthless	0.77***
	Recently made decisions	0.68***
	Recently under strain	0.71***
	Recent difficulties	0.72***
	Recently not useful	0.69***
Recently felt unhappy <sup>++</sup>	0.81 <sup>(N.A.)</sup>	
Recently lost sleep	0.67***	
<i>Locus of control t=2</i> <i>(Age 19-20)</i>	LC: Decide what happens	0.64***
	LC: Failure their fault	0.45***
	LC: Work hard usually succeed <sup>++</sup>	0.51 <sup>(N.A.)</sup>

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised (post estimation). The coefficient represents the change in the indicator variable associated with a 1-SD change in the underlying latent variable. + As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,745 completed bootstraps for this model (out of a requested 2,750); ++ Loading fixed to 1 during initial model estimation in order to make the measurement model identifiable (as these are fixed to 1 during initial estimation the loadings for these indicators cannot be insignificant).

Table C-10: Direct associations in the structural model (reduced SEM)

Dependent variable (latent variables italicised)	Explanatory variable (latent variables italicised)	Association <sup>+</sup>
Impaired skills for employment t=1 (Age 15-16)	<i>Low academic ability (t=0)</i>	0.81***
	No sport (t=0)	0.18***
	<i>Relational exclusion (t=0)</i>	0.01
	General health difficulty (t=0)	0.44***
	<i>Mental health difficulty (t=0)</i>	-0.04
	Either parent ill (t=0)	0.07
	Household: Intermediate (t=0)	0.16***
	Household: Routine/Manual (t=0)	0.38***
	Household: Unemployed (t=0)	1.03***
	<i>Locus of control (t=0)</i>	0.03
	Single parent household (t=0)	0.13*
	University plans (t=0)	0.38***
	Parent thinks YP will do (t=0)	0.45***
	Ever tried cannabis (t=0)	0.07
NEET t=2 (Age 19-20)	<i>Low academic ability (t=1)</i>	0.40***
	No sport (t=1)	0.09
	<i>Relational exclusion (t=1)</i>	0.11
	General health difficulty (t=1)	0.07
	<i>Mental health difficulty (t=1)</i>	-0.02
	Either parent ill (t=1)	0.02
	Household: Intermediate (t=1)	-0.04
	Household: Routine/Manual (t=1)	-0.04
	Household: Unemployed (t=1)	0.28***
	<i>Locus of control (t=2)</i>	0.03
	Single parent household (t=1)	0.37***
	University plans (t=1)	0.25***
	Parent thinks YP will do (t=1)	0.08
	Ever tried cannabis (t=1)	0.18***
Not satisfied with life t=2 (Age 19-20)	NEET (t=2)	0.26***
	No physical activity (t=2)	0.11*
	Few close friends (t=2)	0.38***
	General health difficulty (t=1)	0.07
	<i>Mental health difficulty (t=1)</i>	0.16***
	Either parent ill (t=1)	0.06
	Household: Intermediate (t=1)	0.09
	Household: Routine/Manual (t=1)	-0.05
	Household: Unemployed (t=1)	0.15*
	<i>Locus of control (t=2)</i>	0.22***
	Single parent household (t=1)	0.10
Ever tried cannabis (t=1)	0.12**	
<b>Model Fit Statistics</b>		
CFI		0.94

<b>Dependent variable (latent variables italicised)</b>	<b>Explanatory variable (latent variables italicised)</b>	<b>Association<sup>+</sup></b>
RMSEA		0.02

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised. For the continuous variables, the coefficient represents the change in the dependent variable associated with a 1-SD change in the variable. For the binary variables, the coefficient represents the change associated with a shift in the variable from 0 to 1. +As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,736 completed bootstraps for this model (out of a requested 2,750).

Table C-11: Coefficients for the measurement models (reduced SEM)

<b>Latent variable</b>	<b>Indicator</b>	<b>Association<sup>+</sup></b>
<i>Low academic ability</i> <i>t=0 (Age 13-14)</i>	English SATs score	0.78***
	Maths SATs score <sup>++</sup>	0.86 <sup>(N.A.)</sup>
	Science SATs score	0.92***
<i>Relational exclusion t=0</i> <i>(Age 13-14)</i>	Called names <sup>++</sup>	0.80 <sup>(N.A.)</sup>
	Excluded from group	0.61***
	Robbed	0.50***
<i>Mental health difficulty t=0</i> <i>(Age 14-15)</i>	Recently able to concentrate	0.63***
	Recently enjoyed activities	0.76***
	Recently faced up to problems	0.79***
	Recently felt happy	0.86***
	Recently losing confidence	0.81***
	Recently felt worthless	0.81***
	Recently made decisions	0.67***
	Recently under strain	0.69***
	Recent difficulties	0.76***
	Recently not useful	0.61***
	Recently felt unhappy <sup>++</sup>	0.87 <sup>(N.A.)</sup>
	Recently lost sleep	0.71***
<i>Locus of control t=0</i> <i>(Age 14-15)</i>	LC: Decide what happens	0.24***
	LC: Failure their fault	0.55***
	LC: Work hard usually succeed <sup>++</sup>	0.45 <sup>(N.A.)</sup>
<i>Low academic ability</i> <i>t=1 (Age 15-16)</i>	GCSE points <sup>++</sup>	0.87 <sup>(N.A.)</sup>
	GCSE English pass	0.84***
	GCSE Maths pass	0.89***
<i>Relational exclusion t=1</i> <i>(Age 15-16)</i>	Called names <sup>++</sup>	0.82 <sup>(N.A.)</sup>
	Excluded from group	0.67***
	Robbed	0.60***
<i>Mental health difficulty t=1</i> <i>(Age 16-17)</i>	Recently able to concentrate	0.61***
	Recently enjoyed activities	0.66***
	Recently faced up to problems	0.81***
	Recently felt happy	0.84***
	Recently losing confidence	0.81***
	Recently felt worthless	0.76***
	Recently made decisions	0.68***
	Recently under strain	0.73***
	Recent difficulties	0.73***
	Recently not useful	0.67***
	Recently felt unhappy <sup>++</sup>	0.81 <sup>(N.A.)</sup>
Recently lost sleep	0.69***	

Latent variable	Indicator	Association <sup>+</sup>
<i>Locus of control</i> <i>t=2</i> (Age 19-20)	LC: Decide what happens	0.62***
	LC: Failure their fault	0.47***
	LC: Work hard usually succeed <sup>++</sup>	0.52 <sup>(N.A.)</sup>

**Notes:** \*Significant at 10%; \*\*significant at 5%; \*\*\*significant at 1%. All reported coefficients are standardised (post estimation). The coefficient represents the change in the indicator variable associated with a 1-SD change in the underlying latent variable. + As mentioned in 8.2.2.6, empirical confidence intervals are generated with a minimum of 2,500 bootstrap samples – the strengths of association reported in this table are informed by empirical confidence intervals based on the 2,736 completed bootstraps for this model (out of a requested 2,750); ++ Loading fixed to 1 during initial model estimation in order to make the measurement model identifiable (as these are fixed to 1 during initial estimation the loadings for these indicators cannot be insignificant).