Supporting parent-to-child transfer of responsibility for chronic kidney disease: a grounded theory study

Ruth Nightingale

Submitted in accordance with the requirements for the degree of Doctor of Philosophy

The University of Leeds

School of Healthcare

November 2020

INTELLECTUAL PROPERTY AND PUBLICATION STATEMENT

The candidate confirms that the work submitted is their own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

The work in chapter 2 of the thesis has appeared in publication as follows:
Supporting children and young people to assume responsibility from their parents for the self-management of their long-term condition: An integrative review. Nightingale R, McHugh G, Kirk S, Swallow V. (2019). Child Care Health Dev 45:175–188.

I was responsible for conducting the literature searches, study selection, data extraction, quality assessment, data synthesis and drafting the manuscript. The other authors contributed to study selection, data extraction and synthesis. All authors read, contributed to critical revision and approved the final manuscript.

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ACKNOWLEDGEMENTS

I would like to acknowledge a number of people for their contribution to this thesis.

My thanks go firstly to my supervisors, Professor Veronica Swallow, Professor Gretl McHugh and Professor Susan Kirk for their guidance and support over the years. Their expert knowledge and advice during the study have been invaluable.

I am indebted to Kidney Research UK for provision of funding through an Allied Health Professional Fellowship that enabled me to undertake my PhD. Special recognition to my supervisors for their support and encouragement with applying for the Fellowship award, in particular to Professor Veronica Swallow for her mentorship and belief in me.

Sincere thanks go to the young people, parents and professionals who agreed to participate in the study and shared their experiences with me. My gratitude also goes to the clinicians from the two children's renal services who helped with recruitment to the study.

I am grateful to my family, friends and colleagues for their interest in my work, encouragement and reassurance.

Finally, thank you to Steve Rice, for 'being there'.

ABSTRACT

The responsibility for managing a long-term condition (LTC) such as chronic kidney disease (CKD) typically transfers from parent to child, as children become older. However, children can find it challenging to become independent at managing their LTC and evidence for how health care professionals (HCPs) support transfer of responsibility is limited. This study aimed to explore how young people with CKD assume responsibility for managing their condition and the HCP's role during this process.

A constructivist grounded theory approach guided sampling, data collection and analysis. Individual and dyadic interviews, and focus groups, were conducted with 16 young people aged 13-17 years old with CKD, 13 parents and 20 HCPs.

A grounded theory, *shifting responsibilities,* was constructed. Whereas young people and parents viewed transfer of responsibility within a broader context of developing independence in daily activities, HCPs framed it within the narrower context of transition to adult services. This contributed to uncertainty around the HCP role and the process start and endpoint. Young people and parents viewed assumption of responsibility as a natural extension of the 'normal' process, where becoming older involved increased independence. However, parents and HCPs were aware risks associated with developing independence were heightened for young people with CKD. This led to tension around encouraging young people to assume responsibility, while balancing protection and risk. Young people's, parents' and HCPs' actions and interactions resulted in transfer being initiated, and then either sustained or disrupted. When initiating transfer, parents focused on their child 'doing' self-management, whereas HCPs examined young people's CKD knowledge. Despite these differing constructions, young people, parents and HCPs agreed trust was critical to transfer of responsibility.

HCP support over a longer timeframe, that integrates assuming responsibility with gaining independence in other activities, and focuses on young people 'doing' self-management, could benefit families during the transfer process.

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ABBREVIATIONS

CKD	Chronic kidney disease
ESKD	End stage kidney disease
DAH	Developmentally appropriate healthcare
DoH	Department of Health
GRIPP	Guidance for Reporting Involvement of Patients and the Public
HCP	Health care professional
HRA	Health Research Authority
LTC	Long-term condition
MRC	Medical Research Council
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OT	Occupational Therapy/Therapist
PIL	Participant information leaflets
PPI	Patient and Public Involvement
REC	Research Ethics Committee
RRT	Renal replacement therapies
YP	Young person

GLOSSARY

Children and young people:

The 1989 United Nations Convention on the Rights of the Child, defines the child as everyone under 18 years of age (United Nations, 1989). The term 'children' is adopted throughout this thesis when referring collectively to people aged 0-18 years old. However, as this study is focused on 13-18 year olds, the term 'young people' is used when referring to the study participants. This reflects the World Health Organisation's (WHO) use of the term 'young people' to describe people between the ages of 10-24 years (WHO, 2011).

Long-term conditions:

Although the terms are often used interchangeably, 'long-term conditions' (LTCs), rather than chronic disease, chronic conditions, or chronic illness, is used in this thesis as it is the term most widely used in UK health services and policy (DoH, 2012).

Parents:

Throughout this thesis, mothers, fathers, and primary carers are collectively referred to as 'parents'. Of the 13 parents who participated in the study, 11 were mothers, one a step-father, and one a carer. Although it is recognised that gender and role impact on parenting of children with LTCs (Smith et al., 2015), specific information about parent participants is excluded to avoid potential identification.

Self-management:

Although often used interchangeably with the term self-care, self-management is used in this thesis as it is the term most widely used in UK health services and policy, including the NHS Long Term Plan (NHS England, 2019).

1. INTRODUCTION

1.1 Introduction

This thesis focuses on how young people, parents and health care professionals (HCPs) experience the parent-to-child transfer of self-management responsibility for chronic kidney disease (CKD) stages 3-5. It explains the processes occurring as young people assume responsibility and parents relinquish control; what initiates, sustains and disrupts these processes; and the contextual issues that influence the transfer of responsibility.

This introductory chapter provides a context for the study. First, it outlines the author's motivation for conducting the study, followed by a description of childhood long-term conditions (LTCs). Next, the concept of self-management will be examined, including a discussion of the theoretical literature and policy context. As this study is focused on CKD, the characteristics, causes, prevalence, consequences and management of this condition will be outlined. The organisation of children's kidney services in the UK will be described. Finally, this chapter summarises the structure of the thesis, describing how the chapters are organised.

1.2 The author's motivation for conducting the study

As an Occupational Therapist (OT), I am interested in how people engage in occupations, or everyday activities. I have worked as an OT in child and adult community services, and have a particular interest in working with young people around developing skills and independence as they move towards adulthood. In 2011, having completed a MSc while working clinically, I moved into a research role, working on a study exploring how parents of children with CKD learn to share management with HCPs. Since then I have worked on two further studies focused on developing tools and interventions to support children with CKD and their parents with managing their condition. During this time, I also worked in patient and public involvement (PPI) in research at a children's hospital. This study's origins are an integration of these three areas of interest: young people developing independence, shared management of CKD, and PPI.

1.3 Childhood long-term conditions

The number of children with LTCs is significant and growing, with an increasing number now reaching adulthood (Campbell et al., 2016). Various definitions for LTCs exist, however, Mokkink et al's (2008) four criteria are used in this thesis: 1) occurring in children aged 0-18 years 2) diagnosis based on scientific knowledge and established using reproducible and valid methods 3) not (yet) curable 4) present for longer than three months or will, very probably, last longer than three months. Mokkink et al's (2008) definition has been selected as it is child specific and was developed using rigorous methods, including a systematic review, theoretical modelling and a consensus study. Common LTCs in childhood include asthma, diabetes and epilepsy (RCPCH, 2020). While these conditions differ in severity and complexity of treatment regimens, all children with LTCs need to manage and live with their condition throughout their life and require support to achieve their physical, psychological and social potential (While et al., 2004).

1.4 Self-management

Due to the growing prevalence of LTCs, self-management is increasingly recognised as an important component of health care across all age groups (NHS England, 2019). Self-management has been defined in different ways, but is usually viewed as 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' (Barlow et al., 2002 p. 178). This definition has been challenged however, for its focus on the individual, lack of specificity about the activities involved, and for not reflecting the wider contextual influences on self-management (Mammen et al., 2018). Therefore, in recognition of the complexity of self-management and the role of the family, theories that link self-management with family management have been developed (Grey et al., 2015; Ryan and Sawin, 2009). The Self-and Family Management Framework, for example, identifies factors such as resources and the health care system, that can influence the ability to perform self-management (Grey et al., 2015) and has been used to underpin empirical research into childhood LTCs (Ness et al., 2018; Sullivan-Bolyai et al., 2014).

In addition to taking into account contextual factors, consideration of the unique needs of children is important in relation to self-management. Children with LTCs, especially infants and those in early childhood, are not able to manage their own condition, therefore alternative terms, such as 'supported self-management', have been proposed to describe

the role played by others, in particular parents (Saxby et al., 2020). The Shared Management Model suggests that children with LTCs are usually dependent on or share management with their families and are expected to develop age- and developmentally-appropriate self-management skills as they mature (Kieckhefer and Trahms, 2000). By drawing on developmental and leadership theories, this model advocates that the child's and parent's participation in self-management tasks, roles and responsibilities change over time. This means that self-management in childhood 'is a process that involves shifting, shared responsibility between children/adolescents and their parents' (Schilling et al., 2002 p. 9).

The process of children assuming self-management responsibility has been explored theoretically at both a generic (Modi et al., 2012; Reed-Knight et al., 2014; Kieckhefer and Trahms, 2000) and condition-specific level, for example in type 1 diabetes (Hanna and Decker, 2010; Schilling et al., 2002) and asthma (Mammen and Rhee, 2012; Mammen et al., 2018). Common issues identified in both the generic and condition-specific theoretical literature that appear to influence the transfer of responsibility include the: nature of the condition, treatment regimens, interventions, intrapersonal and interpersonal factors. In examining the research-based literature, chapter 2 will discuss these issues in detail.

Although developing self-management skills is part of growing up for many children with LTCs (Kieckhefer and Trahms, 2000), there is evidence that during adolescence young people can find it challenging to follow treatment regimens which can result in poor clinical outcomes (DoH, 2008). Self-management is often complex, requiring the individual to modify their typical habits and routines to accommodate self-management activities; this can be complicated by the developmental changes associated with adolescence (Gardener et al., 2017).

Health care policy and guidance emphasises the importance of children being helped to manage their own LTC (NICE, 2016; DoH, 2006b). Policy has focused on the transition between children's and adult health services as the key period for children to assume self-management responsibility. Competency and/or task checklists outlining what children need to achieve at different stages of transition are recommended (DoH, 2008) and tools, such as 'Ready Steady Go' (Nagra et al., 2015) have been developed and are used in some UK transition services. However, these tools are: not yet based on rigourous evidence; tend to be based on HCPs' expectations without early input from children or parents; and address the wider transition process rather than focusing on self-management (Stinson et al., 2014). There has been increasing recognition that it can be useful to consider self-management

from a developmental perspective; however, to date, only one set of guidelines exist that outline: a) developmentally appropriate self-management tasks that could be completed by children with LTCs, and b) recommend approaches HCPs could use to support children to manage their condition (Saxby et al., 2020). Although this guidance was developed using consensus methods with an expert panel, there were only 16 participants in the study. The expert panel came from three countries (Australia, USA, UK); however, as only three panel members were from the UK and the study was Australian-led which has a different healthcare system to the UK, further research is needed to evaluate its transferability to clinical practice in the UK. Although Saxby et al (2020) recommended gaining feedback from children and parents on the 'format and appropriateness' of the guidance, the exclusion of children and parents in the guideline development stage is also a potential limitation.

Reflecting the policy focus on transition as the framework for considering children's adoption of self-management responsibility, systematic reviews tend to examine the wider transition process, often concentrating on the transfer between children and adult services, rather than focusing on self-management. Although reviews have identified the barriers and facilitators to children's self-management, and specifically the impact of child-parent relationships on this process, the focus has been on adolescents (Lerch and Thrane, 2019; Lindsay et al., 2011). To date, only one review has been conducted that explicitly focused on the parent-to-child transfer of self-management responsibility and which included studies where the sample comprised children younger than ten years old (Leeman et al., 2015). However, due to its focus on cystic fibrosis and the uniqueness of different LTC treatment regimens, research related to other LTCs is indicated (Hanna and Decker, 2010). This study aims to address this gap.

1.5 Chronic kidney disease (CKD)

1.5.1 Characteristics, causes and prevalence of CKD

This study will focus on CKD, a complex LTC related to irreversible kidney damage and with various causes and complications (Harambat et al., 2012). CKD is progressive and can lead to end stage kidney disease (ESKD), which is fatal without renal replacement therapies (RRTs) such as dialysis or kidney transplantation (DoH, 2006a). Patients with CKD can be classified by stages 1-5, based on their glomerular filtration rate (i.e. the rate at which kidneys filter waste products). The higher the stage, the more 'severe' the CKD and therefore the more complex the treatment regimen required (DoH, 2005).

The causes of CKD differ significantly in children compared to adults (Warady and Chadha, 2007). Tubulointerstitial disease, such as congenital anomalies of the kidneys and urinary tract (CAKUT), accounted for over 50% of all renal diseases in children, whereas diabetes and high blood pressure are the two leading causes of CKD in adults (Harmabat et al., 2012). Table 1 shows the primary causes of CKD in children under the age of 16 years old in the UK (UK Renal Registry, 2019).

Table 1: Primary cause of CKD in children (<16 years old)

Primary cause of CKD	Percentage (%) of total cases
Tubulointerstitial disease	49.1
• CAKUT	47.3
• Non-CAKUT	1.8
Glomerular disease	18.1
Familial/hereditary nephropathies	16.3
Systemic diseases affecting the kidney	3.2
Miscellaneous renal disorders	13.3

Most children with CKD tend to present in early childhood, between birth and five years old (DoH, 2005). As CKD is a lifelong condition, early diagnosis is particularly important for children as they have increased risks of developing long-term complications such as hypertension and renal bone disease (DoH, 2006a). However, as few, if any symptoms are associated with early-stage CKD, diagnosis can sometimes occur at a late stage. For example, some children present with ESKD without warning - a group described as 'crash-landers' by kidney services (Ali, 2017).

Partly, due to the difficulties in diagnosing CKD, in particular the early stages, the number of children with CKD is not accurately known and figures are not available for children with CKD stages 1-4 (DoH, 2006a). In the UK, 966 children under the age of 18 years and 64,887 adults have stage 5 CKD and are receiving RRTs (UK Renal Registry, 2019). Table 2 and Table 3 show the prevalence rate by age group, sex and ethnicity for children aged under 16 years old, have CKD stage 5 and are receiving RRTs (UK Renal Registry, 2019). These numbers are calculated per million population (pmarp = per million age-related population).

Table 2: Age and sex breakdown of children (<16 years old) receiving RRTs

Age group (years)	All children		Male		Female		M: F ratio
	N	pmarp	N	pmarp	N	pmarp	
0-2	26	16.7	17	21.3	9	11.9	1.8
2-4	50	31.5	36	44.2	14	18.1	2.4

4-8	173	52.2	124	73.2	49	30.3	2.4
8-12	245	77.1	140	86.0	105	67.8	1.3
12-16	316	109.9	205	139.2	111	79.2	1.8
<16 yrs	**810**	**64.8**	**522**	**81.5**	**288**	**47.2**	**1.7**

The overall RRT prevalence for children under 16 years old is 64.8 per million population. The prevalence of children receiving RRTs increases with age and is higher in boys compared to girls (Table 2) (UK Renal Registry, 2019).

Table 3: Age and ethnicity breakdown of children (<16 years old) receiving RRTs

Age	White	South Asian	Black	Other
0-4	52	8	4	9
4-8	125	26	4	16
8-12	160	49	13	21
12-16	218	62	19	17
Under 16	**555 (69%)**	**145 (18%)**	**40 (5%)**	**63 (8%)**
pmarp <16 yrs	55.0	135.4	73.2	78.9

Children from minority ethnic backgrounds have higher prevalence for receiving RRTs (Table 3) (UK Renal Registry, 2019). For South Asian children, the prevalence of 135.4 per million population is over double the overall RRT prevalence of 64.8 per million population. Although the number of children in the UK with CKD is small, it has significant cost implications and delaying its progression is cost-effective (Trivedi, 2010).

1.5.2 The organisation of UK children's kidney services

Children with CKD stages 1-2 are usually treated within primary care, whereas those with stages 3-5 are treated by specialist renal teams in tertiary centres (DoH, 2006a). In the UK, there are 13 specialist renal centres each with its own dedicated multi-disciplinary team (MDT) (UK Renal Registry, 2019; Dallimore et al., 2018). A 2014 survey indicated that every MDT was comprised of dietitians, doctors, nurses and play specialists, and some MDTs included clinical psychologists, counsellors/therapists, pharmacists and social workers (Swallow et al., 2015). Children between the ages of 16 to 18 years old can be managed in either paediatric or adult renal services, and is determined by local practices, the child's age when they presented to renal services and the needs and preferences of the family (UK Renal Registry, 2019).

1.5.3 Consequences and management of CKD

Various clinical features and consequences are associated with CKD. One of the most common impacts of CKD, that is specific to children, is growth impairment (DoH, 2006a). Other complications can include: mineral and bone disorders, such as abnormal levels of calcium or phosphorus; anaemia; hypertension and cardiovascular disease (Becherucci et al., 2016). Children with CKD can have other medical and/or developmental difficulties; a third of children on dialysis were found to have non-renal co-morbidities, including cognitive impairment, cardiac or pulmonary conditions (Neu et al., 2012). Therefore, children with CKD are often managed by a range of healthcare specialities including urology, cardiology and surgery.

As a result of the complications associated with CKD, treatment regimens can often be complex. Many children with CKD are prescribed a range of medicines; for example, human growth hormone for growth impairment, erythropoiesis stimulating agents and iron for anaemia, and medicines to prevent renal bone disease (DoH, 2006a). Children with CKD stage 5, or ESKD, are treated with RRTs. Once ESKD is reached, children require treatment for the rest of their life, though it is likely that they will need different types of RRTs, especially if they have a kidney transplant during childhood. In the UK, 76% of children receiving RRTs had a kidney transplant, 13% were receiving haemodialysis (either in-centre or at home) and 11% were receiving peritoneal dialysis (at home) (UK Renal Registry, 2019). Providing RRTs before a child experiences symptoms of ESKD, for example, through pre-emptive transplantation, is also used to manage CKD; this approach has been linked with improved survival rates compared with children who have received dialysis for over one year (Amaral et al., 2016). Although a kidney transplant is viewed as the 'treatment of choice' compared to dialysis, it is not a cure and involves a complex treatment regimen, including immunosuppressant medication to prevent the transplanted kidney being rejected (DoH, 2006a).

Dietary restrictions are also a key part of the management of CKD. Renal diets can include avoiding foods that are high in phosphate and salt, and some children who are not able to eat and drink the amount they need for their growth and development are tube-fed, for example via a nasogastric tube, or gastrostomy tube or button (Nguyen et al., 2016). For some children with CKD, such as those who have received a kidney transplant or have a co-morbid urological condition, the treatment regimen includes drinking significant amounts of fluid. In comparison, fluid intake is limited for children receiving dialysis, sometimes to 500ml per day (DoH, 2006a).

Like other LTCs, CKD can significantly impact on the child's and their family members' quality of life (McKenna et al., 2006; Gerson et al., 2010). Children with CKD, in particular ESKD, often attain fewer developmental milestones compared with healthy peers and children with other LTCs, and are at increased risk for low educational attainment and psychosocial difficulties (Grootenhuis et al., 2006; Icard et al., 2008). Child and family involvement is key to managing CKD (Swallow, 2008). Many aspects of the treatment regimen are performed at home, including dialysis; as a result, children and in particular parents, carry out the majority of management tasks, including activities that are complex and demanding (DoH, 2006a). Table 4 provides examples of the relationships between CKD stages 3-5, typical kidney conditions and self-management needs (Swallow et al., 2008).

Table 4: CKD stages, typical conditions and self-management needs

CKD stage	Example of typical kidney condition	Self-management required by child/family
3	Vesicoureteric reflux	• Urine collection and analysis • Taking oral medication • Taking temperature • Monitoring symptoms
4	Steroid sensitive nephrotic syndrome	• Urine collection and analysis • Taking oral medication • Taking temperature • Monitoring fluid intake/output • Monitoring weight/diet • Monitoring symptoms
5	End stage kidney disease	• Urine collection and analysis • Taking oral medications • Administering subcutaneous/intramuscular injections, intravenous therapy • Completing home dialysis (peritoneal or haemo) • Monitoring weight/diet

Supporting children with CKD stages 3-5 to assume responsibility for self-management is critical due to the progressive nature of the condition, and difficulties engaging in self-management can lead to renal failure (Dallimore et al., 2018). Fewer than 20% of children on dialysis were perceived by HCPs to function autonomously at transfer to adult services (Bell, 2007), and two thirds of children rejected their transplanted kidney within four years of transfer due to limited self-management skills and lack of engagement with adult services

(Harden et al., 2012). Therefore, for children with CKD 3-5, competent self-management is vital to avoid poor clinical outcomes and HCPs and parents need effective ways to help children learn self-management as they move towards adulthood (DoH, 2006b). However, limited evidence about how children assume self-management responsibility, how parents relinquish control and the role of HCPs during this process, means research is needed to better understand the transfer of responsibility. This study aims to address this gap. By identifying how children can be supported to develop independence in managing their condition, evidence-based interventions to facilitate the parent-to-child transfer of responsibility could be developed and evaluated (Sawyer et al., 2007b).

Due to the uniqueness of treatment regimens, and a gap in knowledge about whether the most effective models of self-management are LTC-specific or generic (NICE, 2016), a condition-specific approach is needed when studying how children assume self-management responsibility from their parents (Hanna and Decker, 2010). Therefore, this thesis describes the first in-depth study that explores how young people, parents and HCPs experience the parent-to-child transfer of self-management responsibility for CKD.

1.6 Structure of the thesis

This thesis is organised into eight chapters. Chapter 1 has introduced the study and set it in context, describing childhood LTCs and specifically CKD. It has discussed self-management, including how it has been conceptualised in the theoretical literature and the impact of health policy on service provision. Chapter 2 reviews the existing literature. Through systematically identifying, critically appraising and synthesising the available evidence it examines how children assume responsibility from their parents for self-management of their LTC, and what appears to influence this process. The chapter highlights gaps in knowledge, and demonstrates how further research, especially in under-researched LTCs, such as CKD, is indicated. The study's aims, methodology and methods are described in chapter 3. An overview of the study's qualitative design, its constructivist grounded theory approach and the use of individual and dyadic interviews, and focus groups to generate data, are discussed and a rationale provided for their selection. The chapter also considers potential challenges of conducting research with young people. Chapter 4 describes the conduct of the study. It presents details on the study setting, recruitment, sampling approach, characteristics of the study sample, data collection and analysis. Ethical issues and considerations related to quality and rigour are also discussed.

The findings from the study are presented in chapters 5, 6 and 7. Chapter 5 introduces and describes the theory of *shifting responsibilities* that explains the main process occurring during the parent-to-child transfer of self-management responsibility for CKD. The contextual issues that influence the transfer process are explored in chapter 6. Chapter 7 analyses the actions and interactions that initiate, sustain and disrupt the transfer of responsibility. Data extracts are included throughout these three findings chapters. The final chapter, chapter 8, discusses the findings in relation to existing literature. The study's contribution to knowledge, its strengths and limitations, and the implications for policy, practice and future research are presented. The thesis concludes with a summary of the main findings.

The following chapter will review the primary research that explores the parent-to-child transfer of LTC self-management responsibility.

2. LITERATURE REVIEW

2.1 Introduction

The purpose of this chapter is to present a critical review of primary research that explores the parent-to-child transfer of long-term condition (LTC) self-management responsibility. Through addressing two questions: 1) How do children assume responsibility from their parents for self-management of their own LTC? and 2) What influences the parent-to-child transfer of this responsibility?, the aim of the review is to synthesise previous research and identify gaps in knowledge about the parent-to-child transfer of self-management responsibility for CKD stages 3-5. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed in writing this chapter to ensure quality and transparency (Moher et al., 2009). A paper (Nightingale et al., 2019) led by the author of this thesis that reports on an earlier version of this literature review has been published: https://doi.org/10.1111/cch.12645

2.2 Review method

A mixed methods review, that synthesises data from qualitative, quantitative and mixed methods studies, was selected as most appropriate to address the two review questions (Pluye and Hong, 2014). Although there are a number of approaches to conducting mixed methods reviews, the integrative review was chosen as it integrates conceptual findings rather than aggregates data (Russell, 2005). This approach has the potential to result in a comprehensive conceptualisation of the topic of interest and the generation of new perspectives (Hopia et al., 2016). The methodological strategies proposed by Whittemore and Knafl (2005) guided the review. A review protocol was developed and registered on PROSPERO, an international register of systematic reviews: http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42017080301

2.2.1 Search strategy
To identify relevant literature, key electronic health care databases were used: Ovid MEDLINE, Embase, PsycINFO, CINAHL, AMED, ASSIA, Web of Science and the Cochrane Library. In addition, complementary searching was completed: forward and backward citation tracking, author searching and hand searching of two journals, the Journal of Pediatric

Nursing and Diabetes Educator, which respectively had special issues on LTCs and health care transition.

Using the SPIDER search strategy tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type) (Cooke et al., 2012), search terms relating to children aged 0-18 years old, LTCs and self-management were identified and agreed with the supervisory team (Appendix 1). The SPIDER tool was selected as it is more suitable for mixed methods reviews compared to other tools, such as PICO (Population/problem, Intervention, Comparison, Outcome) which tend to be used for quantitative search strategies. Table 5 outlines the inclusion and exclusion criteria (Cooke et al., 2012). The search strategy was modified to fit each database. University librarians provided advice to ensure a systematic search strategy.

Table 5: Inclusion and exclusion criteria

Criteria	Included in review	Excluded from review
Sample: Participants	• Papers primarily focusing on children aged 0-18 years. • Papers involving or focusing on parents, or professionals that relate to the LTCs described below and the age group above.	• Mean age of children is reported as over 18 years of age.
Sample: Condition	Children diagnosed with: • any physical LTCs • five childhood-onset LTCs (asthma, CKD, cystic fibrosis, diabetes, epilepsy) were specifically included as they differ from each other in the complexity of self-management and prognosis.	• Children with non-physical health conditions such as autism, mental health conditions and attention deficit hyperactivity disorder.
Phenomenon of Interest	• The process of children assuming responsibility from their parent for self-management of their LTC. • The individual child assuming responsibility, and/or parents transferring and/or letting go of responsibility and/or professionals supporting this process.	• The outcome of children assuming responsibility such as adherence or compliance. • The transition from child to adult health services.

Design and Research type	• Primary research including qualitative, mixed methods and quantitative studies of all designs.	• Secondary research, theoretical papers, editorials, protocols, discursive/opinion papers, posters and/or conference proceedings and theses. • Unpublished and grey literature as the aim was for the review to be systematic, transparent and reproducible, and limited guidance is available on how to systematically search for grey literature (Mahood et al., 2014).
Date range	• January 1995 and March 2020; this range was selected as interest in self-management of LTCs developed during the 1990s, leading to policy changes and empirical research in this area (Lorig et al., 1999; Wagner et al., 1996; DoH, 1999).	• Before 1995.
Language	• Only studies published in the English language were included in the review.	• Non-English language.

2.2.2 Study selection

Using the inclusion/exclusion criteria, a two-stage screening process was completed. During stage one, titles and abstracts of identified papers were screened, followed by stage two, where full-text papers were assessed. Consultation with the supervisory team took place when there was uncertainty whether a paper met the inclusion criteria.

2.2.3 Data extraction

A standardised, pre-piloted form was used to extract data from the included studies for assessment of study quality and evidence synthesis (Appendix 2). Extracted information included: research aim; study design; setting; participants; main findings; theoretical framework and whether there was patient and public involvement (PPI) in the design and/or delivery of the study. Information about PPI was extracted as it is recognised as improving the quality and relevance of research (INVOLVE, 2012) yet is not included in any critical appraisal tool. The GRIPP2 (Guidance for Reporting Involvement of Patients and the Public)

short form was used to evaluate PPI (Staniszewska et al., 2017). The content of completed data extraction forms was discussed with the supervisory team.

2.2.4 Quality assessment

The quality of included studies was assessed using a validated critical appraisal tool (Hawker et al., 2002) that is widely used especially in mixed methods reviews (Crowe and Sheppard, 2011). The tool has well-defined criteria and comprises nine items (e.g. sampling, data analysis) that enable an assessment of the methodological rigour of each study (Appendix 3).

2.2.5 Data synthesis

A synthesis approach based on the constant comparison method was adopted, which 'converts extracted data into systematic categories, facilitating the distinction of patterns, themes, variations, and relationships' (Whittemore and Knafl, 2005 p. 550). This method allows for iterative comparisons across all data sources and involves data reduction, data display, data comparison, conclusion drawing and verification. For example, data reduction was conducted by extracting relevant data from each included study to address the review questions. Tabulation was used to display the data, initially at an individual study level, and then combined to create one matrix that assembled the data from all the studies. Data were iteratively compared and diagrams developed to start identifying patterns and relationships across studies. Finally, any conclusions drawn were verified with the primary source data to check for accuracy and confirmability.

2.3 Findings

The search strategy produced 10,211 references; 7,920 did not meet the inclusion criteria. After assessment and deletion of duplicates, 33 papers reporting on 30 studies were included in the review (Figure 1). Appendix 2 provides a summary of each of the included papers, involving qualitative (n = 31), quantitative (n = 1) and mixed methods (n = 1) designs.

Figure 1: Selection process (Moher et al., 2009)

Identification

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┌─────────────────────────────┐      ┌─────────────────────────────┐
│  Papers identified through  │      │  Additional papers identified│
│     database searching      │      │    through other sources    │
│        (n = 10,195)         │      │         (n = 16)            │
└─────────────────────────────┘      └─────────────────────────────┘
                │                                    │
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                               ▼
              ┌─────────────────────────────┐
              │ Papers after duplicates     │
              │       removed               │
              │       (n = 7998)            │
              └─────────────────────────────┘
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Screening

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              ┌─────────────────────────────┐      ┌─────────────────────────────┐
              │      Papers screened        │─────▶│      Papers excluded        │
              │       (n = 7998)            │      │       (n = 7920)            │
              └─────────────────────────────┘      └─────────────────────────────┘
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Eligibility

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              ┌─────────────────────────────┐      ┌─────────────────────────────────┐
              │    Full-text papers         │─────▶│  Full-text papers excluded,     │
              │  assessed for eligibility   │      │        with reasons             │
              │       (n = 78)              │      │         (n = 45)                │
              └─────────────────────────────┘      │  • Not about process of         │
                                                   │    assuming responsibility =    │
                                                   │    32                           │
                                                   │  • Focus on development/        │
                                                   │    evaluation of an             │
                                                   │    intervention = 7             │
                                                   │  • Mean age of participant      │
                                                   │    over 18 years of age = 4     │
                                                   │  • Not about children with      │
                                                   │    physical long-term           │
                                                   │    conditions = 2               │
                                                   └─────────────────────────────────┘
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Included

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              ┌─────────────────────────────┐
              │   Papers included in        │
              │       synthesis             │
              │       (n = 33)              │
              └─────────────────────────────┘
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2.3.1 Study characteristics

Studies included children aged 7-21 years old and focused on a range of physical LTCs (Table 6) the majority on diabetes (n = 23). No studies focused specifically on children with CKD; two that included participants with a range of LTCs involved children with CKD but it is unclear how many and it was not possible to distinguish CKD-specific data from data relating to other LTCs (Jedeloo et al., 2010; Kirk, 2008).

Table 6: Types of long-term condition

Long-term condition	Studies (number, reference)
Diabetes: Type 1	18 (Chilton and Pires-Yfantouda, 2015; Christian et al., 1999; Dashiff et al., 2011; Ersig et al., 2016; Hanna and Guthrie, 2000a; Hanna and Guthrie, 2000b; Hanna and Guthrie, 2001; Babler and Strickland, 2015; Husted et al., 2014; Karlsson et al., 2008; Olinder et al., 2011; Schilling et al., 2006; Spencer et al., 2013; Sullivan-Bolyai et al., 2014; Ness et al., 2018; Castensoe-Seidenfaden et al., 2017; Rankin et al., 2018; Strand et al., 2019)
Diabetes: Type 2	3 (Auslander et al., 2010; Mulvaney et al., 2006; Mulvaney et al., 2008)
Diabetes: Not specified	2 (Newbould et al., 2008; Williams, 1999)
Asthma	4 (Meah et al., 2010; Buford, 2004; Newbould et al., 2008; Rhee et al., 2009)
Cystic Fibrosis	1 (Williams et al., 2007)
Sickle Cell Disease	1 (Kayle et al., 2016)
Heart disease	1 (Meaux et al., 2014)
Arthritis	1 (Stinson et al., 2008)
Mixed LTCs	3 (Akre and Suris, 2014; Jedeloo et al., 2010; Kirk, 2008)

Study participants were predominantly children and/or parents; only two studies included HCPs (Table 7).

Table 7: Study participants

Type of participant	Papers (number, reference)
Children only	11 (Babler and Strickland, 2015; Chilton and Pires-Yfantouda, 2015; Christian et al., 1999; Hanna and Guthrie, 2000a; Jedeloo et al., 2010; Karlsson et al., 2008; Mulvaney et al., 2008; Rhee et al., 2009; Stinson et al., 2008; Strand et al., 2019; Rankin et al., 2018)
Parents/carers only	5 (Akre and Suris, 2014; Dashiff et al., 2011; Hanna and Guthrie, 2000b; Mulvaney et al., 2006; Ness et al., 2018)
Children and parent/carer dyads	15 (Auslander et al., 2010; Buford, 2004; Ersig et al., 2016; Hanna and Guthrie, 2001; Kayle et al., 2016; Kirk, 2008; Meah et al., 2010; Meaux et al., 2014;

	Newbould et al., 2008; Schilling et al., 2006; Spencer et al., 2013; Sullivan-Bolyai et al., 2014; Williams, 1999; Williams et al., 2007; Castensoe-Seidenfaden et al., 2017)
HCPs, children and parents	2 (Husted et al., 2014; Olinder et al., 2011)

Studies took place in North America (n = 18) and Europe (n = 15). Eight of the European studies were conducted in the UK. Fifteen studies reported using theory; for example, when developing the interview topic guide or discussing study findings. The health belief model (Rosenstock et al., 1988) was the most cited theory (n = 5).

2.3.2 Study strengths and limitations

Using a critical appraisal tool (Hawker et al., 2002) to assess the quality of included studies, 21 were assessed as good and 12 as fair (Appendix 4). Although all studies had methodological limitations, their impact on the study findings was considered 'non-critical' rather than 'fatal' (Booth et al., 2016). For example, among the 12 studies assessed as fair, common limitations included: unclear sampling strategies; poor consideration of ethical issues and bias; and limited transferability due to minimal description of the study setting. As these limitations could potentially reflect inadequate reporting, no studies were excluded from the review based on their quality assessment. Study strengths and limitations, however, were taken into account during synthesis.

Twelve studies assessed as good reported an appropriate study design including suitable data collection methods to address the research aims. In studies that provided a limited rationale for the methods used, it was unclear, for example, why focus groups or individual interviews were selected for data collection. Only one study provided a clear sampling strategy to address the research aims and included details about the participants (Buford, 2004). Many of the other studies had unclear sampling strategies; for example, no rationale was provided for sample size and contextual information about the sample (e.g. gender, ethnicity, family structure) was missing, limiting transferability of study findings. Twelve studies demonstrated strengths in data analysis, providing a clear description of analysis, including how qualitative themes were derived and how rigour was enhanced. Other studies did not provide sufficient detail about their methods of data analysis; for example, themes were described but the processes involved in developing these were unclear and limited data were presented to support study findings. Three studies were assessed as good when reporting on ethical issues such as confidentiality and consent, and only one study

discussed issues of reflexivity and bias (Chilton and Pires-Yfantouda, 2015). Only one study, reported in two papers (Mulvaney et al., 2006; Mulvaney et al., 2008) appeared to include PPI in study design. However, as highlighted by the GRIPP2 short form checklist (Staniszewska et al., 2017), insufficient detail meant it was not possible to identify the aim, method or impact of PPI.

As some of the papers assessed as fair were describing selected findings from wider studies (Babler and Strickland, 2015; Hanna and Guthrie, 2000a; Hanna and Guthrie, 2000b; Mulvaney et al., 2006; Mulvaney et al., 2008), it is possible that the focus of reporting was on the findings as methods had been described elsewhere. This highlights the issue that papers reporting on primary research rarely provide sufficient detail about study methods, resulting in quality assessment becoming an appraisal of the reporting quality (Hawker et al., 2002).

2.3.3 Overview of review's themes

Utilising the synthesis approach outlined by Whittemore and Knafl (2005) and described in section 2.2.5, eight themes were identified that addressed the review's two questions. Figure 2 provides an overview of the eight themes: process, strategies, outcomes, the child, the family, social networks, HCPs and the LTC. Sections 2.4 and 2.5 describe and discuss the themes relating to the review questions.

2.4 How children assume responsibility from their parents for self-management of their own LTC

Three key themes, 1) process 2) strategies and 3) outcomes, related to the first review question: how do children assume responsibility from their parents for self-management of their own LTC?

2.4.1 Process

The parent-to-child transfer of self-management responsibility was portrayed as a process in many of the studies included in the review. This sense that a series of changes was occurring was evident in five sub-themes: 1) context 2) scope 3) stages or continuum 4) planned or unplanned and 5) the experience.

Figure 2: Overview of review's themes

How children assume management from their parents for self-management of their long-term condition		
Process • Context • Scope • Stages or continuum • Planned or unplanned • The experience	**Strategies** • Children • Parents • Health care professionals	**Outcomes** • Goal • Result

Influences on the parent-to-child transfer of responsibility

- **The child:** age, developmental stage, gender, ethnicity, motivation, readiness
- **The family:** family structure, parenting approach, socioeconomic, motivation
- **Social networks:** school, peers
- **Health care professionals:** current involvement, potential role
- **The long-term condition:** diagnosis, age and duration, treatment regimen, co-morbidities

2.4.1.1 Context

Across the studies, there was variation in whether children, parents and HCPs considered the transfer of responsibility within a wider context. In some studies, children assuming self-management responsibility was viewed by children and parents as part of normal development and 'natural' (Strand et al., 2019; Karlsson et al., 2008); however, it was also described as a complex, uneven process (Chilton and Pires-Yfantouda, 2015). Roles and

responsibilities of children and their parents changed over time (Christian et al., 1999; Olinder et al., 2011) as children became older and less reliant on their parents and parents 'let go' (Ersig et al., 2016; Babler and Strickland, 2015). Children described how as they gained their parents' trust that they could self-manage, this trust was generalised to other situations such as being relied on to look after siblings (Hanna and Guthrie, 2000a). Only one study, however, viewed the parent-to-child transfer of self-management responsibility within the wider context of the child gaining independence in other areas of their life (Meah et al., 2010).

The literature suggested that children differed from parents and HCPs in placing more emphasis on being 'normal' and identifying themselves by their age and interests rather than in terms of their LTC (Meaux et al., 2014). Whereas parents tended to focus on their child's health care needs, and HCPs on the LTC, children often described how they assumed responsibility for managing their LTC within a wider context that incorporated school, friends and peers (Chilton and Pires-Yfantouda, 2015). HCPs' narrow focus and their tendency to disregard the context in which children were assuming self-management responsibility was illustrated by this child's description of their diabetes doctor:

> *He [HCP] sees it [diabetes] as central, like you have to do this, and this is the most important thing and you have to keep concentrating on it and blah blah blah, and doesn't see this other stuff, like college work, that you've got to cope with as well* [16-year-old female] (Chilton and Pires-Yfantouda, 2015 p.1498).

The limited evidence about how the transfer of self-management responsibility fitted with the wider context of children gaining independence highlights that further research is needed to understand how these processes align.

2.4.1.2 Scope
The scope or range of self-management activities that a child was expected to assume responsibility for, varied across the studies. Self-management has been conceptualised as involving three tasks (medical, role and emotional management) and six skills (problem solving, decision making, resource utilisation, formation of a patient-provider partnership, action planning and self-tailoring) (Lorig and Holman, 2003). Studies described how many aspects of medical management were taken on gradually by children, including symptom recognition and managing medication (Schilling et al., 2006; Buford, 2004). Assuming medical management was an incremental process: children were initially involved in activities led by their parents, such as helping to fill their pill box (Meaux et al., 2014), and progressively undertook more complex activities, reaching a stage where they were

responsible for independently initiating and implementing self-management activities, such as physiotherapy treatment (Williams et al., 2007).

As children assumed responsibility, the literature suggested they developed skills in a wider range of self-management activities, including communicating with HCPs (Chilton and Pires-Yfantouda, 2015) and involvement in decision making (Buford, 2004; Babler and Strickland, 2015; Christian et al., 1999). Contextual influences, however, such as the HCP's discipline and the child's age (Schilling et al., 2006) impacted on skill acquisition. For example, children described feeling confident about raising questions with nurses, whereas they preferred their parents to be responsible for communicating with doctors (Newbould et al., 2008). The influence of the child's age on the transfer of responsibility will be discussed in section 2.5.1. Although children gradually developed skills in aspects of medical management such as managing medication, the actual responsibility for decision making and liaising with services often needed to be acquired suddenly by children when they transferred to adult services (Kirk, 2008).

In contrast, studies rarely discussed children's emotional and role management (Lorig and Holman, 2003), although some parents recognised their child needed to develop coping skills to deal with the emotional aspects of living with a LTC (Auslander et al., 2010). One study that used the Adaptive Leadership Framework for Chronic Illness to analyse data (Anderson et al., 2015) described how, during the transfer of responsibility, children and parents found the 'adaptive work' much more challenging than the 'technical work' (Kayle et al., 2016). For example, children were able to assume responsibility for using pain medication (technical work), whereas they found it difficult to integrate medication management into their daily routine (adaptive work). This suggested some children struggled with adapting to new routines and roles as they assumed self-management responsibility; however, how parents and HCPs potentially needed to adjust their roles during the transfer process has received little attention in the literature.

Although the framework proposed by Lorig and Holman (2003) recognises the complexity of self-management, there are child-specific aspects such as the parental role that it does not consider. For example, some children found assuming responsibility for their medication involved negotiating a different relationship with their parents, rather than developing knowledge in medical management (Akre and Suris, 2014). Other activities and skills perceived to be important during the parent-to-child transfer of responsibility, were described in some of the studies but were not referred to within Lorig and Holman's framework (2003).

These included the need for children to: gain factual and experiential knowledge (Christian et al., 1999; Karlsson et al., 2008); acquire confidence and self-efficacy (Auslander et al., 2010; Meah et al., 2010); and develop the motivation to take on management roles (Williams et al., 2007). This suggests the scope of self-management activities that children are expected to assume, and the skills required during this process, are potentially more complex than Lorig and Holman's framework might suggest.

2.4.1.3 Stages or continuum

Although there was widespread recognition across the studies that the parent-to-child transfer of self-management responsibility was a gradual, complex process (Babler and Strickland, 2015; Karlsson et al., 2008), the transfer process was modelled in various ways; some studies concluded that the child, the parent, or both, sequentially progressed through discrete stages whereas others reported the transfer as a fluid, bidirectional continuum where child and parental roles and responsibilities were regularly changing.

Babler and Strickland (2015) identified four consecutive stages that children needed to progress through as they assumed responsibility for self-management from their parents: 1) depending on your parent 2) taking over some responsibility gradually 3) needing to separate from your parent and 4) assuming full responsibility. This model had similarities with the three stages identified by Schilling et al (2006), who suggested self-management was initially 'parent-dominant', then became 'transitional' as the child became older, and finally during late adolescence was 'adolescent-dominant'. The models differ, however, in their emphasis on the child-parent dyad, and whether it is the child only (Babler and Strickland, 2015), or the child and parent together (Schilling et al., 2006), that move sequentially through the different stages.

In contrast, some studies portrayed the parent-to-child transfer of self-management responsibility as a continuum, or a process occurring very gradually without distinct stages. Chilton and Pires-Yfantouda (2015) suggested the process of children assuming self-management responsibility for their diabetes could be understood as a 'continuum-based framework' (Figure 3). The two ends of the continuum were quite distinct, ranging from the child having 'difficulties' with self-management, characterised by their dependency on their parents to manage their own LTC, to 'successful' self-management, which meant being independent in medical management and communication with HCPs. The child's progress along the continuum was described as a process of adaptation, involving transitional phases and process mechanisms that supported movement between each phase. Adaptation was

not a linear process, but was depicted as: *'complex, multidimensional and impacted by environmental and psychosocial factors'* (Chilton and Pires-Yfantouda, 2015 p. 1501). The factors identified in the literature that influenced the parent-to-child transfer of responsibility will be explored in section 2.5.

Figure 3: Type 1 diabetes adaptation and self-management model (Chilton and Pires-Yfantouda, 2015 p. 1491)
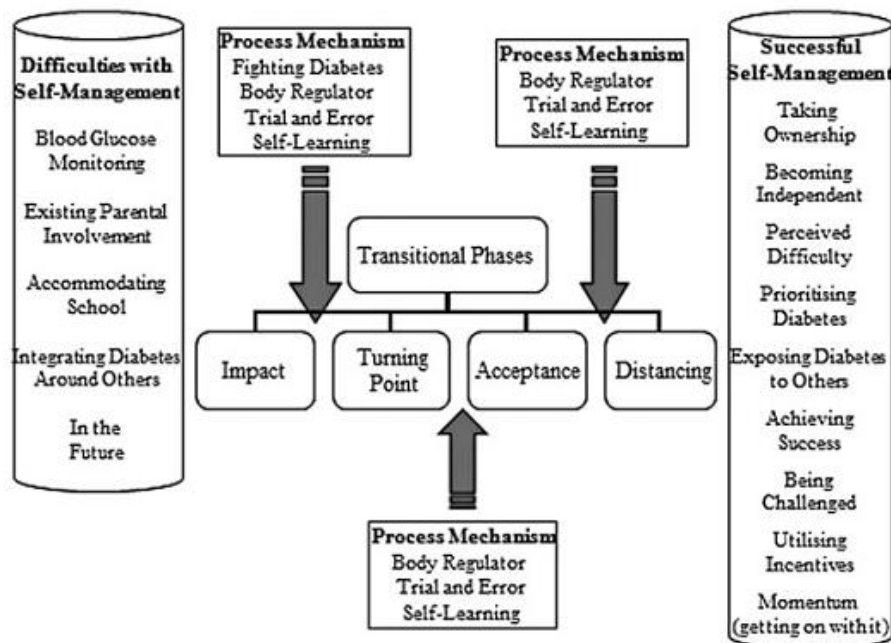
Responsibility for physiotherapy in managing cystic fibrosis was viewed as existing on a continuum involving five child roles and six parental roles (Figure 4) (Williams et al., 2007). The roles comprised of different levels of shared responsibility in terms of initiating, directing and implementing physiotherapy, and movement between roles often resulted in tension or renegotiation between parents and child. Although HCPs expected child and parental roles to progressively move along the continuum as the child got older, there was evidence the movement was fluid and bidirectional (Williams et al., 2007). Other studies also identified that the process of transferring responsibility was not unidirectional; parents would resume management of the LTC when their child was tired, unwell or lacking motivation (Kirk, 2008; Schilling et al., 2006); to enable their child to feel 'normal' (Castensoe-Seidenfaden et al., 2017; Rankin et al., 2018); during stressful periods (Olinder et al., 2011); or when complications arose (Meaux et al., 2014).

Figure 4: Parental and child roles in the initiation and implementation of physiotherapy (Williams et al., 2007 p. 2139)
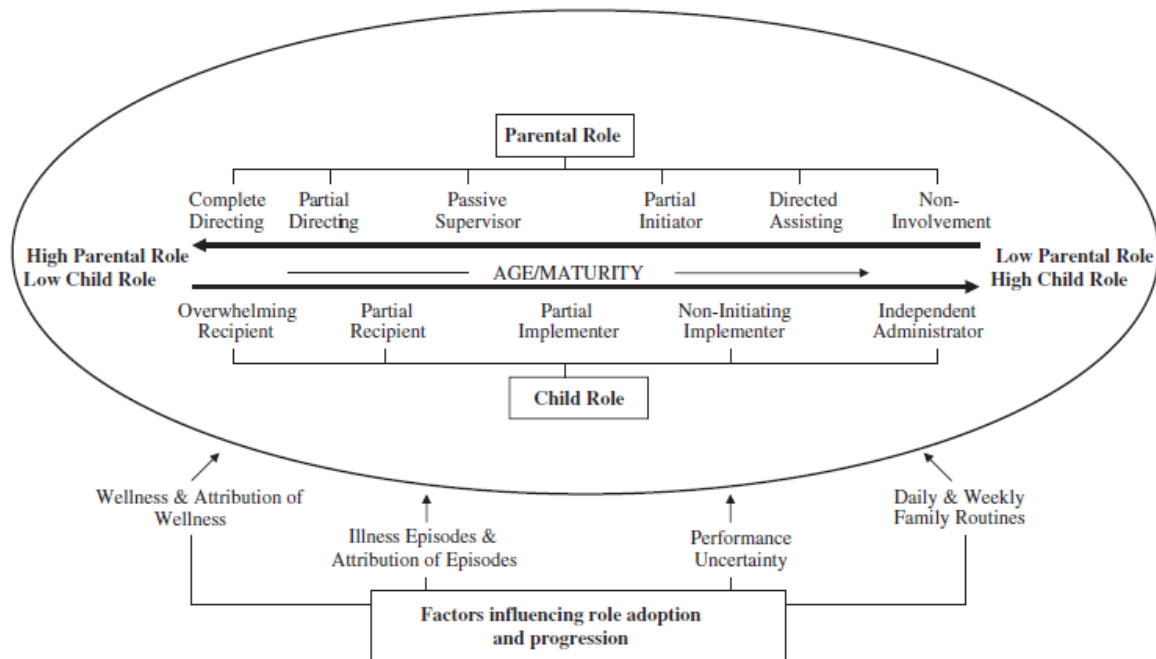
As Williams et al (2007) suggested, both parental and child roles and responsibilities changed during the parent-to-child transfer of responsibility. In one study, parents were perceived as moving from being a 'manager', to a 'supervisor' and finally to a 'consultant' as their child assumed self-management responsibility (Meah et al., 2010), whereas Akre and Suris (2014) suggested parents' experience of transferring responsibility existed on a spectrum with 'controlling' and 'letting go' at opposite ends. These conceptualisations of parental roles, responsibilities and experiences suggest there were different understandings and expectations around the start and end point of the process, in particular around whether parents continued to have some involvement in managing their child's LTC despite their child having assumed responsibility. Although studies described how child and parental roles changed during the transfer of responsibility, there was a dearth of evidence concerning the HCP's role, including whether HCPs adjusted their role as children developed independence in managing their condition and parents relinquished control.

Finally, the parent-to-child transfer of responsibility for asthma management was portrayed in one study as a process that involved a continuum, stages and transitions (Figure 5) (Buford, 2004). In this model, the key concept underlying the transfer of responsibility was 'controlling the situation'; this referred to the family being in control of LTC management, but also managing the impact of the LTC on the family. A family's ability to 'control their situation' moved gradually across a continuum and was influenced by family characteristics such as

parenting styles and health beliefs. Parents also moved through different stages; from being 'out of control' when their child first displayed asthma symptoms, through to 'letting go' when the child was independent in self-management. Progression to the 'autopilot' stage, where asthma care had been incorporated into family routines, was antecedent to beginning the transfer of responsibility (Buford, 2004). Although this model recognised factors that could impact on the transfer process, there was no exploration of what happened in families that were not able to progress from the 'out of control' to the 'autopilot' stage, and how this influenced the child assuming self-management responsibility.

Figure 5: Theoretical model for parent-child transfer of asthma responsibility (Buford, 2004 p. 6)
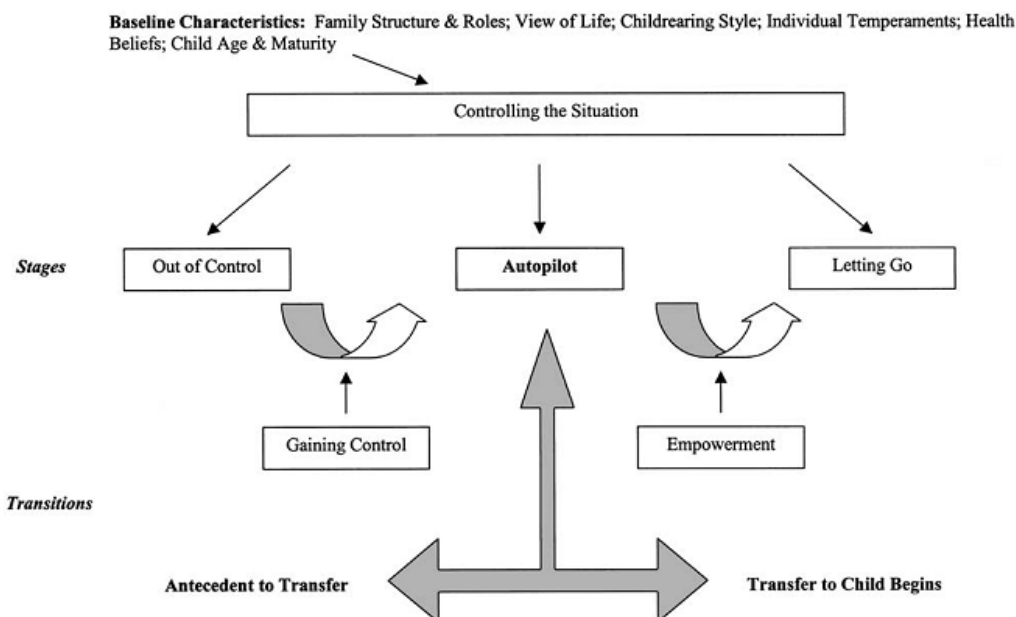
These conceptualisations of the parent-to-child transfer of LTC self-management responsibility in diabetes, cystic fibrosis and asthma, share some similarities in highlighting the complexity of the transfer process. However, as there were tensions around how to model the transfer process both within specific LTCs, and across different LTCs, there is an indication that further research is needed in this area, especially in under-researched areas such as CKD, a LTC with its own unique self-management needs.

2.4.1.4 Planned or unplanned

There were differing findings on whether the process of children assuming self-management responsibility occurred at a tacit level, or if it was planned and, if so, who initiated the transfer process. In some studies, parents adopted a planned, strategic approach; they explicitly

started handing over responsibility as they viewed the transfer process as fitting with longer term goals around their child gaining independence (Williams et al., 2007; Schilling et al., 2006; Newbould et al., 2008). In most families, parents were aware of the need to transfer responsibility and initiated handing it over to their child (Kirk, 2008). Although a few studies identified that some children would self-initiate developing independence in self-management (Buford, 2004), children tended not to think about taking on responsibility and, therefore, did not discuss it with their parents or HCPs. This impacted on the parent-to-child transfer of responsibility and meant some aspects of self-management were missed as neither the child or parent completed the activity (Olinder et al., 2011). In Meah et al's (2010) study, children with asthma were reported to initiate taking on aspects of self-management as they enjoyed, or at least accepted, the increased self-management responsibility associated with growing up. However, it is unclear whether this was due to their age (7-12 years old) or their LTC, and therefore it is uncertain whether this finding would be transferrable to older children and other LTCs.

In contrast, the transfer of responsibility in other families was not planned but happened in response to external events associated with a child's development, such as starting secondary school or staying away from home overnight (Newbould et al., 2008; Rankin et al., 2018). This quotation illustrated how a child with diabetes anticipated needing to assume more responsibility when starting secondary school:

> *When I go to high [secondary] school, I'll have to be able to carb count by myself because it's different. You get a menu for primary school, you pick and you know what you're having. When you go to the academy [secondary school], you don't know what's on that day. You have to line up at whatever queue, for whatever you want* [child, aged 11] (Rankin et al., 2018 p. 5).

Typical adolescent development meant children spent more time apart from their parents as they became older. Studies highlighted how this provided children with opportunities to: practise self-management (Kirk, 2008); develop confidence (Spencer et al., 2013); and acquire skills in problem solving (Christian et al., 1999; Karlsson et al., 2008). In addition to events associated with children's development, the literature suggested that other aspects of family life could be a 'tipping point' and motivate children and families to initiate the transfer process (Rankin et al., 2018). For example, Buford (2004) reported how changes in parents' work or child care arrangements prompted some parents to recognise their child needed to assume more self-management responsibility. Although studies revealed there were different approaches to the parent-to-child transfer of self-management responsibility, there was no clear understanding of whether the transfer process benefitted from being planned or

unplanned, and whether there was a different outcome or experience based on whether it was initiated by the child or parent, or occurred in response to external events.

2.4.1.5 The experience

The literature suggested children and parents had a range of experiences during the parent-to-child transfer of self-management responsibility. The transfer process could be a time of 'discord' (Kirk, 2008) which children and parents found stressful (Ersig et al., 2016; Meaux et al., 2014). Castensoe-Seidenfaden et al (2017) reported both children and their parents experienced misunderstandings and frustration during the transfer of responsibility; however, they rarely shared their feelings, which increased their sense of isolation. In some studies, children and parents experienced conflict as the child aspired to independence, while parents felt they needed to remain vigilant due to concerns about the consequences of their child not being able to self-manage (Babler and Strickland, 2015; Karlsson et al., 2008; Schilling et al., 2006; Williams et al., 2007). This quotation illustrated the level of tension which could exist in families as the child assumed self-management responsibility:

> *Everything to do with taking medication, she manages by herself. If I don't interfere with that, she talks about it. But if I make one sign that I am interfering, it's very violent. In other words, she gets mad and that's it, so I don't ask whether or not she took it [her medication]* [Mother of 15-year-old female] (Akre and Suris, 2014 p. 5).

In some studies, however, children normalised these tensions as they were aware that conflict with their parents was typical during adolescence (Kirk, 2008). Parents were reported to experience frequent worry, fear and sadness during the transfer of responsibility, especially in relation to when and how to let their child take on management responsibilities (Dashiff et al., 2011; Sullivan-Bolyai et al., 2014), their loss of control (Spencer et al., 2013) and whether their child was carrying out specific tasks such as taking medication or testing blood glucose (Akre and Suris, 2014). The parents in Ness et al's study (2018) described feelings that their *'worry will not end',* highlighting the uncertainty in the literature around when the transfer process would finish.

Although most studies reported how families found the transfer of responsibility a difficult experience, a few studies highlighted potentially positive aspects of the transfer process. In particular, families who could perceive benefits for the child, such as gaining freedom, and benefits for the parents, such as taking pride in their child's ability, reported having a more positive experience during the transfer of responsibility (Hanna and Guthrie, 2000b; Christian et al., 1999; Strand et al., 2019).

2.4.1.6 Summary

This section, 2.4.1, has discussed how the parent-to-child transfer of self-management responsibility is portrayed in the literature as a complex, individualised process. Although children assuming self-management responsibility was viewed as part of normal development, it was rarely explored within the context of the child gaining independence in other areas of their life. There were different expectations around the scope or range of self-management activities that children assumed responsibility for. Studies differed in how they modelled the transfer of responsibility; some viewed the process as a continuum, where self-management responsibilities moved backwards and forwards between the child and parent, whereas other studies, reported how the child, the parent, or both, undertook a unidirectional progression through sequential stages. The literature highlighted how, for some parents, initiating the transfer of responsibility was a planned process, whereas for others, 'tipping points' such as the child starting secondary school, prompted parents to begin the transfer process. Finally, the experience of children assuming responsibility from their parents was presented; although a few families had a positive experience, most children and parents experienced conflict and found the process stressful. The next section will discuss the strategies used to support children to assume responsibility and parents to relinquish control.

2.4.2 Strategies

The literature suggested that children, parents and HCPs used a range of strategies during the parent-to-child transfer of self-management responsibility.

2.4.2.1 Children

Studies described the various strategies adopted by children to develop independence in self-management including: gaining factual and experiential knowledge (Karlsson et al., 2008; Christian et al., 1999); learning through experience and by trial and error (Spencer et al., 2013; Chilton and Pires-Yfantouda, 2015); and through noticing and responding to symptoms (Kayle et al., 2016). Some children employed practical strategies such as using alarms and schedules (Babler and Strickland, 2015) and putting medication on their bedside table at the weekend so they could remain in bed for longer (Meaux et al., 2014).

Technology, such as mobile phones and devices to calculate insulin doses, were reported to enable children with diabetes to assume responsibility for managing their condition (Rankin et al., 2018). Children described how managing their LTC was more difficult during busy and unpredictable days, and having structure and familiar activities made it easier to assume responsibility (Strand et al., 2019; Castensoe-Seidenfaden et al., 2017). Studies suggested

that children who were able to develop a routine that supported self-management made it easier for them to integrate it into their life, as this quotation illustrates:

> *It's part of the routine that you have. People have different routines, and if you keep it [diabetes] in check, then, it's going to be normal like everyone else, and you can do what you want, rather than not doing what you want and the diabetes in control of you* [15 year old boy] (Chilton and Pires-Yfantouda, 2015 p. 1497).

In addition to the 'practical' strategies described above, some studies described how children purposefully adopted different attitudes as they assumed responsibility. For example, some children welcomed being able to 'take ownership' and be in control of their LTC; they framed developing independence in managing their condition as an opportunity for learning (Chilton and Pires-Yfantouda, 2015) and for letting go from parents and HCPs (Stinson et al., 2008).

Despite reports in the literature that child-parent relationships during the transfer of responsibility were often characterised by conflict (see section 2.4.1.5), children appeared to mostly gain knowledge about self-management from their parents, rather than HCPs (Kirk, 2008; Sullivan-Bolyai et al., 2014). Some children, however, described how learning from HCPs helped them to assume responsibility (Stinson et al., 2008; Karlsson et al., 2008). Christian et al (1999) suggested children viewed their parents as advisors and developed collaborative relationships with parents and HCPs as they learnt to self-manage. For some children this reliance on parents for support with self-management appeared to reduce over time; as children became older some viewed parental oversight as 'nagging' (Ersig et al., 2016) whereas others continued to rely on their parents to be a 'safety net', expecting them to intervene when they struggled to perform self-management activities (Ness et al., 2018).

Some studies suggested children involved their friends as they assumed responsibility. Having friends who were aware of their LTC meant some children felt more able to perform self-management activities at school or when out with friends (Chilton and Pires-Yfantouda, 2015; Kayle et al., 2016). Other studies reported how children with diabetes or sickle cell disease sometimes relied on their friends for support, through educating them about their LTC and how to respond if they experienced ill health (Kayle et al., 2016; Castensoe-Seidenfaden et al., 2017). It tended to be older children, or children who had fully accepted their LTC, who involved their friends as they took responsibility for self-management. Section 2.5.3 will explore further the influence of peers on children assuming responsibility.

2.4.2.2 Parents

Parents were reported to use a range of strategies to support their child to assume self-management responsibility including: providing coaching, education and guidance (Kirk, 2008; Schilling et al., 2006; Olinder et al., 2011) and offering rewards (Mulvaney et al., 2006). Rather than actively carrying out self-management tasks, parents would gradually reduce their involvement and adopt a more passive role by providing advice and reminders, observing and prompting as their child's responsibility increased (Chilton and Pires-Yfantouda, 2015; Karlsson et al., 2008; Dashiff et al., 2011). Although developing trust in their child was a key aspect of parents' relinquishing responsibility (Babler and Strickland, 2015), parents used strategies to check on their child without their knowing (Mulvaney et al., 2006; Ness et al., 2018) such as covertly monitoring their child's use of their reliever inhaler (Meah et al., 2010) and testing blood glucose while their child slept (Schilling et al., 2006).

Although mothers and fathers were included in studies, the majority of participants were mothers as they tended to be more involved in managing their child's LTC at home. Only one study explicitly reported on how mothers and fathers, as opposed to parents, supported their child to assume responsibility; it found mothers tended to be more present and in charge, whereas fathers would 'let go' of their child and allow them to make mistakes, as illustrated by this quotation:

> *My wife is always behind him, stimulating him. I'm the opposite; I say to myself, he needs to be late once so he understands that he's wrong, that he needs to pull himself together to get organized in order to make it. I think sometimes he needs to fall so that he can learn how to get up alone* [Father, 17-year-old male] (Akre and Suris, 2014 p. 4).

The literature suggested the child's gender could impact on the strategies adopted by mothers during the parent-to-child transfer of self-management responsibility. With sons, mothers tended to offer more practical and emotional support, whereas HCP expectations that girls should be more independent in managing their LTC meant mothers were less involved with their daughters (Williams, 1999). The influence of gender and HCPs' expectations on how children assumed self-management responsibility will be explored further in section 2.5.

Parents and children appeared to differ in their views on whether support from parents was helpful or non-helpful (Hanna and Guthrie, 2001). For example, there was disagreement about the level of parental guidance needed: children valued subtle guidance and reminders, but considered too much guidance as 'nagging' and irritating (Karlsson et al., 2008;

Auslander et al., 2010; Mulvaney et al., 2008). In contrast, parents perceived direct guidance as being helpful in improving their child's performance of self-management activities (Hanna and Guthrie, 2001). Although parents were sometimes aware when their child did not find their involvement supportive, they found it difficult to stop or change their behaviour (Dashiff et al., 2011; Sullivan-Bolyai et al., 2014). Studies suggested some parents found it difficult to know what strategies to use, especially if their child was struggling with assuming self-management responsibility. For example, there was ambivalence about whether learning through trial and error should be adopted or whether parents should reassume self-management responsibility when there were concerns around the child making self-management mistakes (Ersig et al., 2016; Akre and Suris, 2014; Husted et al., 2014; Spencer et al., 2013). These tensions around what strategies to adopt illustrated parents' awareness of the potential consequences of their child's self-management decisions and suggested that parents could benefit from increased support with the transfer of responsibility.

2.4.2.3 Health care professionals

Only a few studies described strategies used by HCPs to support the transfer of self-management responsibility. HCPs were reported to support children to assume responsibility through the provision of information, training, and opportunities for children to become involved in decision making (Spencer et al., 2013; Strand et al., 2019). Williams et al (2007) identified how, through regularly monitoring the child's self-management skills, HCPs provided reassurance and emotional support to parents, which enabled them to relinquish control. Although one study described HCPs' use of specific communication skills, such as mirroring and active listening, as a useful strategy (Husted et al., 2014) there was ambivalence among children and parents about the role of HCPs in supporting the parent-to-child transfer of self-management responsibility. Only two studies included HCP participants (Olinder et al., 2011; Husted et al., 2014). The lack of evidence about what strategies HCPs utilised and what families found helpful indicates a clear need for further research in this area, which includes HCP participants. The role of the HCP will be explored further in section 2.5.4.

2.4.2.4 Summary

This section, 2.4.2, has discussed the strategies used by children, parents and HCPs during the transfer of self-management responsibility. The literature suggested children and parents adopted a wide range of approaches; however, tensions existed around what children and parents perceived to be helpful. There was limited evidence around HCPs' roles and the

strategies or interventions they used, and ambivalence among children and parents around HCP involvement in the transfer process. The focus in the literature was on the strategies used to support children to assume self-management; however, there were gaps in knowledge about the strategies adopted to support parents to relinquish control. The next section will examine how the outcome of the parent-to-child transfer of responsibility was presented in the literature.

2.4.3 Outcomes

There was a lack of clarity in the literature around the outcome of the parent-to-child transfer of self-management responsibility. This included: the goal of the transfer process (or what children and parents were aiming for); and the actual result (whether children had assumed full self-management responsibility and parents had relinquished control).

2.4.3.1 Goal

Although assuming responsibility and achieving independence in self-management was the implied ideal outcome for children with a LTC as they transferred to adult services (Babler and Strickland, 2015), there was limited empirical evidence that this was a realistic goal, in particular for children with complex health care needs. Some studies revealed that as children moved towards adulthood, parents and children viewed continued parental supervision, and/or involvement in some aspects of self-management, as important (Auslander et al., 2010; Meah et al., 2010). This contrasted with other studies where the goal was for the child to achieve complete independence in self-management (Babler and Strickland, 2015); however, it seemed the child being fully responsible for self-management represented an 'ideal future' (Buford, 2004), raising the question whether it was a realistic or desired goal for all families. There was a dearth of evidence amongst the studies regarding whether goals were individualised, or if the child's characteristics such as their age, developmental stage and cognitive ability affected the goal. Williams (1999), however, suggested there were 'gendered concepts of responsibility and dependency', as HCPs had higher expectations of girls to be independent in self-management compared with boys. The influence of the child's gender, and other factors that impacted on the transfer of responsibility, will be explored further in section 2.5.

Studies referred to the challenge for parents in achieving a 'balancing act' regarding the: child's developmental need to move towards independence against the potential consequences of their child struggling with self-management (Hanna and Guthrie, 2000b); and also how parents could be supportive without taking control (Kayle et al., 2016; Meaux

et al., 2014). Parents experienced a dilemma around letting go while remaining alert, as this quotation illustrates:

> *I think that it's mainly a question of evaluating the situation and deciding when it can be educational, meaning when to trust him, giving him the possibility to manage everything while supervising at the same time. It's a complicated age because it's an age where we can't treat him like a child and we can't treat him like an adult* [Father of a 16-year-old male] (Akre and Suris, 2014 p. 4).

The tension experienced by parents between supporting their child to become independent while fearing the potential consequences of their child's 'poor' self-management was thought to highlight the 'absolute nature of parental responsibility'; this was believed to be particularly pertinent to mothers due to the 'moral expectation to conform to good, responsible motherhood' (Meah et al., 2010). The influence of the family on children assuming responsibility, in particular the role of mothers and fathers, will be explored further in section 2.5.2.

2.4.3.2 Result

Although some families aspired to the child assuming full responsibility for self-management, in reality the result was less clear as parents often remained involved in managing some aspects of their child's LTC (Buford, 2004; Christian et al., 1999). Studies suggested children perceived they would only have complete control once they moved out of the family home (Babler and Strickland, 2015); however, for some families, parents continued to play a coaching role and provide support to children even though they had transferred to adult services and left home (Kirk, 2008).

In some studies, differing understandings between children and their parents of what it meant to maintain health (Babler and Strickland, 2015) and to be fully responsible (Meah et al., 2010; Hanna and Guthrie, 2001) resulted in an unclear or unsatisfactory outcome. A child's understanding of responsibility could differ from that of their parents and HCPs as adults were more likely to think about the long-term consequences of self-management choices (Ersig et al., 2016); this could create dilemmas for children trying to balance self-management responsibilities with existing as 'normal' among their peers (Meah et al., 2010). Strand et al (2019) described how some children's motivation to be completely independent in managing their LTC was impacted by their perception that having full responsibility meant it was their fault if they made mistakes. At times, the lack of discussion and clarification around responsibility resulted in some aspects of self-management being neglected (Olinder et al., 2011; Karlsson et al., 2008). For example, in some studies, parents reduced their

supervision as they assumed their child was completing self-management, which led to poor outcomes such as deterioration in their child's blood glucose levels (Spencer et al., 2013).

2.4.3.3 Summary

This section, 2.4.3, has discussed the outcome of the parent-to-child transfer of self-management responsibility. The literature suggested that there was a lack of clarity around children's and parents' goals; some studies described children and parents aiming for shared management whereas in others, the child aspired to being able to independently manage their own condition. Connected to this idea was whether children and parents managed to achieve the result they had hoped for, and how ambiguity around what it meant to be fully responsible potentially contributed to unclear or unsatisfactory outcomes.

2.4.4 Summary

This section has synthesised previous research to address the first review question of how children assumed responsibility from their parents for self-management of their LTC. It has discussed how the transfer of responsibility tended to be portrayed in the literature as a complex, individualised process. Children assuming self-management responsibility was considered to be part of normal development; however, studies rarely explored the process within the context of the child developing independence in other areas of their life. The strategies adopted by children, parents and HCPs were presented, including the tensions around what children and parents perceived to be helpful. The limited evidence about HCPs' roles and ambivalence around what supported the transfer of responsibility were discussed. Finally, the section explored how a lack of clarity around the goals and expectations of children, parents and HCPs resulted in a range of planned and unplanned outcomes.

The following section addresses the second review question in its discussion of the influences on the parent-to-child transfer of self-management responsibility.

2.5 Influences on the parent-to-child transfer of self-management responsibility

Five key themes relating to the second review question were identified from synthesis of the included studies: 1) the child 2) the family 3) social networks 4) HCPs and 5) the LTC. These five factors appeared to interact and influenced the parent-to-child transfer of responsibility.

2.5.1 The child

The literature suggested that the child had an impact on the transfer process in relation to their: age or developmental stage, gender, ethnicity, and motivation and readiness for assuming responsibility.

2.5.1.1 Age or developmental stage

In some studies, the transfer of self-management responsibility was related to the child's increasing age (Babler and Strickland, 2015; Karlsson et al., 2008; Meaux et al., 2014), whereas in other studies the transfer was influenced by the child's developmental stage (Kirk, 2008; Rhee et al., 2009). Strand et al (2019) described how children perceived that, as they became older, their parents and HCPs expected them to assume responsibility for self-management activities and communicating with HCPs. Although most studies suggested adolescence was associated with developing independence, only one study described a particular age: Christian et al (1999) identified that children with diabetes began the process of assuming responsibility at around 12 years of age. Other factors related to the child's increasing age, such as spending more time away from the family home and staying overnight with friends, were perceived as prompting children to become more involved in managing their LTC (Strand et al., 2019; Newbould et al., 2008).

In contrast, some literature suggested the child's developmental stage influenced the transfer of responsibility. Typical developmental aspects of adolescence such as: thinking about the short-term rather than long-term implications (Ersig et al., 2016; Dashiff et al., 2011; Hanna and Guthrie, 2000a); wanting to be 'normal' and fit in with peers (Chilton and Pires-Yfantouda, 2015); changing relationships with parents (Auslander et al., 2010; Mulvaney et al., 2008; Mulvaney et al., 2006); and risk-taking (Meaux et al., 2014), were described as impacting on when and how children assumed responsibility, and, importantly, on whether parents' felt able to relinquish control. In some studies, children and parents described how 'typical' behaviours associated with adolescence influenced the transfer process. These predominantly appeared to be invoked when the child was struggling with self-management and included parent-child conflict, deception (e.g. around eating habits or checking blood) and laziness (Babler and Strickland, 2015; Mulvaney et al., 2006). This was illustrated in one child's account:

> *I know when I'm not checking my blood enough. I know when I'm being lazy with it but I'm a teenager and teenagers are lazy. I know that I'm not supposed to be lazy but I think that is a natural human habit to be lazy when you are a teenager. I know*

it's not an excuse, there is nothing drastically wrong with me, I'm just lazy
[Adolescent with diabetes] (Babler and Strickland, 2015 p. 656).

Instead of age and development, some studies suggested the child's maturity influenced the parent-to-child transfer of responsibility. Children in Chilton and Pires-Yfantouda's study (2015) perceived that self-management would become easier as they developed maturity, as their understanding and priorities would change. The sense that maturity involved both cognitive and emotional development was evident in some studies, where it was perceived increased understanding, knowledge and acceptance of their LTC, impacted on children's readiness to assume responsibility (Hanna and Guthrie, 2000a; Rankin et al., 2018). The child's readiness will be explored further in section 2.5.1.4.

2.5.1.2 Gender

As discussed in section 2.4.2.2, studies suggested that the child's gender could influence the parent-to-child transfer of responsibility. Jedeloo et al (2010) identified four profiles in relation to children's preferences for self-management, which they associated with the child's gender. Girls were assessed as more likely to match two of the profiles ('backseat patient' or 'worried and insecure') which meant they tended to prefer ongoing parental support with managing their condition; for example, they appreciated their parents' reminders about self-management tasks and support during appointments with HCPs. Interestingly, the children represented in each of the two profiles differed in how they viewed the HCP's role in supporting them to assume self-management responsibility; 'backseat patients' perceived it was their parent's role to help them learn to manage their LTC, whereas children matching the 'worried and insecure' profile welcomed HCP involvement in the transfer of responsibility.

This understanding of the relationship between gender and responsibility contrasted with other studies. Williams (1999) described how girls were more likely to incorporate diabetes into their identity, whereas boys viewed diabetes as having a stigma attached to it, and as a result would make diabetes a small part of their lives by denying or dismissing it. These gendered understandings of diabetes were reported to influence the parent-to-child transfer of responsibility as girls were more independent in self-management, whereas boys were dependent on their parents to provide practical and emotional help. A study assessing the barriers to self-management in adolescents found girls perceived less barriers to self-management compared to boys and therefore struggled less with assuming self-management responsibility (Rhee et al., 2009).

2.5.1.3 Ethnicity

Only two studies explicitly explored the influence of ethnicity on children assuming self-management responsibility. Children with asthma from Black and Hispanic backgrounds reported more barriers to self-management compared to White children, as higher levels of negativity towards their treatment regimen, and poor relationships with HCPs, meant they experienced more difficulties with assuming responsibility (Rhee et al., 2009). Auslander et al (2010) explored the resources and barriers to self-management in African American adolescents with type 2 diabetes; they concluded that as this population was more likely to be obese and have other co-morbid conditions which made self-management more complex, this impacted on the transfer of responsibility. The influence of the LTC and co-morbidities will be further discussed in section 2.5.5 and considered in relation to ethnicity as some LTCs are more prevalent in children from ethnic minority backgrounds, including type 2 diabetes (Auslander et al., 2010), sickle cell disease (NICE, 2014) and CKD (UK Renal Registry, 2019).

2.5.1.4 Motivation and readiness

The literature suggested a child's motivation influenced how they assumed responsibility from their parents for self-management of their LTC (Karlsson et al., 2008). In some studies, children were motivated by working towards a goal; for example, Meaux et al (2014) found children aspired to be independent in self-management by the time of leaving the family home to attend college. Rankin et al (2018) reported children were motivated to assume responsibility to alleviate parental burden but also to develop autonomy, enabling them to participate more in activities with their peers. Children's motivation was influenced by how they perceived the benefits associated with managing their condition; children who viewed the transfer of responsibility as an opportunity to gain knowledge and confidence in their own self-management abilities, and to receive approval from others and acquire more freedom, had greater motivation to assume responsibility (Hanna and Guthrie, 2000a; Williams et al., 2007). When the benefits were weighed against the child's perceived barriers to self-management, this impacted on the child's motivation to engage in managing their LTC (Rhee et al., 2009).

In some studies, the child's cognitive and emotional readiness influenced the parent-to-child transfer of responsibility (Karlsson et al., 2008; Kirk, 2008; Akre and Suris, 2014). It was predominantly parents, rather than HCPs, who made a judgement that the child was ready, basing their assessment on experience with older siblings or the child showing an increased

interest in aspects of self-management (Buford, 2004; Schilling et al., 2006). This quotation illustrated how parents considered their child's developmental readiness:

> *I remember, years ago, the idea was that the earlier you potty-trained the child, the better. It was a shameful thing if you didn't potty-train them early enough. With our children, it wasn't until they turned three and they started being interested and we said fine, now it's time. I think the same thing is true with diabetes care. We've really, to a large extent, waited until [the child is] ready. We gave hints; we gave opportunities. But it was more as [the child] was ready, then it was an easier transition* [Parent of a child with diabetes] (Schilling et al., 2006 p. 419).

Parents were reported to vary in how much they considered a child's motivation and readiness to assume responsibility. As discussed in section 2.4.1.4, situations sometimes prompted parents to transfer responsibility regardless of their child's readiness. For example, the child starting secondary school or changes to parents' working patterns meant some parents' decisions to relinquish control were based on pragmatic reasoning, rather than whether they identified their child was willing to start the transfer process (Buford, 2004).

2.5.1.5 Summary

This section has discussed previous research that explored how the child influenced the transfer of responsibility. Factors such as the child's age, development, gender, ethnicity, motivation and readiness, all seemed to impact on how children assumed responsibility and parents relinquished control. However, the contrasting findings in the literature around how and why some of these aspects, such as age and gender, influence the transfer process, make it difficult to draw conclusions and highlight a need for further research. The influence of the family will be examined in the following section.

2.5.2 The family

The research suggested that the child's family appeared to influence the transfer of responsibility, in relation to the family structure, parenting approach, socioeconomic background and parents' motivation to handover responsibility to their child.

2.5.2.1 Family structure

The structure of the family was identified in studies as a potential influence on how the child assumed self-management responsibility. For example: whether the household had one or two parents due to the differences in how mothers and fathers dealt with their child assuming responsibility (see section 2.5.2.2); whether parents worked; and the presence of another

family member with the same LTC as the child, who could impact on the transfer process (Buford, 2004; Akre and Suris, 2014).

Studies suggested parents with the same LTC as their child drew on their own experiences to make decisions about their child's self-management ability. These parents were often aware that self-management was associated with becoming attuned to symptoms (Chilton and Pires-Yfantouda, 2015; Kayle et al., 2016) and, therefore, they were more likely to consider their child an expert in recognising their own bodily symptoms (Meah et al., 2010). Children perceived it was beneficial to be able to learn from, and share the experience of managing a LTC with a parent; and 'friendly competition', for example around blood glucose control, could be helpful (Mulvaney et al., 2008). However, studies identified that the transfer process could put additional pressure on the parent as they felt they needed to be a good role model (Mulvaney et al., 2006) and it was important for the child to find their own way of managing their LTC (Rankin et al., 2018).

When a family member with the same LTC had serious complications resulting from difficulties with self-management, some studies reported how parents used stories about the family member to induce fear and motivate their child to self-manage (Mulvaney et al., 2006; Auslander et al., 2010), However, as this quotation illustrates, this strategy was not always effective:

> *She scares me about my sugar because she has two wounds, and she almost died. She scares me. She doesn't try to, it's just watching what she's going through. It makes me want to take better care of my diabetes, but I don't. It's inconvenient. It takes up too much time* [Adolescent with type 2 diabetes talking about her mother who has the same LTC] (Mulvaney et al., 2008 p. 679).

As the quotation suggests, the factors that appeared to influence a child's motivation to assume responsibility were complex and included the demands of the treatment regimen (see section 2.5.5.3).

2.5.2.2 Parenting approach

Studies suggested that the approach, communication style and attitudes of parents could influence how a child assumed self-management responsibility (Husted et al., 2014). These aspects were perceived to directly impact on child-parent relationships, in particular whether children and parents were able to collaborate, which was perceived as essential to the transfer of responsibility (Castensoe-Seidenfaden et al., 2017). Parents who were responsive to their child's needs as they assumed responsibility were recognised by children

to be helpful (Hanna and Guthrie, 2001) whereas parents not understanding their child's experience of living with a LTC was perceived to be a barrier to self-management (Rhee, 2009). Children found the transfer process less challenging when they felt able to communicate with their parents about their LTC (Mulvaney et al., 2008; Kayle et al., 2016) and when their parents demonstrated encouragement, trust and belief in their ability to self-manage (Meah et al., 2010; Stinson et al., 2008; Williams et al., 2007).

Some studies described how mothers and fathers adopted different parenting approaches (Akre and Suris, 2014), whereas others suggested the style of parenting and parent-child relationship was unique within each family (Spencer et al., 2013). Although the literature acknowledged diverse approaches to parenting, there was no discussion in any of the studies regarding whether parents' adoption of a particular approach was intentional or unplanned, and whether parents adjusted their approaches to support the transfer of responsibility.

2.5.2.3 Socioeconomic

The influence of the family's socioeconomic status (SES) on the child assuming self-management responsibility was discussed in two studies. Rhee et al (2009) identified that children whose parents had a higher SES (for example, those with a greater level of education and/or household income) perceived fewer barriers to self-management. Parents who worried about health insurance and paying for medication as their child became an adult experienced more challenges with transferring responsibility to their child (Ersig et al., 2016). As both these studies took place in the USA, it is unclear how SES might influence the transfer process for families living in countries with a different health care system.

2.5.2.4 Motivation

The final family influence that was evident in the literature was parents' motivation to transfer self-management responsibility to their child. Studies found some parents were highly motivated for their child to assume responsibility and were willing to 'let go' (Dashiff et al., 2011; Babler and Strickland, 2015), whereas others struggled and had to 'force' themselves to relinquish responsibility; for example, some parents were reported to work longer hours so they would be less present at home to support their child's self-management (Akre and Suris, 2014). The literature suggested parents' motivation to transfer responsibility was affected by worry; some parents were fearful of the potential complications that could result from their child's self-management decisions (Olinder et al., 2011; Meaux et al., 2014) and

were concerned about conflict with their child resulting from difficulties discussing management issues (Kayle et al., 2016).

Studies suggested parents considered the benefits and barriers related to their child independently managing their condition, and that this influenced their motivation to transfer responsibility. They recognised that their child would gain freedom, independence and control and they themselves could benefit by being relieved of the burden of self-management responsibility (Williams et al., 2007; Hanna and Guthrie, 2000b). However, parents' perceived barriers, such as their own loss of control and feelings of stress, worry and guilt, lessened their motivation to transfer responsibility (Hanna and Guthrie, 2000b). As discussed in section 2.4.1.4, the transfer of responsibility was an unplanned process for some families, therefore it is questionable how much parents would reflect on the benefits and barriers prior to making a decision to initiate the transfer process.

2.5.2.5 Summary

This section has examined the research evidence that suggested the family influenced the parent-to-child transfer of self-management responsibility. Various aspects of family life, including the family structure, parenting approach, socioeconomic status and parental motivation have been discussed. The next section will explore how social networks shaped the transfer process.

2.5.3 Social networks

The child's social networks, such as school and peers, were reported to potentially influence the transfer of responsibility.

2.5.3.1 School

Studies suggested that the child's school or college influenced how children assumed responsibility from their parents for self-management of their LTC. Some children found managing a LTC within a busy and structured school environment challenging, in particular dealing with competing demands such as school work, sports and spending time with friends (Chilton and Pires-Yfantouda, 2015; Christian et al., 1999; Strand et al., 2019). Children in Babler and Strickland's study (2015) reported difficulties with achieving balance in their daily life and found they needed to 'juggle' self-management with other responsibilities such as school work. Communicating with teachers about their LTC and symptoms, especially if they were not visible, seemed difficult for children and could be frustrating if school staff lacked understanding of self-management (Kayle et al., 2016).

The literature suggested that parents found the school environment presented challenges for their child assuming self-management responsibility, due to limited opportunities for healthier eating and engaging in exercise (Mulvaney et al., 2008; Mulvaney et al., 2006). Support from school staff with their child's self-management was valued by parents (Olinder et al., 2011; Stinson et al., 2008), although, in some studies, parents experienced frustration that school staff were rarely involved in monitoring their child's self-management (Dashiff et al., 2011). In one study, parents felt they needed to advocate strongly to ensure their child's self-management needs were met at school, which impacted on their child's ability to develop independence in managing their LTC (Kayle et al., 2016).

2.5.3.2 Peers

In various studies, peers were perceived by some children as a barrier to assuming self-management responsibility, in particular for adolescents, when 'fitting in' became key (Dashiff et al., 2011; Babler and Strickland, 2015). It was reported some children, and specifically boys, who were more likely than girls to consider having a LTC as stigmatising, worried about telling peers about their LTC due to concerns that others would respond negatively (Strand et al., 2019; Williams, 1999). This meant integrating self-management in a social context was difficult, as children were embarrassed about the attention they may attract when carrying out self-management tasks (Chilton and Pires-Yfantouda, 2015; Mulvaney et al., 2008; Hanna and Guthrie, 2000a), as this quotation illustrates:

> *Some days I check my blood like twice, I know that is horrible. You realize you are different from everyone else and you are trying to fit in. If you are going to a movie to eat popcorn, you don't want to be 'Hold on I've got to check my blood'* [Adolescent with diabetes] (Babler and Strickland, 2015 p. 655).

For those children who prioritised participating in social activities over managing their LTC, peers were perceived to be a barrier to assuming self-management responsibility (Spencer et al., 2013; Rhee et al., 2009). However, in one study, children who were learning to manage their condition, described how self-management was a 'convenient excuse' to avoid participating in activities with peers they perceived as 'risky', such as drinking alcohol or taking drugs (Stinson et al., 2008).

The literature suggested that as children became older and increasingly adapted to having a LTC, they recognised the importance of having friends know about their condition (Christian et al., 1999) despite some being teased or bullied (Mulvaney et al., 2006). Disclosure appeared to support the transfer of responsibility; some children found having their friends'

reminders and emotional support with self-management, and the reassurance they had a 'safety net' if they needed help while away from home, encouraged them to assume responsibility (Spencer et al., 2013; Ersig et al., 2016; Auslander et al., 2010).

Children in the studies tended not to know others their age who had the same LTC and there was ambivalence around whether this would help when assuming responsibility. Some studies found children and parents thought having peers with the same LTC could be a positive influence as some children found it helped them feel 'normal', and therefore encouraged them to engage with self-management (Mulvaney et al., 2008; Castensoe-Seidenfaden et al., 2017). In contrast, other studies found children were reluctant to meet peers with the same LTC and did not perceive it would support the transfer of responsibility, as they thought self-management of their LTC was 'very personal and individualised' (Sullivan-Bolyai et al., 2014).

2.5.3.3 Summary

This section has explored the evidence about how the child's social networks potentially influenced the parent-to-child transfer of self-management responsibility. Studies suggested the child's school or college mostly made it more challenging for children to assume responsibility; however, peers could both facilitate and act as a barrier to the transfer process. The next section will discuss the influence of HCPs on children assuming self-management responsibility from their parents.

2.5.4 Health care professionals

Both the current involvement and potential role of HCPs in the parent-to-child transfer of self-management responsibility was discussed in the literature.

2.5.4.1 Current involvement

There was limited evidence regarding the role of HCPs in supporting the parent-to-child transfer of self-management responsibility. Only two studies included HCP participants (Husted et al., 2014; Olinder et al., 2011) so where HCPs were discussed this was mostly based on data from children and parents. When reported on, there was ambivalence around HCP input. Support from HCPs was viewed as helpful by some parents in facilitating the transfer of responsibility through: information giving; training; confidence building; and emotional support (Williams et al., 2007; Kirk, 2008; Meaux et al., 2014). Some children in Castensoe-Seidenfaden et al's study (2017) reported receiving helpful advice from HCPs

and valued it when they were involved in discussions about managing their LTC, rather than feeling they were being 'scolded'. However, some children and parents found HCP involvement less helpful due to: poor communication with HCPs (Rhee et al., 2009; Williams, 1999); provision of irrelevant advice due to unfamiliarity with the child's everyday activities and life situation (Castensoe-Seidenfaden et al., 2017; Karlsson et al., 2008); or a perceived lack of interest in supporting the transfer of responsibility, as illustrated by this quotation:

> *I tried to mention it to her [HCP] once but she just sort of said, 'Oh, you can work it out at home.' They are very nice and all that, but I think they are more concerned with the results, you know the HbA1c rather than who does what* [Mother of child with diabetes, aged 12 years] (Newbould et al., 2008 p. 125).

In one study, some parents thought HCPs considered them *'bad parents'* and were threatened with social services involvement if they were not physically involved in their child's diabetes management, due to HCPs' concerns around glycaemic control; as a result parents were fearful of being honest and lost trust in HCPs (Sullivan-Bolyai et al., 2014). This contrasted with the findings from another study, where parents found that, due to HCPs' expectations that children should assume self-management responsibility, they were criticised for being over-protective, yet were also blamed if their child had poor blood glucose control (Williams, 1999). Due to limited negotiation between the child, their parents and HCPs, tension sometimes resulted between family members and HCPs around who should be responsible for self-management, which impacted on the transfer process (Williams, 1999; Williams et al., 2007).

Although parents tended to recognise a role for HCPs in supporting the transfer of responsibility and approached them for support (Meah et al., 2010), children mostly turned to their parents for help (Ersig et al., 2016). This occurred for various reasons, including children feeling HCPs should not be involved in supporting independence development, as they considered it a private family issue (Sullivan-Bolyai et al., 2014; Jedeloo et al., 2010), and difficulties communicating effectively with HCPs around self-management concerns (Stinson et al., 2008).

2.5.4.2 Potential role

Despite the limited evidence and ambivalence regarding HCP input, many studies recommended an increased role for HCPs in supporting the parent-to-child transfer of responsibility (Buford, 2004; Dashiff et al., 2011). Recommendations included HCP involvement that was focused on the child, the parent or child-parent dyad (Table 8).

Table 8: Recommendations for potential HCP involvement

Child focused	Parent focused	Child-parent dyad focused
Developing partnerships with child and adapting consultations so they focus on difficulties perceived as important by the child (Sullivan-Bolyai et al., 2014; Husted et al., 2014)	Helping parents to move from a paternalistic role to one that acknowledges the goals and independence of their child (Williams et al., 2007)	Education with child and parents to develop child's and parents' communication skills (Kayle et al., 2016; Hanna and Guthrie, 2001)
Viewing the child within a wider context rather than focusing solely on their LTC (Sullivan-Bolyai et al., 2014; Christian et al., 1999)	Advice on how to handle separation anxiety and situations where the child and parent are separated (Buford, 2004; Dashiff et al., 2011)	Defining self-management through the family's view, rather than the HCPs view and avoiding a uniform policy of promoting independence (Buford, 2004; Williams, 1999)
Increasing opportunities for problem solving, experiential learning, to make mistakes and learn through trial and error (Mulvaney et al., 2006; Spencer et al., 2013)	Advice on continuing to provide supervision as the child assumes responsibility and role modelling interdependence/shared management between the child and their parent (Sullivan-Bolyai et al., 2014; Christian et al., 1999)	Facilitating discussions between child and parent to clarify self-management responsibility and support renegotiations as roles/responsibilities change (Olinder et al., 2011; Newbould et al., 2008)
Encouraging the child to communicate with their parents around the self-management they can do, what tasks they want help with and the kind of help they want (Hanna and Guthrie, 2001)	Reassurance about the child's self-management ability (Dashiff et al., 2011)	Education around normal developmental tasks and gradual acquisition of self-management skills (Meaux et al., 2014; Schilling et al., 2006)
Encouraging the child to communicate directly with the HCP, rather than through their parent (Buford, 2004)	Supporting parents to coach other parents on how to transfer responsibility (Dashiff et al., 2011)	Collaboration and goal setting across the child-parent-HCP triad (Kayle et al., 2016; Meaux et al., 2014)
Focusing on the child's readiness to assume responsibility rather than adopting an age/stage-orientated approach (Christian et al., 1999)	Education around typical adolescent development and developmental cues that indicate readiness to assume responsibility (Buford, 2004; Dashiff et al., 2011)	Teamwork between child, parent, HCP and peers (Mulvaney et al., 2006; Spencer et al., 2013)
Training to increase coping skills and reduce stress (Babler and Strickland, 2015; Auslander et al., 2010)		

Providing positive reinforcement (Sullivan-Bolyai et al., 2014)		
Supporting the child to weigh up the benefits and barriers to assuming responsibility (Williams et al., 2007)		
Peer support group (Ness et al., 2018)		

Although the literature suggested the parent-to-child transfer of responsibility involved changes to both the child's and parent's roles and responsibilities, the majority of the recommendations were solely child or parent focused, rather than HCPs working jointly with the child-parent dyad. Recommendations were focused on education and skills training for children and/or parents with the aim of changing attitudes and behaviours; however, the need for HCPs to acquire new skills and adapt their behaviour was implied rather than explicitly recommended. The focus on 'behaviour change' in the recommendations suggested that other factors were not considered, including the activities involved in self-management, and the impact of the environment and wider contextual factors on the transfer of responsibility. Due to the limited evidence in this area, the need for further research to explore the role of HCPs, and develop and evaluate interventions that support families with the parent-to-child transfer of self-management responsibility, is indicated.

2.5.4.3 Summary

This section has discussed study findings in relation to HCPs' involvement in the transfer of responsibility. Current HCP involvement and recommendations for increased HCP involvement have been presented. Gaps in knowledge regarding HCPs' role during the transfer process indicate further research is needed, in particular in under-researched conditions, such as CKD.

2.5.5 The long-term condition

The nature of the LTC was identified in some studies as influential on children assuming self-management responsibility. Factors included the diagnosis, age of diagnosis and LTC duration, the treatment regimen and co-morbidities.

2.5.5.1 Diagnosis

Most studies focused on a specific LTC and did not aim to compare how different diagnoses could influence the parent-to-child transfer responsibility. Only one of the studies that

included participants with a range of LTCs described how types of LTC impacted on how the child assumed responsibility (Jedeloo et al., 2010). Study findings suggested children with a congenital condition were less likely to want help from parents and HCPs in developing self-management skills, whereas those with a recently acquired condition were more likely to value parental and HCP support in learning how to self-manage (Jedeloo et al., 2010). Authors provided information about the types of LTCs experienced by the children that participated in the study, but, unfortunately, they did not distinguish between which conditions were congenital and those that were recently acquired.

The literature suggested that other factors related to the child's diagnosis were influential on the transfer of responsibility. For example, where LTCs were progressive rather than stable, or resulted in the child being regularly hospitalised, parents were more likely to resume responsibility in response to their child becoming unwell (Newbould et al., 2008; Meaux et al., 2014; Williams et al., 2007). Studies suggested that, when children had symptoms that were complex, unpredictable or invisible, this could prompt them to feel helpless and reduced their motivation to assume responsibility (Kayle et al., 2016; Karlsson et al., 2008). Section 2.5.5.3 discusses how different LTCs unique treatment regimens could impact on the transfer of responsibility.

2.5.5.2 Age and duration

Study findings suggested there was ambivalence around how the age of diagnosis and LTC duration influenced the parent-to-child transfer of responsibility. In Sullivan-Bolyai et al's study (2014) children diagnosed with diabetes at two years old started to assume responsibility when they were ten years old, whereas those diagnosed when they were older (e.g. aged seven) were involved immediately in self-management. For some children, a diagnosis from birth or early childhood meant they were more likely to view their treatment regimen as part of their normal daily routine and therefore experience less difficulties with assuming self-management responsibility (Karlsson et al., 2008; Auslander et al., 2010). However, no relationship was found between the duration of diagnosis and perceived barriers to self-management in Rhee et al's study (2009). The uncertainty around the influence of LTC duration on the transfer of responsibility was evident in Spencer et al's study (2013). They reported how for some children, longer duration meant it was easier to integrate self-management activities into their daily life, whereas, for others, it increased the burden of the self-management regimen and reduced their motivation to assume responsibility.

2.5.5.3 Treatment regimen

The individual treatment regimen was reported to have an impact on children assuming responsibility (Jedeloo et al., 2010). Medication frequency (Christian et al., 1999), the need to adjust treatments based on fluctuating symptoms (Karlsson et al., 2008) and level of risk of a particular procedure (Kirk, 2008; Olinder et al., 2011) could mean children valued parental support and parents were reluctant to relinquish responsibility (Jedeloo et al., 2010). The complexity of the treatment regimen could affect the transfer process in different ways; for example, parents of children with asthma were confident in their child's use of reliever inhalers, but had concerns about their child correctly using preventer medication and so would be more involved in this aspect of self-management (Meah et al., 2010). This contrasted with regimens for other LTCs such as diabetes, where children took on more responsibility as their parents did not know how to use the insulin pump due to its technological complexity (Olinder et al., 2011; Schilling et al., 2006). Other studies suggested the technology used in diabetes self-management could support the transfer of responsibility as it enabled parents to remotely monitor their child's glucose levels and helped children to calculate their own insulin doses when they were apart from their parents (Ness et al., 2018; Rankin et al., 2018). How children perceived their treatment regimen was reported to influence how they assumed responsibility; children who were more negative about their regimen, due to experiencing side effects and distressing bodily changes, perceived more barriers to assuming self-management responsibility (Rhee et al., 2009). As none of the studies focused specifically on CKD, which has condition-specific self-management needs such as renal diet, restricted fluids and home dialysis, the need for research in this area is indicated.

2.5.5.4 Co-morbidities

Some studies suggested that when children with LTCs had additional conditions, such as obesity and learning disabilities, this could influence the transfer process (Mulvaney et al., 2008; Mulvaney et al., 2006). Co-morbidities could increase the complexity of self-management and if a child had cognitive difficulties that affected their ability to make judgements about their health, parents were sometimes more reluctant to relinquish control (Auslander et al., 2010). The three studies that discussed co-morbidities all focused on children with type 2 diabetes, therefore it is unclear whether this finding would relate to other LTCs.

2.5.5.5 Summary

This section has discussed how the LTC potentially influenced the parent-to-child transfer of responsibility. Various aspects of the LTC, including the diagnosis, age of diagnosis and LTC duration, the treatment regimen, and co-morbidities, have been explored. The suggestion that the specific LTC, and in particular its treatment regimen, could impact on how children assumed responsibility indicates that further research is needed in under-researched LTCs, such as CKD.

2.5.6 Summary

Section 2.5 has synthesised previous research to address the second review question of what influenced the parent-to-child transfer of responsibility. It has discussed how multiple factors, such as the child, family, social networks, HCP and LTC, appeared to interact and influence how children assumed responsibility. The contradictory findings around the influence of the child's age, developmental stage and gender on the transfer process, were presented. The section explored the potential influence of the family and child's social networks, such as school and peers. The limited evidence around HCPs current involvement and recommendations for an increased role for HCPs, were presented. Finally, the section examined the literature that suggested the nature of the LTC and individual treatment regimen could impact on how children assumed responsibility and parents' relinquished control.

2.6 Strengths and limitations of this review

The main strength of this review was the use of the integrative review method. Through using the methodological strategies proposed by Whittemore and Knafl (2005) and synthesising a broad range of evidence, this chapter has described the complexity of different perspectives and presented a comprehensive, and new, understanding of how children assume self-management responsibility from their parents (Hopia et al., 2016). Due to methodological diversity within and between qualitative, quantitative and mixed methods studies, it has been questioned whether mixed methods reviews are feasible or acceptable (Dixon-Woods et al., 2005; Sandelowski et al., 2006). By adopting a systematic and rigorous approach in this integrative review, and in particular using established data analysis techniques from primary qualitative research in data synthesis, the aim has been to reduce bias and error (Whittemore and Knafl, 2005).

The studies included in the review were from the United Kingdom, Europe and North America, suggesting there could have been bias towards western cultures. Only two studies (Auslander et al., 2010; Rhee et al., 2009) explicitly explored how ethnicity could affect the transfer of self-management responsibility, suggesting this is an area where further research is needed. Many of the studies examined specific LTCs, which may limit the generalisability and transferability of the findings; however, through using the methodological strategies proposed by Whittemore and Knafl (2005), it was possible to explore the relationships between studies and identify common concepts across a range of childhood LTCs.

Another potential bias is that only the author conducted initial screening, data extraction and quality assessment, although the supervisory team were involved in reviewing eligibility and data extraction forms, with any discrepancies being resolved through discussion. The search strategy was systematic, but, as this is not a well-indexed field of research, it is possible that some relevant studies were excluded. As the inclusion criteria comprised English language papers only, some relevant non-English studies may have been omitted.

2.7 Literature review conclusion

This chapter has reviewed and synthesised the available evidence relating to the parent-to-child transfer of LTC self-management responsibility. The two review questions have been addressed and eight themes identified that offer new understanding of the transfer of responsibility. Children assuming responsibility from their parents for self-management of their LTC was portrayed as a complex, individualised process. Although the transfer of responsibility was seen as part of normal development, it was rarely viewed within the wider context of the child gaining independence in other areas of their life. Although children, parents and HCPs adopted various strategies, there was limited evidence around HCPs' roles and ambivalence around what supported children to assume responsibility, and parents to relinquish control. Where the literature did explore HCPs' roles, this was predominantly from the perspectives of children and parents, with a noticeable absence of HCPs' perspectives. The lack of clarity around children's, parents' and HCPs' goals and expectations resulted in a range of planned and unplanned outcomes, including the child assuming full responsibility for self-management, and the child-parent dyad sharing management of the LTC. Multiple factors such as the child, family, social networks, HCPs and LTC, appeared to interact and influenced how children assumed responsibility.

The literature review suggests that there is a need for greater understanding of the transfer process, in particular around: when children start to assume responsibility; who initiates and is subsequently involved in supporting the transfer process; why the process is initiated; what aspects of self-management are transferred; what supports the process; how this transfer process aligns with children gaining independence in other areas of their life; when the process is completed; and what the outcome is for children and parents. Furthermore, as many of the studies included in the review focused on specific LTCs, studies focused on under-researched LTCs, such as CKD, which is progressive and has its own unique self-management needs, are indicated.

This literature review has demonstrated that to date there has been no research that has explored children's, parents' and HCPs' views on the parent-to-child transfer of self-management responsibility for CKD, or identified families' support needs during this transfer of responsibility. Through gaining increased understanding of the processes that occur as children assume responsibility for their CKD, and parents relinquish control, this current study aims to address these gaps in knowledge.

The next chapter presents the methodology and methods used in the study.

3. RESEARCH METHODOLOGY AND METHODS

3.1 Introduction

This chapter describes the methodology and methods selected for the study. First, the research aims and objectives will be outlined, followed by an overview of the study design. Grounded theory and data collection methods will be discussed and a rationale provided for their selection. The chapter will also examine issues associated with conducting research with children.

3.2 Study aims and objectives

Through reviewing the literature and identifying gaps in knowledge about the parent-to-child transfer of self-management responsibility, this study's aims and objectives were developed.

3.2.1 Study aims

The aims of the study were to: 1) explore young peoples', parents' and HCPs' views on the parent-to-child transfer of self-management responsibility for CKD stages 3-5; 2) identify young people's, parents' and HCPs' perceptions of families' support needs during this transfer of responsibility; and 3) develop a theory to understand and explain the processes that occur during the parent-to-child transfer of self-management responsibility.

3.2.2 Objectives

1. To gain a detailed insight into young peoples', parents' and HCPs' views and experiences of the parent-to-child transfer of self-management responsibility, including what influences this transfer and how it fits within the wider context of the young person gaining independence.
2. To examine the role HCPs play in the transfer of self-management responsibility.
3. To explore young people's, parents' and HCPs' perspectives on what currently supports young people with CKD 3-5 and their parents as their self-management responsibilities change.
4. To identify young peoples', parents' and HCPs' perceptions of families' potential support needs with the parent-to-child transfer of responsibility.
5. To explore young people's and parents' support preferences during this transfer process.

3.3 Study design

The literature review identified limited published evidence about how young people with CKD 3-5 (hereafter referred to as CKD) and parents, negotiate the transfer of self-management responsibility, and the role of HCPs in this process. Having identified this evidence gap, the current study aimed to conduct an in-depth exploration of these issues. When the phenomena being studied are complex, not well understood and rooted in participants' understanding of themselves, a qualitative research design is suitable (Ormston et al., 2014). As the literature review concluded in section 2.7, the parent-to-child transfer of self-management responsibility is a complex process with multiple factors influencing how a child assumes responsibility. Therefore, qualitative research methods were selected as most appropriate for this study, as it aimed to explore, understand and theorise the processes that occur for young people, parents and HCPs during the transfer of self-management responsibility. Prior to discussing qualitative research design, the philosophical assumptions that underpin qualitative research will be considered.

3.3.1 Philosophical assumptions

Qualitative research is underpinned by various philosophical assumptions that shape the formulation of the research question and influence how information is sought to answer the question (Cresswell and Poth, 2018). These include beliefs about ontology (the nature of reality), epistemology (how reality is known and what counts as knowledge) and methodology (how we gain knowledge about the world) (Denzin and Lincoln, 2011; Staller, 2013). Denzin and Lincoln (2011) state that the 'net' that holds the researcher's epistemological, ontological and methodological principles can be termed a paradigm, or a 'basic set of beliefs that guides action' (Guba, 1990 p. 17). These philosophical assumptions will each be discussed, including their influence on this study.

This study took a relativist ontological position, which asserts the existence of multiple realities (Cresswell and Poth, 2018; Denzin and Lincoln, 2011). This belief was reflected in the study's aims and objectives, where different people's perspectives on the parent-to-child transfer of CKD self-management responsibility were explicitly sought. Epistemological beliefs flow from the ontological position adopted and are concerned with how we find out about phenomenon (Giacomini, 2010). In adopting an interpretive epistemology, this study was underpinned by the belief that knowledge is known through people's subjective experiences (Cresswell and Poth, 2018). Interpretive epistemology emphasises how 'different perspectives lead to diverse meaningful interpretations of social phenomena'

(Giacomini, 2010 p. 133). Rather than taking an objective view, the researcher is viewed as being part of the social world who can affect the phenomena that are being studied (Giacomini, 2010; Denzin and Lincoln, 2011). This study utilised a naturalistic set of methodological procedures which included: following an inductive logic; studying the topic within its natural context; and using an emerging design (Denzin and Lincoln, 2011; Cresswell and Poth, 2018).

By assuming these epistemological, ontological and methodological premises, this study can be positioned within the constructivist paradigm (Denzin and Lincoln, 2011). Cresswell and Poth (2018 p. 35) outline the central tenets of constructivism as:

- multiple realities are constructed through our experiences and interactions with others;
- reality is co-constructed between research participants and the researcher and shaped by individual experiences;
- use of an inductive method of emergent ideas.

The influence of these philosophical assumptions on the grounded theory approach adopted in this study will be discussed in section 3.4.

3.3.2 Qualitative research design

Qualitative research is concerned with 'making the world visible' and attempts to 'make sense of, or interpret, phenomena in terms of the meanings people bring to them' (Denzin and Lincoln, 2011 p. 3). It is a suitable approach when an issue needs to be explored, and can be used to: gain a complex and detailed understanding of both the issue and social context; develop a theory to address gaps in understanding; and explain an issue (Cresswell and Poth, 2018). Qualitative approaches to health research have roots in the social sciences and seek to 'answer "what", "how" or "why" questions about the social aspects of health, illness and health care' (Green and Thorogood, 2018 p. 26).

Although there is a wide variation in qualitative research, there are common elements of this approach (Ormston et al., 2014 p. 4):

- aims which are directed at providing an in-depth and interpreted understanding of the social world by learning about participants' experiences and perspectives,
- the use of methods of data generation that are sensitive to the social context of the study and can be adapted for each participant to allow exploration of emergent issues,
- data that are detailed, rich and complex,

- analysis that retains complexity and nuance, and is open to emergent categories and theories,

- a reflexive approach, where the role and perspective of the researcher is acknowledged.

A qualitative research design was considered appropriate as this study aimed to gain understanding of the parent-to-child transfer of self-management responsibility and develop theory to explain and conceptualise the social processes occurring during this transfer. This decision was made, however, with an awareness of the potential limitations of qualitative research.

3.3.3 Challenges to qualitative research

Although there is increasing recognition of the value of qualitative research in focusing on questions of understanding and process, the limitations of qualitative methodologies have been debated (Green and Thorogood, 2018). These criticisms tend to arise due to different ontological and epistemological assumptions; for example, if an individual starts with a belief that there is a single reality, the researcher is independent and science is value-free, they are potentially more likely to view qualitative research as 'unscientific', anecdotal and only producing subjective accounts (Gray, 2018).

Qualitative research can be viewed as 'unscientific' as its methods tend to be more inductive than quantitative methods; this means the focus is on starting from the data and generating theory, rather than starting with a theory from which hypotheses are developed, and then testing these against the data (Murphy and Dingwall, 2003). As the researcher is using inductive reasoning based on their knowledge, values, and theoretical preconceptions, this means analysis is not 'neutral' and a different researcher could analyse the same data and reach different conclusions (Gray, 2018; Charmaz, 2008). Linked to this is the assumption that, because qualitative research often explores people's views, or various understandings of a phenomenon, its findings are subjective (Green and Thorogood, 2018). Qualitative researchers, however, would argue that they go beyond producing anecdotes or subjective accounts, as, through analysing participants' experiences, understanding and meaning can result (Cresswell and Poth, 2018). Green and Thorogood (2018 p. 24) outline a number of strategies used in qualitative research that differentiate it from other activities, such as art or literature, that also describe or represent social life. These include:

- an attention to evidence: qualitative research aims to provide evidence for descriptions and interpretations,

- a critical approach to subjective accounts: researchers situate participants' accounts within a context and ask questions of the data with the aim to produce an understanding,

- a critical approach to analytic accounts: assumptions built into the research question and emerging analysis are constantly tested through reflexivity. This will be discussed further in section 3.4.3.6.

Similarly, Murphy and Dingwall (2003) suggest qualitative research can be 'scientific', through rigorous collection and analysis of data, and by researchers subjecting their assumptions and values to critical scrutiny. Rigour and quality in qualitative studies will be discussed in section 3.7.

Despite these potential limitations, a qualitative research design was adopted as its philosophical assumptions and strengths meant it would best meet the study's aims and objectives. This then led to the consideration of what qualitative approach to select for the study.

3.3.4 Approaches in qualitative research

Although qualitative research shares the key elements detailed in section 3.3.2, there are many different qualitative approaches and multiple ways of categorising them (Cresswell and Poth, 2018). These approaches are underpinned by different philosophical assumptions and, therefore, differ in aspects of the research design, including: the research topic; the way a research question is posed; data collection and analysis; what is learned and how the information learnt is presented (Staller, 2013). Cresswell and Poth (2018) outline five approaches to qualitative research that are most frequently seen in health literature: narrative research; phenomenology; ethnography; case study, and grounded theory. Table 9 summarises the foundational considerations of these five approaches (Cresswell and Poth, 2018 p. 104). Each approach will be briefly discussed and a rationale provided for the approach chosen for this study.

Table 9: Foundational considerations of qualitative approaches

Foundational consideration	Narrative research	Phenomenology	Ethnography	Case study	Grounded theory
Research focus of approach	Exploring the life of an individual	Understanding the essence of the experience	Describing and interpreting a culture-sharing group	Developing an in-depth description and analysis of a case or multiple cases	Developing a theory grounded in data

Unit of analysis	Studying one or more individuals	Studying several individuals who share an experience	Studying a group that shares the same culture	Studying an event, a program, an activity or more than one individual	Studying a process, an action, or an interaction involving many individuals
Type of research problem	Aiming to tell stories of individual experiences	Aiming to describe the essence of a lived phenomenon	Describing and interpreting the shared patterns of culture of a group	Providing an in-depth understanding of a case or cases	Grounding a theory in the views of participants

Narrative research 'begins with the experiences as expressed in lived and told stories of individuals' (Cresswell and Poth, 2018 p. 67). Researchers using this approach are interested in telling the stories of individual(s') experiences, exploring the context in which the narrative is embedded and arranging the stories in chronological order (Ormston et al., 2014). Adopting a narrative approach in this study would have been appropriate if the aim was to explore the life stories of young people with CKD and their parents; however, as the focus was on studying a process, an alternative approach was required.

Case study research may also focus on a single individual, but can additionally involve a community, organisation or an event; the case is usually selected to illustrate an issue, is bounded by time and place, and is studied within a real-life, contemporary setting (Lewis and McNaughton Nicholls, 2014). The aim is to gain an in-depth understanding of the case, through providing detailed description, and identifying patterns or explanations that can be 'learnt' from studying the case (Green and Thorogood, 2018). Although this study could potentially have selected cases to study, such as paediatric renal units or families where responsibility was being transferred from the parent to the child, the aim was to go beyond description and to develop a theory.

Whereas narrative research reports the stories of experiences of an individual, or several individuals, phenomenology describes the essence of a lived experience for a number of individuals (Ormston et al., 2014). The focus is on describing what participants have in common when they experience a phenomenon; this description comprises 'what' they experience and 'how' they experience it (Starks and Trinidad, 2007). If this study had started from the philosophical assumption that experience is already meaningfully organised and can be uncovered and described, rather than viewing realities as constructed, phenomenology would have been an appropriate approach (Charmaz, 2011).

In ethnography, the focus is on studying a culture-sharing group; the researcher describes and interprets the shared patterns of culture, such as the values, beliefs, behaviours and language of the group (Hammersley and Atkinson, 2007). Ethnography uses various methods to collect data; however, observation, where the researcher is immersed in the life of the group and observes and interviews group members, is key (Cresswell and Poth, 2018). An ethnographic approach was considered not appropriate for this study for various reasons, including: the study aims were more focused; interactions between young people with CKD, their parents and HCPs could be fairly irregular and so it would be unlikely they would develop a shared culture; and the parent-to-child transfer of self-management responsibility was unlikely to occur in bounded times or places, therefore making observation of this process practically very difficult.

Finally, a grounded theory study moves beyond description, to define patterns in the data, develop new concepts and theorise processes in the data (Charmaz and Bryant, 2011). The aim is to construct a theory that is grounded in the views of participants and is an understanding or explanation of a process or an action (Charmaz, 2014). Starks and Trinidad (2007) report that the theory developed in a grounded theory study can be used to design interventions to support people engaged in the processes explained by the theory. As this study aimed to explore a social process, the parent-to-child transfer of self-management responsibility, and develop a theory to understand and explain this process, grounded theory was considered an appropriate approach.

3.4 Grounded theory approach

The objective of grounded theory is to study a social process (Starks and Trinidad, 2007). Charmaz (2014 p. 17) describes how a process 'consists of unfolding temporal sequences, that may have identifiable markers with clear beginnings and endings and benchmarks in between'. Grounded theory techniques support an iterative-inductive approach to data collection and analysis which is appropriate when studying an area where limited research has been conducted (Higginbottom and Lauridsen, 2014). The aim of this approach is to construct a theory that is 'grounded' in the data, and understands and explains the social processes involved in dealing, and/or coping with an issue (Charmaz, 2011; Birks and Mills, 2011). For these reasons, it was thought to be a relevant approach for this study. Moreover, grounded theory offers systematic, yet flexible guidelines for collecting and analysing data (Charmaz, 2014); as a grounded theory novice, I found these invaluable.

3.4.1 Background to grounded theory

Grounded theory was developed by Glaser and Strauss (1967) in the 1960s as a method to generate theory from data (Birks and Mills, 2011). At this time, research was predominantly deductive and focused on testing existing theory; in response to concerns around theory stagnation, grounded theory emerged as an inductive method where field research was used to develop theory (Howard-Payne, 2016; Higginbottom and Lauridsen, 2014). Key components of the approach included: simultaneous involvement in data collection and analysis; sampling aimed towards the construction of theory; and constant comparison that allowed for development of theory that is analytically grounded in the data (Charmaz, 2017). These components will be discussed in more detail in section 3.4.3.

Glaser's quantitative training meant the philosophical assumptions underpinning his work were those associated with the positivist paradigm, such as the existence of an external reality and the idea of an objective, value-free observer (Ormston et al., 2014). This contrasted with Strauss' interest in symbolic interactionism, a theoretical perspective developed by Blumer (1969) based on Mead's (1934) earlier work. Symbolic interactionism emphasises the centrality of interaction in creating social meanings (Dyson and Brown, 2006; Jeon, 2004). Blumer (1969) described how symbolic interactionism has three central premises:

- social meanings arise out of interactions,
- meanings are modified through an interpretative process, and
- humans act towards 'things', such as objects, other people, institutions, activities or situations, based on the meanings that the 'things' have for them.

The meanings which are attached to a 'thing' are based on active interpretation of it rather than its innate qualities (Charmaz, 2014). By focusing on social interaction, and the actions of individuals, symbolic interactionism differs to other perspectives that view reality as external, and objects as having their own intrinsic meaning that can be discovered by a neutral researcher (Charmaz, 2008).

Charmaz (2005 p. 510) described how Glaser and Strauss' grounded theory combined their differing philosophical assumptions and offered 'guidelines and legitimacy for conducting research'. However, one of the criticisms of the original version of grounded theory was Glaser and Strauss's decision not to write about these assumptions, instead focusing on the strategies and techniques that could be used (Birks and Mills, 2011; Bryant, 2009). The different ontological and epistemological positions adopted by Glaser and Strauss

contributed to their disagreement about aspects of grounded theory, that resulted in the development of separate schools in the late 1980s (Higginbottom and Lauridsen, 2014). 2014). For example, in their subsequent work, Glaser viewed the researcher as maintaining a neutral stance towards the data, whereas Strauss, in his joint work with Corbin, described the researcher as active in data collection and analysis (Howard-Payne, 2016). Charmaz (2005) outlined how Strauss and Corbin introduced new technical procedures for data analysis; however, Glaser criticised these procedures as prescriptive and thought they led to the 'forcing' of data into preconceived categories and prevented researchers from developing creativity that is necessary for 'discovering' theory (Jeon, 2004). There was also divergence around the role of verification; Strauss and Corbin made theory verification an explicit goal of a grounded theory study, whereas Glaser believed verification was only possible after theory had been developed, via subsequent quantitative analyses (Howard-Payne, 2016). However, during the 1990s, the earlier versions of grounded theory that were associated with positivism were challenged. One of the alternative versions developed, that built on its symbolic interactionism roots, was constructivist grounded theory (Charmaz and Bryant, 2011).

3.4.2 Constructivist grounded theory

Constructivist grounded theory 'adopts grounded theory guidelines as tools but does not subscribe to the objectivist, positivist assumptions in its earlier formulations' (Charmaz, 2005 p. 509). This approach to grounded theory is underpinned by constructivist assumptions that reality is multiple and constructed, though constructed within a particular context and time (Higginbottom and Lauridsen, 2014). By drawing on symbolic interactionism, the research process is viewed as emerging from interaction; instead of the researcher 'discovering' data in an external world, the researcher is located in this world and together with the participant, jointly co-constructs the data (Charmaz, 2008). This means data are a product of the research process, rather than observed objects of it (Charmaz, 2011).

As a result of the differences in the ontological and epistemological positions that guide the various approaches to grounded theory, the theory that is developed is also 'foundationally' different (Higginbottom and Lauridsen, 2014). In Glaser and Strauss's (1967) original grounded theory, theory is discovered as emerging *from* the data by the 'scientific observer', who has no interpretive frame of reference. In contrast, theory developed in constructivist grounded theory is based on co-construction; the researchers' interests and experiences, their relationships with participants and the research context all influence what is defined as

data (Charmaz, 2005). This results in an 'interpretive portrayal' of the social world, rather than an 'exact picture' of it (Charmaz, 2014).

Charmaz's (2014) constructivist approach to grounded theory was used in this study as its underpinning ontological and epistemological assumptions aligned with the study's aims and objectives and the author's beliefs. For example, the assumption that social reality is multiple, processual and constructed aligned with the aim to explore the parent-to-child transfer of self-management responsibility from multiple perspectives. Additionally, the beliefs underpinning constructivist grounded theory resonate with the theoretical principles that guide occupational therapy (the author's professional disciplinary background), and which emphasise the importance of understanding the individual's subjective experience within their physical, social and temporal context (Higginbottom and Lauridsen, 2014; Pentland et al., 2018).

3.4.3 Grounded theory strategies

Charmaz (2014 p. 15) outlines the strategies used by researchers that adopt a grounded theory approach:

- Data collection and analysis conducted simultaneously in an iterative process
- Analysing actions and processes rather than themes and structures
- Use of comparative methods
- Systematic data analysis to develop abstract analytic categories
- Emphasise theory construction rather than description, or application, of current theories
- Engage in theoretical sampling.

Figure 6 illustrates how some of these strategies fit together during the process of conducting grounded theory research (Birks and Mills, 2011 p. 13). As the figure highlights, writing memos is a significant part of the process and records the 'path of theory construction' (Charmaz, 2014 p. 164). The following sections will discuss some of the key strategies that underpin grounded theory studies.

Figure 6: Key grounded theory strategies (Birks and Mills, 2011 p. 13)
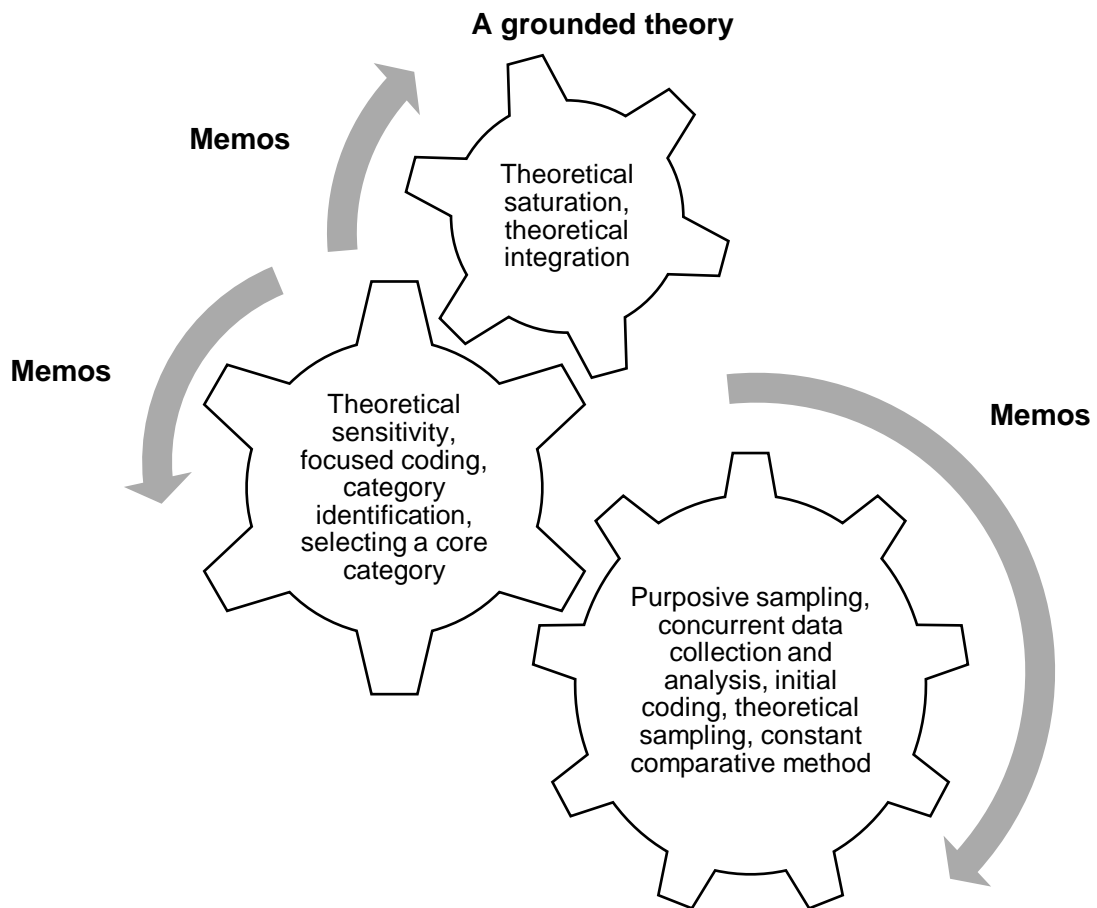
3.4.3.1 Data collection

In grounded theory studies, data are most often gathered from sources that are qualitative in nature as both are underpinned by similar philosophical assumptions (Birks and Mills, 2011). Charmaz's (2008) constructivist approach to grounded theory asserts that the researcher and participants co-construct the data; this means data are a product of an interactive research process, rather than something to be discovered. The term 'thick description' has been used to describe the densely textured accounts of people and places, which enable readers to understand the phenomenon being studied and draw their own interpretations about meanings and significance (Geertz, 1973; Patton, 2015). A key characteristic of grounded theory is concurrent data collection and analysis (Higginbottom and Lauridsen, 2014). Rich data is necessary to develop a theory that is grounded in the data, and may involve gathering different types of data and adopting varied data-gathering strategies (Charmaz, 2014). Interviews are the most common data collection methods in grounded

theory studies (Birks and Mills, 2011). Section 3.5 describes the methods used for data collection in the current study.

3.4.3.2 Theoretical sampling

A characteristic of qualitative research is samples that are relatively small in size, to allow for in-depth exploration of the phenomenon (Ritchie et al., 2014). Purposive sampling is central to many qualitative approaches to ensure diversity within the sample, and involves selecting participants based on their characteristics that are known or expected to be relevant to the research topic (Bryman, 2012). As illustrated by Figure 6, grounded theory research often starts with purposive sampling (Charmaz, 2014). As the research progresses, theoretical sampling is used to sample participants on the basis of their potential contribution to refining the theoretical categories being developed (Ritchie et al., 2014). The aim is to obtain data that will support construction of robust categories, including clarification of their properties and the relationships between categories (Birks and Mills, 2011). Charmaz (2014) describes various ways to conduct theoretical sampling including: completing follow-up interviews to seek data to illuminate categories; revising the interview topic guide to include focused questions to learn further about a category; searching for 'negative cases' and presenting categories to participants in later interviews to find out whether the categories resonate with each person's experience. Negative cases are cases or data that do not fit the emerging pattern that accounts for most of the data (Corbin, 2011). Grounded theory researchers often use negative cases to help explain theoretical categories, and to present alternative explanations from their developing theory (Charmaz, 2014). Corbin (2011) outlines how identifying and explaining negative cases can enhance the credibility of study findings; however, this has been questioned depending on whether negative cases arise 'naturally' in the data or are 'imported' into the study (Charmaz, 2014).

Theoretical sampling continues until theoretical saturation is reached; this is when theoretical categories are 'saturated' with data, and gathering additional data reveals no new properties or generates any further theoretical insights about the emerging grounded theory (Ritchie et al., 2014; Charmaz, 2014). Charmaz (2014 p. 209) discusses potential difficulties associated with theoretical sampling; these include deciding when to conduct it, as categories may remain unfocused if theoretical sampling occurs too early, and integrating the emergent process of theoretical sampling with 'institutional constraints on research', such as obtaining approvals from an ethics committee. Section 4.4.2 will discuss how theoretical sampling was used in this study to aid theory construction.

3.4.3.3 Constant comparative method

The constant comparison of data is an inductive method of analysis that is core to grounded theory research. Constant comparison occurs throughout the process of concurrent data collection and analysis and involves the comparison of data with data, data with codes, codes with codes, and codes with categories (Birks and Mills, 2011; Hallberg, 2006). Through making comparisons, researchers are able to establish the properties of their categories and 'illuminate both visible and hidden processes' (Charmaz, 2017 p. 3). Each step generates increasingly more abstract concepts and theories and contributes to theory construction (Charmaz and Bryant, 2011). In this study, systematic comparison of the data was supported by the use of computer software and this will be discussed in section 4.8.

3.4.3.4 Theoretical sensitivity

Developing theoretical sensitivity is a key part of the grounded theory process and involves the researcher's ability to understand and define phenomena in abstract terms (Charmaz, 2014). Birks and Mills (2011 p. 11) describe how researchers are a 'sum of all they have experienced', and this needs to be acknowledged in the research process, in particular when theorising. Theoretical sensitivity is developed through theorising about data and involves:

- looking at studied life from multiple viewpoints; for example, a researcher's subjectivity can provide a way to view, engage with, and interrogate data (Gentles et al., 2014). This process can require reflexivity, which will be discussed further in section 3.4.3.6.
- making comparisons
- following leads and
- building on ideas (Charmaz, 2014 p. 244).

In Glaser and Strauss's (1967) approach to grounded theory, they advocated developing theoretical sensitivity by delaying the literature review until analysis was completed to ensure theory was truly grounded in the data. Strauss subsequently acknowledged that a researcher is not free from ideas when starting data collection, and literature could be used as an analytic tool, sensitising the researcher to potentially significant aspects in the data (Heath and Cowley, 2004; Howard-Payne, 2016). Within constructivist grounded theory, there is recognition that using pre-existing theories and research during data collection and analysis has advantages if used in a 'sensitive, creative and flexible way' (Thornberg, 2012 p. 249); for example, it can be used as both a source of comparison and to place the developed theory within a context.

Theoretical sensitivity is also linked with abduction, a form of reasoning that involves considering all possible theoretical explanations for a surprising finding, making inferences for each possible explanation and returning to the data to check whether the explanations are plausible (Charmaz, 2011; Bryant, 2009). Abduction has been criticised for limiting creativity as it is linked with previous knowledge; however, Charmaz (2014) contends that abduction involves an 'imaginative leap', resulting in the creation of a new theory or putting existing theories together in an innovative way. The way that abductive reasoning supported data analysis in this study will be discussed in section 4.8.3. In addition to abduction, strategies used for analysing data in grounded theory research help to foster theoretical sensitivity, and this will be discussed next.

3.4.3.5 Data analysis

As stated in section 3.4, the aim of grounded theory is to build a theory, which is achieved through the generation of analytic categories, the identification of their properties and the relationships between them (Spencer et al., 2014). Analysis is an iterative, inductive process and involves the researcher moving back and forth between data collection and analysis and interacting with the data (Charmaz, 2014). Constructivist grounded theory assumes realities are not given but are constructed through actions, therefore data analysis is viewed as interpretative, rather than providing an objective report (Charmaz, 2011). These philosophical assumptions are reflected in the analytic practices of coding, categorisation and memo-writing.

Grounded theory coding consists of at least two phases: initial coding followed by focused coding, although it is recognised that in practice these phases overlap (Birks and Mills, 2011). Coding involves applying labels to pieces of data that simultaneously take data apart and define what it means (Charmaz, 2011). Through coding, the researcher aims to move beyond 'concrete statements' in data, avoiding a descriptive account, to making 'analytic sense of stories, statements and observations' (Charmaz, 2014 p. 111). Charmaz (2014) provides detailed suggestions on how to code in grounded theory research. In the initial coding phase, the researcher uses short, precise codes to name words, lines and segments in the data. The emphasis is on emergence; codes develop from reading the data rather than from applying preconceived concepts adopted from the literature (Charmaz, 2011; Spencer et al., 2014). Through coding with gerunds, that reflect action, the aim is to identify actions and processes, rather than focusing on themes or topics (Charmaz, 2014). The use of participants' language, as in-vivo codes, helps the researcher to more closely interact with the data and begin analysis from the participant's perspective (Birks and Mills, 2011;

Spencer et al., 2014). Constant comparative methods are used to find similarities and differences, and contribute to the analytic process (Charmaz, 2011).

The second phase of coding in grounded theory is focused coding. This involves using the most significant and/or frequent initial codes to analyse larger amounts of data (Charmaz, 2014). Through making decisions about which initial codes make the most 'analytic sense' in categorising the data, analysis becomes more abstract and theoretical (Spencer et al., 2014). Charmaz (2014 p. 140) suggests starting focused coding by evaluating initial codes, and using a comparative process to 'distinguish those codes that have greater analytic power'. Through comparing focused codes with other codes and with data, gaps in the data are identified which the researcher can aim to address through further data collection (Charmaz, 2014).

Category identification follows on from focused coding. Categories are 'emergent conceptual terms' that account for the data and codes (Charmaz, 2017 p. 3). A focused code that explains data better than other codes can be raised to a category or an abstract term can be created that conceptualises codes (Charmaz, 2011). The process of categorising raises analysis from description to a more theoretical level. Using theoretical sampling, the researcher aims to define the properties of each category, the conditions under which it operates, and its relationship to other categories (Charmaz, 2014). Birks and Mills (2011 p. 12) describe how in some grounded theory studies, the researcher may identify a 'core category that encapsulates and explains the grounded theory as whole'. As Figure 6 demonstrates, the final output of the analytic process in grounded theory research is a comprehensive, integrated grounded theory that understands and explains a social process associated with a particular phenomenon (Birks and Mills, 2011). Section 4.8 describes how analysis in this study moved through these different phases and led to the development of a grounded theory.

Figure 6 illustrates how memo-writing is an essential part of grounded theory research, as it is '*the* fundamental process of researcher/data engagement that results in grounded theory' (Lempert, 2007 p. 245). Charmaz (2014) describes how memo-writing encourages researchers to pause, record what is happening in the data, explore codes and identify the links between them. As analysis progresses, memos are used to describe and compare emerging categories and assist with identifying what additional data are needed to elaborate and refine the categories (Charmaz, 2011). Memos act as a link between data and emergent theory and record the process of constructing theory (Lempert, 2007). In addition to memo-

writing, diagramming can be used as part of the analysis process (Charmaz, 2014). Through reconceptualising data in a visual form, diagrams can assist with the generation of new ideas and prompt the researcher to see connections between codes and categories (Lempert, 2007). Section 4.8 describes how memo-writing and diagramming were used in this study as part of the analytic process.

Data analysis in grounded theory has been seen as raising a number of challenges. The process of initial coding has been critiqued for 'fracturing' the data (Thomas and James, 2006); however, Holton (2010) argues this encourages the researcher 'off the empirical level' and prompts conceptual, abstract thinking about the data. Earlier versions of grounded theory advised carrying out initial coding with no preconceived concepts in mind (Glaser, 1978; Glaser, 1992); however, while Charmaz (2014) agrees initial coding should be open-ended, she acknowledges that researchers have prior ideas and experiences that can impact on data analysis. The importance of reflexivity in addressing this challenge is discussed in the following section.

3.4.3.6 Reflexivity

In qualitative research, researchers aim to be reflexive about their role and how their interests, beliefs and position influence the research process (Ormston et al., 2014). As constructivist grounded theory is underpinned by the belief that research is constructed, not discovered, and rejects the idea of a neutral researcher, reflexivity is viewed as essential (Charmaz, 2014). Gentles et al (2014) suggest reflexivity should be used to explore the influence of researchers on the research design, interactions with participants during data collection, the analysis and writing. As discussed in section 3.4.3.4, theoretical sensitivity can be viewed as a form of reflexivity, as researchers consider how their preconceptions impact on theorising about data (Gentles et al., 2014). Various strategies to develop reflexivity are suggested including debriefing and reflection on interview transcripts (Mruck and Mey, 2007; Starks and Trinidad, 2007). Charmaz (2014 p. 165) recommends researchers write their 'methodological dilemmas, directions, and decisions' in a journal to engage in reflexivity and notes how journal entries can prompt ideas for memos. Section 4.11 discusses the reflexive stance that I took during this study.

3.4.4. Limitations of grounded theory

Various aspects of grounded theory have been critiqued. As discussed in section 3.4.1, grounded theory developed at a time when a positivist paradigm and quantitative methods were dominant, potentially leading to the need to demonstrate scientific respectability of

qualitative research (Bryant and Charmaz, 2007). As a result, grounded theory has been viewed by some researchers as the 'ten commandments', leading to criticisms of it being over-prescriptive (Atkinson et al., 2003; Hodkinson, 2008). However, Charmaz (2014 p. 13) argues that constructivist grounded theory 'highlights the flexibility of the method and resists mechanical applications of it'.

Grounded theory has also been criticised for developing theories that are too small or decontextualised, as they fail to take into account the impact of the wider context on participants' lives (Hodkinson, 2008). Although Charmaz (2014) acknowledges that this can occur as grounded theory is inductive, starting from participants narratives, she contends a researcher who is aware of concepts that focus on larger social structures can develop a contextualised grounded theory, and theorise connections between the local and macro context.

Additionally, some aspects of the earlier versions of grounded theory have been critiqued for being difficult to follow. For example, Glaser and Strauss (1967) encouraged researchers to delay the literature review until analysis was completed to ensure theory was grounded in the data (Heath and Cowley, 2004). However, it is now acknowledged that the literature can be used to inform theory development by sensitising the researcher to concepts in the data (Thornberg, 2012). Through engaging in reflexivity, researchers can acknowledge how existing literature can shape the way they interpret data and develop novel theory, rather than confirming preconceived ideas (Howard-Payne, 2016).

Despite these limitations, grounded theory has been recognised as 'a major - perhaps *the* major – contributor to the acceptance of the legitimacy of qualitative methods in applied social research' (Thomas and James, 2006 p. 767). Taking into account its strengths and limitations, grounded theory was considered the most appropriate approach as this study aimed to explore a social process, the transfer of self-management responsibility, and develop a theory to explain this process.

3.5 Data collection methods

Methods for data collection in qualitative research tend to adopt a more open approach compared to quantitative research, to enable understanding of concepts and values (Arthur et al., 2014). Interviews and focus groups are core qualitative methods; they are based on the belief that individuals actively construct their own social worlds and provide opportunities

for participants to articulate their own meanings and interpretations (Lewis and McNaughton Nicholls, 2014). In grounded theory studies, the aim is to collect rich data that reveals 'participants views, feelings, intentions, and actions as well as the contexts and structures of their lives' (Charmaz, 2014 p. 23). As obtaining in-depth data is essential for developing robust theories, individual interviews are primarily used to generate data in grounded theory studies; however, focus groups are increasingly being used in grounded theory both on their own and in combination with interviews (Charmaz and Belgrave, 2012). This study used interviews (both individual and dyadic) and focus groups to generate data. The following sections will discuss the rationale for using these methods, their strengths and limitations, and how combining qualitative data from different methods can enable researchers to gain deeper understanding of the phenomenon being studied.

3.5.1 Individual interviews

Lewis and McNaughton Nicholls (2014) suggest the reasons for choosing individual or group methods to collect data depends on the nature of the data being sought, the subject being explored and the research population. Individual interviews were thought to be an appropriate method to collect data that would address this study's aims, as they provide opportunities to examine the subject area in depth and develop understanding around a participant's thoughts, feelings and actions (Charmaz and Belgrave, 2012). Interviews can also be particularly valuable when studying the individual's perspectives within the context of personal history or experience (Lewis and McNaughton Nicholls, 2014). The intensive nature of individual interviewing focusses the topic, but also provides 'interactive space and time to enable the research participant's views and insights to emerge' (Charmaz, 2014 p. 85). As discussed in section 2.4.1.4, the literature suggested the transfer of self-management responsibility potentially occurs at a tacit level; therefore, it seemed particularly important that participants had time and space to articulate their story.

The research population can also influence whether individual or group data collection methods are used; for example, the need for participants to come together in a communal location for a face-to-face group discussion can constrain the use of focus groups (Lewis and McNaughton Nicholls, 2014). Taking into account the pragmatic challenges of arranging focus groups with young people with CKD and their parents, who lived across a wide geographical area, individual and dyadic interviews were used to collect data with these types of participants.

Qualitative interviews are generally categorised as either semi-structured or unstructured. Semi-structured interviews are based on a set of pre-determined open-ended questions with other questions emerging from the dialogue between the participant and researcher, whereas unstructured interviews are more like 'guided conversations' where one or two topics are explored in depth (DiCicco-Bloom and Crabtree, 2006). In grounded theory studies, interviews can either be semi-structured or unstructured; however, in early interviews, Charmaz (2014) suggests asking only a few questions to encourage the participant to tell their story, while keeping in mind the fundamental grounded theory question that opens a study: 'what is happening here?'. As earlier interviews are analysed, the interpretation of what is happening focuses subsequent interview questions. Semi-structured interviews were conducted in this study to enable exploration of unforeseen areas and those that were of importance to participants, while ensuring the interview remained focused on meeting the study's aims. However, as discussed in section 4.7.2, the level of structure and the role I took while interviewing varied depending on individual participants and the stage of data collection and analysis.

As discussed in section 3.4.2, constructivist grounded theory assumes that reality is multiple and constructed, and data are co-constructed by the participant and researcher as part of the research process (Charmaz, 2008). Interviews are considered an 'emergent social interaction', where 'knowledge is constructed in the interaction between the interviewer and interviewee' (Brinkmann and Kvale, 2015 p. 4); this means the researcher should 'attend to the situation and construction of the interview, the construction of the participant's story and silences, and the interviewer-participant relationship, as well as the explicit content of the interview' (Charmaz, 2014 p. 91). Reflexivity can help with considering these issues, in particular the influence of researcher-participant interaction on data construction (Gentles et al., 2014).

The value of interviews has been questioned and many of these criticisms can be linked to underpinning ontological and epistemological assumptions. There have been critiques that interview data does not report on an external reality; only reveals what is happening in a particular interview; and that what participants say may not reflect what they do (Charmaz, 2014; Hammersley, 2008). However, it is now widely acknowledged that interviews generate accounts that are socially situated, so rather than viewing interview data as an accurate portrayal of reality, it is 'real' in that data offers an account of participants' worlds (Brinkmann and Kvale, 2015). In recognition that interview data is a product of the research process, (Charmaz, 2011) discusses the need for it to be analysed in relation to the particular

circumstances and context in which it is generated. The philosophical assumptions that underpinned this study meant interviews were recognised as subjective and contextual, reflecting what participants brought to the situation as well as the interactions that occurred during data generation (Charmaz, 2011). As a result, the findings chapters provide an interpretation of the data, not an objective report of them (Charmaz, 2014).

3.5.2 Dyadic interviews

Dyadic interviews, where two participants are interviewed together, were also considered to be a relevant method to collect data that would address the study's aims. Morgan et al (2016) associate dyadic interviews with focus groups, as data are generated through interaction between participants and one participant's comments prompts responses from the other; however, data are generated in more depth than in focus group discussions. Dyadic interviews tend to be utilised in family research where participants share a pre-existing relationship (Morgan et al., 2013). In this study, only young people and their parents were offered a joint interview, and the decision to conduct either individual or dyadic interviews was based on the preference of the family and primarily the young person.

Although grounded theory research tends to focus on generating data via in-depth individual interviews, dyadic interviews are compatible with constructivist assumptions as they enable participants to co-construct their version of the research topic; by building on, and differentiating from, what the other has said, the discussion can move in directions unanticipated by the researcher (Morgan et al., 2016). Reczek (2014) suggests dyadic family interviews draw on symbolic interactionism and the assumption that meaning is created through interaction and interpretation; rather than discovering an objective family truth, dyadic interviews can help gain understanding of 'how family members construct and interpret their own social reality in the context of shared family realities' (p. 320)

As dyadic interviews tend to be conversational in style, with participants 'sharing and comparing' with minimal prompting from the researcher (Morgan et al., 2016), they have unique strengths in comparison with individual interviews and focus groups. For example, rapport can be easier to build in dyadic interviews, in particular if one participant is more comfortable with the interview process (Reczek, 2014). Morgan et al (2013) suggest that the dynamic of dyadic interviews can be particularly useful when talking with participants who may be reluctant to engage in research and/or with the researcher. The possible influence of using this data collection method on this study's recruitment of potentially 'hard-to-reach' groups, such as teenagers and families from black and minority ethnic groups, will be

discussed in chapter 8. Dyadic interviews can be especially useful in examining how family members co-construct an understanding of daily life and provide opportunities for observing family dynamics and communication (Reczek, 2014); this was particularly relevant in the context of this study's aims as it generated rich data around how the transfer of self-management responsibility is constructed and negotiated by the young person and their parent.

Despite their strengths, concerns have been expressed about dyadic interviews, in particular around whether participants will talk openly in front of one another, in comparison to an individual interview (Reczek, 2014). This is particularly relevant in dyadic interviews conducted with a child and their parent, due to issues around power relations and family dynamics (Harden et al., 2010; Gardner and Randall, 2012). However, it has been recognised that parents can complement their child's narrative through 'prompting and scaffolding'; for example, supplementing their child's contribution by providing explanations and context (Gardner and Randall, 2012). Harden et al (2010) query whether joint interviews provide opportunities to observe typical dyad behaviour and suggest the child and their parent may be presenting an 'ideal' version of themselves. Another potential limitation associated with dyadic interviews is uncertainty around how to analyse the data; as data is generated through interaction, it is suggested both the content of the data and also the impact of interactions on the co-creation of data needs to be examined (Morgan and Hoffman, 2018). Potential analytical methods will be discussed in the following section.

3.5.3 Focus groups

In addition to individual and dyadic interviews, focus groups were used in this study. Focus groups are a form of group interview, where data are generated as a result of the interaction amongst participants (Morgan, 2012). However, 'instead of the researcher asking each person to respond to a question in turn, people are encouraged to talk to one another: asking questions, exchanging anecdotes and commenting on each other's experiences' (Kitzinger, 1995 p. 299). Focus groups are a relevant methodological tool for research underpinned by a constructivist approach; by rejecting the assumption of a single reality, focus groups, like interviews, can be viewed as 'situated encounters' where knowledge is created and meaning is co-constructed (Caillaud and Flick, 2017). In contrast to individual interviews though, group dynamics can help participants to explore and clarify their own views, and examine the similarities and differences between their opinions compared with others in the group (Freeman, 2006).

As discussed in section 3.5.2, individual interviews are the predominant method used in grounded theory research; however, Charmaz and Belgrave (2012) recognise that focus groups are a viable and growing part of grounded theory studies. Although focus groups can be viewed as an efficient and cost-effective method of generating large amounts of data in a short time (Kitzinger, 1994), this efficiency has led to concerns about their use in grounded theory studies; for example, if they are used to 'short-circuit' the iterative processes of concurrent data collection and analysis (Webb and Kevern, 2001). Charmaz and Belgrave (2012) suggest focus groups can be valuable for grounded theory if used 'strategically' and recognise how combining individual interviews and focus groups has 'proven to be fertile ground for developing grounded theories' (p.12). Grounded theory researchers that have combined interviews and focus groups concluded that mixing methods supported the iterative process, influenced subsequent data collection and analysis, and resulted in a richer conceptualisation (Lambert and Loiselle, 2008; Furness et al., 2006).

Caillaud and Flick (2017) suggest focus groups can be used to encourage participants to comment on and interpret findings from earlier interviews. As one of the aims of the focus groups in this study was to discuss the ideas suggested in preceding interviews about young people's and parents' support needs, focus groups were used towards the end of the data collection phase. The decision to use focus group methodology with HCPs only, was based on the rationale that they had pre-existing relationships, whereas young people and parents rarely knew other families that were receiving support from the renal MDT. For HCPs, discussion with MDT colleagues around how they work with a child and their family is a key aspect of their role (Swallow et al., 2013). Therefore, it seemed relevant to draw on these existing relationships to explore how individual HCPs and the collective MDT view and support the parent-to-child transfer of self-management responsibility. Additionally, the nature of the setting, which meant young people and parents lived across wide geographical areas, influenced the decision to use focus groups with HCPs only.

The usefulness of focus groups has been debated in the literature as it is suggested the nature of group interaction and dynamics can sometimes inhibit some participants from speaking and/or push 'participants to express more socially desirable and stereotypical answers' (Acocella, 2012). Group composition, and the extent of homogeneity/heterogeneity of participants, influences interaction (Freeman, 2006). Morgan (2012) suggests interaction is more likely to be facilitated when participants share similarities in regard to the research topic. To address this concern, focus groups were used with pre-existing groups only in this

study, and the potential impact of group composition on interaction and data generation was considered as part of data analysis (see section 4.8.4).

Focus group studies have also been critiqued for their lack of transparency in relation to data analysis methods (Webb and Kevern, 2001). In particular, there are concerns that analysis does not take into account, or report on, the interaction between participants, despite it being a key feature of focus groups (Kitzinger, 1994). A number of authors have emphasised the importance of data analysis taking into account how the context of the discussion shaped data generation (Halkier, 2010; Willis et al., 2009; Wilkinson, 2016; Morgan, 2010) and various data analysis methods have been proposed. These include: questions to guide analysis of interactions proposed by Stevens (1996) and adapted further by Willis et al (2009); a template that focuses on group dynamics (Lehoux et al., 2006); and a coding system that labels transitions between speakers (Morgan and Hoffman, 2018).

Although focus groups are increasingly recognised as a viable method for generating data by grounded theory researchers (Charmaz and Belgrave, 2012), no specific guidance could be found for analysing group interaction in the context of a grounded theory study. Due to this gap in the literature, the author reviewed a number of grounded theory studies that used focus groups to evaluate how data had been analysed (Ginsburg et al., 2009; Fox et al., 2007; Ferreira et al., 2010; Beard et al., 2009; Ahmad et al., 2006; Furness et al., 2006; Sargent et al., 2017). Only one study (Lambert et al., 2009) explicitly reported on analysing interactions, using the questions developed by Stevens (1996) and Lehoux et al (2006) to guide the analysis. To analyse interaction in both dyadic interviews and focus groups in this study, it was decided to use the approach developed by Lehoux et al (2006) as its focus on the differing 'knowledge claims' put forward by participants and the researcher, seemed to resonate with the interpretive epistemology underpinning the current study. Section 4.8 describes how this additional approach was used in conjunction with grounded theory analytic methods.

3.6 Conducting research with children

This study aimed to explore young people's, parents' and HCPs' views of the parent-to-child transfer of self-management responsibility, therefore one of the key groups of participants were young people aged 13-18 years old, with CKD. Although conducting research with children can help gain increased understanding about their experience of their worlds, there are also potential challenges when researching in this area (Greene and Hill, 2005). These

include both methodological and ethical challenges; however, before these issues are discussed, theoretical issues around conducting research with children will first be considered.

3.6.1 Theoretical issues

Gallagher (2009) discusses how concepts, such as ontology and epistemology, can help researchers when conducting research with children. As discussed in section 3.3.1, ontology is concerned with the nature of reality; for example, addressing questions such as who are children, and what is childhood? In this study, a range of ontological positions influenced the conduct of the study, including the beliefs that children are competent agents who actively contribute to shaping the social world through their everyday activities (Prout and James, 2015), are experts in their own lives (Thomas, 2017), yet are also potentially vulnerable, especially within the context of having CKD (Gallagher, 2009). Additionally, the belief that children are usually connected to their families underlined the importance of this study also exploring parental views (Greene and Hill, 2005).

When questioning what can be known about children and how this knowledge can be acquired, a range of epistemological positions influenced the conduct of this study. These included the belief that knowledge about children is not 'out there' to be collected, but is co-constructed during interaction between the child and researcher (Gallagher, 2009 p. 68). The awareness that it is difficult for adults to know what it is like to be a child, as their own experience of being a child was within a different context, reinforced the belief that listening to children's views is critical to develop understanding about children's worlds (Christensen and James, 2017). Linked to these theoretical issues, consideration was also given to methodological and ethical challenges that can arise when conducting research with children.

3.6.2 Methodological issues

The ontological and epistemological positions that underpin a study also influence the methodology, or the practices and principles that shape how knowledge is generated (Gallagher, 2009). Kirk (2007) identified two key methodological issues in conducting research with children: 1) the different cultures of childhood and adulthood, and 2) the heterogeneous nature of childhood. The way a researcher perceives children, for example, whether children are viewed as the same or different to adults, can influence how research is conducted (Punch, 2002). Strategies to manage the different cultures of childhood and

adulthood include reflexivity and patient and public involvement (PPI), or actively involving children in the research process (Kirk, 2007; Punch, 2002). Both these strategies were used in this study and will be discussed in chapter 4.

By drawing distinctions between childhood and adulthood, there is potential to present children as a homogenous group; however, the acknowledgement that children are a diverse group has methodological implications (Kirk, 2007; Greene and Hill, 2005). As well as chronological age and cognitive development, children differ to adults in other ways including their language, understanding and life experience (Christensen and James, 2017). Creative and task-based data collection methods, such as drawing, diary completion and taking photographs, have been proposed as techniques to ensure children have the maximum opportunity to actively participate in research (Gallagher, 2009). However, there is also recognition that using traditional 'adult' research methods, such as interviews, means children are treated the same as adults and offered opportunities to display their competencies (Punch, 2002). In this current study, a combination of techniques were used during data collection based on various factors including: the specific research context; the characteristics of the individual young person such as their age, language and understanding; and importantly the extent to which I was able to develop rapport with them and how they responded to me. The specific techniques used to engage young people in this study are discussed in section 4.7.

3.6.3 Ethical issues

Although ethical issues need to be taken into account in all health research, there are specific ethical considerations that are relevant when conducting research with children (Alderson and Morrow, 2011). These include informed consent/assent, power differentials and confidentiality. These three issues, and their implications for this study, will be examined in the following sections. Chapter 4 discusses strategies used in this study to address these ethical issues.

3.6.3.1 Consent/assent

Consent is required from parents of children under 16 years of age to take part in research, and the recommendation is that assent of the young person is also sought (RCPCH, 2014; MRC, 2004). Duncan et al (2009) suggest this can create confusion around the role of the parent and limits to confidentiality as 'adult gatekeepers' may expect to be told what their child has spoken about. As qualitative research tends to involve less structured, and potentially more variable, processes for data collection, it can also mean less clarity around

what is being consented to; this is especially relevant for children, who may have more difficulty with anticipating how they may respond to in-depth discussions that often characterise qualitative research (Mishna et al., 2004). The provision of accessible and age-appropriate information about the research can support participants to provide informed assent/consent (Hill, 2005). Richards and Schwartz (2002) argues that consent should be viewed as a process rather than a one-off event; for example, by checking the participant wishes to continue participating, both verbally and by being aware of verbal and non-verbal cues.

3.6.3.2 Power differentials

Power differentials between adults and children need to be considered when conducting research with children (Alderson and Morrow, 2011). The inequality in power and status can be particularly relevant when conducting qualitative research due to the direct interaction between the child and researcher (Mishna et al., 2004). For example, it could potentially be easier for a child to discontinue completing a questionnaire on their own, than to ask an adult interviewer to stop, especially if they have been effectively engaged. Strategies have been suggested to reduce this power imbalance including: using creative and task-based methods to provide maximum opportunities for children to provide their views; being responsive to children's own agendas; and involving children in PPI to ensure methods and language are accessible, age- and developmentally-appropriate (Punch, 2002; Kirk, 2007).

3.6.3.3 Confidentiality

In qualitative research, the participant can choose to share their private views and experiences with the researcher; however, this may result in the disclosure of information that neither the participant or researcher anticipated (Mishna et al., 2004). When conducting health research with children, this can become particularly relevant due to understandings around confidentiality and expectations from adult gatekeepers (for example, parents and HCPs) around information being shared (Hill, 2005). Richards and Schwartz (2002) suggest that the duty of confidentiality is much clearer for HCPs than it is for researchers, which can result in conflict for HCP researchers. Recommendations for minimising and managing ethical dilemmas around confidentiality include: clarifying with participants the limits to confidentiality; discussion with research team colleagues if disclosure suggests any person is at risk of harm; dealing promptly with any issues that arise; and documenting any breaches to confidentiality (Duncan et al., 2009).

3.7 Assessing quality and rigour

There are multiple perspectives on how to evaluate the quality of qualitative research (Cresswell and Poth, 2018). For example, Denzin and Lincoln (2011) proposed a set of four criteria that could be used to evaluate a study's quality and rigour: credibility, transferability, dependability and confirmability.

Credibility has been defined as whether the research findings represent an accurate interpretation of participants' experiences; this means participants and others who share the same experience are able to recognise themselves, or their life, in what is being reported (Patton, 2015). Procedures to establish a study's credibility can include triangulation of methods and data sources, and prolonged engagement between the researcher and the researched (Lincoln and Guba, 1985). Transferability refers to whether study findings have applicability beyond the context in which they were collected (Thomas and Magilvy, 2011). 'Thick' description of the study setting can enhance transferability, as readers are able to assess what might be relevant to other contexts (Green and Thorogood, 2018). Dependability occurs when someone else is able to follow the decision trail used by the researcher; for example, by providing a detailed description of the research methods (Thomas and Magilvy, 2011). To determine dependability, auditing of the research process is suggested (Cresswell and Poth, 2018). Finally, confirmability has been defined as being able to establish that data and interpretations of the findings are not 'figments of the researcher's imagination', but are clearly derived from the data (Patton, 2015). Thomas and Magilvy (2011) suggest reflexivity is essential to establishing confirmability, as readers are more likely to find a study trustworthy if researchers are explicit about their influence on the research process. Section 4.10 discusses how Denzin's and Lincoln's (2011) four criteria were used to evaluate the quality and rigour of this study.

The guiding questions developed by Charmaz (2014) were also used to evaluate the theory constructed in this study. These were chosen as they were developed specifically for assessing rigour in grounded theory studies. The questions are grouped into four categories: credibility, originality, resonance and usefulness.

Credibility can be evaluated by asking questions, including:
- has the research achieved familiarity with the setting or topic?
- are the data sufficient to merit the claims?
- are there strong logical links between the gathered data and the argument and analysis?

- has the research provided enough evidence for the claims to allow the reader to form an independent assessment – and *agree* with the claims?

Questions to establish originality include:
- do the categories offer new insights?
- does the analysis provide a new conceptual rendering of the data?
- what is the social and theoretical significance of this work?
- how does the grounded theory challenge, extend, or refine current ideas, concepts and practices?

Resonance can be evaluated by addressing questions, such as:
- do the categories portray the fullness of the studied experience?
- have taken-for-granted meanings been revealed?
- does the grounded theory make sense to the participants or people who share their circumstances, and offer them deeper insights about their lives?

Finally, questions to establish the usefulness of the study include:
- does the analysis offer interpretations that people can use in their everyday worlds?
- can the analysis spark further research in other areas?
- how does the work contribute to knowledge?

Chapter 8 discusses how these criteria were applied to evaluate the theory developed in this study.

3.8 Summary

This chapter has presented the study's aims and objectives, and its qualitative design, including the philosophy and guiding principles underpinning the research. It has critically examined the grounded theory approach that underpinned its design and how constructivist assumptions informed both the methodology and methods that were selected for the study. Justification has been given for the use of individual and dyadic interviews, and focus groups, as methods of data collection. Finally, the criteria for assessing quality and rigour has been discussed.

The next chapter will provide an account of how the study was carried out including gaining access to the study setting; sampling and recruitment decisions; procedures for data generation and analysis; ethical issues; and considerations related to study rigour.

4. CONDUCT OF THE STUDY

4.1 Introduction

This chapter describes the conduct of the study. Details are presented on the study setting, study advisors, recruitment, sampling, data collection and analysis. Ethical issues and considerations related to quality and rigour will also be discussed.

4.2 Study setting

Section 1.5.2 describes how, in the UK, there are 13 children's kidney services based in NHS Trusts. The setting for this study was two of these services; one based in a city in the north of England (Site A), which manages approximately 80 young people aged 13-18 years old with CKD, and the other based in London (Site B) which manages approximately 130 young people. The rationale for deciding to conduct the study at these two sites included:

- as the two sites combined managed approximately 210 x 13-18 year olds with CKD, recruiting young people and parents to reach theoretical saturation would be feasible;
- opportunity to recruit a diverse sample across two wide geographical areas in north and south England;
- differing models of care for supporting young people with CKD. Site A has a transition clinic, focused on young people transferring from child to adult kidney services, whereas young people in Site B are managed in clinics based on their CKD stage and treatment modality;
- I was known to both kidney services through my work as a researcher on previous studies conducted with children with CKD and had an employment contract with one of the NHS Trusts; these both facilitated my access to the study setting.

While planning the study I met with HCPs from each kidney service to discuss the research aim and plan, the feasibility of conducting the study and initial ideas for sampling and recruitment. A clinical psychologist and consultant nephrologist at Site A, and a senior nurse at Site B, agreed to act as local lead investigators for the study. This role included providing support with gaining local NHS Trust approvals and promoting the study to multi-disciplinary (MDT) colleagues. As gatekeepers, they were also key to identifying potential participants and informing them about the study.

4.3 Study advisors

The cooperation of the local lead investigators at the two sites was essential in setting up and conducting the study. In addition to their support, two advisory groups were established to advise on the research. The two groups were 1) study advisory group and 2) patient and public involvement (PPI) advisory group.

4.3.1 Study advisory group

This group was established in year one and consisted of paediatric and adult renal clinicians, academics with research interests in transition and health psychology, two young adults with CKD, and two parents of young people with CKD. Terms of reference were developed and agreed by the group. The group met three times during the study to provide expertise and advice on the design and conduct of the study. Meeting minutes were taken and circulated to all group members following each meeting.

4.3.2 Patient and public involvement

Patient and public involvement (PPI) is the active involvement of patients and members of the public in the design and delivery of research (Mitchell et al., 2018). Examples of PPI include: developing and prioritising research ideas; contributing to study design; carrying out research; and advising on dissemination (Bate et al., 2016). Involving children in child health research, as opposed to asking parents to represent their children, is increasingly recognised as important (Bird et al., 2013). PPI was integrated into this study as it is recognised as improving the quality and relevance of research (INVOLVE, 2012). As discussed in section 3.6.2, PPI was also used to manage the methodological issues in conducting research with children, including how to adapt data collection so young people had the maximum opportunity to actively participate in the study. The GRIPP2 short form reporting checklist (Staniszewska et al., 2017) was used to report on PPI in the current study.

4.3.2.1 Patient and public involvement in this study

The aim of PPI in this study was to involve young adults with CKD and parents of young people with CKD to improve the design and conduct of the research. A mixed approach to PPI was adopted due to various factors including the stage of the project, the nature of the advice being sought, the type of consultation process needed and pragmatic issues. Table 10 summarises the methods used for PPI at different stages of this study. I had previously

worked in PPI at a children's hospital, which had involved facilitating research advisory groups for young people and parent/carers. The initial idea for this current study was discussed with these two groups. As part of my PPI role I had met once with the hospital young people's forum; as detailed in Table 10, I consulted with this group in year 2 of this study. In addition to conducting PPI with these generic groups, a study-specific PPI advisory group was established. An advertisement and terms of reference for the group were developed. Six people were invited to join this advisory group: two young adults with CKD and two parents of young people with CKD who had been PPI contributors on previous renal studies I had worked on; and two young adults with CKD who had previously been members of the young person's research advisory group. All agreed to join the group; however, two of the young adults' commitments changed during the course of the current study which meant they were no longer able to participate in PPI activities. Four members of the PPI advisory group were also members of the study advisory group.

Table 10: PPI methods used in this study

Stage of study	Type of PPI	Group members involved in PPI activity	Advice sought
Initial research idea/before study started	Children's hospital young person's research advisory groups. One-off face-to-face meeting	15 x young people aged between 11-18 years old. Some had LTCs, including CKD	Relevance of research idea; potential methods; help to write plain English summary
Initial research idea/before study started	Children's hospital parent/carer research advisory group. One-off face-to-face meeting	8 x parent/carers of children who had LTCs and/or disabilities	Relevance of research idea; potential methods
Year 1	Study specific advisory group. Via email	3 x young adults with CKD. 2 x parents of young people with CKD	Review of participant information leaflets
Years 2-3	Study specific advisory group. Via email	2 x young adults with CKD. 2 x parents of young people with CKD	Review of topic guides and task-based methods used during individual and dyadic interviews
Year 2	Children's hospital young people's forum. One-off face-to-face meeting	31 young people aged between 11-24 years old. Most had LTCs and/or disabilities	Discussion around study and trialling of task-based methods used during individual and dyadic interviews
Years 1-3	Study specific advisory group. Via tele/video conference	2 x parents of young people with CKD	Participation in three study advisory group meetings. Discussion included study design such as data collection methods and study findings

4.3.2.2 Outcome of patient and public involvement

There is continuing debate around how to demonstrate and assess the impact of PPI on research (Brett et al., 2014). Although a framework has been developed to assess the impact of PPI, it has been acknowledged that this is primarily aimed at research teams that include professional researchers, that using it is a complex process and the context in which it is applied needs to be considered (Popay et al., 2014; Collins et al., 2018). Therefore, I used the GRIPP2 checklist (Staniszewska et al., 2017) to guide reporting rather than the framework, as it was more appropriate to the type and level of PPI conducted during this study. This involved critical reflection of how PPI influenced both the study and me, as the researcher.

The influence of PPI on the study was manifold. When discussing the initial research idea, parent group members described how many HCPs expected young people with LTCs to become independent in managing their own health. However, they thought this was not a priority for some young people and families and thought it key that health services were more individualised in their approach. Both this group and the young person group outlined support that they had found helpful during the parent-to-child transfer of self-management responsibility, but emphasised the importance of this being personalised to each family's situation. These discussions confirmed that this was an area of health care that was relevant for young people and parents and needed further research. Young people from the research advisory group contributed to writing the lay summary for the funding application form, helping to ensure it was accessible and written in plain English.

The study specific PPI advisory group reviewed the participant information leaflets (PILs) that I had developed; their suggestions around changing some of the language and design were incorporated where possible. These changes potentially made the leaflets easier to understand, enhanced their design and, through provision of improved information, supported participants to make an informed decision about whether to participate (INVOLVE, 2012). This group had further impact on the study through group members' comments on the topic guides. They suggested: additional questions to ask; exploring other aspects of self-management they thought relevant; altering existing questions so they were easier to understand; and adjusting the order of the questions. Group members also provided advice regarding the use of task-based methods during interviews and suggested simplifying the tool used to generate information about a young person's level of responsibility. All these suggestions were used to revise the topic guides and data collection methods. Section 4.7.3 provides more information about development of the topic guides.

Finally, consultation with the young people's forum had a positive impact on the study. Some of the task-based methods, such as timelines and mind maps that would potentially be used during interviews, were trialled. Group members engaged with these methods, confirming they were a valuable way to facilitate discussion with young people around self-management. During discussions, none of the young people used the term 'self-management', instead describing 'being in control' and 'taking charge' of their health care; this had a significant impact on the language I used during data collection. An unanticipated impact of consulting with this group was that one of the members with CKD expressed further interest in the study and subsequently participated in an interview.

In conclusion, PPI influenced important aspects of this study. This was potentially related to several factors including: the PPI advisory groups had previously received training around research methods; pre-existing relationships between the PPI contributors and myself, which potentially meant virtual involvement could be used more effectively; funding; and my experience in PPI, in particular involving young people in research. However, there were limitations to the PPI. Due to the timescales and processes involved in grant applications, it was not possible to develop the study-specific PPI advisory group at the early stages of the study; therefore generic advisory groups were involved. Engaging with young people with CKD, and parents of children with CKD, from the beginning of the study may have resulted in more specific discussion around the research idea, enabling this group to have shaped the study from the start.

Conducting PPI also had an influence on me, in my role as the researcher. Through working with PPI contributors, I had opportunities to explain and discuss the study in plain English, which influenced how I communicated with others, particularly potential participants. Having contact with PPI contributors also helped me to maintain motivation and perspective during the study and provided reassurance that the study was important, relevant and could potentially benefit young people and their families.

4.4 Sampling

For the purposes of applying for ethical approval, the stated aim was to recruit 48-60 people to the study, consisting of 16-20 young people aged between 13-18 years old, 16-20 parents and 16-20 HCPs from the children's renal MDTs. This sample size was based on recommendations that qualitative research involves 50-60 participants (Ritchie et al., 2014;

Vasileiou et al., 2018). However, it was acknowledged that, in grounded theory studies, the final sample size is determined by theoretical saturation being reached (Charmaz, 2014). As discussed in section 3.4.3.2, grounded theory research often starts with purposive sampling, moving to theoretical sampling as the research progresses. Both types of sampling were used in this current study.

4.4.1 Purposive sampling

Purposive sampling was initially used to achieve maximum variation in the sample. The aim of using this type of approach was to select participants based on their characteristics which were expected to be relevant to the research topic. Selection was informed by the literature review, advice from the local lead investigators and my prior knowledge of issues relating to CKD self-management. Chapter 1 has information about age, sex, ethnicity and treatment type of paediatric patients on renal replacement therapies that informed the sampling strategy. I aimed to sample young people based on their age, developmental stage, sex, ethnicity, CKD stage, disease duration, treatment type and self-management needs. Purposive sampling was also used to ensure maximum variation of HCPs who worked in the renal MDT (e.g. clinical psychologists, dietitians, doctors, nurses, play-workers and social workers).

4.4.2 Theoretical sampling

As the study progressed, theoretical sampling was used to generate data that the emerging analysis suggested was needed to support the construction of robust categories. As discussed in section 3.4.3.2, there are various ways to conduct theoretical sampling. This study incorporated a range of activities including sampling young people with specific characteristics, revising the topic guide, conducting follow-up data generation and searching for negative cases.

After the initial set of individual and dyadic interviews, I had identified an emerging core category and two sub-categories. As part of the process of elaborating and refining these theoretical categories, I consequently sampled young people based on characteristics, such as CKD stage and treatment modality, that the emerging ideas suggested were important. As a result, the sample who participated in the second phase of data generation was comprised of more young people with CKD stages 3-4, on dialysis or who had received a transplant. Section 6.4.3 discusses how the health condition, including the CKD stage and type of treatment, influenced how young people assumed self-management responsibility.

In addition to sampling participants on the basis of their potential contribution to further developing the theoretical categories, I also completed follow-up interviews using a revised topic guide. After conducting individual and dyadic interviews with 30 participants, the categories I had developed appeared relatively robust, but they were not saturated; therefore, I was aware that I needed to return to the field to seek pertinent data to clarify the properties and dimensions of these categories more fully. I decided to conduct further individual and dyadic interviews with young people and parents, and focus groups with HCPs. As discussed in section 3.5.3, focus groups were selected for several reasons; but, importantly, it was thought that exploring the group perspective of the renal MDTs, especially their comments on, and interpretations of, the findings from earlier interviews around what facilitated the transfer of self-management responsibility, would contribute rich data that would further develop the categories.

Prior to this second phase of data generation, I revised the topic guide to include focused questions about what sustained the transfer process, with the aim of reaching theoretical saturation. Different task-based methods were adopted in the later research encounters with the aim of enhancing understanding and achieving theoretical saturation. Further information about developing and revising the topic guides is provided in section 4.7.3. Section 4.7.4 examines how task-based methods were used in earlier and later stages of data generation.

Finally, theoretical sampling was used by identifying and explaining two negative cases that arose in the earlier stages of data collection. The data generated from interviewing these two parents did not fit the emerging pattern that accounted for most of the data and, therefore, supported further development of the theoretical categories. The impact of these two cases on data analysis is considered in section 4.8.3.

As discussed in section 3.4.3.2, one of the potential difficulties associated with theoretical sampling is integrating its emergent process with institutional research procedures. In this study, my decision to revise the topic guide and methods meant I needed to submit a substantial amendment to the Health Research Authority (HRA) before moving into the second phase of data collection. As a result, recruitment to the study needed to 'pause' for a few months while waiting for the substantial amendment to be approved. This had an impact on the planned end date of the study and meant I needed to submit a minor amendment to extend the study closure date by three months.

With recruitment of the study sample, I was dependent on the clinicians who were identifying and approaching potential participants. I was unsure of how conscious or sub-conscious bias may have influenced their decisions around whom to approach. Throughout recruitment, I emphasised the inclusion and exclusion criteria (see following section) to these clinicians, and asked for potential participants with characteristics related to the initial purposive, and subsequent theoretical, sampling criteria. Within time restrictions, sampling continued until all the categories were theoretically saturated; this meant they were well developed and that gathering additional data generated no further theoretical insights.

4.4.3 Inclusion and exclusion criteria

The inclusion criteria was young people aged 13-18 years old, who had a diagnosis of CKD stages 3-5 (including kidney transplant recipients) managed by a paediatric renal MDT. As a result of having CKD, the young person was required to undertake self-management such as taking medication, monitoring diet and fluids, and completing home dialysis. Young people aged 13 and older were selected for this study as UK guidance recommends that planning for adulthood should begin when young people are 13-14 years old (NICE, 2016). Participants required the level of cognition needed to develop self-management skills. If parents and HCPs considered the young person lacked the cognitive skills to participate, or were too ill, they were excluded. I relied on the HCPs involved in identifying families to advise me if there were any issues or change in circumstances, such as distress or child protection concerns, that would affect families' participation in the study. Parents/carers of each young person and HCPs who had a role in supporting the parent-to-child transfer of self-management responsibility were invited to participate. Young people and parents who were not able to understand verbal and/or written explanations in English were not invited to participate as there was no budget in the study to cover the costs of translation and interpretation.

4.5 Recruitment

Through working as a researcher on previous studies with children with CKD, I had pre-existing relationships with the local lead investigators for the study and was also known to some of the HCPs in the kidney services that took part in the study. These relationships were key to supporting the recruitment process.

4.5.1 Young people and parents

As discussed in section 4.2, potential young people participants, and their parents, were identified by local lead investigators for the study. These clinicians initially provided a brief verbal summary of the study to young people and/or their parents either in clinic or by telephone. If they expressed interest in considering taking part, the clinician gained verbal consent from either the young person, depending on their age and capacity, and/or their parent, for their contact details to be forwarded onto me. All young people/parents initially approached about the study agreed for their contact details to be shared with me. Consequently, the clinician advised me of the young person's and/or parent's telephone number and/or email address and any communication preferences and needs. I aimed to contact the young person/parent within a few days of the clinician talking with them about the study. During this contact I would explain the study and what participation would involve in more detail, ask if they had questions about the research, answer questions and ask if they would be interested in receiving written information about the study. All the young people and parents I initially contacted agreed to receive information either in the post or via email. The participant information and consent/assent forms had been reviewed by the PPI group as discussed in section 4.3.3. Examples of these are included in Appendices 5-8.

To ensure young people/parents had time to consider whether they would like to participate, and/or if they had not already notified me of their decision, I contacted them approximately one week after sending the written information. During this contact I would answer outstanding questions, and reiterate participation was voluntary and their decision would not affect their/their child's care. If they were interested, I arranged a time and place to conduct the interview. Young people/parents who preferred to meet in person for the interview were offered a home visit or meeting at the children's hospital. Alternatively, a virtual interview (by telephone or video chat) was offered if preferred. Young people and parents were also offered the opportunity to be interviewed together or separately. Section 4.7 provides details of how many individual and dyadic interviews were conducted.

4.5.2 Health care professionals

Local lead investigators also identified HCPs to potentially participate. As part of this process, they briefly explained the study to their colleagues and shared with me contact details of HCPs interested in considering taking part. I contacted the HCP via email or telephone to explain the study, answer questions and provide written information. All HCPs I initially contacted agreed to receive written information. With those interested in participating, I arranged a time to conduct interviews and, later in the study, the two focus groups. For

individual interviews, I offered to meet in person at the children's hospital or arrange a telephone interview.

4.6 Study sample and characteristics

Using the strategies described in previous sections, this study was able to recruit participants to reach theoretical saturation and exceeded the original recruitment target. The study sample and characteristics of participants are presented.

4.6.1 Study sample

Over a 12-month period, from August 2018-Augst 2019, 70 people were approached about the study and 49 participants took part. The sample was comprised of 16 young people, 13 parents and 20 HCPs.

Ten young people, ten parents and one HCP who were provided with written information about the study did not take part. Although not required to explain their decision to not participate, some family members volunteered an explanation. Reasons offered included inconvenient timing due to other commitments or poor health. Some families and the HCP initially expressed interest but did not respond when I contacted them again to discuss their participation. I decided not to follow up one young person who expressed interest in participating due to a significant change in her social circumstances. The ethical issues that shaped my decision-making around recruitment are discussed in section 4.9.

4.6.2 Characteristics of the study participants

The characteristics of the young people, parents and HCPs who participated in the study are presented in tables 11-13. The young people and parent participants represented 18 families; this consisted of 11 young person/parent dyads, five young people and two parents.

Table 11: Characteristics of participating young people (n = 16)

Characteristics	Girls (n = 9)	Boys (n = 7)	Total
Age			
13	1	2	3
14	1	3	4
15	2	1	3
16	4	1	5
17	1	0	1

Ethnicity			
White	4	3	7
South Asian	3	2	5
Black	2	1	3
Other	0	1	1
CKD stage/treatment			
Pre-emptive transplant	0	3	3
Dialysis	4	3	7
• *In-centre haemodialysis*	*1*	*3*	*4*
• *Home haemodialysis*	*2*	*0*	*2*
• *Peritoneal dialysis*	*1*	*0*	*1*
Transplant	5	1	6

Table 12: Characteristics of participating parents (n = 13)

Characteristics	Number
Relati onship	
Mother	11
Step-father	1
Carer	1
Ethnicity	
White	7
South Asian	2
Black	4
Other	0
Child's sex	
Girl	8
Boy	5
Child's age	
13	2
14	4
15	1
16	5
17	1
Child's CKD stage/treatment	
CKD stage 3-4	2
Pre-emptive transplant	2
Dialysis	5
• *In-centre haemodialysis*	*3*
• *Home haemodialysis*	*1*
• *Peritoneal dialysis*	*1*
Transplant	4

Table 13: Characteristics of participating HCPs (n = 20)

Discipline	Number
Doctor	5
Nurse	4
Social Worker	4
Clinical Psychologist	3
Play worker	3
Dietitian	1

4.7 Data generation

Section 3.5 discusses the data generation methods used in this study. There were a total of 32 research encounters, which included 21 individual interviews, nine dyadic interviews and two focus groups. Table 14 presents details regarding these research encounters.

Table 14: Data generation

Method	Number of encounters	Number/type of participants	Length of encounter (range, in minutes)
Individual interview	21	21 • Young people = 7 • Parents = 4 • HCPs = 10	24-78
Dyadic interview	9	18 • Young people = 9 • Parents = 9	46-93
Focus group	2	13 HCPs • Focus Group Site A = 9 x HCPs (clinical psychologists = 2; doctors = 3; nurse = 1; play worker = 1; social workers = 2). 3 of these HCPs also took part in an individual interview • Focus Group Site B = 4 x HCPs clinical psychologist = 1; play worker = 1; social workers = 2)	46 54

4.7.1 Setting of the research encounters

The setting of the individual and dyadic interviews was based on participants' preferences and what was most convenient for them. Of the interviews, 21 were conducted face-to-face in the hospital setting as young people and/or parents found it more convenient to meet

while they were at the hospital for an appointment. I conducted four home visits to interview young people and/or their parents and five telephone interviews with four HCPs and one parent. Some home visits were potentially more relaxed encounters, often involving more informal conversations and engagement with other family members, but this did not influence data generation as much as I had anticipated. I found that through developing rapport and engaging participants in the hospital setting, or by telephone, equally rich data was generated.

Various spaces were used in the hospital setting to conduct interviews. For the majority of interviews, I was able to access a separate room. I also conducted some interviews while young people were on haemodialysis either in individual rooms or a bay shared with others also on dialysis. When interviewing in the bay, I drew curtains around the cubicle to increase participants' privacy and provide an opportunity for them to speak more openly despite the presence of HCPs and other patients nearby. However, I am aware that the lack of a quiet, confidential space could potentially have impacted on participation in interviews as young people and parents may have been more reluctant to discuss difficulties with self-management if they were concerned HCPs could overhear. Most interviews were carried out during the day on a weekday, although some were undertaken in the evenings or weekends to accommodate families' schedules.

There were often interruptions during interviews. In the hospital setting, this was mostly from HCPs; for example, checking if the room was occupied or because they needed to carry out a procedure on the young person such as checking their blood pressure while on dialysis. During home visits, interviews tended to be interrupted by other family members coming into the room and participants answering the telephone. During interruptions I switched off the digital recorder used to record the interview.

The two focus groups with HCPs were conducted in meeting rooms in the hospital setting on a weekday, during the day. One took place during the hour time slot in which the MDT usually had their fortnightly meetings; this meant nine HCPs were able to participate in the focus group as this time was set aside in their schedules, but also resulted in the focus group needing to end after 46 minutes as many of the HCPs had other meetings scheduled. As this particular focus group took place first and was anticipated to include a larger number of participants, one of my supervisors was present as the second facilitator. The second focus group took place late afternoon, which meant there was less time pressure and the discussion was able to come to a natural conclusion.

4.7.2 Conduct of the research encounters

At the start of each interview with young people, parents and HCPs, I introduced myself as a research student, who was independent of the clinical team. During the introduction to the focus groups, I advised the HCPs that I was an OT as I thought this could potentially help with developing rapport. I had the impression during some encounters with young people and parents that they thought I was a member of the clinical team as they assumed I had knowledge about aspects of renal care, for example when they recalled the names of medication taken. At these times, I would: reiterate my background; adopt a position of ignorance regarding renal self-management; ask participants to explain any medical issues; and ensure I avoided voicing any assumptions about what signifies 'good' self-management (Harries et al., 2019).

Following introductions, I: checked that participants had read the information sheet; explained the study verbally; and restated that their decision to participate was voluntary and that they could stop the interview or withdraw from the study at any time. Participants were told about confidentiality and that the only reason information would be shared with a third party would be due to concerns about someone's safety. I also explained that there were no right or wrong answers and that I was interested in hearing participants' views and experiences. All participants provided written consent/assent to participate in the study and for the research encounters to be recorded using a digital recorder. For the majority of interviews, only those who had consented to participate were present. However, during an individual interview with one young person, a HCP was present as the young person had asked that she be there to provide support. This HCP occasionally verbally prompted the young person about aspects of self-management and provided reassurance throughout the interview. The HCP subsequently participated in an individual interview.

During the research encounters, I used a topic guide and task-based methods as described in the following sections. In order to focus fully and encourage a more conversational feel, I decided not to take notes during the interviews, instead documenting any reflections in fieldnotes. As discussed in chapter 3, I aimed to be responsive and flexible during data generation, and adjusted my communication according to how participants engaged and responded to me. For example, I incorporated the language participants used to describe their experience in my subsequent questions and used closed questions strategically to encourage participants to make a choice rather than respond with a 'don't know'.

During dyadic interviews with a young person and their parent, I was particularly aware of power differentials and adjusted my communication to ensure the young person had the opportunity to speak. This involved various techniques such as directing the first question to the young person, using participants' names regularly to signify who the question was being directed at, and explicitly asking the young person for their response to what their parent had said. In the focus groups, I used some similar techniques to encourage the 'quieter' group members to contribute to the discussion; for example, using HCPs' names when asking follow up questions, as well as making use of eye contact and how I physically positioned myself to promote particular individuals to respond. In both the dyadic interviews and focus groups I was aware that my interventions were less frequent compared to the individual interviews and that I was comfortable relinquishing some control to ensure data were generated through interaction between participants.

Throughout data generation, I was open to pursuing unforeseen topics that were raised and that were deemed important by participants. At times this meant the topic guide I had developed was used very loosely, and at the end of some interviews I realised only a few of the questions had been asked; however, when reviewing the transcripts with my supervisors I found the conversation had covered many topic areas I had aimed to discuss. As the study progressed, I remained responsive to the issues that participants wanted to discuss, but, in line with the principles of theoretical sampling, asked more focused questions to learn more about the theoretical categories. At the end of each research encounter, I thanked participants and asked if they had further questions. A number of participants asked what would happen next with the study and expressed interest in hearing about the findings. As an additional 'thank you', all young people received a £20 shopping voucher. As detailed in Table 14, the length of research encounters ranged from 24-93 minutes.

4.7.3 Topic guide

I developed interview topic guides that were informed by the literature, consultation with PPI contributors and my own clinical experience working as an OT. For example, the first question in the topic guides for young people and parents was a typical opening question I used as an OT when meeting children and adults, as I found most people were able to answer this question regardless of their age, developmental stage and/or level of understanding. Initially three topic guides were created; one each for young people, parents and HCPs (Appendix 9). Each topic guide explored similar topic areas; however, the questions for young people and parents focused on their individual experience of gaining or relinquishing self-management responsibility, whereas HCPs were encouraged to reflect

more generally on their experience of supporting families with the transfer of responsibility. As discussed in section 4.3.2.2, PPI had a significant impact on the development of the topic guides; for example, I phrased questions to include language that families used, such as 'taking control' and 'being in charge'. I was careful to avoid using the term 'transition' during research encounters for various reasons including: differing understandings of what 'transition' means; aiming to keep the focus on the transfer of self-management responsibility – a process that could potentially begin before formal transition processes start in adolescence; and to shift the focus so parents' as well as young people's experiences were also explored. Despite this, a number of participants, predominantly HCPs, tended to focus on transition processes; this finding will be discussed in chapter 8. When conducting dyadic interviews with young people and their parents, I used the topic guide developed for young people to prompt me to focus on the young person's experience first.

As the study progressed the topic guides were revised. These revisions were based on my experiences and reflections during and after research encounters and as part of theoretical sampling to generate data that would support further development of the theoretical categories. Earlier topic guides had included questions about young people's and parents' support needs with the transfer of self-management responsibility. However, I found that in the first stage of research encounters, participants were particularly interested in discussing their experience of the transfer of self-management responsibility, including how this happened and what influenced this process. This meant data were generated that supported the construction of two robust categories, but I needed to ask more focused questions to reach theoretical saturation of the third category. Consequently, the revised topic guides that were used in the second stage of research encounters focused more on what sustained the transfer of responsibility (Appendix 10). During these later research encounters, I remained responsive to topics that participants considered relevant, but was aware of the need to ensure there would be an opportunity to generate data that would progress the analytic direction of the study. The following section will explore how using task-based activities may have assisted with balancing these sometimes disparate aspects of the interviews.

4.7.4 Task-based methods

Section 3.6 discussed how creative and task-based methods can be used to address methodological and ethical issues associated with conducting research with children. In this study, task-based techniques were used during research encounters with all groups of participants, although a greater number and range of techniques were considered for

interviews with young people. During earlier interviews, all participants were asked to consider a line (Figure 7).

Figure 7: Line used during interviews

Could you mark on the line how much you think you (your child) are (is) responsible for taking care of your (their) kidney condition?

| **Not** | | **Fully** |
| **responsible** | | **responsible** |

Young people and parents were asked to mark on the line how much they thought they/or their child was responsible for taking care of their kidney condition, and HCPs were shown the line to prompt further discussion around self-management responsibility. During dyadic interviews, I asked the young person and the parent to complete separate lines. Observing young people and parents undertake this task provided contextual data around their relationship. For example, during dyadic interviews some parents tried to 'correct' what their child had done, whereas, in individual interviews, some parents' assumptions around where their child would 'put their mark' prompted further discussion. Using 'the line' generated rich data which will be discussed in section 5.5.2. Appendix 11 is a record of the lines completed by young people and parents.

When initially developing the topic guides I had considered using a tool (Appendix 12) that was suggested as a potential method to evaluate how much self-management responsibility a young person has assumed (Olinder et al., 2011). Although gathering quantitative data about a young person's responsibility was not relevant to the study's aims, I thought the tool could be useful to explore different perspectives, in particular around the concepts of 'responsibility' and what it means to be 'fully responsible'. Following discussion with the PPI advisory group, who thought the original tool was too complex, and suggested a horizontal line was used instead, the tool was simplified.

In later research encounters, task-based methods were also used to support data generation. Data generated during earlier interviews around what facilitated the transfer of responsibility were iteratively offered to participants for consideration. In the interviews with young people and parents these were presented as ideas that I had typed, printed on coloured card and laminated (Appendix 13). The young person and/or parent were handed

the cards and asked to consider each of them. In focus groups, participants were also presented with data about what sustained the transfer process. However, a different format was used - a typed list of eight ideas printed on coloured A4 paper and handed to each HCP to consider (Appendix 14). Fewer ideas were presented in the focus groups as the larger number of participants meant less time was available for discussion of each idea. Using these task-based methods in later research encounters generated data in response to the more focused questions around what supported the parent-to-child transfer of self-management responsibility. This resulted in theoretical saturation of the three categories.

4.8 Data analysis

As this study adopted a grounded theory approach, analysis was an iterative, inductive process which meant data collection and analysis was conducted concurrently. The constant comparative method was used throughout this process as a way to interact with the data; through comparing data with data, and data with the developing codes and categories, I was able to gradually establish the properties of each theoretical category.

4.8.1 Data management

All participants provided written consent for the research encounters to be digitally recorded. The digital recordings were uploaded to a password-protected computer following the interview and the recording on the digital recorder was subsequently deleted. Transcription was undertaken by a commercial transcription company approved by the NHS Trust that was hosting my Fellowship award, and a data sharing agreement was in place. Once transcriptions were completed, I checked them for accuracy against the original recording and anonymised them by removing any names, places or other details that could potentially identify a participant or site.

I coded the first five transcripts in Word while I became familiar with the computer software (QSR NVivo Plus Version 11) used to support data analysis and management. Transcripts from all 32 research encounters were then imported into NVivo and I used the software to compete initial coding. After using Word, I initially found it challenging to use NVivo to code, but I gradually developed skills in using the software and in particular found it useful for systematic comparison of data; for example, comparing data from one transcript with data from a second, comparing data to codes, and codes with codes. At a practical level, NVivo was also useful for organising, storing and retrieving large amounts of data.

4.8.2 Data coding and category identification

Coding comprised two overlapping phases, as described in section 3.4.3.5. Initial coding involved applying labels (or 'nodes' in NVivo) to lines and segments of data. A 'fundamental grounded theory question' that opens a study and guides analysis – *what is happening here?* – was a useful steer during this process (Glaser, 1978; Charmaz, 2014). I also adopted the technique of coding with gerunds to encourage a focus on actions, rather than themes or topics. The following questions suggested by Charmaz (2014, p. 127) were useful during the initial coding phase and also prompted me to explore participants' emotional responses to the transfer of self-management responsibility in subsequent interviews.

- What process(es) is at issue here? How can I define it?
- How does this process develop?
- How does the participant(s) act while involved in this process?
- What does the participant(s) profess to think and feel while involved in this process? What might his or her observed behaviour indicate?
- When, why, and how does the process change?
- What are the consequences of the process?

Additionally, participants' language and terms were used as in-vivo codes. For example, HCPs use of the term 'crash-lander' to describe children who are diagnosed with CKD when they are in end-stage renal failure, and parents' description of themselves as an 'anchor' and 'propping up' their child, were used from an early stage of initial coding.

The first five interviews coded in Word generated over 650 separate codes. I was aware there was overlap among these codes and realised I was coding at a level that was too detailed (Bazeley and Jackson, 2013). At this stage, having decided to start using NVivo, I began to consider focused coding, the second phase of coding in grounded theory studies. Through comparing data with data, and codes with codes, I selected 41 codes that made the most 'analytical sense'. These focused codes evolved as data generation and analysis progressed. Appendices 15-16 contain examples of focused coding and the NVivo node structure.

Using strategies such as memo-writing and diagramming, I began the process of identifying categories, or conceptual terms that accounted for the data and the focused codes. The terms created for each category were developed as analysis became more abstract and theoretical. Having identified the properties of the core category (*shifting responsibilities*) and

two sub-categories (d*eveloping independence;* and *making changes),* I focused on defining the relationships between categories. Although Charmaz (2014) suggests some researchers find 'axial coding' useful to explore how categories relate to sub-categories, I decided against rigidly applying the formal procedures proposed by Strauss and Corbin (1998) as they encouraged 'forcing the data' into an organising scheme, rather than 'following the leads' in the data (Kelle, 2005). However, I found it helpful to consider the questions that axial coding aims to answer, such as 'when, where, why, who, how, and with what consequences?' during theoretical integration of the categories (Strauss and Corbin, 1998 p. 125). Charmaz (2014 p. 148) explains that, as part of axial coding, Strauss and Corbin propose applying an analytic frame to the data to address the questions above. This includes:

- conditions (the circumstances or situations of the studied phenomenon) answer the 'why, where, how come, and when?' questions,
- actions/interactions (participants' routine or strategic responses to issues, events or problems) answer the 'whom and how?' questions, and
- consequences (outcomes of actions/interactions) answer the questions on 'what happens?'

These questions helped me to clarify and extend the properties and dimensions of categories, and determine the relationships between the core-, and sub-categories.

Throughout data generation and analysis, memo-writing and diagramming were critical. Although guidance is provided on how to write early, more descriptive memos and advanced theoretical memos (Charmaz, 2014), I did not use this as it seemed overly prescriptive. I started by writing memos to develop my ideas about the focused codes, exploring my ideas and making comparisons between codes, and between codes and data. These early memos encouraged me to 'pause' and interact with the data, ask questions of, and clarify, my developing ideas, and 'fine-tune' subsequent data generation (Giles et al., 2016). Throughout the research process, my memos became increasingly analytical, as I used them to construct and examine the theoretical categories. In addition to writing memos, I also kept separate handwritten notes as I found this helpful to capture spontaneous thoughts that would emerge when I was away from the computer and engaged in other activities.

Diagramming was an integral part of the analytical process. I found that reconceptualising the data in visual form was key to developing my ideas and identifying connections between codes and categories. Hand sketching diagrams encouraged me to interact more creatively with the data and helped clarify my thinking. As Buckley and Waring (2013) suggest,

diagrams supported the process of theory construction and helped to communicate my emerging ideas to others, including supervisors, the study advisory group and PPI group members. Appendices 17-18 contain examples of a memo and diagrams that illustrate the analytic process.

Through focusing on process, flexible use of the axial coding questions, memo-writing and diagramming, I developed a theory *shifting responsibilities* that explains the parent-to-child transfer of self-management responsibility. *Shifting responsibilities*, as the core category, provides the 'strongest explanatory power' for the grounded theory and subsumes and integrates the two sub-categories, *developing independence*, and *making changes* (Madill, 2008 p. 131).

4.8.3 Theoretical sensitivity

As previously discussed in section 3.4.3.4, developing theoretical sensitivity involves the researcher using various sources such as the literature, personal knowledge and experience to theorise about the data. This is of particular relevance during data analysis. For example, the codes and categories developed in this study were shaped by my own subjectivity and way of viewing the world. Consistent with constructivist grounded theory, how I viewed, engaged with and interrogated the data was influenced by multiple factors such as my age, gender, ethnicity, socio-economic status, personal and professional background. In particular, I was aware of how being an OT and my interest in 'doing', activities of daily living, developing independence, roles and routines explicitly influenced the initial codes I identified that subsequently became focused codes and categories. However, to avoid 'forcing' preconceived ideas onto the data, I adopted strategies suggested by Charmaz (2014). Strategies included: following the guidelines for initial coding to encourage me to remain close to the data; using the constant comparative method, in particular comparing data with data to find similarities and differences; and reflexivity, to think critically about my influence on analysis. For example, memo-writing and diagramming about the links between the data, codes and categories, and OT models encouraged me to examine how my professional experience was potentially shaping the research process. Using these strategies helped maintain an emphasis on 'emergence' and ensure codes and categories evolved from reading the data rather than applying a previously developed framework to them.

Conducting a literature review prior to data collection and analysis also contributed to the process of developing theoretical sensitivity. This provided 'sensitizing concepts' (Blumer, 1969), that were used flexibly to guide the study, and were useful when developing my ideas

about the processes that I identified in the data. For example, existing research, that had explored how young people with other LTCs took on self-management responsibility, was used as a source of comparison, in particular when identifying theoretical categories. Continuing review of the literature was conducted as analysis progressed and while writing up this thesis to place the findings and developed theory within the context of existing and recently published knowledge.

Finally, abductive reasoning was used during data analysis to try and account for surprising findings. Two negative cases were identified, where data from two families did not fit the emerging pattern that accounted for most of the data. In these two families, the young people had appeared to lose motivation, and had disengaged from assuming self-management responsibility as they got older, which contrasted with other young people's experiences. By engaging in abduction, I considered other possible theoretical explanations for this finding, including potential influences such as the age of diagnosis, CKD stage and trajectory, unexpected deteriorations in the young person's health, the family's social situation and who contributed to data generation. By returning to the data to see whether any of these explanations were plausible, I found that abductive reasoning supported the development of theoretical sensitivity and data analysis, in particular refining the sub-category *developing independence.*

4.8.4 Analysing interaction

As the grounded theory analytic practices discussed in the previous sections do not explicitly analyse interaction, an additional approach (Lehoux et al., 2006) was used to examine how the context of the discussion shaped data generation in the dyadic interviews and focus groups. The rationale for using this approach in a grounded theory study is presented in section 3.5.3. Table 15 lists the questions that were used to guide analysis and Appendix 19 provides examples of how I applied the questions to a dyadic interview and focus group discussion (Lehoux et al., 2006).

It was beneficial to use these questions to consider how dyad/group dynamics, group composition and the position I adopted during research encounters shaped data generation and development of the categories. Reflections arising from using this analytical approach are integrated throughout the findings chapters and illustrate how combining focus group data with data from individual and dyadic interviews assisted with gaining a deeper understanding of the parent-to-child transfer of self-management responsibility.

Table 15: Questions to analyse interaction

Group processes	Epistemological content
Contrasting researchers' purposes with those of the participants	
• Who do participants represent when they speak? • What are the explicit purposes of participants? • What could be their implicit purposes?	• To what extent do participants comply with the researchers' cues or seek to foster discussion on other issues? • Why do these issues matter? And to which participants? • What do participants' purposes tell us about the research topic?
Understanding interactions and what is shared as a result of relational positioning of participants	
• What types of interactions occur among participants? • To what extent do these interactions reflect the broader social contexts? • Which participants dominate the discussion? How does this affect the contribution of other participants? • Which participants adopt a passive role? How do other participants respond to this position?	• What do dominant and passive positions reveal about the topic at hand? • What types of knowledge claims are endorsed or challenged by participants? On what basis? • What types of knowledge claims receive less support? Why?
Considering the extent to which the researcher participates in the construction of views	
• How does the researcher set the tone at the beginning? • How does the researcher succeed in making room for each participant to contribute to the 'common ground'? • Do participants accept or challenge the leadership of the researcher? How and when is acceptance or defiance manifested? How does the researcher respond?	• How does the researcher respond to the validation or disputing of knowledge claims? • What is the overall impact on the group's 'common ground'? • Does the 'common ground' remain stable over time?

4.9 Ethical issues

As this study involved NHS organisations in England, approval was gained before commencing the study from the Health Research Authority (HRA). HRA Approval combines the assessment of governance and legal compliance with an ethical opinion by a Research Ethics Committee (REC). The REC favourable opinion and HRA Approval letters can be seen in Appendices 20-21. Following receipt of these two letters, the local NHS research and development departments at the two participating sites provided confirmation that each NHS Trust had the capacity and capability to deliver the study. Guidance on conducting

ethical research was followed throughout the study to address key issues including consent, power relations, confidentiality and risk (MRC, 2004; RCN, 2009; RCPCH, 2014).

4.9.1 Consent

Section 4.5 describes the process of gaining consent from participants. Consent was viewed as a process rather than as a one-off event. Throughout the research encounters, I checked that participants wished to continue their involvement, both verbally and by being aware of non-verbal cues, such as body language and emotions (MRC, 2004; RCPCH, 2014). For example, I was aware that in interviews some young people became restless, distracted and increasingly responded to questions with 'don't know', which I interpreted as a cue to bring the interview to a conclusion.

4.9.2 Power relations

During research encounters, I was aware of the potential power imbalance, especially between young people participants and myself as an adult researcher. Methods used to address this challenge included being responsive to participants' own agendas, using task-based methods to provide maximum opportunities for them to provide their views and involving young people in the PPI group to ensure methods and language were accessible and age-appropriate. I emphasised my role as a 'listener', aimed to set a non-judgemental tone and encouraged participants to raise topics they thought were relevant. As a result, I sensed that participants were not telling me what they thought I wanted to hear, as both young people and parents openly discussed the difficulties they experienced with managing CKD.

4.9.3 Confidentiality

Issues around anonymity and confidentiality were explained to participants both in the information leaflets and verbally at the start of the interview. Young people were given the option to be interviewed alone without their parents; however, of the 16 young people who participated in the study, nine chose to be interviewed jointly with their participating parents. Paper documents, such as signed consent forms, were stored in a locked cupboard in a locked room. All electronic information, such as participants' names and contact details, and transcripts, were stored securely in a password-protected computer accessible only to me (RCN, 2009). During the course of the study, ethical issues arose in relation to confidentiality and what participants chose to share during interviews. During a dyadic interview a parent disclosed that she had been contacted by the young person's school, who were concerned

that the young person had a cut and was potentially self-harming. As this information suggested the young person could be at risk of harm, I discussed the issue with my supervisors. Consequently, I spoke with the parent again about the disclosure and gained their consent to discuss what had happened with the clinical team. The HCPs advised me that the young person was receiving emotional support from a therapist from the renal MDT who would explore the concern at the next appointment. Additionally, two parents expressed concerns during individual interviews about the deterioration in their child's condition and ability to self-manage. I explored these issues further during the interviews and was able to confirm with the parents that HCPs were aware of their concerns, and that both families were receiving support from the clinical team with these difficulties.

4.9.4 Risks

During the design stage, I had thought it unlikely that there were risks associated with taking part in the study; however, I was aware some participants could find it distressing to talk about some aspects of their lives. The information leaflets provided guidance on the risks and benefits of taking part and advised participants that they could pause or stop the interview at any time and choose not to answer a particular question. During an early interview, one parent became visibly upset as she talked about her child becoming an adult and moving to adult renal services. Although I offered to stop the interview or move onto a new topic, the parent was keen to continue talking as she thought it was 'important'. At the end of the interview I checked how the parent was feeling and offered to contact the clinical team to provide support, an offer she declined. The encounter prompted me to reflect on the emotional experience of the transfer of self-management responsibility and parents' support needs as they relinquish control to their child.

Consideration was also given to potential risks to me, such as being a lone worker undertaking interviews in home settings. Lone working policies and protocols were followed, which included completing a risk assessment. Although I was aware of the possibility that I may find some of the content of the interviews distressing, I found my clinical and research experience and discussions with supervisors helpful in managing any concerns.

4.10 Ensuring quality and rigour

As discussed in section 3.7, the four criteria proposed by Denzin and Lincoln (2011) were used to evaluate the quality and rigour of this study in terms of its credibility, transferability, dependability and confirmability.

4.10.1 Credibility

In the current study, a range of strategies were used to enhance credibility. Employing both purposive and theoretical sampling ensured there was variation in the sample and meant theoretical saturation was reached. The inclusion of different groups of participants (young people, parents and HCPs) from two sites, and having diversity within each of the groups, ensured comprehensiveness and credibility of the data generated. Using individual and dyadic interviews, together with focus groups, to generate data also enhanced credibility. In particular, using focus groups in the later stages of data generation to explore the category *making changes*, and in particular what actions and interactions sustained the transfer of responsibility, increased the likelihood that findings represented an accurate interpretation of participants' experiences.

The iterative process through which data were generated and analysed meant I was immersed in the data for a prolonged period. This provided maximum opportunity for understanding the different meanings that young people, parents and HCPs constructed around the transfer process. Taking a flexible approach to data generation and being responsive to participants' concerns also potentially gave greater credibility to findings. During research encounters, I followed up on topics that were important to participants and learnt to become increasingly comfortable with moments of silence so participants had the opportunity to expand on their initial thoughts. Credibility was also enhanced by searching for negative cases and using this data to develop the dimensions of the theoretical categories. As discussed in section 4.8.3, two negative cases were identified in this study. Data about how the transfer of self-management had been disrupted in these two families further strengthened theory construction.

4.10.2 Transferability

Various strategies were employed to enable readers to assess whether this study's findings have applicability beyond the context in which they were collected. Providing 'thick' description to reflect the social context of the research, and presenting participants' own words throughout the findings chapters, enables the reader to see the data alongside my interpretation of it. Transferability is also explored in the discussion chapter, as the connections between this study's findings and existing literature in both CKD and other childhood LTCs are examined.

4.10.3 Dependability

Provision of a detailed description of the research methods and decisions taken during this current study contributed to dependability. Robust documentation provides an audit trail of the research process, and includes: evolving topic guides; developing coding structure; NVivo database; memos and diagrams; field notes; transcripts; recordings of research encounters; email contact with PPI advisory group members; and minutes from the study advisory group meetings. Examples of these documents are included in the appendix and all documents are available for scrutiny to determine dependability.

4.10.4 Confirmability

As discussed in section 3.7, researcher reflexivity is essential to establishing confirmability and enhancing confidence in a study's findings. Theoretical sensitivity, as discussed in section 4.8.3, also stimulated reflection on the data. The following section explores reflexivity in further detail.

Finally, the application of grounded theory strategies contributed to the study's rigour. Using strategies such as detailed coding, constant comparison, searching for negative cases, memo-writing, and diagramming maintained the trustworthiness and authenticity of the data. These approaches supported the construction of a theory that met the criteria developed by Charmaz (2014) of credibility, originality, resonance and usefulness. Evaluation of the theory against these criteria is presented in the discussion chapter.

4.11 Reflexivity

A central method I used to enhance rigour and quality of the study was to take a reflexive stance. Various strategies were adopted to engage in reflexivity and critically examine how my personal and professional experience could have shaped the research, in particular key aspects such as the topic area, data generation and analysis.

4.11.1 Strategies to support reflexivity

I kept a research journal to write down any reflections, dilemmas and decisions throughout the duration of the study. After each research encounter, I wrote field notes where I recorded my general impressions, observations about the setting and participants, significant or emerging issues and any discussion that occurred once the digital recorder was switched off. I found the process of writing especially useful in articulating ideas that had occurred to

me during research encounters. In particular I found it helpful to consider how my personal characteristics and presentation of self may have had an influence on how trust and rapport was established, the interaction with participants and how this may have impacted on co-construction of data. I also reflected on methodological issues, such as the use of task-based methods, the questions I had asked, and what areas to explore in subsequent research encounters. These notes informed successive data generation, data analysis and prompted ideas for memos.

Regular meetings with supervisors provided the opportunity to review and reflect on aspects of the study including sampling strategies, recruitment, coding and emerging theoretical categories. Supervision meetings also provided a space where I could consider how my experience influenced how I conducted the study, especially my interactions with participants, co-construction of the data and analysis. While taking care not to disclose any confidential information, I also found discussing aspects of the study with colleagues, friends and my family encouraged me to take a reflexive stance.

4.11.2 Topic area

As discussed in chapter 1, the origins of this study emerged from my clinical and research experiences and interests. My professional background as an OT working in community services for children and adults had a significant impact on how I viewed the topic area. As an OT I am interested in how people engage in and perform 'occupations', or daily activities, and in particular how they can be supported to maintain or develop their skills and independence. However, I am aware that people's values, interests and priorities around what activities they want and need to perform are individualised and can sometimes conflict with what others, such as HCPs, think are 'good for them'. This conflict shaped how I approached the topic area, as I tried to balance the concept of self-management responsibility while respecting an individual's autonomy. This linked with my own beliefs around responsibility for health, and my observation that discourse around self-management can sometimes view an individual's health behaviours as a moral responsibility, or examine self-management in isolation from the contextual issues, such as socio-economic status, housing, employment and education, that can potentially impact on it. Consequently, I aimed to keep these tensions in mind in my approach to the topic area.

4.11.3 Data generation

As discussed in section 4.7.2 I introduced myself to young people and parents as a research student, deciding not to advise them my background was in OT as I wanted to emphasise my role as a researcher, not a HCP. However, it seemed that some young people and parents may have thought I was a HCP, perhaps due to my interactions with them and because many of the encounters occurred in a hospital setting. Interestingly, no participant asked if I was a parent, despite being a similar age, or older than many of the parents that participated. This may have been a consequence of how I presented myself, my personal characteristics and the hospital setting. Although I emphasised my role as a 'listener' and aimed to set a non-judgemental tone in terms of what constitutes 'good' self-management and 'good' parenting, it is likely that the assumptions that participants made about whether I was a HCP and/or a parent, influenced data generation. However, it seemed that I was able to develop trust and rapport, as many participants spoke openly about their difficulties with assuming or relinquishing self-management responsibility.

Being already known to some of the HCPs who participated through my work on previous studies is also likely to have influenced data generation. Although I was able to develop connections during research encounters with HCPs, the HCPs that I had pre-existing relationships with were more likely to speak openly about the dilemmas and difficulties in supporting the transfer of self-management responsibility. I only advised HCPs taking part in the focus groups that I was an OT. I had thought this might potentially help with developing rapport but also reinforce that they are the 'experts', as it would have indicated that I did not have experience working with children with CKD as OTs are not represented in the renal MDT.

4.11.4 Data analysis

Finally, taking a reflexive stance included thinking critically about how my experience and assumptions shaped data analysis. As discussed in section 4.8.3, I was aware that my background in OT influenced the analytic process, and that I naturally found myself thinking about the data in terms of OT models that emphasise the interaction between the person, the occupation and the environment. While employing strategies to ensure the codes and categories I developed were based on reading the data, I also recognised that my OT knowledge and experience provided 'sensitizing concepts' and could offer a unique interpretation of the transfer of responsibility. The distinctive contribution that OT could potentially offer to childhood LTCs and self-management will be explored in chapter 8.

4.12 Summary

This chapter has presented a detailed account of how the study was carried out including gaining access to the study setting, input from study advisors including PPI, sampling and recruitment decisions. The study sample and characteristics of participants have been presented. The procedures for data generation and analysis, and ethical considerations, have been discussed. Finally, the chapter considered the processes for ensuring quality and rigour, and reflexivity.

The next chapter is the first of three findings chapters and presents *shifting responsibilities,* a grounded theory to explain the processes that occur during the parent-to-child transfer of self-management responsibility.

5. SHIFTING RESPONSIBILITIES

5.1 Introduction

A grounded theory, *shifting responsibilities*, was constructed from the narratives. The theory is comprised of a core category (*shifting responsibilities*) and two inter-related sub-categories (*developing independence* and *making changes*). This chapter will start by briefly introducing the theory and three categories. The remainder of the chapter will present the core category. The two sub-categories are then discussed in detail in chapters 6 and 7.

Shifting responsibilities explains the main process found to occur during the parent-to-child transfer of self-management responsibility for CKD. Responsibilities appeared to move along a continuum between parental-led management and young person-led management. *Shifting responsibilities* was multifaceted; it was central to young people's, parents' and HCPs' experiences and also explained how the transfer process was fluid and bidirectional, not linear. Young people, parents and HCPs appeared to expect that self-management responsibilities would shift during adolescence; that young people would assume increased control of their health care as they became older; and parents would relinquish control. While some young people and parents welcomed HCPs' involvement in this process, others felt ambivalent about whether the transfer of responsibility was primarily the family's concern and whether HCPs should be involved. Linked to this were the tensions around where the transfer process occurred: the family home, hospital setting, or other environments where the young person engaged in self-management. Different understandings and expectations around the timeframe of the transfer of self-management responsibility meant different temporal landscapes existed for young people, parents and HCPs. This included when the process started and when it finished. *Shifting responsibilities* also describes the endpoint as well as the process. Conflicting views around how 'effective' self-management was defined, what it meant to be responsible and who had ultimate responsibility for a young person's health, contributed to the lack of agreement and clarity around what young people, parents and HCPs were trying to achieve – was this a young person sharing management with their parent, or being completely responsible for their own self-management? This core category will be presented in detail in this chapter.

The two sub-categories mutually influenced how and when responsibilities shift. The sub-category, *developing independence,* provides the context and is examined in chapter 6. For parents, HCPs and most young people, moving from child- to adulthood was associated with acquiring independence and becoming less dependent on parents. Young people assuming

self-management responsibility was seen as a natural extension of this 'normal' process. The unique developmental aspects of adolescence, and the associated behaviours and expectations of young people, their parents and HCPs, influenced how responsibilities shifted. These 'normal' processes were viewed as being more challenging when the young person had CKD, as the risks associated with increased independence were heightened. When the 'stakes were high', parents and HCPs experienced tensions with encouraging the young person to assume self-management responsibility, while balancing protection and risk. Contextual factors, such as the young person, parents and family, health condition and environment, interacted and influenced the transfer of self-management responsibility. Young people's and parents' motivation appeared to be central, impacting on both the initiation and continuation of young people *developing independence.*

The second sub-category, *making changes* is discussed in chapter 7. *Making changes* explains how young people, parents and HCPs adjusted their actions and interactions during the process of *shifting responsibilities*. Actions and interactions could initiate, sustain or disrupt the transfer process. There was ambiguity around how to initiate the transfer of responsibility. Parents initially focused on what self-management activities their child could do, whereas HCPs concentrated on a young person's knowledge of their CKD. A range of actions and interactions sustained the parent-to-child transfer of self-management responsibility, including: promoting a gradual transfer; encouraging partnership; developing a routine; fostering positivity; building and maintaining trust; facilitating connections with others; learning from mistakes; and individualising support. Actions and interactions could also disrupt the process as young people disengaged from assuming responsibility. Whether the disruption was temporary or lasting, parents' and HCPs' trust in young people was lost. As a result of young people, parents and HCPs adjusting their actions and interactions, the transfer process would mostly resume following a disruption. However, for some families, there remained uncertainty around whether *shifting responsibilities* would continue or had reached a premature end.

The components making up the theory are represented diagrammatically in Figure 8.

Figure 8: The shifting responsibilities theory
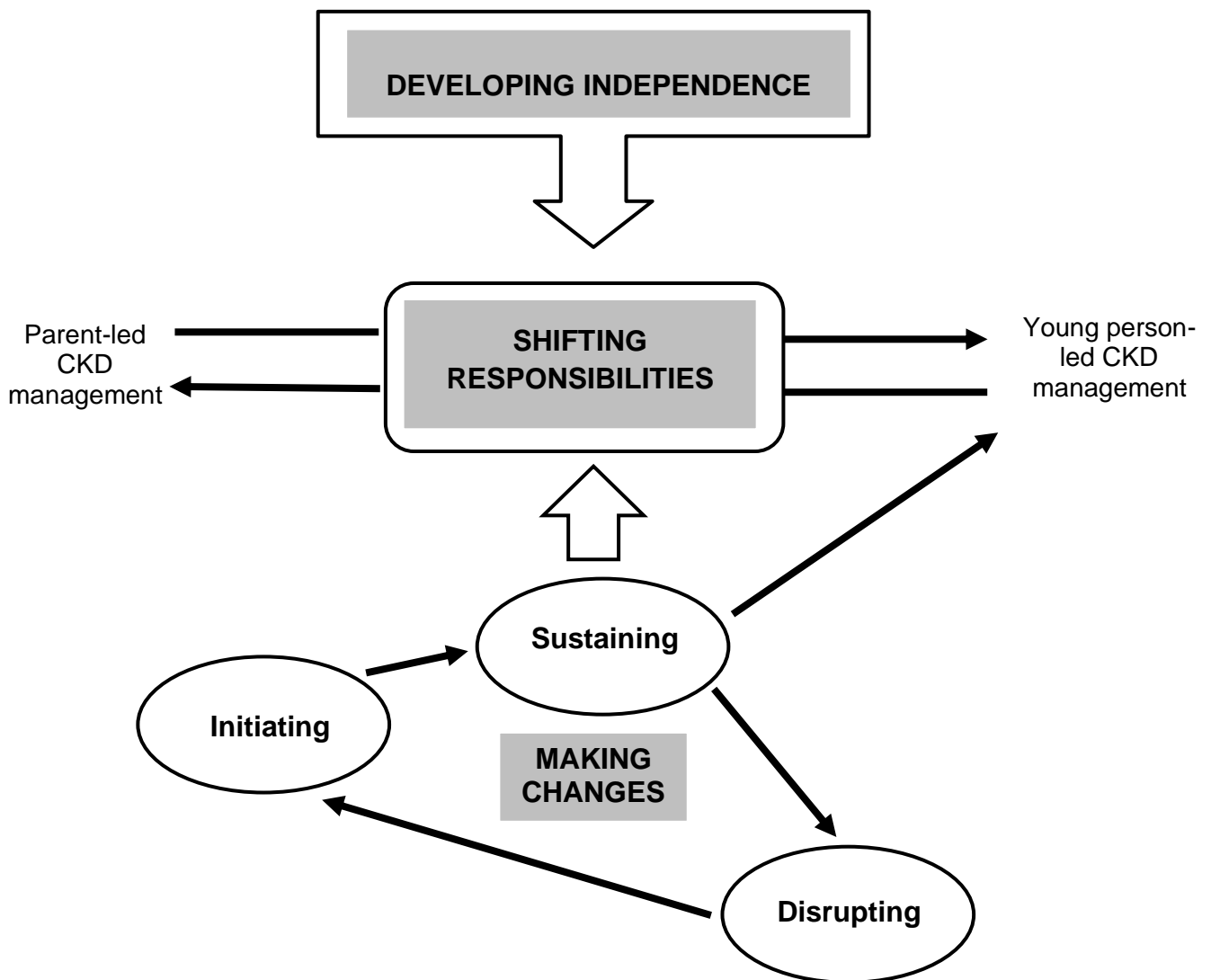
Data extracts are included throughout the findings chapters to illustrate the categories and relationships between them. Extracts are presented verbatim, with disfluencies such as 'ums' and 'uhs' removed during transcription for ease of reading. Bold font in these data extracts is used to denote where participants themselves stressed specific words or phrases in their accounts. Transcripts were anonymised; therefore, data extracts are identified by the type of participant (young person [YP], parent, HCP) and the participants' numerical study identifier (1-20) to demonstrate the similarities and differences between groups and the range of participant voices presented. The sex and age of young people is included with the data extract to provide some contextual information; however, only limited clinical information is included to avoid potential identification. Information regarding the HCP's discipline (e.g. dietitian, doctor) and parent role (e.g. mother, father) are excluded to avoid

their being recognised, as some sub-groups contained only one participant. Section 4.8.4 considered the process of analysing interaction in dyadic interviews and focus groups; this analysis is integrated throughout the findings chapters. Data extracts of interactions between participants in the dyadic interviews and focus groups, and between participants and me, will be used to illustrate how interaction generated new insights and contributed to theory construction.

The remainder of this chapter presents the core category, *shifting responsibilities*. Different aspects of the transfer process, including: what was happening; young people's, parents' and HCPs' roles during transfer; when the process began and was completed; where it occurred; and what the endpoint was, will be examined.

5.2 A fluid process

Responsibilities moved forwards and backwards along a continuum between parental-led management and young person-led management (see Figure 8). Parents were expected by HCPs to assume responsibility for managing their child's condition following a CKD diagnosis. All the young people participating in this study, regardless of the age when they received their diagnosis, initially experienced self-management as being parent-led; on the continuum in Figure 8 they were positioned towards the left-hand side. Over time, management became increasingly shared as young people became older and started to assume responsibility and their parents relinquished control. As this transfer process took place, responsibility shifted along the continuum towards the right-hand side as the young person took more of the lead in managing their condition. The sense that responsibilities moved along a continuum, where change happened very gradually, yet the extremes were quite distinct, was suggested in one HCP's account:

> *What I would like, at an individual pace, was a development while they [child] were growing up. Slightly different in different children because we're all different. They would be constantly shifting up, and then if they were acutely unwell or regressed, then they would step back a bit. Then they would continue up again. At one point the parents have no responsibility, they can't do anything about it, because they don't live together, and obviously a baby can't do anything, so it's going from one extreme to the other.* (HCP6)

Importantly, as the quotation highlights, the parent-to-child transfer of self-management responsibility was not a linear process; shifts in responsibility were fluid, bidirectional and uneven, with significant variation between young people and also over each young person's

developmental trajectory. Indeed, the process was completely individualised to each family. Responsibility shifted backwards and forwards between young people and their parents. At times, young people transferred responsibility back to their parents; for example, when they felt unwell, were tired, lacked motivation or their treatment changed. This fluidity was illustrated by one young person's account of her experience in managing her condition:

> *It's OK, some bits are hard though. I'm lazy, so some days I just don't want to do it. On those days, I'll do it, but my parents might help with bits.* (YP5, 16 year old girl)

Most parents would accommodate this fluidity; their responsibility temporarily increased until their child felt able to engage in self-management again. However, while parents adapted when their child *temporarily* relinquished their self-management responsibility, difficulties arose when this timeframe was extended and there was uncertainty around if, and when, the young person would reassume responsibility. In these situations, there was a sense that the transfer process was disrupted; this is explored further in section 7.4.

At other times, parents considered it necessary to assume an increased level of responsibility, such as when their child's condition and treatment changed. One young person who had an acute rejection episode of her transplanted kidney, due to not taking her medication or achieving her fluid intake, described how following this experience, responsibility shifted back along the continuum as her parents took increased control:

> *After my [transplant] rejection, my dad's constantly nagging me. Before, they [parents] did trust me with medication. Now, after my rejection, my parents are constantly on my back for drinking water, and checking my medications. It [checking medication] was weekly, now it's Wednesdays we do it and then my dad will want to see it again on Friday, it's constantly, constantly. Over time, I think they'll finally let go, but at the moment they're obsessing over it, because it's [the rejection] just happened.* (YP14, 16 year old girl)

Young people who had valued having some independence in managing their condition found it difficult to adjust to this increased dependence on their parents. Parents could also find this shift in responsibility difficult but believed it was non-negotiable, due to concerns around the potential consequences if their child struggled with self-management. During a dyadic interview, a 16 year old girl and her mother discussed how responsibility shifted after she had received a transplanted kidney:

> **Young person**: *Before my transplant I was responsible for taking my tablets of an evening, and you would just know. You wouldn't even-,*

> **Parent:** *She only took two tablets. She took them at night and at that point I never used to check in. Now and again I used to say, 'Have you taken your tablets?' when I said goodnight, but it's not like it is now. I think it's the importance of the tablets, because tacrolimus [immunosuppressive medication], if you forget it, it's massive…. I was a lot more slapdash then.*
> **Young person:** *I would like you to get like that again, to be honest.*
> **Parent:** *So would I.* (YP8/Parent8)

As illustrated by this data extract, it tended to be parents who made the decision around how much responsibility to hand over to their child. Parents' decision-making appeared to be shaped by various factors including the perceived level of risk associated with a self-management activity, as demonstrated above. Other influences on parents' decision-making and the transfer of self-management responsibility are explored in chapter 6.

Although the transfer of self-management responsibility was a fluid process, most young people did assume responsibility as they became older. Parents began to encourage their child to develop independence in specific self-management activities. As a result, responsibility started to shift as parents increasingly shared management responsibility with their child. Condition management was shared between the young person and parent in all families taking part in the study, although the extent to which it was parent-led or young person-led varied significantly. Although young people developed independence in self-management activities, they continued to rely on their parents, in particular for reminders:

> *I have been taking responsibility for what I can do, but I still need Mum's input. Even though I don't like it when she nags me, it's a good thing, because then it reminds me.* (YP1, 14 year old girl)

As the above quotation suggests, some young people were ambivalent about sharing management with their parents; they recognised their need for parental support, but could experience it as 'nagging'. In contrast, parents tended to view sharing management with their child as beneficial:

> *I get so many phone calls about him. He could be listening and I'm thinking, 'Oh, I can't remember what they say.' He'll say, 'No, Mum, they said this, they said that.' He helps me remember appointments. He would remind me sometimes, so we do share some responsibilities together. I think for me and him it helps. It's just reminding each other.* (Parent4, 14 year old boy)

As responsibility shifted, and management became increasingly shared, parents described how they adopted a 'supervisory' role. This was evident in this parent's account when describing how she shared management with her son:

> *He does things on his own, because we're not always with him, and he takes responsibility. I do more of a supervisory job to come and ask, 'Have you taken-,' 'Remember to take-,'* (Parent6, 14 year old boy)

'Supervising' also involved overseeing and coordination responsibilities, in addition to reminding. While young people developed independence in performing specific activities such as self-catheterisation, taking medication and following their renal diet, parents continued with many of the organisational activities such as ordering repeat prescriptions and liaising with HCPs. As responsibility continued to shift, and the young person took more of a lead in managing their condition, some parents' accounts suggest that their supervisory support became less explicit. The sense that parents moved into the background as their child assumed responsibility was evident in the language that parents used when discussing the less visible ways they supported their child to manage their condition:

> *I don't think she really realises what I still do. Maybe, by the time she goes off to uni, [she would be ready], but she wouldn't be ready to go **yet** because I'm still propping it all up. I think she thinks she's totally independent, is in charge, knows everything, and is in control, but I still have to make calls to the hospital, and I still have calls from the hospital and have emails. I'm not completely not needed.* (Parent2, 17 year old girl)

> *I feel like if I am around, regardless of what life and having a long-term condition is going to throw at her, she will still have that, 'Okay Mum, I've got an anchor and I know where I can go back to.' Just making sure that when it is all over the place, I am the consistent one in her life.* (Parent1, 14 year old girl)

Parents' feelings that they needed to 'prop up' their child's self-management, or that their child needed stability or an 'anchor', reinforced the sense that some parents struggled with relinquishing control and would remain in the background to ensure their child was able to manage their condition safely. The lack of clarity around whether young people, parents and HCPs viewed shared management or self-management as the goal, the conflicting views about the endpoint of the transfer process, and what young-person led management meant, will be explored in section 5.5.

Young people, parents and HCPs found the process of *shifting responsibilities* difficult. Although young people varied in how motivated they were to assume responsibility, most young people felt they had no choice in becoming more responsible for management of their condition:

> *At one point I'm going to have to be able to do it. I have to learn, because it's not going to go away. I know that I'm always going to be ill, so I have to learn to be able to do everything myself. It's good I should start learning how to do things now.* (YP4, 14 year old boy)

As the quotation illustrates, young people were aware that CKD was a LTC that needed ongoing self-management and that as they became older, responsibility would shift from their parents to them. Young people appeared to accept that assuming responsibility was a process and that they needed to prepare for the 'point' at which they would be responsible for managing their condition. Parents also appeared to view the transfer of responsibility as a process, as illustrated by this extract from a dyadic interview with a young person and her parent:

> **Parent:** *I think it would be awful for me to all of a sudden go, 'There you go, I'm not doing this anymore.' The best thing I can do for you, and this is what transition's all about, is to increase the responsibility over a gradual process, so it's not overwhelming for you.*
> **Young person:** *You can do that without coming to these [transition] clinics though, can't you? You just start handing over control to me, a bit more.*
> **Parent:** *Yes, but I'm saying I will do that in line with the hospital as they do that with you. I don't intend to keep hold of everything, and I will pass it over, and do it in a systematic way…I was saying that to Dad the other day, she has got 18 months to get through this process, and we do see it as a process. We're very early in it. That's totally my goal.* (Parent8, YP8, 16 year old girl)

What is evident in this data extract, and apparent in other parents' accounts, was the sense that parents viewed shifting responsibilities as a process that ideally took place gradually, systematically and in collaboration with HCPs. However, young people tended to view the role of HCPs differently to their parents; this tension around who should be involved will be explored in section 5.3. Despite perceiving the transfer of responsibility as a process where their child would take an increased lead in managing their condition, many parents struggled with 'letting go'. Parents were aware of the potential risks of relinquishing responsibility, and this made it difficult for them to balance protection with fostering their child's independence:

> *It is a big step for **me,** letting her do it, because it's what keeps her kidney healthy, these drugs, but she knows it…if I suddenly disappeared, she would be fine. It's **me,** it's **really** hard for a parent to pass on that responsibility.* (Parent2, 17 year old girl)

HCPs' accounts indicate they were aware the transfer of self-management responsibility was a difficult process for young people and their parents. During a focus group, HCPs discussed issues that made shifting responsibilities so complex including: risk; differing expectations;

and achieving alignment between young people's readiness to assume responsibility and parents' willingness to relinquish control:

> **HCP17:** *You could have the scenario where the child wants to push ahead with something and the parent has difficulty letting go, or you might have it where the parents are trying to encourage the care. When you've got that disparity, it is about nudging them both together in the same direction, at the same time. I say this to my teenagers' [parents], for your young person to step up, you need to step back, you need to give them the space to do that, and that is terrifying.*
> **HCP19:** *And it's extra hard when it comes to post-transplant, the doctors are saying that one missed medication can cause the graft to be lost, how do you trust as a parent that your child is going to do those things. Especially if you've been doing it for many years and your child gets to 15, 16, and says, 'I want to start doing this for myself'…It's a lot of responsibility.*
> **HCP18:** *When it's high risk as well. Some children have the luxury of growing up and being able to take risks and it's not going to be disastrous. You can push children to take a bit more risk or be a bit more independent, but you have to still provide the safety net. I think that HCP17's right that sometimes it does work in reverse as well. We have some families that are encouraging them to be too independent before they're actually ready. So we have to have conversations about how do you continue to be a safety net, how do you continue to oversee even though you're encouraging them to do things for themselves.*

The sense that responsibilities would ideally shift for young people and parents 'at the same time', is illustrated in the above data extract. HCPs' actions to encourage this process included acknowledging with families that the process could be 'terrifying' and suggesting parents support their child to develop independence while continuing to oversee management. The ways actions and interactions were adjusted to facilitate the transfer process will be explored further in chapter 7. The extract also highlights how generating data as a result of the interaction between participants in a focus group contributed to a richer understanding of the transfer of responsibility, as the HCPs were able to explore and clarify their own views, and examine the similarities and differences between their opinions compared with their colleagues.

This section has discussed the parent-to-child transfer of self-management, including what the process was, what was happening and how young people, parents and HCPs experienced *shifting responsibilities.* The next section will continue to discuss the process, by exploring who was involved and, linked to this, where the transfer process occurred.

5.3 Defining roles

Young people, parents and HCPs tended to have differing views about who should be involved in the transfer of self-management responsibility. The ambivalence around whether the process should be family- or HCP-led was related to the uncertainty around whether the process was initiated in the family home or within the healthcare setting.

All parents believed that it was a key part of their role as a parent to support their child to develop independence in everyday activities, including LTC self-management. The sense that parents saw this as part of their 'job' is demonstrated in the following quotation and was evident in other parents' accounts:

> *I feel you need to support your kids all the way until the end, until they're ready to get on their own ladder and support themselves. I'm very supportive with my kids, I like to make sure that I've done my job for them. Until they're ready to go on their own little way, it's what you have to do.* (Parent5, 16 year old girl)

Young people appeared to accept that this was what parents 'did'. All young people described how their parents, and predominantly their mothers, were key in helping them to assume responsibility for managing their condition. Some parents compared their own role with their child's other parent, suggesting there were gendered role responsibilities in some families. A few mothers acknowledged they tended to be more involved in managing their child's condition and as a result held more responsibility for supporting their child to develop self-management skills. During a dyadic interview with his mother, one young person explained who helped him to assume responsibility:

> **Young person:** *It's Mum because Dad doesn't move from that chair most the time.*
> **Parent:** *Brilliant, through the eyes of a child... It has been in our family and I think in most families it's Mum who does the majority of the caring.* (YP11, Parent11, 13 year old boy)

Although the transfer of self-management responsibility appeared to take place between the mother and their child in most families, this finding needs to be considered with caution, as only one father participated in the study. In a few families, the mother and father took responsibility for different aspects of self-management and so were both concerned with encouraging their child to become more involved in managing their condition. One mother, whose child had recently received a transplanted kidney that had been donated by her father, explained how 'jobs' were distributed in their family:

Her dad is very hot on the fluids side. I tend to do the medicines and he does the fluids, he donated the kidney, and I would say that he's got this real sense of vested interest in it, that he wants it to work. Also, as the mum, I've always been the one that gets the repeat prescriptions from the GP surgery, comes to most of the appointments. That's how it fell in our family, it just naturally happened, we complement each other. (Parent8, 16 year old girl)

In some families, the young person's siblings were also involved in supporting self-management. Young people described how their siblings helped by: providing reminders to carry out activities; prompting around their fluid intake and renal diet; and giving reassurance, for example by taking photographs of the empty dossette box to confirm all their medication had been taken. The sense that for some families the transfer process was the whole family's responsibility was illustrated in one parent's account:

Even the siblings, they help. They will be shouting, 'Take your drugs.' If he's taking too much fluid, one of them come and take the bottle, 'This is too much.' Everybody in the family is carrying it, everybody's watching. (Parent6, 14 year old boy)

The role of HCPs in supporting the parent-to-child transfer of self-management was more ambiguous. HCPs believed they had a responsibility to encourage young people to develop independence in managing their condition; they viewed it as part of their role, and an important aspect of their work in preparing young people for the transfer to adult renal services:

I think we owe it to the kids because we owe it to transition. We have to get some independence because otherwise it's one big shock going into an adult service if your parents have done everything. If we send them to adulthood like that we are letting that child down and we're letting that parent down. (HCP3)

HCPs thought they should be involved in supporting young people to assume self-management responsibility, but there was less clarity around whether HCPs had a role in helping parents to relinquish their responsibility. Although some HCPs described the need to work 'systemically' – thinking about the young person and their social context – it seemed HCPs' main focus was on the young person, rather than the young person-parent dyad. During a focus group, HCP5 reflected on her own experience as a parent, which prompted discussion around how HCPs supported parents during the transfer of responsibility:

HCP5: *I'm thinking about transition and primary school to high school at the moment. As a parent, you're worried about whether your child's going to settle in. The school have invited us to sessions and we've had speeches from the head teachers to reassure **us** as parents to overcome **our** anxieties. I don't know if there's something adult services could hold, like an event.*

HCP15: *That's what we do with our transition clinics, is to break that barrier down. Meet the adult team, have a walk around the ward, this is the clinic you'll be coming to, this is where you'll be having bloods. It is part of the process.*
HCP8: *It's a fair point. We don't do much for the parents, we do it all for the children. We don't focus - because, actually we often say the biggest problem we're going to have is the parent.*

The above data extract highlights how the use of data generation methods based on interaction between participants resulted in a richer understanding of the remit, and limits, of the HCP role. The suggestion that some HCPs perceived parents as the 'biggest problem', and a potential barrier to the transfer process, will be explored in chapter 7.

While some young people and parents welcomed HCPs' involvement in the transfer process, others felt ambivalent about whether HCPs should be involved. Only a few young people described how HCPs had helped them. For example, young people who were carrying out aspects of their dialysis care explained how the nurses had facilitated their learning while in hospital. However, other young people struggled to identify how HCPs had been involved and did not seem to recognise HCP involvement as contributing to their increased independence. When asked if HCPs had supported her to develop self-management skills, one young person responded:

> *Well, sort of, I guess. They talk to me a lot, and say, 'What time did you have your tac [medication] last night?', and things like that. They never say, 'Oh, you should use this,' or suggest an app.* (YP8, 16 year old girl)

When young people discussed how HCPs had helped, they tended to focus on the more tangible, explicit actions taken by HCPs, such as recommending the use of a dosette box to organise medication. In contrast, parents were more likely to identify and appreciate HCPs' subtle actions, such as adjusting their interactions to be more inclusive of the young person in appointments. Young people's and parents' different understandings around how HCPs could help were highlighted in a dyadic interview with a 14 year old girl and her parent as they discussed who was involved in the transfer process and where it occurred:

> **Young person:** *For me, when you say, independent, I think I'm taking my tablets by myself and stuff like that. That's just a habit I got into. We'd tell them [HCPs], 'She's started taking her tablets by herself,' but I don't remember **them** [HCPs] having much input. It was a transition that happened at home. From memory, it was something that I'd started doing. I don't know if the doctors have much to do with that really.*
> **Parent:** *Interesting, isn't it? I think the transition clinic helped. It got [child] thinking about responsibility. It helped me to identify that now it's a different phase in [child's] life, and it would be nice to give her that responsibility and help her towards being fully responsible for her own healthcare needs. It was **definitely** the conversations*

*that were happening in [transition] clinic that made **me** start thinking… So, I think the healthcare professionals **did** help, because of that transition structure, because it made **me** move forward.* (YP1, Parent1, 14 year old girl)

The data extract reinforces the sense that young people tended to view HCPs' roles in the transfer process as marginal, and that ultimately it was a process that took place in the family home between a parent and their child. The differences between how young people and parents constructed HCPs' roles is also evident, and in particular how parents perceived HCPs' subtle actions (e.g. 'conversations') could help with shifting responsibilities. The extract also highlights how generating data through dyadic interviews provided a richer understanding of the uncertainties around who should be involved and where the process took place.

As the above data extract illustrates, parents tended to acknowledge and value HCPs' involvement in the transfer of self-management more than young people. Some parents struggling with their child assuming self-management responsibility appreciated HCPs' support, and other parents attached importance to the sense of working collaboratively with HCPs as responsibilities shifted. One parent described how the transfer process had been initiated at home, but HCPs' subsequent involvement helped with developing her child's self-management independence:

> *We started it at home, me and my husband, but the parents, the nurses, the doctors and even the dietitian, everybody was involved. Everybody was carrying it along and worked as a team with the parents to achieve where we're at today. (*Parent6, 14 year old boy)

Although many parents welcomed HCPs' involvement, a few appeared ambivalent around the role of HCPs. These parents appeared to view it as primarily their role to support their child to develop independence, as they were more able than HCPs to judge whether their child was ready to assume responsibility. These parents were motivated and made decisions about shifting responsibilities without HCP involvement. One parent explained how she had decided independently to teach her child to swallow tablets (rather than dissolve the capsule contents as instructed by HCPs) and 'they' [HCPs] had not been involved:

> *Some of the things, like, setting out his tablets, they [HCPs] know I do that, but I never consulted them or involved them, I just taught him. Maybe when I started it they would not have been happy with me having to start at the age when he started… when he started taking tablets they said I need to take the capsules out because he might not be able to swallow them. They thought he was too young to swallow them and I should have been doing this.* [Parent4, 14 year old boy]

The quotation illustrates how some parents chose not to involve HCPs when they taught their child to be more independent in self-management activities due to concerns that HCPs may think the child not ready or too young to assume responsibility. Section 5.4 explores the uncertainty around when the transfer process should start. It seemed that underpinning parents' ambivalence around the involvement of HCPs was their unspoken fear that they were being judged by HCPs, in particular around their ability to manage their child's condition. The differing expectations around self-management and who had ultimate responsibility for the young person's health will be discussed further in section 5.5.

This section has discussed the different perceptions about individual roles in the parent-to-child transfer of self-management responsibility. Although the process was ultimately family-led, there was ambivalence around the role of HCPs and to what extent initiation of the transfer process occurred in the family home or in the healthcare setting. The uncertainties around the temporal landscape will be explored in the following section, including when the transfer process started and when it was completed.

5.4 Differing temporal landscapes

Different understandings and expectations around the timeframe of the transfer of self-management responsibility meant different temporal landscapes existed for young people, parents and HCPs. This included when the process started and when it finished. Figure 9 illustrates these different temporal landscapes.

Figure 9: Temporal landscapes of the transfer of self-management responsibility
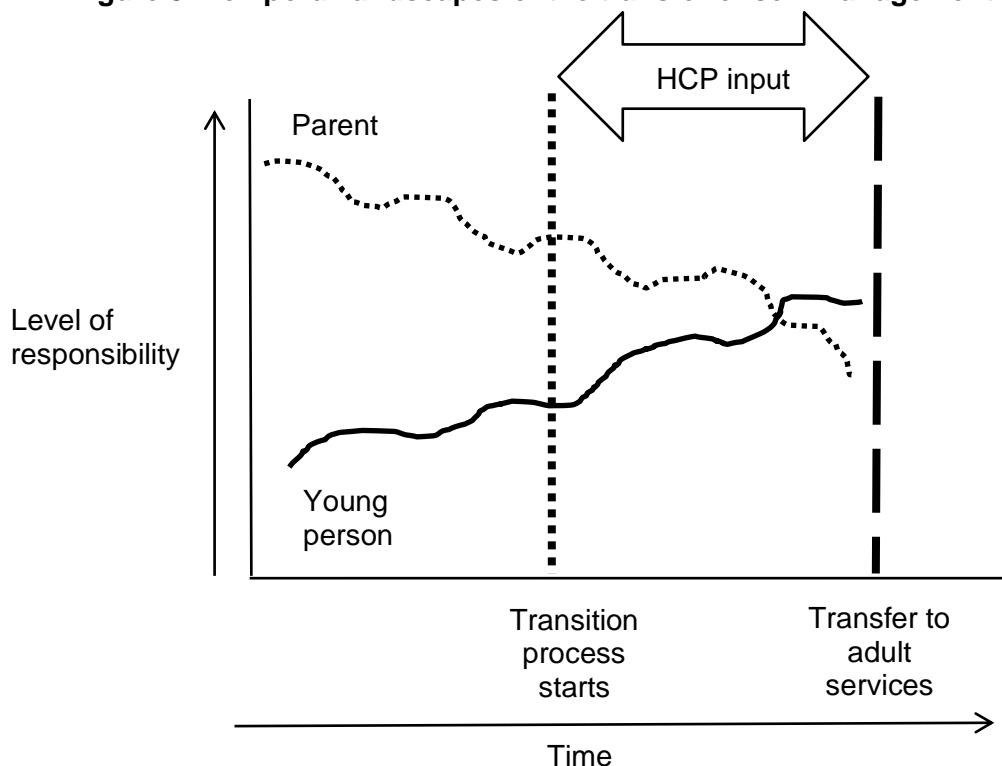
As Figure 9 suggests, the transfer of self-management responsibility between parents and their child could start when the child was relatively young in age, especially if they had been diagnosed with CKD at birth or early childhood. In these situations, many parents appeared to take the 'long view'; they were aware that, in the future, their child would need to develop independence in managing their condition and considered this as a process occurring over a long period. Chapter 6 describes how young people assuming self-management responsibility was seen as an extension of a 'normal' process, where becoming older was associated with acquiring independence in many aspects of life. As a result, both young people and their parents described how they/their child had started to become more involved in self-management activities while at primary school; for example, learning to swallow tablets at aged five, self-catheterising at aged seven, and taking medication on their own when they were 10 years old. Individual interviews with a young person and her parent illustrated how being involved in self-management activities from a young age meant they experienced the transfer of responsibility as a 'natural' and lengthy process:

> *I think because I've been doing it [medication] for **so** long… I've **always** been involved in it, so it's just natural.* (YP2, 17 year old girl)

> *She always hovered around or helped when I was setting up her tablets, so it was very natural… she just did it because she was doing it, there were so many pills to pop out, she often did it with me. Before I knew it, she was doing it herself.* (Parent2)

As Figure 9 suggests, the timing of HCP involvement tended to occur later on, often after the transfer process had already started within the family home, and management responsibility had started to shift. HCPs' accounts indicated their aim was to start the process when a young person was around 12 or 13 years old:

> *It tends to start when they turn 13. Some of them might start the process a bit earlier when they go to secondary school. It depends when they're ready, because some are ready earlier, and some we hold off. It depends how complex they are, in terms of how much is going on medically, but it tends to be secondary school, year eight [age 12-13] or year nine [age 13-14].* (HCP2)

However, as the quotation illustrates, HCPs' decision-making around when to start the process took into account issues that might impact on a young person's readiness to assume responsibility. This could include: a young person's developmental stage; maturity and readiness; the complexity and stability of their condition; and the parents' willingness to relinquish control. Although HCPs described how they individualised the start of the transfer process according to the young person's and parent's needs, they tended to view young people assuming self-management responsibility as part of the transition between child and

adult services. When asked when young people started to assume responsibility, most HCPs spontaneously talked about transition:

> *We take a paternalistic stance as we feel that some 11 year olds are too little to have those discussions or, sorry, I should say developmentally not at an appropriate stage where the actual discussions of transition would be a bit much for them. But, generally, at an age of 11 to 13, we'll **start to formally go through the process**…it's mainly through the transition process.* (HCP8)

HCPs' involvement in the transfer process was influenced by national and local transition guidelines which mostly recommend HCPs start planning a young person's transfer from child to adult services around the age of 13 years old. HCPs' framing of the transfer process in relation to the provision of healthcare, rather than as a process occurring between a young person and their parents within the family home, could result in tension between young people, parents and HCPs around when the transfer process started. This conflict around the different temporal landscapes was evident during a dyadic interview with a young person and her parent:

> **Parent:** *It [transition clinic] started about a year ago. It's a nice amount of time, until she'll have transitioned at 17, 18. It's not rushed, it's very gradual so it gives you time to have those discussions. For me, it was what they [HCPs] were doing that helped me to move forward a little bit.*
> **Young person:** *No, because the transition clinic only started last year, but I'd been taking my tablets **by myself a long time.** So, for me, I don't think the doctors had much input with that. The transition clinic's **different for me**, because they're just telling me about going older into the other years, but I don't think they really help with anything else… I've been taking my tablets by myself since I was 11, 10.* (Parent1, YP1, 14 year old girl)

In addition to the uncertainty around when the transfer process started, there was also ambivalence around when the process would finish. Some young people believed they would have assumed self-management responsibility from their parents by the time they were 18 years old, associating the endpoint of the process with becoming an adult and leaving home. In contrast, parents appeared ambivalent about whether their child would be able to manage their condition independently at this stage. During a dyadic interview, one young person talked with her parent about when she hoped to get 'there' – to a position of being 'fully responsible' for managing her condition:

> **Young person:** *I'm hoping I'll nearly be there ['fully responsible'] by the time I've moved out [the family home]. I'm not scared to leave and start doing this on my own. Mum is.*
> **Parent:** *I'm not scared.*

> **Young person:** *I know that you want me to stay at home so you can keep an eye on me. By the time I'm at university, I would like to be at least basically there.*
> **Parent:** *Well, if you go to university, you'll have to be **fully** there.*
> **Young person:** *Yes, I know, that's what I mean, but would you still call me every morning and things like that? By the time of uni, I would like to be there. If I start doing it on my own for years, then I'll get used to doing it. It'll just be something I know, and I'll sort out my own, 'Well, if I take my tac [medication] here, then I'll have to take it at this time of night, and how does that fit around my plans?' I'll just be able to get on with it.* (YP8, Parent8, 16 year old girl)

As the data illustrate there were differing understandings around what it meant to have self-management responsibility and how to define the completion of the transfer process. The lack of clarity around the endpoint of the process will be explored further in section 5.5. The extract also highlights how generating data through dyadic interviews provided a richer understanding of how young people and parents discussed self-management responsibility with each other, and the differences in how they viewed the transfer process timeframe.

Parents' views on when the transfer process might end appeared to be shaped by various issues. Parents discussed the approaching time point when their child would move into adult health services and were aware that, as a young adult, their child would be expected to be able to manage their condition on their own. Additionally, parents anticipated that their child 'should' have assumed self-management responsibility when they left home. However, parents were ambivalent around whether this would be achieved. This appeared to relate to their uncertainty around whether their child would have the skills and maturity to perform all aspects of self-management, but also whether they themselves would feel able to relinquish control. Some parents appeared to believe they would continue to provide self-management support even when their child had reached adulthood:

> *I'm a mother. Even when he is 30 years I will still be asking him some things, as a mother, you keep supervising.* (Parent6, 14 year old boy)

The quotation raises questions around whether the process of *shifting responsibilities* would ever end for parents. As Figure 9 illustrates, the endpoint of HCPs' involvement in the parent-to-child transfer of self-management responsibility was determined by local service provision. All the HCPs participating in this study worked in children's kidney services, therefore, once the young person moved to adult kidney services, they were no longer involved in supporting the young person to assume self-management responsibility. As a result, most HCPs aimed for the young person to be able to manage their condition independently at the point they left children's services:

Ideally they should be looking at full responsibility from about 16, 17, so you've got a couple of years in paediatrics to manage that fully responsible. This would be in an ideal world, you get them fully responsible and then you've got that rocky phase where they're still being watched like hawks because as soon as you move over to adults they haven't got that phase anymore. We've got a responsibility to try and get them to that stage, in a secure environment so that we can move them over. (HCP3)

As the quotation suggests, and was evident in other HCPs' accounts, this was the 'ideal'. HCPs described how a few young people were able to manage their condition independently when they moved to adult services; however, the majority of young people continued to need ongoing parental support after they left children's services. HCPs' accounts revealed their frustration that the young person's chronological age, rather than their ability to self-manage, determined when they moved from child to adult services:

HCP14*: I wanted to be contentious about the slightly artificial age because brain development goes on at least till 25.*
HCP8: *Well, we are driven by the artificial age, there are young people at 15 who are better equipped to live in the adult medical environment than some 25 year olds. That drives the process, so a lot of it is age, but there are other factors that drive when we do transition rather than the patient.*
HCP11: *It depends as well where you work. We have a [NHS] Trust that mandates that we move patients over at the age of 16…but there are other Trusts where between 16 and 19, young people are offered a choice, 'Do you want to go to paediatric services, or move up to adult services?' So how we practise as clinicians is dictated by the management who decide how they want to do things within this Trust. You go 50 miles down the road, they do things very differently.*
HCP14: *Even in the same Trust with different areas, oncology has a young adult service that other specialities don't have.*

In addition to the 'artificial' age that governed young people's transition into adult services, HCPs described local service provision as also directing when their involvement in the transfer process finished. As a result, some HCPs thought the children's kidney teams should work with young people until they were independent in managing their condition, whereas other HCPs thought adult kidney teams had a role in continuing to support the transfer of self-management responsibility. Chapter 7 will explore further the actions and interactions that facilitated young people to assume responsibility.

This section has examined the temporal landscape of the transfer of self-management responsibility, including when the process started and when it finished. The following section builds on the uncertainty around when the process was completed, by exploring what young people, parents and HCPs perceived as the endpoint of the process.

5.5 Conflicting endpoints

There were differing understandings and expectations around the endpoint of the parent-to-child transfer of self-management. As responsibilities shifted, there were conflicting views amongst young people, parents and HCPs around how 'effective' self-management was defined, what it meant to be responsible and who had ultimate responsibility for a young person's health. This appeared to contribute to the lack of agreement and clarity around whether the endpoint of the transfer process was for the young person to share management with their parent or to be 'fully' responsible for managing their own condition.

5.5.1 Defining self-management

Young people, parents and HCPs appeared to define self-management differently and have conflicting expectations around what it meant for the young person to assume self-management responsibility. When discussing self-management, young people tended to describe the daily activities they engaged in; for example, taking medication and managing their fluid restriction, as well as communicating with HCPs during clinic appointments. In contrast, parents' accounts included other aspects of managing CKD, such as contacting HCPs for advice between appointments, ordering medication and accessing online health records to check blood results. Data generated through dyadic interviews often illustrated the tensions that existed in relation to young people's and their parents' perceptions of self-management responsibility. When asked to describe self-management during a typical school day, one young person, who had recently received a transplanted kidney, and her parent explained:

> **Young person:** *I'm yet to go back to school but I'll work my way around it. If I need to take tablets during the day, I'll take them at breaks and lunch times.*
> **Parent:** *I think this is a really good highlight of where expectations from [child] are totally different to mine. I'm already thinking about that now. We've just had a consultation with the doctor, I was asking whether these antibiotics can be moved, because I'm thinking about making a plan that's easier for her, that's got as few medication times in the day as possible.*
> **Young person:** *I shouldn't have to take very much, a lot of it is the morning anyway.*
> **Parent:** *That's what I'm saying, I'm planning that for you. You're not planning it, are you? You're just going, 'I'll just take what I'm told.' I think that shows exactly what this is all about.* (YP8, Parent8, 16 year old girl)

The sense that parents' understandings of self-management differed to their child's, and that parents often adopted a role that involved planning, supervising and monitoring was evident in many young people's and parents' accounts. When discussing what self-management activities they supported young people to assume responsibility for, most HCPs tended to

focus on the same activities as young people: medication, diet, fluid intake, discrete aspects of their dialysis care such as connecting and disconnecting to the machine, and communication during clinic appointments. It seemed that for some HCPs, the process of participating in the study interview, prompted them to reflect more broadly on other activities involved in managing CKD:

> *We expect the children to know what they're doing, why they're doing it, and what that means, but it's the bits and bobs that come with it. You know, contacting the patient directly to discuss the results. I don't know if we do encourage that. We need to have those discussions more, because it's those bits **after** the appointment, not just whilst they're in the appointment.* (HCP2)

As well as the ambiguity around what self-management involved, there was also uncertainty around how 'effective' self-management was defined. As their child developed independence in managing their condition, parents adjusted their expectations around what was 'good enough' self-management. For example, parents described how they expected their child to know the names of their medication but not know the medication dose, and that their child would occasionally lose motivation or forget to take medication:

> *I don't expect her to never miss her tablets or do everything perfectly, because even adults who've been on long-term medication can forget an odd time to take their tablets, or maybe eat the wrong thing now and then.* (Parent7, 16 year old girl)

As the quotation illustrates, parents' expectations of their child took into account the difficulties of consistently engaging in self-management activities; as a result, parents often adopted a supervisory role to reduce the likelihood of negative consequences occurring as a result of their child's 'less than perfect' self-management. Some HCPs also acknowledged the challenges of complex self-management routines. They described how they adjusted their expectations and anticipated that the young person may make some mistakes; however, there appeared to be ambiguity among HCPs around what was 'good enough' self-management. Although HCPs did not expect young people to be 'perfect' in managing their condition, there was uncertainty around what was acceptable:

> *We know patients with chronic kidney failure struggle with their diets. Does it mean they're not fully responsible if they're having the odd high potassium? No, because they're not going to get it right every single time… There's always going to be mistakes and we don't live in a world where things are perfect. You've got to look at what's gold standard but what's acceptable? Is silver acceptable? Is bronze acceptable? Realistic expectations of what someone can achieve.* (HCP3)

The sense that HCPs defined 'effective' self-management differently meant young people and parents did not always get consistent advice from HCPs. Later in her account, HCP3 described the difficulties that could result from a lack of agreement in the MDT about what was 'acceptable' self-management:

> *What I think is acceptable might not be what someone else thinks. I look at their bloods and think, 'That's a really good potassium after a weekend,' where I've got a consultant saying, 'Dreadful.' So, they [families] get some confusion. We've got to set realistic expectations. We've got to find out what's safe and what's acceptable.* (HCP3)

In contrast, some HCPs thought young people and parents were able to tolerate ambiguity and, even if HCPs did reach a shared understanding of what was 'acceptable' self-management, there were difficulties with communicating this consistently to families. Chapter 7 explores HCPs' actions and interactions when they had concerns that the young person's self-management was neither 'safe' nor 'acceptable'.

5.5.2 Being responsible

In addition to the differing definitions of self-management there was also a lack of shared understanding of what it meant to be responsible. This contributed to the conflicting views around what the endpoint of the transfer process should be. Section 4.7.4 explained how young people and parents were asked during interviews to mark on a line how much they thought they/their child was responsible for taking care of their kidney condition. As was evidenced by the discussion around the lines, young people and parents tended to have different understandings of what being responsible meant. Although some young people-parent dyads agreed about the amount of responsibility the young person had assumed, their accounts suggested that their perceptions differed around what was involved in being responsible. Young people appeared to focus on their responsibility for performing specific self-management activities, whereas parents tended to consider self-management more broadly in terms of their child's knowledge and understanding of living with CKD. This was illustrated during a dyadic interview, when the young person and her parent were asked why they had indicated the young person was 'fully' responsible for managing her condition:

> **Young person:** *I do my tray properly [preparation for connecting to the home dialysis machine], I don't make any mistakes and I am mostly responsible for my fluid intake and my food and I do it very well. I'm also responsible when I'm at school, I have to follow what the nurses said. I do basketball but I have to be careful, if I get weak, I catch my breath first, then I can go on.*

Parent: *If you came here when we first started I wouldn't say fully responsible, because she was struggling. Now, she **knows** what it's all about. Before she gets bloated. Now, she'll say, 'I had too much to drink,' so she knows. She wouldn't want to go beyond [the fluid restrictions] because she knows the consequences. If someone of her age could think that, then she is **fully** responsible for her care.* (YP3, Parent3, 15 year old girl)

As the data extract highlights, parents made judgements around what was an appropriate level of responsibility for their child based on their age. Although some of the young people-parent dyads disagreed around how much responsibility they/their child had assumed (Appendix 11: dyads 1, 2, 5, 6, 8, 11), both young people and parents appeared to associate being responsible with consistently engaging in self-management activities. A dyadic interview with a young person and her parent illustrated this shared belief:

Young person: *For me, it [being fully responsible] would be being constant at drinking my water, constant at my medicines because sometimes I miss my medicines on a night or recently my water drinking's not been too good.*
Parent: *I think she's 50% responsible and that's because she's sometimes inconsistent. There are times when she's brilliant and there's no concern, and then there are days when I'm like, 'Oh, she's whatever.' Those days are fewer. She's halfway there.* [YP1, Parent1, 14 year old girl]

Similar to young people and parents, some HCPs thought responsibility was about the young person consistently engaging in self-management activities, such as regularly taking their medication. HCPs' accounts suggested they also considered other aspects of self-management, such as communication during appointments, when judging whether a young person had assumed self-management responsibility:

On an objective front, they would be coming to clinic, be the one that's directing the consultation, be completely at ease with speaking to the [HCP]. Know their medications, have sensible questions to ask in clinic…I've never really thought in the past about other things like going to get your medication or somebody who's making the decisions in their care in conjunction with a [HCP]. (HCP9)

The quotation suggests that HCPs believed some aspects of self-management could be assessed 'objectively', whereas other aspects were potentially less tangible, such as a young person's involvement in decision-making. Chapter 7 explores how HCPs and parents assessed whether a young person was ready to assume responsibility, and the ambiguity around whether this assessment was an 'objective' process. Although HCP9 admitted that participating in an interview prompted her to think more broadly about what it meant to be responsible, for example sharing decision-making, some HCPs described how they did

consider these types of activities as part of the transfer process. For example, HCP8
explained how they associated responsibility with making informed decisions:

> *Fully responsible means that they know exactly what they need to do to look after
> themselves and are taking full, responsible authority in all their decisions around their
> healthcare. It doesn't mean that they are right or they are in keeping with what's been
> advised…They could be saying, 'I am not taking my medicine', that is still taking full
> responsibility though it is not necessarily doing it in the right way.* (HCP8)

The extract suggests that being responsible included having the 'authority' to make
decisions and being accountable for the consequences. The uncertainty around who was
ultimately responsible for a young person's health is explored in the following section.

5.5.3 Being accountable

As well as the conflicting views around what it meant to be responsible, there also appeared
to be some uncertainty around who had 'ultimate' responsibility for a young person's health.
This appeared to influence how young people, parents and HCPs perceived the endpoint of
the transfer process. HCPs were aware that, legally, parents retained parental responsibility
until their child was 18 years old. As parental responsibility meant parents were accountable
for their child's health, this meant, in law, young people were considered to have ultimate
responsibility for their health only when they became 18 years old:

> *You would never make them [young person] responsible if there is a negative
> outcome because they've not been managing as well as they should have. The
> parent would always hold that last bit for the outcome of it all. And they do, because
> for a child under 18, especially under 16, if there was a problem around adherence,
> or the family didn't come to a clinic appointment, there would be no point the parent
> saying, 'Well, I've put them in charge. They're responsible.' Because parents hold
> parental responsibility and healthcare is part of that responsibility. It's a much more
> grey area above 16, but there is also the statute of law.* (HCP1)

Despite the legal status of parental responsibility, HCPs' accounts illustrated some of the
tensions experienced around accountability as a young person assumed self-management
responsibility. HCPs' actions and interactions to manage some of these 'grey areas',
including whether the young person was competent to make self-management decisions,
are discussed in chapter 7. The tensions around responsibility and accountability extended
to HCPs' roles and remit. Some young people and HCPs reported how they perceived HCPs
would always have some accountability for managing the young person's CKD; therefore,
the young person would never have complete responsibility for managing their condition.

*I'll never be totally responsible for everything. I'll be fully responsible for looking after myself, and saying if there is something wrong, but I'm **not** the one checking my levels when my bloods get taken. They're [HCPs] doing that, and they're responsible for looking at things to see if there was something wrong* (YP2, 17 year old girl).

If you're going to say fully responsible, you think that it's just on them [young person], and there's no one else. I don't think they'd ever be fully responsible, because whilst they're responsible for coming into clinics, it's up to the medical team to look at their bloods and decide if they need to change medications or dialysis regimes or fluids, they're never going to be expected to do that. It is always a partnership and a team (HCP10).

As the extracts above highlight, there was a sense that the endpoint of the transfer process could be a position where responsibility was shared between young people and HCPs. The role of parents at this final point, however, appeared more ambiguous. The lack of clarity around what young people, parents and HCPs were hoping to achieve during the parent-to-child transfer of self-management responsibility will be explored in the following section.

5.5.4 Reaching the endpoint

As discussed in section 5.2, responsibility gradually shifted as young people and parents increasingly shared management responsibility. Shared management was perceived to be a transitional part of the transfer process as young people assumed responsibility and parents relinquished control. However, there was uncertainty around what the endpoint of the process was – would it be reached when the young person took the lead in sharing management with their parent, or when the young person had assumed complete responsibility for managing their condition? This sense of ambiguity was clearly evident in participants' accounts. None of the young people taking part in the study had reached a point of achieving self-management independence, despite some imminently transferring to adult services and most young people, parents and HCPs believing that adult services expected young people to have full responsibility for managing their condition.

Most young people described aiming for self-management independence; they appeared to view the endpoint of the process as being completely responsible for managing their condition and believed they would reach this goal. A young person explained how she planned to be '*able to do things without anyone there'* when she was 18 years old, and described further what this meant to her:

It's doing everything on my own. Being able to cope with doing my medicines without my mum waking me up. I can now cope with doing my fluid allowance on my own.

> *So, like the major things that I have to struggle with, do it by myself, independently.* (YP5, 16 year old girl)

In contrast, parents were more ambivalent around the endpoint of the transfer of self-management responsibility. As discussed in section 5.4, some parents hoped for their child to be independent in managing their condition by the time they left the family home; however, there was ambiguity in their accounts around whether they thought this point would ever be reached. This uncertainty was evident during a dyadic interview, where the young person had recently received a kidney transplant and was taking immunosuppressive medication to prevent rejection of the transplanted organ:

> *Thinking ahead, she's 16 now and she could go to university in a couple of years and I will probably be phoning every morning, saying, 'You are out of bed and you've taken that [medication]?' That's awful, isn't it? For a parent, that's horrible, because I would like you off my hands.* (Parent8, 16 year old girl)

As the data extract illustrates, and was evident in other parents' accounts, it appeared some parents viewed sharing management with their child as a more achievable goal and potentially the endpoint of the transfer process. There was also ambivalence among HCPs around whether the goal of transferring self-management responsibility was young person led-management, with continued parental oversight, or the young person independently managing their condition. Some HCPs' aim was for young people to assume full self-management responsibility by the time they transferred from child to adult services; however, their accounts revealed a tension between this 'target' and whether in practice this endpoint was ever achieved:

> *It's a target that we're aiming for. I don't think that we fully achieve it really. A lot of that is often external factors that we can't change in that how much the parents let go and the child's level of maturity is not always linked to their chronological age.* (HCP9)

In recognising that 'external factors' could influence whether a young person was able to assume full or partial self-management responsibility, there was also ambiguity around how much impact HCPs could have on the transfer of responsibility. Chapter 7 explores HCPs' actions and interactions during the process of shifting responsibilities, and those perceived as supportive.

In addition to the uncertainty around whether assuming full self-management responsibility was a realistic goal for all young people, some HCPs questioned whether it should be the goal. Conflicting views around the concept of independence were evident in HCPs'

accounts, and these seemed to influence what HCPs thought should be the endpoint of the transfer of responsibility. During a focus group, HCP14 challenged both her HCP colleagues and this study's question:

> *Some of the development psychology literature talks about **interdependence** being a much healthier model and concept to look at than **independence.** Your question is about supporting 13 to 18-year olds to become **independent** but could we challenge that basic concept of independence at 18? How many 18-year olds go to university and don't still phone their parents when they get into a pickle? Is there a continuum, a concept of **interdependence** which needs to shift?* (HCP14)

The conflicting views around whether the goal was for young people and parents to be interdependent and share management, or whether young people should be achieving self-management independence by the time they transferred to adult services, reinforced the sense that shifting responsibilities was a complex process. Together with the uncertainties around how 'effective' self-management was defined, what it meant to be responsible and who had ultimate responsibility for a young person's health, this meant a lack of clarity around knowing when the endpoint of the transfer process had been reached.

5.6 Summary

This chapter has discussed *shifting responsibilities*. As the theory and core category, it captures and explains the main process occurring during the parent-to-child transfer of self-management responsibility for CKD. Responsibilities shifted along a continuum between parental-led management and young person-led management. Although the process was completely individualised to each family, it was always fluid and bidirectional and not linear. There appeared to be ambivalence around who should be involved in the transfer of self-management responsibility. Both parents and HCPs thought it was their role to support young people to assume self-management responsibility; however, some young people and parents felt the process was primarily the concern of the family, whereas others valued working in partnership with HCPs. Regardless of who was involved, the transfer process was mostly initiated by parents, occurring within the family home. The ambiguity around the timeframe of the process, including when it started and when it was completed, was also explored. There was a sense that different temporal landscapes existed for young people, parents and HCPs which seemed to relate to young people and parents viewing the transfer process within a broader context of developing independence in daily activities, and HCPs framing the process within the narrower context of the transition to adult health services. Finally, the conflicting views around the endpoint of the transfer process were discussed,

including how 'effective' self-management was defined, what it meant to be responsible, and who had responsibility for the young person's health. These tensions contributed to the lack of agreement and clarity around whether the goal or endpoint of the transfer process should be for young person-led shared management with their parent – a state of interdependence – or for the young person to be completely independent in managing their condition.

The next chapter examines the first sub-category, *developing independence.* In providing a context for the transfer process, it explains why responsibilities shift and what influences young people assuming self-management responsibility and parents relinquishing control.

6. DEVELOPING INDEPENDENCE

6.1 Introduction

This chapter examines the first sub-category, *developing independence.* This sub-category provides the context for how and why responsibilities shift between the parent and the young person. While assuming self-management responsibility was seen as an extension of the 'normal' process where moving to adulthood was associated with acquiring independence, the 'stakes were raised' for young people with CKD when developing independence. Finally, the chapter explores the contextual influences on *shifting responsibilities*. These include: the young person; the parents and family; the health condition; and the environment. Motivation appeared to be central to the parent-to-child transfer of self-management responsibility and will be explored throughout this chapter.

6.2 Extending the 'normal' process

6.2.1 Young people's perceptions of the 'normal' process

For young people, becoming older was associated with developing independence. This process was viewed as part of 'normal' child development where becoming an adult was associated with no longer being dependent on parents. The majority of young people associated increased responsibility with moving towards adulthood. They actively thought about their future and the prospect of gaining autonomy; for example, through learning to drive, leaving home or going to university.

Young people described how they needed to develop independence as they got older; some welcomed opportunities to develop their skills in everyday activities, such as organising for their school day, and expressed feelings of pride about what they had achieved. One young person explained how her independence increased when she was able to walk home from school on her own:

> *Since start of Year 6, that's when I became most independent because that's the first time I started going home by myself, I wouldn't have to go to the afterschool clubs anymore. I'd be home alone until seven o'clock when my mum and dad came home.* (YP12, 15 year old girl)

The quotation illustrates that for young people, developing independence in everyday activities were important milestones and often involved being trusted to spend time on their own without parent or adult supervision.

Assuming self-management responsibility was perceived to be part of the 'normal' process of growing up for most young people. They recognised that as they became older they would be less dependent on their parents for help with managing their condition; for some, this motivated them to start becoming involved in performing self-management activities:

> *When I'm 18 I'm going to uni and I can't rely on my mum then, I have to remember to do all this stuff [self-management activities] myself. So, I might as well start earlier, start doing it nowadays.* (YP18, 16 year old boy)

For this young person, it seemed the prospect of becoming 18 years old and leaving home, motivated him to start doing self-management activities on his own. Similar to other young people, he seemed to think it 'normal' that self-management responsibility would be transferred to him, therefore he '*might as well'* start to assume responsibility at a younger age in preparation for the future. The sense that young people felt they did not have a choice about assuming responsibility is illustrated in the above quotation, and was evident in other young peoples' accounts:

> *I've always had to do it. I've always had the help, but as I've got older, I've had to be aware of what I can and can't do. I'm okay with it because I know that it's something that I have to do. I don't have a choice.* (YP8, 16 year old girl)

Other young people, however, appeared reluctant to develop independence. Some perceived that the advantages of being dependent on their parents exceeded the advantages of increased independence, whereas others appeared to find it difficult to imagine their future which reduced their motivation to assume responsibility. Several young people described how they prioritised other activities over self-management. One young person explained how her motivation to engage in school work rather than self-management resulted in a rejection episode of her transplanted kidney:

> *The reports [blood results] were not good and it progressively got worse. It's my fault as well. I didn't take my drinking water seriously…I wasn't drinking enough, because I had school and then after school I'd be revising for my exams. I forgot about drinking water. I'd drink water here and there but not properly.* (YP14, 16 year old girl)

The self-awareness demonstrated in this quotation was evident in other young people's accounts. Some older teenagers demonstrated understanding of how 'being a teenager', impacted on how they assumed self-management responsibility. They explained their engagement with self-management in terms of what they viewed as 'typical' teenage behaviour. This self-awareness and self-reflection was only evident in some of the older teenagers' accounts, suggesting that maturity may have influenced how young people perceived the factors that could impact on how and when they developed independence. For example, a 16 year old explained why it was difficult to assume responsibility for her medication:

> *Sometimes it's hard to wake up in the morning to take the tablets. That was the hardest thing for me, I would not wake up and my mum's, like, 'Come on, you know you have to'. I tried but it's so hard. I'm a teenager and no teenager likes waking up in the morning.* (YP5, 16 year old girl)

This young person justified her actions by drawing on assumptions, and potentially stereotypes of what is considered 'normal' in adolescence. Another young person explained how it could have been helpful to have started assuming some self-management responsibility at a younger age, in alignment with developing independence in other areas of his life. However, he acknowledged that spending time with his friends was more important than learning to manage his condition at this stage in his life:

> *Probably 13, 12, because that's when I started being independent about other things apart from my health. I started becoming more independent in sports, in education, stuff like that. I think I should have-, I could have started on my healthcare at that age also….*
> **Q.** *What is it that was stopping you from doing it?*
> *Being a teenager! (laughing). It's that age where you want to relax and have fun with your friends.* (YP18, 16 year old boy)

This quotation illustrates how prioritising other valued activities could impact on young people's motivation to assume self-management responsibility. This tension around the optimum time to initiate the transfer of responsibility, taking into account young people's and parents' motivation, is explored further in the following section.

6.2.2 Parents' perceptions of the 'normal' process

Similarly, parents tended to view their child developing independence as part of the 'normal' process of moving from childhood to adulthood. Many parents described how their child had gained independence in everyday activities and anticipated a future when their child would

leave home. The experience of their child having already developed some independence, and an expectation that this would continue into the future, shaped how parents viewed the transfer of self-management responsibility. For many parents, their child assuming responsibility for managing their condition was a natural extension of them developing independence in other areas of their life. Similar to young people, parents viewed the transfer process within the wider context of their child becoming older, growing up and gaining independence.

Parents' motivation and decision-making to start encouraging their child to develop independence in self-management was shaped by various considerations. These included the demands and risks of the self-management activity, and changing circumstances which meant the child and parent spent more time apart, such as the parent starting work. One parent described how the burden of medication prompted her to teach her child to swallow tablets when he was five years old:

> *I had to wear a mask, empty the tablets into a cup to dissolve them, and then give them as a syringe through the PEG [feeding tube]. It was taking a long time to prepare. So, I taught him to take the tablets as they are, to make my life easier, and help him get used to it because if I wasn't there he had to wear the mask but he never did.* (Parent4, 14 year old boy)

The quotation illustrates how a child developing skills in managing their condition could benefit both the child and parent. The advantages for their child of increased independence were discussed by many parents. They were aware that their child taking on self-management responsibility could result in increased autonomy in other areas of their child's life. One parent explained how her child was able to choose when she went to bed since assuming responsibility for dis-/connecting herself to her home dialysis machine:

> *It gives her more freedom, instead of connecting her really early because I'm tired…today is the weekend, I don't need to be rushing to set her up. Learning that will give her more freedom, instead of me forcing her to be tied up upstairs. She'll be able do her own stuff.* (Parent9, 13 year old girl)

'Normal' developmental activities such as starting school, which increased the time that children and parents were separate from one another, prompted some parents to start teaching their child to learn aspects of self-management. Other significant milestones in their child's life, such as starting secondary school, also motivated parents to transfer self-management responsibilities to their child. One young person explained that it had been the

final year at primary school when his parent had taught him to self-catheterise, rather than his parent and school staff having responsibility for this:

> *It was my mum that suggested it. She said I was starting secondary [school] and I was going to have to start doing it by myself. So, she suggested that I start doing it earlier.* (YP13, 13 year old boy)

Parents' decision to encourage their child to assume self-management responsibility prior to starting secondary school seemed to relate to various contextual factors. Starting secondary school was associated with their child developing independence and gaining autonomy in other areas of their life, such as travelling to school on their own. Some parents were also aware of how primary and secondary school environments differed, both physically and socially. For example, having different subject teachers, and moving between classrooms, often meant school staff were not able to provide support with self-management. The differences between primary/junior and secondary/high school were explained by one parent whose child had received a transplanted kidney and therefore needed to drink throughout the school day:

> *When she was in junior school, it was easier and there was more communication. In high school, we seem to need to revisit it [young persons' self-management needs] frequently, because there are different teachers. And they have rules, 'No big bottles, you can't go [to the toilet]'.* (Parent1, 14 year old girl)

This quotation illustrates how the difference in school environments, meant some parents needed to intervene more frequently once their child was at secondary school to ensure staff were aware of their child's self-management needs. The impact of the environment on young people's self-management will be explored further in section 6.4.4.

Some parents appeared to associate the difficulties they experienced with transferring self-management responsibility with what they perceived as the unique developmental aspects of adolescence. They found their child asserting their autonomy could sometimes conflict with HCPs recommendations around self-management. One parent described the interactions she had with her child around taking medication:

> *She's hit and miss with the tablets. If I say to her, 'Have you had your tablets?' 'No, I'll take them. It's my life. It's up to me.' You can't push them, but at the end of the day I'm responsible for her…Sometimes she can be good taking them. She'll have phases. I suppose all teenagers will act this contrary.* (Parent7, 16 year old girl)

The tension experienced by parents who were encouraging their child to develop independence whilst ensuring their health was maintained is highlighted in this quotation. By understanding their child's engagement in self-management in terms of 'typical' teenage behaviour, parents tended to shift their expectations and make allowances when their child found self-management difficult. As illustrated by the extract above, some parents believed there was little value in 'pushing' their child and therefore, adjusted their actions and interactions to try and reduce or avoid conflict around self-management.

Parents thought about their child's future. They were aware that at some stage 'they wouldn't be around' and therefore perceived it was critical their child learnt to manage their CKD. Some parents also believed that as their child assumed responsibility, they themselves would be able to develop independence. They were hopeful of a future where they would no longer have the responsibility for managing their child's condition, and would be able to do activities they currently felt unable to, such as going on holiday. These parents were able to anticipate the impact on their own lives from their child having assumed self-management responsibility as Parent1 explained:

> *I said to [child's name], 'I would like to get on with my life also. I would like to think you're 18, you're at uni or wherever you want to be. I'm cool with that, but then that gives me permission to get on with my life. I don't want to feel like I'm always your primary carer. I want to be able to do what I want to do. I will always be your mum, you'll always have me', but I feel confident in knowing that [child's name]'s got this [self-management] covered.'* (Parent1, 14 year old girl)

This quotation also illustrates how despite their child reaching adulthood and developing self-management independence, many parents perceived their role as a parent was ongoing. This links to the discussion in chapter 5 around when the transfer process ends, and parents' confidence in whether their child would ever be 'fully' responsible for managing their condition.

6.2.3 Health-care professionals' perceptions of the 'normal' process

HCPs knowledge and understanding of child and adolescent development shaped their narratives of working with young people with CKD. Most viewed adolescence as a transition period between childhood and adulthood, and a time of physical, social and emotional development. HCPs were aware that most children developed independence and assumed responsibility for everyday activities as they became older. Some had discussions with families about these 'normal' processes when they believed the young person was developmentally ready to be more involved in managing their condition:

We talk about circles of responsibility. When they're a baby, the responsibility all lies with mum and dad. As you get bigger you take on more. You get yourself dressed, you feed yourself, you do those things for yourself, and the logical progression is to take more responsibility for your medicines, so taking them, laying them out for yourself, ordering your prescriptions. (HCP8)

This HCP implied that young people assumed responsibility as part of 'normal' development and like other HCPs, viewed the transfer of self-management responsibility as a logical extension of a 'normal' process. Some HCPs discussed the impact of 'typical' behaviours associated with being a teenager on self-management, such as spending more time with friends and risk-taking. As a result, they adjusted their expectations, and made changes to their actions and interactions when working with young people, to accommodate these behaviours. Chapter 7 will explore further how HCPs aimed to facilitate the transfer process.

HCPs were aware that expectations around young people assuming responsibility were context-specific. They recognised that families had different beliefs around childhood and parenting, and that individual characteristics of the young person could impact on the 'normal' process of developing independence. However, there appeared to be shared assumptions amongst HCPs about what was *'appropriate'* independence for a child based on their age and developmental stage. These expectations influenced how HCPs worked with families to support the transfer of self-management responsibility. The discussion that took place in a focus group illustrates HCPs different understandings of 'age-appropriate' independence:

HCP17: *Where parents have high expressed anxiety, they perhaps already struggle with letting them [child] do age-appropriate things. So you're fast forwarding to teenage years and thinking, 'If you're struggling to let them go on a play date when they're six or seven, then you're really going to struggle with them taking their own meds when they're 15 or 16'.*
HCP18: *That's key, thinking about what's age-appropriate. Families are different, so what one family thinks is age-appropriate another family might not, and that might be influenced by their cultural aspects. You've got to take all those things into account.*
HCP19: *It's about listening to the family and what their rules are, but it's also about listening to the medical team and seeing what they think is normal, and in our profession what we think they should be doing at that age. And then try and find a way to help the family to move forward.*

The first HCP's suggestion that parents who struggle with their child developing independence in 'normal' age-appropriate activities may have difficulties with relinquishing management control is expanded on by her colleague, who advocates cultural values can impact on expectations around developing independence. The above data extract highlights

how using data generation methods based on interaction between participants, resulted in a richer understanding of how HCPs' constructions around independence influenced the ways they worked with families.

HCPs recognised that young people were acquiring independence in other everyday activities as they became older. However, for the majority of HCPs, their sole focus was on self-management activities. By viewing self-management as separate to other activities which young people carried out as part of their daily routines, it seemed HCPs were decontextualizing self-management. This disconnect potentially resulted from how HCPs viewed their role and remit when working with families. One HCP's strategy of looking more 'broadly' at young people's engagement in everyday activities contrasted with the more typical, 'narrow' focus on self-management adopted by most HCPs:

> *I sometimes find that the children who've been very well nurtured or wrapped up in cotton wool that they've got no idea how to use the washing machine, they don't take their laundry downstairs. So I look at a **broader** thing, 'Let's look at less challenging, less dangerous tasks, how about you do your laundry?' Then they'll start to think about how they can start taking on medical care in that same way. That feels **much** safer.* (HCP17)

By taking into account parents' concerns around the potential risks associated with their child assuming self-management responsibility, this HCP looked more holistically at where the young person could initially develop independence in other activities which carried less risk. However, it appeared that none of the HCPs considered how self-management was integrated with daily activities and routines. HCPs primary focus on self-management meant they rarely supported young people with incorporating managing their condition into everyday living, such as how to deal with situations when valued activities (e.g. playing with friends) and self-management were in conflict. The difficulties associated with young people prioritising other daily activities over self-management are explored in section 6.3.

This section has discussed how assuming self-management responsibility was viewed by both young people and parents as a natural extension of the 'normal' process where becoming an adult meant attaining independence. Equally, some parents anticipated a future where they themselves would develop independence as their child needed less support with managing their condition. Beliefs about 'typical' teenage behaviour shaped how young people, parents and HCPs viewed the transfer of responsibility. Finally, the section suggests that though HCPs appeared aware of the wider context of child and adolescent development, their focus on self-management as separate to other activities that young people engaged in, meant they tended to decontextualize self-management. The next

section describes how potential risks associated with increased independence were intensified for young people with CKD – the 'stakes were raised' – especially when young people struggled to assume self-management responsibility.

6.3 CKD 'raising the stakes'

The data suggest that the risks associated with developing independence were increased for young people with CKD. Parents and HCPs described the risks and potentially serious consequences of young people assuming responsibility. This perception that the 'stakes were high' could impact on *shifting responsibilities*, in particular on parents' confidence in relinquishing control. This discussion between a 16 year old girl, who had recently received a transplanted kidney and her mother, demonstrated their awareness of how living with CKD impacted on developing independence:

> **Parent:** *We've had conversations where I've said, 'You aren't ever going to be that young person at uni who gets drunk, has a kebab, goes to sleep and wakes up tomorrow afternoon.' There's this element that you have to have control. I'm glad it's not me, because I did have the kebab, go to sleep and wake up the next afternoon. Life's different for you.*
> **Young person:** *Yes, but it's always been different. It's not that I used to do that and now I've got to stop and take control. I've always had to have more awareness than my friends. Even if that was not drinking at a party when they were all drinking. I think I'm a bit more responsible than you give me credit for (laughing).*
> **Parent:** *I do give you credit, but I worry about you hitting that phase that teenagers hit where you go, 'I want to be the same as everybody else. I'm not going to take my tablets and it'll be alright'.*
> **Young person:** *It's different, because this one keeps my kidney going. It's more important.* (YP8, parent 8)

The quotation illustrates how some young people with CKD assumed responsibility differently to their healthy peers. Parents' reluctance to relinquish self-management responsibility was influenced by various factors including their fear of the potential risks and complications that could result from their child's engagement in self-management. The extract also highlights how generating data through dyadic interviews provided a richer understanding of how young people and parents discussed self-management responsibility, including the young person's attempt to encourage her mother to relinquish some control by demonstrating her own trustworthiness. The importance of trust during *shifting responsibilities* will be explored in chapter 7.

HCPs recognised there were additional risks associated with young people with CKD developing independence, compared to their healthy peers. If a young person struggled with

self-management, there could be significant consequences for their health. One HCP reflected on the difficulties experienced by parents of relinquishing self-management responsibility when the 'stakes are high':

> *Because the child's health is such a precious commodity, it's a hard prospect for the parents to let go of it. If the stakes are high, you've got a lot to lose, which in the worst case is the loss of a transplant. I say to parents, 'It's easy for us to say that [to let go], but you've lived through your child being on dialysis, you don't want it to happen again.' I'm a parent, I understand parents who struggle to let go, and I often come across people who are in that situation because things have gone desperately wrong for them.* (HCP1)

Awareness of the risks associated with their child assuming self-management responsibility, meant many parents struggled with balancing protection and risk, with fostering their child's independence. As a result, parents experienced ambivalence around relinquishing self-management responsibility. HCPs described understanding that handing over control was difficult for many parents, especially if the child was young when diagnosed with CKD, as the parents would have held management responsibility for a number of years. The tensions experienced by parents around 'letting go' is highlighted in this extract from a dyadic interview with a parent and her 13 year old son, who was diagnosed with a kidney condition at birth:

> *Because he's had it since he was born we've always done it [manage his CKD]. I've **tried** to say, 'Come on,' and never helped him with things. He has to learn to do it because ultimately it's his condition not mine, but at the same time he's still a child so it's tough love versus smothering. Also because your condition's got worse, you're realising more what it means when your kidney's fail. This is helping you so you can work towards being more grown up and taking responsibility.* (Parent11)

The quotation illustrates the dilemmas parents faced when transferring self-management responsibility to their child: awareness that they are growing up but ultimately still a child; promoting their child's independence whilst keeping them safe; and understanding that CKD is a progressive condition, which could impact on self-management responsibility.

This section has described how the risks associated with young people with CKD developing independence are intensified. Therefore, the parent-to-child transfer of self-management responsibility occurs within a context where the 'stakes are high'. The next section will examine the other contextual issues that shaped how young people developed independence in managing their condition.

6.4 Influencing the transfer of responsibility

A range of contextual issues appeared to influence the process of *shifting responsibilities*. These included: the young person; parents and family; health condition; and environment. These issues interacted, and mutually influenced one another and young people's and parents' motivation for assuming, or relinquishing responsibility.

6.4.1 The young person

Most young people and parents associated age with developing independence and had expectations and assumptions around a young person's engagement in self-management as they became older. The young person becoming 16 years old seemed to be viewed as a key milestone, with both young people and/or parents hoping to achieve more independence by this stage. One parent described how her child associated being 16 with increased self-management responsibility:

> *The minute she turned 16, she wanted to be more independent with her tablets. She sees it as part of her life, it's one of the jobs that she needs to do, and didn't think it was my role anymore once she'd turned 16… they talk about transition here and taking responsibility. She probably heard that and once she turned 16, she thought, 'I need to start doing things like this.'* (Parent2, 17 year old girl)

In contrast, a parent of a 16 year old who was reluctant to assume self-management responsibility, discussed her own expectations around his independence:

> *He's 16 now. He should be taking all this in and being able to do it himself, because he'll go into transition, which he's already started from children's up to adult's…If I didn't get those tablets, he wouldn't get them, and if I didn't go to appointments, I don't think he'd come. He's got to learn to look after himself, and because he's 16, he should be taking responsibility for himself.* (Parent10, 16 year old boy)

As the data illustrate, young people's and parents' emphasis on 16 years of age as a key milestone resulted from their awareness of the transfer from children's to adult's services; this approaching deadline seemed to reinforce the expectation that the young person needed to take on self-management responsibility. Other significant milestones influenced young people's and parents' views on independence. Starting secondary school appeared to be associated with increased independence and a shift in families' expectations around what the young person should be responsible for. When discussing what had had influenced him in assuming self-management responsibility, one 14 year old explained how secondary school was associated with developing independence in other everyday activities:

> *Starting secondary school, I've become more independent as you do your things yourself. Like, getting my own clothes out, getting my books ready, doing my homework by myself.* (YP16, 14 year old boy)

In addition to chronological age, parents and HCPs were aware that a young person's developmental stage influenced the transfer of self-management responsibility. When working with young people whose development was delayed, HCPs described how they adjusted their expectations and attempted to accommodate the young person's individual needs. The importance of focusing on the young person as an individual and taking into account their age, development, and motivation is illustrated in this extract from a HCPs account:

> *It is very individualised. We try to make sure that they're essential to their care from whatever age. Even when you think of younger children and doing a blood pressure, they get to know what's involved. They'll work alongside you, even a toddler. We have young patients on dialysis who are 11, 12, who are learning the art of putting in their own needles … hopefully that will serve them in terms of feeling active advocates in their self-management. It has to be tailored for each individual young person and their family and what they feel able for at a given time.* (HCP7)

The young person's level of maturity was also recognised as influential. Parents and HCPs acknowledged that maturity was not necessarily linked with age, and that both cognitive and emotional maturity could impact on a young person's readiness to assume responsibility. Some parents reflected on whether their child would have been ready to become more involved in self-management at a younger age. A parent of a 13 year old boy suggested HCPs could start to involve children more in their clinic appointments when they were 10 years old:

> *I'd say the age of 10 to begin that transition, so they're not the silent partner, which looking back on, they are. Some children at 10 are very mature and others are still only six…Once they can go in there [the clinic appointment], they should be started to be treated with a bit more responsibility. That would help **all** of them to realise what it's about. So we all work together but they're more included.* (Parent 11)

Although this parent recognised children of the same age could have varying levels of maturity, she thought it would be useful to start the transfer process earlier for *all* children. The quotation also illustrates how shifting from parental-led management to parent-child shared management where the young person, parent and HCP are 'working together' could potentially prepare young people for assuming 'full' responsibility for managing their condition.

Levels of maturity also seemed to influence whether young people associated assuming self-management responsibility with developing independence in other areas of their life, or whether they viewed self-management separately, or as conflicting with the everyday activities that they needed or wanted to do. Some young people struggled to integrate self-management activities into their daily lives as they chose to prioritise other activities which they placed higher value on. This could create tension between the need to self-manage and participate in activities that provided opportunities to develop independence, such as spending time with friends. One parent described how her son chose to prioritise playing over self-management, and hoped that as he became more mature his priorities would shift:

> *At the moment he thinks, 'I'd rather play than do my catheter'. He doesn't know the more he plays he'll damage that kidney, or he will make his condition worse. They do understand at a certain level, but not the way I understand it. When it gets to that point, he'll be more mature, knowing more of his condition, able to help himself, and not rely on me or other people.* (Parent4, 14 year old boy)

As young people developed maturity, they seemed to find ways to balance participation in activities they valued, with self-management. They were able to start viewing self-management activities as 'normal', develop habits around performing these activities and integrate them into their daily routines. Individual interviews with a young person and her parent highlight how this integration was key to being able to self-manage her condition:

> *I felt **ready** to do it. I knew I'd have to do it eventually. It's my body, so the responsibility at the end of the day is on me. It's finding ways to make that as easy and as normal as possible* (YP2, 17 year old girl)

> *[Name] gets up and just gets on with it now. She gets her tablets which she's already set out in her box. She knows which one she takes in the morning. Then has her breakfast. A big thing is making sure she does her fluid allowance. She knows she has to do 2.2 litres, she's got it sussed. She gets on with school and then comes home, takes her tablets again... she just gets on with it. It's not a big deal.* (Parent2)

The influence of gender on young people developing independence in managing their condition was rarely mentioned in participants' accounts. However, one parent who had both male and female children, thought gender impacted on the assumption of responsibility:

> *It sounds awful but I think boys are worse at taking responsibility. I don't know when that will ever happen! (laughing). I know it will happen because it has to, but I'll always be **there** as a bit of a **nag** until he's gone [left home] and then I'll have to accept it (laughing). Hand him over to somebody else.* (Parent11, 13 year old boy)

By pre-empting her observation, *'it sounds awful'*, it seemed the parent was potentially aware that her opinion could be thought 'controversial'. Although this young person and parent were participating in a dyadic interview, the parent made this observation whilst her child had temporarily left the room, suggesting she may have felt unable to share her thoughts whilst he was present. None of the HCPs discussed gender as influencing the transfer of self-management responsibility, although one HCP considered how boys viewed having to self-catheterise:

> *That is an **excruciatingly** difficult thing for boys to talk about because they're of an age where they're very self-conscious and it's saying my penis isn't working, I think that's how they view it. That's a really difficult conversation to have. One of the doctors introduced a 14-year old to another boy who's coming through the other end and is now talking comfortably and confidently about these things. The doctor introduced these two boys, about three years age difference, to try and help, and that was really successful.* (HCP18)

This HCP recognised that boys might have particular difficulties with some aspects of self-management, especially when they reach adolescence. The benefits of meeting others in a similar situation, and how this can potentially support young people to assume self-management responsibility, is highlighted in this data extract and will be explored further in chapter 7.

6.4.2 The parents and family

There was recognition that a young person's parents and family influenced when and how self-management responsibilities shifted. This included the family structure, relationships between family members and parenting approaches.

The structure of the family, such as whether parents lived together or separately and whether or not the young person had siblings, seemed to impact on the transfer of responsibility. Siblings could influence a young person's motivation to become more independent. Some young people with older siblings who had left home, were motivated to assume responsibility as they were also interested in living independently from their parents. The prospect of leaving home, for example, to go to university, could provide a timeframe for some young people to work within. One parent described how her child's motivation to develop independence in managing his condition had increased when she had a baby as it meant he had more control over self-management:

He was diagnosed in December, I had the baby in January. The first month I helped him for the medicine. I was getting more busy with the baby, maybe that was helping. He had to wait for me to come, it might be I was feeding her [the baby]. That made him, like, 'I can do it myself'. He doesn't need to wait for me, that means he is confident. Otherwise, he needs to wait for me to finish my job with the baby, to have his medicine. (Parent16, 14 year old boy)

The presence of other family members with CKD or another LTC and/or disability seemed to influence the process of young people assuming self-management responsibility. It could impact on young people's motivation to become more independent and parents' willingness to relinquish responsibility. A young person described how having an unwell younger sibling had prompted her to start taking responsibility for managing her condition:

I wanted to help my mum and dad. I knew how hard it was to look after all four of us [three siblings and herself], because my brother had an [organ] transplant and he was too young to look after himself. (YP5, 16 year old girl)

Interestingly, in a subsequent interview with the parent of this young person, the parent believed it was the young person's personality that had driven her interest in becoming more independent, describing her as *'wanting to learn, enthusiastic…a hands-on approach from the start'*. This suggests young people and parents were not always aware of one another's motivations for assuming or relinquishing self-management responsibility.

Parents who had CKD, and had increased knowledge and understanding about self-management, such as dietary restrictions and medication, appeared to have a positive influence on how their child managed their condition. They described how their own experience of living with the condition shaped their decision-making about their child's ability to self-manage. These parents appeared more able to relinquish responsibility to their child as they described having confidence in being able to live well with CKD, and had integrated self-management into daily life. There was a sense that the young person could benefit from being able to see their parent live a 'normal' life with CKD and this could enhance their motivation to take on self-management responsibility. This interaction during a dyadic interview between a parent who had CKD and their child illustrates how parental lived experience could impact on the child's self-management:

Parent: *Even at the worst time, I always knew she would be alright. I've had insight into it, with it happening to me. Some Mums, I can't imagine what and how they manage it. For [child's name] as well, she's always known me well. It was just a blip we had to get over. That would've probably made things easier for you, do you think?*
Young person: *Yes, because, like, eating and stuff, you knew I could have this, I couldn't have that. We wouldn't have to ask about it, because you already knew.*
(Parent17, YP17, 16 year old girl)

Other aspects of family life, such as whether parents worked, also had an influence on young people developing independence in managing their condition. When young people and parents spent increasing time separate from one another, this seemed to prompt parents to handover responsibility for aspects of self-management. One parent described how being at work encouraged her child to assume responsibility for managing his condition:

> *When you start doing other things. It's helping that I go to work. He knows, 'Mummy's going to work, I have to do that.' He remembers things, or he's reminding, 'Mum, I've got to take the tablets, you have to ring and remind me otherwise I'll forget.'* (Parent4, 14 year old boy)

The relationships between a young person and their parents, or between parents and other family members could influence how a young person assumed self-management responsibility. Parenting approaches, which included parents' attitudes, behaviours and communication styles, could also impact on the parent-child relationship and affect the transfer of responsibility. In their accounts, parents described how their approach to parenting could differ to that of other families, and recognised that this shaped how and when their child developed independence. A parent who had taught her child when he was aged five to swallow tablets, rather than needing them crushed, reflected on how her own upbringing influenced her approach to parenting:

> *It's the way I was brought up, the way people are brought up in different ways. My friends say, 'My son won't take tablets. It's too much'. My friends are adults and they can't take tablets. My mum never dissolved tablets for me and there was nothing wrong with me swallowing. I know people are different.* (Parent4, 14 year old boy)

HCPs perceived family relationships and parenting approaches could influence the process of *shifting responsibilities*. In their accounts, HCPs described how the long-term nature of CKD, meant they were able to build relationships with young people and parents over a number of years, and therefore gained some understanding of how individual families functioned. HCPs attempted to incorporate this knowledge and understanding of each family's situation into their work. For example, some HCPs recognised that if the two parents adopted different approaches to parenting, this could create tension within the family, and potentially resulted in difficulties in the young person managing their condition:

> *I've had conversations with families, where mum might say, 'Dad doesn't get involved. He's horizontal the whole time. It's me doing it all. Checking he's had enough to drink, making sure he's done his dosette box'… we can all agree handing over responsibility is the right move forward, and we want to support a young*

person's drive for independence, but if mum feels she's doing it all, and dad's saying, 'I'm happy with that, but I'm not going to get involved,' then it is actually really difficult. (HCP1)

As the above quotation illustrates, HCPs perceived that parenting approaches could influence how parents shared management of their child's condition as well as how responsibility was transferred to the young person. The following section will explore how the health condition itself impacted on young people developing independence.

6.4.3 The health condition

Young people, parents and HCPs all believed that the nature of CKD influenced how young people developed independence in managing their condition. This included the age of diagnosis, CKD stage and type of treatment. Additionally, comorbidities appeared to impact on how young people assumed self-management responsibility for their CKD.

Amongst the young people participating in the study, there was significant diversity in when they had been diagnosed with a kidney condition; some were diagnosed before birth, whereas others were diagnosed during childhood or adolescence. There seemed to be ambivalence around how being diagnosed antenatally or as a young child and subsequently *'growing up in the system'* had an impact on the transfer of self-management responsibility. When diagnosis was confirmed at a young age, some families seemed to view the young person developing independence in managing their condition as a 'natural' process, as self-management had always been part of their life. However, some families and HCPs thought young people who had lived with CKD for many years, could potentially struggle to assume responsibility due to perceiving self-management as a burden and limited understanding of how their condition had progressed over time. This ambivalence was evident in a dyadic interview with a parent and young person who was diagnosed with CKD as a baby, was on dialysis and received a kidney transplant a few years later:

> **Young person:** *At first it's easy because Mum was doing all the work. Because it started at a young age, it was just in my life, handed to me. I had to deal with it. Now that I'm older, I have to take on the responsibilities that my mum would do. I have to take my tablets myself and make sure I've got my bottle. It's easier because it's always been there. If I was this age [14 years old] and I had a transplant, I would find it a lot harder, because it's so unexpected. Because I was only four, it just became a part of my life and I don't remember anything different…There's never been any other thing that I've experienced, it's always been there.*
> **Parent:** *[Child's name]'s always had it, but she doesn't have the memories of being ill and having dialysis, so she didn't quite understand the importance of it [self-management]. It's like, 'Am I really ill? All I know is that I have to take this*

*medication'. When she had her rejection episode that was the first time **she** understood the significance of it. That has changed [child's name]'s thinking as it's the first time **she** remembers being poorly.*
Young person: *The [HCP] used to say to me, 'I wish I could pull the memories out of my head and give them to you'.* (YP1, Parent1, 14 year old girl)

The belief that young people could be more motivated to assume responsibility if they had 'memories' of how their condition had progressed is illustrated in the data extract above, and is explored further by the HCP that is referred to, during a subsequent focus group. The value of using dyadic interviews to generate data is highlighted as the extract demonstrates how young people and their parents beliefs about the transfer process shift as they co-construct their accounts.

Some young people who were diagnosed during adolescence struggled to assume self-management responsibility. HCPs talked of 'crash-landers' - young people who first presented without warning when they were in end stage renal failure. Of the four young people in the study who had this experience, all started dialysis within a few weeks of first presenting to the renal service. HCPs felt that the shock of being acutely unwell, receiving a CKD diagnosis, realising there was no cure and needing RRTs had a massive impact on young people and their families. As a result, they described adjusting their ways of working with the family compared to young people who had 'grown up in the system':

*Ideally we **plan** to start them on dialysis, as we'd see the trend in their blood's getting worse. When we're having conversations with families about different modalities of dialysis, we try to involve them and say, 'This is something you could do, this is what your mum could do, and this is what would impact on your life'. We can help them decide what therapy might be best. The children that crash-land, that's a different situation. There's mass shock, they're grieving the diagnosis. So, to say, 'You've now got to do this,' when they've just been diagnosed with renal failure, you need to give them a bit of time.* (HCP10)

Some young people, however, who 'crash-landed' during adolescence appeared to adjust to living with CKD; though they initially found aspects of their treatment difficult, in particular the dietary and fluid restrictions that are often part of needing dialysis, they were motivated to develop independence in managing their condition. Some parents described their surprise at their child's ability to assume self-management responsibility. They were proud of their child '*taking control'* and as result, parental expectations and parent-child relationships shifted. This interaction during a dyadic interview with a parent and her child who had first presented in renal failure aged 15, started dialysis the following week and subsequently had a transplant, illustrates how young people's motivation to *'step up'* could challenge parents' expectations:

> **Parent:** *That was very difficult, as a mum, when your child is really poorly. If somebody told you that was going to happen, I would have thought [child's name] would never have managed. She was very young in her age, and-,*
> **Young person:** *Never had a blood test before.*
> **Parent:** *Never been to the doctors, never been poorly, so all of a sudden to have injections, scans, biopsies-,*
> **Young person:** *Transplants!*
> **Parent:** *When you were on dialysis, I never would have thought she could have managed but she was amazing, she just got on with it. And grew up as well, became an individual. She didn't need me as much because everything she was doing was for herself. I was there, but [child's name] took control. She just stepped up and did it. She's fighting all the time, never cried, only that once when we had a bit of a blip with the dialysis, and that's when you knew that she wasn't a real adult and she needed her mum.* (Parent17, YP17)

In this extract the young person and parent co-constructed a shared account of how the young person was able to assume self-management responsibility despite 'crash-landing', and highlights how the use of dyadic interviews contributed to a richer understanding of the transfer of responsibility, than solely using individual interviews to generate data.

The progression of a young person's CKD appeared to influence how and when they assumed responsibility for managing their condition. Typical in the CKD population, there was variation amongst the young people who participated in the study, in the rate that their condition progressed from one CKD stage to the next. Young people and parents reflected on previous periods when the young person's kidney function deteriorated and the impact this had on their ability and motivation to perform self-management activities. For some young people, the deterioration prompted them to realise the seriousness of their condition, and motivated them to assume more responsibility:

> *In Year 9, my dad was more in charge, he used to do all my medication, and my mum set up my [home dialysis] machine. I was naive as to what's happening. And then Year 10, that's when it [CKD] got more serious. That's when I started to realise, it hit me and I started taking charge. When I used to come in [to clinic appointments] I asked the members of staff, 'What's happening?' Like, my medication and all this stuff I'd like to know. I got interested.* (YP14, 16 year old girl)

However, for some young people the realisation that their kidney function was deteriorating appeared to have the opposite effect – a reduction in their motivation to engage in self-management activities. Two young people in this study had recently been told their condition was worsening and they would need a transplant; their parents explained how this deterioration had not been expected and it had a significant impact on their child's self-management:

When she started off with her medication, the doctors were really impressed with her, they said she was an inspiration. She knew all the names of the medication, she understood it all straight away. When we got to July of this year, she went to hospital and they said that she'd have to have a transplant, out of the blue. We thought she was going to get better with this [clinical] trial. That hit her, she said, 'What's the point of taking all these tablets? They're not making me better'. (Parent7, 16 year old girl)

He's meant to get up, have breakfast, have a snack, have dinner, have tea and then supper. [Child's name] isn't doing that, because we never knew that he needed a kidney transplant, we just got it said to us one day in the clinic. It's hit him really hard. I've been saying in clinic, he's not looking after himself. He's lost loads of weight. He's struggling. It's had a massive impact on him. (Parent10, 16 year old boy)

This finding needs to be considered with caution as the two young people mentioned did not participate in interviews. However, it suggests disease progression, and young people's realisation that 'it's serious' can influence the transfer of responsibility in disparate ways.

The treatment regimen appeared to influence how and when young people assumed responsibility for managing their condition. Amongst the young people who took part in the study, there were significant differences in their treatment and the self-management activities that HCPs asked them to perform, many of which were CKD-specific. All took daily medication and had been advised to follow an individualised renal diet. Other self-management needs included: self-catheterisation; gastrostomy feeds; restricted fluids or fluid targets; and home dialysis. The complexity of self-management, such as the need to adjust treatments based on fluctuating symptoms, and the risks associated with performing specific tasks, influenced the transfer of responsibility. HCPs described how they considered a young person's individual treatment regimen when supporting the transfer of responsibility:

*If treatment is fairly stable, with few changes to medication or treatment regimen, and, - the young person is 14 or 15, so they're starting to think about their healthcare, because it tallies with their general developmental trajectory at that age, to seek more autonomy. When that comes together, and their disease is relatively stable, then we can think about handing over. If somebody's immediately post-transplant, and maybe 16 or 17, but there's a **lot** of changes to medication, a **lot o**f things to remember, and it is such a crucial period, then there's no point, and parents wouldn't want to engage in a conversation about it.* (HCP1)

As the above quotation highlights, treatment modality also appeared to influence the transfer of responsibility. As discussed earlier in this chapter, some young people on dialysis appeared to struggle more with developing independence, compared to those receiving other types of treatment. Various factors potentially influenced this, including the significant demands of being on dialysis such as attending hospital three days a week for in-centre

dialysis, fluid and diet restrictions, and coping with side effects such as fatigue, pain and nausea. Young people and their parents often viewed being on dialysis as *'not a life',* and believed that receiving a transplant would mean they would *'get their life back'*. One parent of a 15 year old girl on home dialysis described how having a transplant would mean both her daughter, and herself could '*move on'*:

> *I don't wish her staying long in this [dialysis], because it's not a life. It's not easy, you don't want to be in this situation. What I understand this country to be like, it's helping people to live a normal life, being on dialysis for another three or four years, it's not…So, I really want for them to put her on the kidney [transplant] list, and if she's already there, she gets a match and help her move on with her life, and help me too.* (Parent3)

For young people on dialysis, an uncertain future made it more difficult to make plans. Consequently, it appeared to reduce young people's motivation to assume responsibility as well as their parents' motivation to relinquish control. In contrast, young people who had received a transplant seemed to view their future differently; they anticipated a time when they would be less dependent on their parents and leave home to live independently. These longer-term goals appeared to provide motivation for some young people to take on responsibility for managing their condition. Some young people considered it *'not fair'* that other young people had not received a transplant and were on dialysis; they believed themselves fortunate to have undergone kidney transplantation and it was their *'duty'* to look after the transplanted organ. One young person with a transplanted kidney, described how she viewed her self-management responsibility:

> *It is a privilege that I can take control of it, because it shows that I'm well enough to be able to manage everything, and before I wasn't.*
> **Q.** *You said that you feel like it's a privilege?*
> *Yes, because some people can't. Some people **don't** have transplants. You need to look after it, I'm well enough to take my own medication, so I have to look after that.* (YP2, 17 year old girl)

Finally, being affected by other conditions in addition to CKD, could influence how and when a young person assumed self-management responsibility. HCPs described how they took into account a young person's comorbidities as it might increase the complexity of self-management. For example, with young people who were under the care of multiple health teams, or had physical and/or learning disabilities, HCPs tended to shift their expectations around what could potentially be achieved in managing their CKD. However, some young people who had additional health conditions, found self-management for their CKD had less of an impact on their lives than their comorbidities. Data from individual interviews with a

young person and her parent highlight how assuming self-management responsibility for her CKD was *'easy'* in comparison to managing her other health conditions:

> *My kidneys are the easiest part of all my medical things…I wouldn't say there's any problem with it. My kidney just keeps going. It's a small part of my life compared to other things, that I don't really notice it. I take my medication, I do this and that, that's everything. I don't really need to do anything else.* (YP2, 17 year old girl)

> *She'll need help more for mobility. It depends on her skin. It's more the skin and the joint pain. If it was just the kidney, she'd be absolutely fine, she'd be up here on her own today [at the hospital] but it's when you have those additional issues, which I know a lot of kids have, and it's not just the kidney.* (Parent2)

This section has explored the influence of the health condition itself on how young people assumed responsibility for managing their condition. The final section in this chapter, will discuss the impact of the environment on the transfer of responsibility.

6.4.4 The environment

Both the physical and social environment appeared to influence how young people developed independence in managing their condition. It was recognised as children became older, they tended to spend more time apart from their parents in different physical environments, including school and out with friends. As discussed in section 6.2.2, the 'normal' process of young people starting secondary school prompted many parents to start transferring responsibility to their child as they were aware of how the environment differed to primary school. However, for many young people, the secondary school environment made self-management more difficult. School policies stipulated young people could not use their mobile telephones during the school day, which meant HCPs mostly contacted parents rather than the young person directly, to discuss their condition. The policies also meant young people were unable to use mobile phone technology to support self-management, for instance to set alarm reminders to take medication or use apps to record fluid intake. Although some schools adjusted their policies to accommodate young people's self-management needs, such as allowing young people to drink during lessons, some young people found these adjustments stigmatising. For example, young people were reluctant to use a 'toilet pass' to indicate when they needed to leave a lesson to visit the bathroom as they felt it drew attention to them being 'different':

> *It made me feel really different that I had this pass [toilet pass]. It was quite big and really graphic. It had pictures on it. I was expecting a little coloured card that said, 'I'm allowed my bottle out and to go to the toilet.' I didn't really use it. It was just me*

> *and I don't want everyone to be, 'Why's she got a pass?' I don't feel comfortable being the talk of the school.* (YP1, 14 year old girl)

This quotation highlights how some young people felt too self-conscious to perform self-management within the school environment, and how some of the strategies that school's adopted to support young people, could increase their sense of being different. This tension was illustrated in one parent's account of her child's reluctance to self-catheterise during the school day:

> *He might know that it's time to go, but it's having the confidence and not feel what people say to him. He worries what people think, where he's going, what he's going to do. He doesn't want people to know that he has to catheterise himself. He wants to fit in, not say about it at school, and be like the others, but then he doesn't look after himself as he should.* (Parent4, 14 year old boy)

As the above quotations illustrate, many young people found self-management more difficult in environments where their friends and peers were present, as they found engaging in self-management conflicted with their motivation to 'fit in'. Some young people's decision-making around what to have for lunch at school was influenced by what their peers chose, rather than following the renal diet that had been recommended by HCPs. One parent described how her child struggled to make the 'right' choices about what to eat when outside the family home:

> *She wasn't very good at having the right stuff when she wasn't at home. I work at the school where she was. I'd see her at lunchtime and she was getting, like, pizza and chips, because she didn't want to be different. I said, 'Have I to make you something to take?' 'No, I don't want to be different to everybody else.' Which you can appreciate, when they're teenagers. She wanted to be like everybody else.* (Parent7, 16 year old girl)

Although peers were sometimes a barrier to young people assuming self-management responsibility, some young people found their friends were supportive. Amongst young people, there was variation in whether they told peers about their CKD. However, those who had disclosed their condition, tended to find their friends helpful, for example with reminding them to take medication and providing emotional support. One young person described how he had always been *'open'* about his condition, and as a result his friends supported him to engage in self-management whilst at school:

> *Drinking isn't an issue. In school, if I get my bottle out and because it's like Mountain Dew or Lucozade, that normal children wouldn't be allowed, and the teacher has a go, my friends stick up for me saying, 'Actually he is allowed to drink'. If they*

> *[teachers] don't believe them [friends] I show them my pass. Especially [name of friend]. He got an after school detention sticking up for me.* (YP11, 13 year old boy)

There appeared to be recognition amongst some HCPs that both the physical and social environment influenced the transfer of self-management responsibility. HCPs described being aware that many young people valued 'fitting in' with their peers and therefore, found it difficult to integrate self-management within a social context. Peers were perceived to be both a potential barrier and source of support to young people assuming self-management responsibility, as illustrated in this HCPs account:

> *Many young people, their mates will know, but there's many who don't want to be seen as different. Taking your phosphate binders out when you're having your lunch, that's not something that you normally see people at school doing. Having a peer group that you feel secure enough with, who are going to stand by you, whereas others think, 'I don't want to be seen differently'.* (HCP7)

Some HCPs perceived that different environments could influence how young people assumed self-management responsibility. The busy and structured environment in schools often presented unique challenges. HCPs worked with school staff and recommended strategies to support young people to manage their condition during the school day:

> *Children on a potassium-restricted diet, I'll inform school and we'll look at trying to make things easier for them at school. Sometimes it's, 'I'm always last in the queue,' because they're in year 11, so there's not a choice by the time they get to the front of the queue that's appropriate for what they can eat. A lot of it stems from not wanting to be seen to be different. It's trying to make things not a big issue, or making it really obvious, maybe it could be that they [school kitchen staff] keep something [appropriate food] back.* (HCP2)

Although some environments made it more difficult for young people to assume responsibility, HCPs described how one environment, the in-centre dialysis unit, had been adapted to encourage young people to become more involved in aspects of their dialysis treatment. By dividing the unit into 'teenage' and 'younger' days, young people were able to observe their peers perform activities, such as self-needling, which HCPs believed encouraged them to develop independence. HCPs described the effect they felt this had on young people's motivation, including on one of the young people participating in the study:

> *If they are in an environment where there are other teenagers then it impacts on how they take on their care. If they've got peers around them that are putting their needles in, making up their trays, then it encourages and inspires them, 'That's the norm, I want to do what the others are doing'. [YP5] came on the younger days at first, but*

once she switched to the teenage days and saw the others, preparing their fistulas, putting the needles in, it encouraged her and it just naturally happened. (HCP4)

Although this environment was perceived to be supportive of young people assuming responsibility, it was significantly different to 'normal' environments such as family homes and schools. Whereas HCPs could adapt an in-centre dialysis unit to encourage young people to become involved in aspects of their dialysis treatment, different approaches were needed in other environments to support the parent-to-child transfer of self-management responsibility. The ways that HCPs adjusted their actions and interactions during the transfer process will be discussed in chapter 7.

This final section has explored how the physical and social environment influenced how young people assumed self-management responsibility. The structure of school environments appeared to act as a barrier to young people engaging in self-management, despite some school staff and HCPs' strategies to accommodate young people's self-management needs. Friends and peers were perceived to influence the transfer process in different ways. Many young people's motivation to appear 'normal' meant they tended to prioritise 'fitting in' which often conflicted with self-management, whereas other young people found friends supported them as they developed independence in managing their condition.

6.5 Summary

This chapter has examined the first sub-category, *developing independence,* which provides the context for the parent-to-child transfer of self-management responsibility. Young people, parents and HCPs discussed how moving from child- to adulthood was associated with acquiring independence and becoming less dependent on parents. Young people assuming self-management responsibility was viewed as a natural extension of this 'normal' process. The chapter also suggested that the risks associated with developing independence were heightened for young people with CKD; as a result, parents and HCPs could experience tensions with encouraging the young person to assume responsibility, and balancing protection and risk. The interaction and influence of contextual issues, such as the young person, parents and family, health condition and environment, on the process of *shifting responsibilities* were discussed. Young people's and parents' motivation appeared to be central, impacting on both the initiation and continuation of young people *developing independence*, and was examined throughout the chapter.

Chapter 7 examines the remaining sub-category, *making changes* - the ways that young people, parents and HCPs adjusted their actions and interactions, which initiated, sustained or disrupted the process of *shifting responsibilities*.

7. MAKING CHANGES

7.1 Introduction

This chapter examines the second sub-category, *making changes.* This sub-category, together with the first sub-category, *developing independence,* influenced how responsibilities shift. *Making changes* explains how young people, parents and HCPs adjusted their actions and interactions during the process of *shifting responsibilities.* Firstly, the actions taken by, and the interactions that occurred between young people, parents and HCPs to initiate the transfer process are presented. Next, the chapter will discuss the actions and interactions that sustained and facilitated young people to develop independence and parents to relinquish control. Finally, it explores the actions and interactions that disrupted the transfer of responsibility and how young people, parents and HCPs responded to these disruptions to enable the process of *shifting responsibilities* to resume.

7.2 Initiating the transfer of responsibility

Young people, parents and HCPs all adjusted their actions and interactions to initiate the process of *shifting responsibilities*. As discussed in section 5.4, there was ambiguity around *when* the process started. The ambiguity around *how* to begin the parent-to-child transfer of self-management responsibility will be explored in this section. These differences in *how* were evident in: the self-management activities which young people initially assumed responsibility for; whether the focus was on the young person 'doing' an activity, or their knowledge around self-management; and how a young person was 'assessed' as ready to assume responsibility.

Some young people and parents initiated the transfer of responsibility by focusing initially on medication, such as the young person being involved as the parent organised the dosette box or taking medication without parents reminding them. In contrast, other young people and parents initiated the transfer process by focusing on other self-management activities, for instance the young person learning to self-catheterise independently. Parents appeared to be responsible for deciding what aspects of self-management to transfer first. Section 6.4 explored the contextual influences that shaped this decision, including the young person's motivation, and pragmatic issues such as the young person spending increasing amounts of time separate from their parents. For example, one parent explained why her child being able to self-catheterise at school was a priority:

I used to go to the school every two hours to catheterise him. There was a teacher who felt for me, having to come to school, even when it was raining or snowing. She said, 'I'm willing to learn what to do.' Somebody from here [hospital] went to show her how to do it, she signed forms and I gave consent that she could be involved. Afterwards, I taught him how to do it himself. [Child] was about six when he started doing that. (Parent4, 14 year old boy)

Interestingly, the quotation illustrates how the responsibility for catheterisation initially transferred from the parent to a teacher, and how HCPs' involvement made this handover of responsibility a significantly more formal process. This contrasted sharply with how the parent transferred responsibility for self-catheterisation to her child, which appeared to occur without HCP involvement. The role of the HCP during the transfer process was explored in section 5.3.

When initiating the transfer of responsibility, young people and parents appeared to focus on what self-management tasks the young person could 'do'. This initial focus on 'doing' was especially evident when the young person had been diagnosed with CKD antenatally or in early childhood, as the child often started performing aspects of self-management independently for pragmatic reasons whilst at primary school. In contrast, HCPs appeared to initially approach the transfer of responsibility at a later stage, often when the young person was at secondary school, and focused on what the young person 'knew' about self-management. This 'knowing' approach adopted by HCPs was evident in their accounts, as they described adjusting their interactions to assess the young person's knowledge:

I'll start with talking about medication, because it's something that is fairly objective. 'Do you know what medicines you're taking? When do you take them? Do you know what the medicines are for?' (HCP9)

When they become teenagers, I spend my time trying to make them tell me how they are. I ask, 'Why are we meeting today?' They look taken aback by that, think that I should know. I persist and say, 'I know why we're meeting, but it would be good to hear what you think.' They say, 'I'm here for a check-up'. Then I say, 'What kind of check-up?' They might say 'The kidneys'. Sometimes it becomes a bit tense and I say, 'You do remember? It is like going to school, to come in to me. I always ask you questions'. (HCP6)

As the extracts suggest, some HCPs focused on the young person's knowledge of their medication or condition as it was viewed as 'objective' and 'testable'. There was a sense that HCPs potentially felt more comfortable assessing a young person's knowledge, rather than evaluating what a young person was 'doing'. Young people's performance of self-management was possibly more difficult for HCPs to assess as it was mostly carried out in

the family home. However, there were occasions when HCPs initiated the transfer of responsibility by focusing on a young person's actions, or 'doing' self-management. Young people on dialysis were encouraged by HCPs to take responsibility for aspects of their dialysis care, such as setting up the tray of equipment so they could be connected to the dialysis machine. This transfer of responsibility differed to the parent-to-child transfer as it involved HCPs (predominantly nursing staff) teaching a young person to perform an activity that their parent would not be expected to do, such as self-needling. When teaching young people these skills, HCPs tended to base their approach on the way student HCPs are trained; for example, observing the young person perform an activity, and using documents to support assessment procedures and record the young person's 'competency'. One young person explained the contents of her 'competency' booklet:

> *Hand washing, I've been fully signed off on that. Checking fistula, needling, checking for signs of infection, I've done that. They [HCPs] watch me four times before I get signed off, which is good, because you can't sign someone off on one, it needs to be more than once to know they're not going to do it wrong.* (YP5, 16 year old girl)

Interestingly, this process, where HCPs observed a young person perform self-management and assessed them as independently and safely able to complete the task, was only used when young people assumed responsibility for aspects of their dialysis care. When self-management was transferred from the parent to their child, HCPs were rarely involved in assessing the young person's skills. It seemed that the responsibility to decide whether a young person was safe to carry out the activity was tacitly handed over to parents.

There also seemed to be tension amongst parents and HCPs around how to identify whether a young person was ready to assume self-management responsibility. Parents' accounts suggested that an innate quality of being a parent, and having knowledge of their child, meant they could 'pick up' when their child was ready to develop self-management independence. This was evident when parents were asked what prompted them to initiate transferring responsibility to their child:

> *I've got a bit of a knack with it. It's having that awareness, I seem to be hyperaware, it's the way I'm programmed. I'm quite a **feely** person, so I pick up very quickly and I'm acutely aware of it.* (Parent1, 14 year old girl)

> *It comes to you in little things, like when they started walking, you knew they were ready to walk on their own. You have that feeling in your heart. When you know, you know, don't you?* (Parent5, 16 year old girl)

The sense that parents 'felt' or instinctively 'knew' their child was ready to assume responsibility is illustrated in the above two quotations. There was also a suggestion that parents identified it was time to initiate the transfer of responsibility by seeing their child develop independence in other everyday activities:

> *What they [parents] see is young people show the ability to manage things in other areas of their life. They observe them being more organised about their schoolwork, getting themselves out of bed in the morning, sorting out their PE kit for that day. They get a sense from **other** areas of their life that they're ready. It's little things that add up to the point where parents feel the young person is ready.* (HCP1)

As the above quotations suggest, parents' 'sense' that their child was ready to assume responsibility was based on observing changes in their child's actions. In contrast, some HCPs seemed to struggle with identifying when a young person was ready to assume responsibility. An interaction with HCP9 during an interview highlighted the tensions HCPs experienced around whether the process of assessing a young person's readiness was subjective or objective and based on 'knowing' or 'feeling':

> **Q:** *You mentioned that from about the age of 11 you alter the way that you interact with the young person, you're trying to engage them more in the consultation. How do you make a decision that they're ready for that?*
> **HCP9:** *It's very subjective. You're guided by the child. There are some children on dialysis and you're saying to the nurses, 'What was so and so's weight and blood pressure?' Before the nurse has had a chance to say anything, the child's told you everything. So, you get a feeling that that child is taking note of things. You get verbal and non-verbal clues that they are engaged, they're ready for information and those responsibilities.*

Interestingly, though the data extract suggests HCPs' assessment of whether a young person was ready to assume responsibility was based on various factors including 'non-verbal clues', it seemed HCPs' primary focus was on a young person's demonstration of their knowledge during interactions with HCPs.

This section has explored the ambiguity around how to initiate the process of *shifting responsibilities*. The contrast between parents' focus on their child's actions and the self-management activities they are 'doing', and HCPs' focus on the young person's demonstration of self-management knowledge during their interactions with HCPs, have been presented. The differing ways that parents and HCPs identified whether a young person was ready to assume responsibility have been discussed. The following section will explore what actions and interactions were perceived to sustain the transfer process, once it had been initiated.

7.3 Sustaining the transfer of responsibility

There appeared to be similarities amongst young people, parents and HCPs around what was perceived to sustain the process of *shifting responsibilities.* This included actions and interactions that: promoted the gradual transfer of responsibility; encouraged partnership; developed a routine; fostered positivity; built and maintained trust; facilitated connections with others with CKD; supported learning from mistakes; and were responsive to young people's and parents' individual preferences and needs.

7.3.1 Promoting a gradual process

As discussed in chapter 5, the parent-to-child transfer of self-management responsibility tended to occur gradually over time. Connected to this was the perception that actions and interactions were supportive if they promoted a gradual transfer of responsibility. A dyadic interview with a young person and her parent illustrated how making changes to their actions over a long period supported the young person to progressively assume responsibility for taking her medication:

> **Young person:** *It's always been in my life, I knew that I'd have to take on responsibility at some point. Mum didn't throw it in my face, 'Here, you can take them. I'm not going to watch, I'm not going to do anything.'*
> **Parent:** *I used to sit her on the kitchen worktop, and we used to count her tablets, 'Bedtime tablets, morning tablets…' That went on for a long time. She was, 'I can take them, Mummy.' I was, 'How can you? Do you know?' I'd supervise this, supervise this, supervise this, and then it was like, 'Yes, she can take them.'* (YP1, Parent1, 14 year old girl)

As the extract highlights, and was evident in other accounts, there was a sense that parents adjusted their actions and interactions with their child to encourage them to gradually develop independence in self-management. Some parents appeared to adopt a teaching or coaching role and used structured approaches to help their child learn self-management activities. This included breaking down an activity into smaller steps and showing their child first how to do an activity before observing them carry it out. One young person explained how his mother had helped him to learn how to change his PEG:

> *She'll show me how to do things, and then next time I have to do it. She'll help me do it on my own. Like, when I have to change my PEG, she'll show me how I take it out, and the process of putting it back in. Then the next time I have to do it whilst she watches.* (YP4, 14 year old boy)

Both data extracts above suggest how young people and parents appeared to accept that the transfer of self-management responsibility was a process that occurred gradually over time. HCPs also described how actions and interactions that promoted a gradual transfer of responsibility seemed to be helpful. However, as discussed in section 5.4, the different expectations around the timeframe of the transfer of responsibility meant HCPs tended to become involved after responsibilities had already started to shift from parents to their child. As a result, there was a perception amongst some parents and HCPs that HCP involvement at an earlier timepoint would support the transfer process to occur more gradually, over a longer timeframe. During a dyadic interview, a young person and parent discussed whether HCPs changing their interactions to include young people in clinic appointments when they were younger would support them to assume responsibility:

> **Parent:** *If they [HCPs] could've talked to you [when younger], would you think that's a good idea?*
> **Young person:** *No, I'd be annoyed because I wouldn't understand most of it.*
> **Parent:** *But if they explained it to you?*
> **Young person:** *They explain it in their doctor's language that I don't understand. I understand it better now but when I was younger I didn't.*
> **Parent:** *I think sometimes the clinics should separate the child from the parent for a part of it so they get the child's point of view. It's very easy for us to talk **about** them. Actually, it's his condition but nobody's talked to **him** about it…if they're used to talking about it then they'll be more able to understand what's going on. That might help, because suddenly it's all upped and it's trying to explain to him what **we've** been talking about for 13 years.* (YP11, Parent11, 13 year old boy)

As the extract highlights, there was a perception that, if HCPs engaged young people more in consultations at an earlier timepoint, it could promote a gradual process, rather than HCPs' interactions 'suddenly' being 'upped' when the young person becomes 13 years old. The sense that HCPs' earlier involvement in supporting young people to develop independence could support the gradual transfer of responsibility was also discussed by HCPs during a focus group:

> **HCP14:** S*tarting independence early is good if it's appropriate independence. It might be a two-year-old choosing between vanilla or strawberry yoghurt. It's not automatically a health thing but it's looking at the way some of these children are overprotected in other areas too and broadening their development.*
> **HCP8:** *Yes, you see some teenagers that are taking a bus into [city], going out drinking, but their parents set out the dosette boxes for their medicines. Then you have some [teenagers] that take complete responsibility for ordering their medicines, but their parents won't let them get a bus. There's different facets of their life that seem to be restricted whilst others are not.*

As the above data extract implies, HCPs' involvement at an earlier timepoint would potentially require a shift in how HCPs contextualised the transfer of responsibility. HCP14's suggestion that HCPs could look more broadly at young people's independence in everyday activities across their developmental trajectory challenges HCPs' typical framing of the transfer process within the narrower context of the transition to adult health services.

There was also a perception amongst some HCPs that they could support the transfer process to happen gradually by continuing their involvement after young people had moved into adult services. As discussed in section 5.4, HCPs expressed frustration that young people's transition from child to adult services was determined by their chronological age, rather than their ability to self-manage. Consequently, some HCPs described how children's kidney teams could continue working with young people, until the young person could independently manage their condition:

> *Leave the young people with us [children's services] until we [HCPs] deem them fully responsible. That would be my preference, because we are using chronological age not an ability to take responsibility. I would really like to have a young adult speciality, so there was bridging, like a young adult's unit.* (HCP8)

The sense that the timeframe for the transfer of responsibility could be extended by developing young adult clinics was evident in the above quotation, and other HCPs accounts. Alternatively, some HCPs perceived the transfer process could occur more gradually if HCPs in adult renal services provided ongoing support with the transfer of self-management responsibility. HCP9 described her expectations around HCPs continuing to support young people to develop independence in managing their condition once they had moved into adult services:

> *No matter how good our transition is you can't fall off the cliff into adult services. They need an equal supportive process when they've gone to adults. We don't see it as being all of a sudden, they're ready to move and everything's going to be fine. It's a little bit fluid and so they need the same level of support after they've moved [into adult services], initially.* (HCP9)

As the quotation suggests, and was explored in section 5.2, the transfer of responsibility was a fluid, completely individualised process. Therefore, extending HCP involvement so it promoted a gradual process, and was more able to accommodate young people's and parents' individual needs, was perceived to sustain the process of *shifting responsibilities*. Section 7.3.8 will discuss individualised support in more detail.

7.3.2 Forming partnerships

Young people, parents and HCPs described how actions and interactions that encouraged the formation of partnerships sustained the transfer of self-management. This included collaboration between the young person and their parent, the young person and HCPs, and the young person-parent-HCP triad. Young people and parents explained how doing activities together and discussing self-management encouraged the young person to develop independence in managing their condition. One parent explained how working as a 'team' with her child meant they shared responsibility for completing complex self-management, such as administering iron injections over five minutes:

> *There's very good teamwork between the two of us, she's correcting me and I'm correcting her. She knows the days of a big medication day. On Tuesdays, she has four medications that she has to take, including iron. They [HCPs] said, you'll be giving it for five minutes. Left to me, I've forgotten, I wanted to push everything. [Child said] 'No! It's for five minutes'. Now when I bring that medication, she picks up her phone to set the alarm for five minutes.* (Parent3, 15 year old girl)

As the quotation suggests, and was evident in other accounts, young people and parents also formed partnerships to find solutions for self-management 'problems'. Consequently, young people assumed responsibility through adjusting their actions, such as setting alarms, or moving medication from a communal family room into the young person's bedroom:

> **Young person:** *The time where I wasn't taking my tablets, the doctors were, 'How can you get back on track?' When we went home, mum was, 'What do you want to do, because you can't not have your tablets?' So, we suggested that I'd put them in my room… because it was just easier for me to see them. I can't ignore them.*
> **Parent:** *We've done **lots** of different things. I look at ways of making it as easy as possible for [child]. Often that's discussing it. 'What do you think? Would this work?'* (YP1, Parent1, 14 year old girl)

The extract highlights how collaboration between young people and their parents was sometimes complemented by HCPs' interactions that encouraged partnership through asking young people for their views. Though there was ambivalence amongst young people and parents around HCPs' involvement in the transfer of responsibility (see section 5.3), some young people and parents described helpful interactions with HCPs that supported young people to assume responsibility. This included: HCPs communicating with the young person rather than their parent; actively listening; and involving young people in problem solving. One young person described how she found it supportive when HCPs adjusted their interaction to include her more in the consultation:

It's a two-way thing. They [HCPs] want your take on it, because they don't want to be saying things and then me leave and be, 'Forget that. I'm not doing that.' They ask our opinions, how it would work. They are very supportive in that way. It's your opinions and their opinions, but they mostly want your take on it, so you can help them understand. I like the independence, they're treating me like an adult rather than a kid. (YP1, 14 year old girl)

HCPs described how they made changes to their existing ways of acting and interacting to support the transfer of self-management, either when the young person was approximately 13 years old, or had 'passed' the 'knowledge test' described in section 7.2. HCP accounts illustrate how they shifted focus onto the young person during consultations, and adopted approaches that suggested collaboration. This included: directing communication primarily at young people rather than parents; exploring young people's concerns and their motivation to assume responsibility; joint goal-setting; findings solutions together; and acting as an advocate for the young person, helping them to negotiate with their parents around the transfer of responsibility:

Having those open discussions with the patient about what they want to do-, we need to agree on a goal, and then trying to come up with a plan, together, on how we get there. It does become a negotiation, 'This is where I would like you to be at, but how do we get there?' and then trying to come up with ways of building up on something, or setting little targets. Listening to what they like, what they don't like, and trying to work with that. Trying to be flexible without compromising on their health. Making a plan directly with the child is the best way of achieving your goal. (HCP2)

As discussed in section 5.4, HCPs' involvement in the transfer of responsibility was usually determined by the young person's age as they framed the transfer process within the context of preparing young people for their move into adult services. A key approach adopted by most HCPs was encouraging young people to attend clinic appointments on their own as they believed forming a partnership with the young person was instrumental to them assuming self-management responsibility. The impact of this approach was discussed by HCPs during a focus group:

HCP19: *In some clinics, as soon a child is 13, they [HCPs] will see the child by themselves. It's getting that child prepared for being seen by doctors by themselves.*
HCP18: *If the parents aren't in the room, children talk. I remember the boy that used to put his hood over his head, but if you get him on his own, he would talk to you.*
HCP19: *He's got no choice. If mum's there he would look to mum and expect her to answer and she would. It works well to give them that space to themselves. And it makes people [HCPs] more mindful that they're talking to the child rather than about them to somebody else.*

As the extract illustrates, the strategy of including or excluding parents from appointments was used flexibly depending on both the young person's ability to participate in the appointment and the parents' willingness to relinquish control. HCPs described being sensitive to parents' changing roles during the transfer process; however, there were conflicting views amongst HCPs around how much parents should be included and whether they were a barrier or facilitator to HCPs forming partnerships with the young person, and the process of *shifting responsibilities*. This tension was exacerbated as HCPs were aware that transition guidance recommended that young people should see HCPs without their parents in preparation for transition to adult services. For example, HCP6 described how he rarely asked young people to attend appointments on their own, as he believed partnership was needed with the young person-parent dyad:

> *I've not done that, not very much. I have a strong feeling that it's hard to be a parent for these children. I don't want them to feel excluded, because I know they worry terribly much, if they don't feel that they are involved…I like to emphasise, 'Even if I spend time with you and you are the person [patient], I also rely on your parents supporting you in this'. I don't think there is any teenager who can do this fully on their own.* (HCP6)

Young people and parents responded in different ways to HCPs inclusion or exclusion of parents during the transfer process. The few young people who had experienced meeting HCPs separately to their parents, mostly valued the opportunity; they described being able to talk more openly, and focus on issues important to them, when their parents were not present. Young people's accounts suggested they preferred HCPs interacting and forming partnerships primarily with them, rather than their parents. One young person described how she felt about being excluded from interactions with HCPs, when she was in hospital for her transplant surgery:

> *They [HCPs] were talking about the person who's had the transplant, and they're keeping all the secrets. When the surgeon left, I went, 'What are they talking about?' I want to know. I feel they're keeping me out. I'm old enough now to know everything. After that operation, I wanted to be the person the doctor talked to. I feel I'm old enough and you should talk to me, not my parent.* (YP14, 16 year old girl)

The sense that young people believed HCPs interacting with them rather than their parents sustained the transfer of responsibility, was also evident in other young people's accounts. Parents, however, appeared more ambivalent about HCPs' decisions to include or exclude them from consultations. Some parents found it helpful when HCPs adjusted their interactions to encourage their child to participate in appointments, or met with their child on

their own, as they felt this facilitated the transfer of responsibility. One parent described how she responded when HCPs recently increased engagement with her son in clinic:

> *Until recently it's always been he's sat and I've talked to the consultant. But they are now dealing with him. In fact, one of the consultants asked a question, I answered it and he told me to be quiet. He was, 'No mum, shush. [Child] talk.' I thought, 'That's brilliant,' because actually it is his condition. They're dealing with **him** as a person now.* (Parent11, 13 year old boy)

In contrast, other parents struggled with relinquishing control when HCPs met with their child on their own. Although parents seemed to accept HCPs forming a partnership with their child was a necessary stage in their child assuming responsibility, there was a sense some parents were reluctant to let go as they perceived their child as a 'child' in contrast to HCPs seeing them as a young person moving towards adulthood:

> *It was really hard when [child] came in [to hospital]. There was a young doctor. He was talking to [child] and I was annoyed that I hadn't been involved. She was just under 16, she was my baby, and there was a doctor talking to her about life and boyfriends and girlfriends, one thing and another. It made me realise that she was growing up. I spoke to that doctor because I didn't think it was right, but I probably would change my opinion now. I see it differently, then she was this frail little girl, whereas now she's an adult and she's grown through that.* (Parent17, 16 year old girl)

Though it seemed most HCPs adjusted their interactions to shift focus onto the young person during the transfer of responsibility, a few HCPs described the value of HCPs working in partnership with the young person-parent dyad:

> *It does need to be in tandem, because they are closely entwined. The danger of doing it in isolation is that the young person comes home and goes, 'Right mum I've talked to this nurse, I want to take my own meds', and the parent goes, 'No bloody way!' Unless you're doing it together, I mean it could work, but it's going to be **more** successful if you're doing it as a combined approach.* (HCP17)

HCPs' accounts suggested that, by adopting a collaborative approach, they could prompt young people and parents to make changes to their actions and interactions which would support the transfer process. One HCP described how working jointly with young people and parents to understand their respective views on the transfer of responsibility was potentially perceived as supportive by young people and parents:

> *The concerns of the parents and of the child are quite different. If you can tackle those two things together, that's quite useful. A parent might say, 'What do we do about this situation?' The teenager will say, 'Why are you asking that question?*

That's fine.' Then the teenager will ask a question and the parent will be like, 'Why are you worrying about that?' It's trying to appreciate that both of them will have different worries. If you can try and work on those, you can understand each other better. That reassures the parent, and it reassures the patient. (HCP2)

The sense that HCPs potentially had a role in supporting young people and parents to understand each other's perspectives, and form a partnership, reinforced the perception that working collaboratively with both the young person and parent helped sustain the transfer of responsibility.

7.3.3 Developing a routine

Young people, parents and HCPs described how structure and routine facilitated the transfer of self-management responsibility. It seemed that for young people to be able to assume responsibility they needed to find ways to assimilate self-management activities into their everyday lives, so self-management became habitual. One parent described how making changes with his child around her renal diet meant they were able to find a routine that supported self-management:

If you look at it [food], and you know that's going to make you ill, then if you want it, have it within guidance, don't have loads of it. Every day we take it and see how we progress in the day. We'll think, 'That's gone right,' or 'We need to tweak that a little bit'. Eventually you get there, you get your routine and then it's job done. (Parent5, 16 year old girl)

HCPs' accounts suggested some HCPs recognised that routines sustained the process of *shifting responsibilities*. There was also a perception that developing a routine also supported young people to balance participation in self-management, with other daily activities they needed and wanted to do:

There are those patients who seem to cope with what is being asked of them. It's become part of their life. They share that it's like brushing their teeth, they take their medicines. (HCP7)

As the quotation suggests, and was evident in other accounts, the development of routines helped young people to start viewing self-management as 'normal', and potentially supported the integration of self-management into their daily life. When an established routine was disrupted, for example, when the young person's treatment changed, or during school holidays, young people and parents found it difficult to sustain the transfer of responsibility. One young person described her experience of continuing with self-management activities over the summer holiday:

It's harder to keep up with my water drinking, because there's not that structure of school. There's not the morning break, lunch and home-time. I find it more difficult because it's a routine that I'm used to, it's changing for them seven weeks that we get off, and then back to normal again, so it's hard. (YP1, 14 year old girl)

When routines were disrupted, as discussed in section 5.2, self-management responsibilities would shift back along the continuum; parents' responsibility temporarily increased until the routine was re-established.

Young people and parents described how addressing the practicalities of self-management could support the adoption of new habits and development of routines. Their accounts illustrated how they: tested out different size water bottles until they found one that could be accommodated into daily life; used dosette boxes; and employed digital technology, such as mobile telephones and mobile applications (apps), to facilitate the young person to develop independence in managing their condition. Young people used their mobile phones to create structure and routine by: setting alarms to remind them to take medication or self-catheterise; to diarise consultations and self-management activities that did not happen daily such as injections; and to monitor their fluid intake. In a dyadic interview, a young person and parent described how digital technology supported the young person to form routines around her fluid target:

Young person: *I have an app for my water, which is quite good, because every hour it tells you to drink and I can log it to see how much I've had.*
Parent: *The one thing a teenager always has is their phone. It is still remembering, when you've finished that bottle, to put it on. There are times where your dad, because he's doing it on his phone on an app as well, so he's asking her and they look to see is that tallying. He'll say, 'I've only got 3000, how come you've got 3,700?' She'll say, 'I did finish another bottle.'*
Young person: *Sometimes the communication is quite good, other times if he goes out, comes back in and goes, 'What have you had?' I go on and see what I've had, I'll give him that information.*
Parent: *If he's out, and she's drank a lot, she'll WhatsApp him. It's this joint responsibility.* (YP8, Parent8, 16 year old girl)

As the extract highlights, digital technology could prompt young people to adjust their actions, and provide new ways for young people and parents to interact. Although young people were using apps to develop routines, some explained how some of the apps they had trialled were not useful. A young person described her experience of using apps to remind her to take her transplant medication:

I tried apps, but I never got on with it. They were reminding you to take this then, but it never worked for me, because I never took them at a set time. It would get annoying, I'd be, 'I've taken it!' (YP2, 17 year old girl)

As the quotation suggests, and was evident in other young people's accounts, young people only found apps supportive if they were flexible, and could accommodate the changes they made to their daily routines. Young people, parents and HCPs described how development of new digital technology could potentially sustain the transfer of responsibility through creating structure and routines around self-management. HCPs' accounts revealed they had limited knowledge of apps that young people were using, or were available to support self-management routines. However, they perceived technology could facilitate young people to develop independence in managing their condition. This was evident in a focus group discussion:

HCP18: *HCP17 and I worked with an eight-year-old where we did a fluid chart that he could colour in every time [he had a drink]. You're not going to do that with a teenager. What can we do with teenagers?*
HCP19: *You've got to think about them using their phones. To set a reminder when to take medication, and having a chart on their phone they can tick off. It would be good if there was an app.*
HCP17: *There are some for taking medications.*
HCP19: *Are there? Obviously, young people love their phones.*
HCP18: *Could we find out the technology that they could use, that's the equivalent of doing a fluid chart with an eight-year-old?*
HCP17: *I don't know about a fluid chart, but taking your meds, there's loads of apps like that. The fluid target, you set a reminder, but for a fluid restriction, I don't know of an app that monitors, that you can put in what you've drunk.*

The extract also highlights how generating data as a result of the interaction between participants in a focus group contributed to a richer understanding around how HCPs facilitated the transfer of responsibility. It also illustrates how focus groups can provide a forum for information sharing and identifying areas to make changes, as it seemed some HCPs were prompted to consider adjusting their actions to support young people to develop independence in managing their condition. During a dyadic interview, a young person who had recently received a transplanted kidney discussed with her parent the benefit of an app that would support her with self-management, by providing structure and routine:

Parent: *We tried to download a water app, it didn't work well. If there was an app where you could put in all your tablets, it bleeped to tell you when to take them and you could tick off how much you've drunk. When it finished, it bleeps and congratulates 'You've drunk your water today'. That might be interesting. And where you could put your appointments in, with the hospital?*

Young person: *Yes, that would be good. The water app we tried, you could never have four and a half litres on it, it would be one litre. It wouldn't alert you to drink it, it just put down what you'd drank out of the litre.*
Parent: *It would be good if you could put in that you've got four and a half litres to drink a day.*
Young person: *And you've got to drink a certain amount by a certain time.*
Parent: *And it's, 'Have you drunk this? This is your target today.'* (YP17, Parent17, 16 year old girl)

The data extract highlights how the interaction in dyadic interviews not only provided a fuller understanding of the transfer of responsibility, but could also result in generating ideas, in particular around tools that young people could use to develop self-management routines. Idea generation was also evident during a dyadic interview where the young person and her parent had been discussing apps that could promote the formation of habits to support self-management:

> **Parent:** *It's [digital technology] not a substitute for the person taking responsibility themselves and doing it, but it's about tools to help. They could have some sort of dosette box that knows if the tablets have gone out of it, that links to your phone and says, 'Those tablets are still in there.' I bet there would be the technology.*
> **Young person:** *I am on my phone all the time, so if there was something that would beep up for me, that would be great.* (YP8, Parent8, 16 year old girl)

As the above extracts highlight, young people, parents and HCPs all perceived there was scope for developing new tools that would facilitate the transfer of responsibility by supporting young people to develop routines.

7.3.4 Keeping positive

In addition to developing routines, other actions and interactions perceived as sustaining the transfer of self-management responsibility included keeping positive. Young people, parents and HCPs described how interactions that acknowledged when the young person had been able to manage their condition, and focused on what was going well, supported the transfer process. Parents acknowledged that self-management was difficult; in their accounts they described what their child had achieved and emphasised the importance of keeping positive, even when their child was struggling with self-management. This was evident in one parent's account as she described the interactions she had with her child around medication:

> *Sometimes she'll [child] say, 'I'm doing well with my tablets, aren't I?' I'll be like, 'Oh, yes.' I try to be positive about it but I can't say if she's had any tablets yesterday. I try to look at the positive stuff, she could be a lot worse than what she is, behaviour wise, but it is a concern to me.* (Parent7, 16 year old girl)

HCPs' accounts suggested they also recognised acknowledging a young person's strengths could help sustain the transfer of self-management responsibility. There was a sense, however, that this rarely happened as interactions during consultations tended to focus on problems, or when the young person experienced difficulty in assuming responsibility:

> *Sometimes patients do **nine** tasks out of ten really well, but the focus in clinic will be on the one they're not doing, which is disheartening on the young person, because they probably really tried, and it's the one thing that they've not managed to stay on top of. Conversations tend to be so negative, that it puts them right off trying again. Somebody needs to say, 'Well done for doing your medicine, turning up today, engaging in your healthcare, but we need to work a little bit on-,'* (HCP1)

As the quotation suggests, HCPs adjusting their interactions with young people to acknowledge what they had achieved and provide positive feedback could potentially support young people's motivation to continue engaging in self-management.

7.3.5 Building and maintaining trust

Young people, parents and HCPs perceived trust was essential to facilitating the transfer of self-management responsibility, and in particular for parents to relinquish control. This included trusting relationships between young people and their parents, and between young person-parent dyads and HCPs. Additionally, some young people suggested trusting themselves, or having confidence in their ability to manage their condition, was an aspect of assuming responsibility.

Actions and interactions that built and maintained trust between young people and parents were perceived as sustaining the process of *shifting responsibilities*. As discussed in section 5.5.2, responsibility was associated with the young person consistently engaging in self-management; once young people demonstrated they were able to do this, parents started to trust that their child could be relied on to perform self-management:

> *It became a habit, I got good at taking them [medication], there was that trust. Then I stopped taking them. I think that trust is there again, but when I stopped taking them, I was obviously not being responsible.* (YP1, 14 year old girl)

As the quotation highlights, if the young person's engagement in self-management became inconsistent, parental trust was lost. The impact of this on the transfer of responsibility will be explored in section 7.4.2. Parents' accounts suggested that trust involved 'knowing' that their child had assumed responsibility; this was evident as parent2 described how her child managed her medication and fluid intake:

It's been nice for me, her taking over, because I know she'll do it. She won't miss them [medication]. She takes them, I just know she does. She always has drunk the water…she was told that she has to drink this amount, so she does it. I've never had to say to her, 'Have you drunk enough today?' because I know she will have done.
(Parent2, 17 year old girl)

As highlighted in the above quotation, and was evident in other accounts, parents adjusted their actions and interactions as trust was built with their child; for example, they reduced how much they reminded their child to take their medication or monitored their renal diet. There was a sense that for parents to relinquish control, they needed to be able to trust their child to engage in self-management. Though some parents had confidence in their child's ability to manage specific aspects of their condition, many found it difficult to trust their child would be able to independently self-manage without any parental support. The tensions parents experienced around trusting their child were evident in parents' accounts:

*That I could **trust** him will be the biggest thing, at some point that's got to come. That he will be able to take his tablets and be in **full** control of overnight drainage [self-catheterisation]. That is going to be hard.* (Parent11, 13 year old boy)

Q. *What advice would you give to another parent?*
Please trust your boy, so he can take responsibility for himself, but also keep reminding them because they need it! (Parent16, 14 year old boy)

As the extracts suggest, parents thought trust was essential to facilitating the transfer of responsibility; however, building and maintaining it was difficult, potentially due to fear of the possible risks and complications that could result if their child struggled with self-management.

HCPs described how trust between young people and their parents was instrumental to young people assuming responsibility and parents relinquishing control. Some HCPs' accounts suggested they thought they had a role in supporting parents to develop confidence in their child's ability to manage their condition. HCPs described how they focused on opportunities where the young person would be able to demonstrate to their parents that they could be trusted to engage in self-management. This included different activities, such as the young person connecting themselves to their dialysis machine, or following their renal diet when outside the family home, as explained by HCP2:

With the diet, one thing happens at home, and another thing happens at school or when they're out with their friends. One way that I tackle it, is for them to take on more responsibility for what happens when they're not at home first. If they can show their

parents that they're managing well when they're out on their own, and the parents can trust them to make the right decisions, then that shows them that they are capable of managing… it's trying to build up the trust between the child and their parents. (HCP2)

In addition to trust between young people and their parents, trusting relationships between young people-parent dyads and HCPs were perceived as supporting the transfer of responsibility. HCPs' accounts suggested that time was needed during consultations and longitudinally as young people became older, to form relationships with young people and parents that were built on trust:

> *If they trust in you, I think that's very helpful. I've looked after most of these people for the last 14 years, I'm a familiar face. We've got a relationship, we've built up trust over time, that really helps. To analyse the problems, the young person has got to be open first.* (HCP8)

The quotation suggests that trust needed to be two-way, that HCPs needed to be able to trust families, as well as young people and parents trust HCPs. This seemed to link with the perception, that to sustain the transfer of responsibility, young people needed to be 'open' with HCPs, which was more likely if there was a trusting relationship. Honesty during interactions with HCPs seemed particularly important when the young person was struggling to assume responsibility. This was evident in two parents' accounts, whose children were not engaging in self-management:

> *When she goes to the hospital, she's perfectly honest. She's never making out, she's not being dishonest about it, saying, 'Yes, I'm taking it.' She says, 'Sometimes I forget to take my tablets.'* (Parent7, 16 year old girl)

> *If I don't think he's telling the truth I'll say, 'You should be truthful with them [HCPs].' Otherwise he'll say, 'I'm fine, I feel alright,' but I know 100% that he's not.* (Parent10, 16 year old boy)

Though parents and HCPs hoped young people would be honest in their interactions and actions, it was evident that some young people did not feel able to, potentially due to a lack of trust in HCPs. The impact of losing trust on the transfer of self-management responsibility will be explored in section 7.4.2.

Some young people described how being able to trust themselves was an aspect of developing independence in managing their condition. Their accounts suggest that having self-confidence and belief in their own ability to consistently perform self-management impacted on how much their parents were able to trust them and relinquish control. This was illustrated when a young person described why his parent continued to monitor his renal diet:

> *I can't trust myself with food, because I like a lot of food that I'm not supposed to eat. Sometimes I won't be able to contain myself from not eating it. My mum, she cares too much about me to stop reminding me about the things I eat, so she won't hand me that responsibility that easily.* (YP15, 15 year old boy)

Actions and interactions that supported young people to trust themselves, and develop self-confidence, have been discussed earlier in this chapter and included keeping positive, and acknowledging when young people were managing their condition. Connecting with other people who had CKD was also perceived to support young people to believe in their ability to assume responsibility; this will be explored in the next section.

7.3.6 Connecting with others with CKD

Interactions with other people who had CKD was perceived by some young people, parents and HCPs as sustaining the transfer of self-management responsibility. This included young people meeting other young people with CKD, and parents meeting other parents who had a child with CKD. Although young people and parents had only limited, 'ad hoc' contact with peers, a few described their experience of connecting with others who had similar experiences:

> *It is helpful, because it shows you that you're not the only one going through this. There are other people with the same condition as you, and you can feel relaxed about it.* (YP18, 16 year old boy)

As the quotation suggests meeting peers could impact on young people's well-being by helping them feel less alone. In addition to providing emotional support, meeting others with CKD was also perceived to facilitate the transfer of responsibility as young people and parents could gain advice around managing CKD. One young person described how in contrast to her father, her mother interacted with other parents when opportunities arose:

> *My mum does that a lot, she'll talk to other parents. She'll explain my situation and ask advice, they share their problems. My dad, he's not like that, he's more closed, he talks about my stuff with his sister… the doctor says everything, but she [mum] wants the parents' view on it.* (YP14, 16 year old girl)

The quotation highlights how meeting with peers could provide different and additional support to that offered by HCPs. As discussed in section 7.3.8, it also illustrates how individuals' needs and preferences for support differed. HCPs' accounts revealed how they would occasionally arrange for a young person who was struggling with self-management to

meet another young person with CKD, believing that the interaction could support independence development. During a focus group, HCPs discussed why a meeting between two teenage boys, who both needed to self-catheterise, had been beneficial when one of them was not engaging in self-management:

> **HCP18:** *That was really successful. It was two boys, peer group. The younger one was going to look at the older one and think 'He's cool and he's dealt with it, so I can deal with it'. It was a young man talking to a young man.*
> **HCP17:** *It's the lived experience. A doctor can tell you the practicalities of what it's going to be like, but no one can tell you what it's **really** like unless it's someone who's done it.*

As discussed in section 7.3.6, and suggested by the above data extract, connecting with other people with CKD could support young people to develop self-confidence in managing their condition.

For young people and parents who had not met others with experience of managing CKD, there was a perception that it could be supportive to meet peers or have a role model, during the transfer of responsibility. Some young people and parents expressed a preference for meeting in person, whereas others preferred online contact or via social media. Young people described how they would like to connect with others of a similar age, or an older person with CKD to gain emotional and informational support. They explained how HCPs provided information but they did not '*actually know what it feels like to go through the whole thing'.* There was a shared perception that hearing how non-famous and celebrity role models who had CKD were *'getting on with their everyday life'* could inspire young people and provide motivation for them to assume self-management responsibility. A young person explained why she thought meeting with others with CKD, in particular those of a similar age, would be supportive:

> *When I come here [hospital] it feels awkward, especially for haemo [dialysis]. I'd be with the patients wanting to bond. We were all ages, we'd sit there having haemo but none of us would communicate. It'd be better if we had a group, that way we'd have support from someone our own age. When I tell mum and dad I feel like they don't understand because they're not my age. And when I tell my friends, because they haven't been through it, they don't understand.* (YP14, 16 year old girl)

This perception that connecting with others with CKD could provide emotional support and facilitate young people assuming responsibility was evident in other young people's accounts. Parents perceived that their child having a role model or meeting other young people with CKD at either a one-to-one level, or as a group, could support the transfer of

responsibility. A parent explained that hearing how someone else had achieved their goals after having received a transplanted kidney could encourage and motivate her child to continue developing independence in managing his condition:

> *[Child] loves football and tennis - is there any person who's had a kidney transplant who has established [a sports career]? It would be nice to read the story. We would be happy to take him to a talk from people who had a transplant. It doesn't need to be professionals or VIPs. Any person who carries on good with this, carrying on with family life, it would be very inspirational to them. (Parent16, 14 year old boy)*

Parents' accounts revealed that having opportunities to interact with other parents who had a child with CKD to share experiences and gain advice could also sustain the transfer of responsibility. However, young people's and parents' needs and preferences around connecting with others with CKD could differ; this was highlighted in a dyadic interview when the young person was asked about peer support:

> **Parent:** *If somebody was in your condition now and-*
> **Young person:** *I'd happily talk to them, but I didn't need any help.*
> **Parent:** *If somebody had what you had, somebody rang you and said, 'Would you speak to them?', would you do that?*
> **Young person:** *I'm an awkward person, so I don't know if I'd want to.*
> **Parent:** *You're not awkward.*
> **Young person:** *I don't like talking to people I don't know.*
> **Parent:** *If you think it could give that person some reassurance to see you and how well you are, what you've been through. (*YP17, Parent17, 16 year old girl)

The young person's reluctance to meet other young people with CKD, despite her parent's perception that it could be supportive, reinforces the idea of individualised support that is discussed in section 7.3.8. HCPs' accounts suggested they thought connecting with peers or with role models with CKD could facilitate young people to assume responsibility and parents to relinquish control:

> *Young people learn from other young people. When that transfer of responsibility doesn't go well, what tends to happen is the parents take it back, they don't see it as a learning curve. Young people, who had a rocky road with their transfer of responsibility, get there in the end. There's a valuable learning opportunity there that we [HCPs] don't make use of. Having somebody who's done it successfully, honestly reflecting on the journey, normalises the things that go on in the process. It would give parents confidence that it might be a rocky road, but we have to give the young person the opportunity, and these are the things that are normal along the way. (HCP1)*

The benefit of young adults who had assumed self-management responsibility and transferred into adult renal services, reflecting on their experience and sharing their learning,

was evident in other HCPs' accounts. The quotation also highlights the value of learning from mistakes, which will be explored in the following section.

7.3.7 Learning from mistakes

Young people's, parents' and HCPs' perceived learning from mistakes helped sustain the transfer of responsibility. This seemed particularly relevant for young people who had experienced difficulties with self-management. Young people's accounts illustrated how some recognised the consequences of not performing self-management on their health, which in turn impacted on their treatment. For some young people, this seemed to prompt them to re-engage with self-management:

> *I realised how bad my weight was getting and how bad it was to go over the fluid allowance. I would have extra days on my [dialysis] machine.* (YP5, 16 year old girl)

> *I definitely learnt from my mistake. I keep my water bottle near now. I make sure I'm keeping on top of things. I have all my medications properly, and check and double-check that I've got all my medications during the day because I have some in school.* (YP14, 16 year old girl)

Parents' accounts suggested they accepted their child would find performing self-management difficult; therefore, making mistakes was 'normal' and could provide opportunities for their child to learn:

> *What I'd tell parents with teenage children is, when they make mistakes, let them see. Let them understand that sometimes they will make mistakes. Don't teach them there's no mistake, no, then you make them so rigid, let them be free with you. Tell them it's a mistake and this is the repercussion, so they know.* (Parent3, 15 year old girl)

As the quotation suggests, acknowledging that young people would make self-management mistakes, would hopefully support young people to be 'free' or honest with their parents when they were struggling with self-management. The connection between honesty and maintaining trust was discussed in section 7.3.5.

HCPs also described how young people being able to make mistakes could facilitate the transfer of responsibility. Some HCPs adjusted their interactions with young people and parents to discuss how making mistakes could provide opportunities for young people to develop understanding about the consequences of their self-management decisions. However, like parents, HCPs' accounts illustrate their awareness that there were risks

associated with making mistakes and the impact on their health could be significant, such as losing a transplanted kidney:

> *Being a teenager is about making mistakes, it's learning from your mistakes. But we don't want them to make mistakes that cause them harm… I talk to the family, I say making mistakes is the learning process, let them make mistakes safely, and not letting them make any mistakes is not safe.* (HCP8)

Although the focus was mostly on young people learning from their experiences, some HCPs described experiential learning as important for HCPs. There was a sense that, through engaging in reflective practice, HCPs could make changes to their actions and interactions to facilitate the transfer process:

> *We learn more through trial and error than research. Seeing things that have worked and haven't worked. Building that relationship with the family, to be able to do things over a longer period of time…you can be honest with them, and they build trust with you. You can say, 'We'll try it like this. We haven't done it before, it might be a complete disaster, but let's see. If it doesn't work we'll think again.'* (HCP10)

In addition to highlighting the value of learning from mistakes, the extract also reinforces ideas explored in previous sections that honesty, partnerships, and trust were key to sustaining the transfer of responsibility.

7.3.8 Individualising support

HCPs described how individualising support to the needs and preferences of young people and their parents, facilitated the transfer of responsibility. Throughout HCPs' accounts there were reports of how they adjusted their actions and interactions to support each young person to develop independence in managing their condition:

> *We have to tailor it in a bespoke fashion. It's very much bespoke to the young person. Some are very motivated, have a lot of understanding about their condition. Some have absolutely zero understanding. Some don't want any understanding.* (HCP8)

Discussions during focus groups around the actions and interactions that HCPs perceived to facilitate the transfer of self-management, reinforced the sense that individualising support was important. As described in section 4.7.4, participants in the HCP focus groups were presented with data about what sustained the transfer process. In both focus groups, the discussions that were prompted by reviewing the data highlighted the value HCPs placed on adjusting their involvement depending on the young person's needs:

> **Q.** *I wondered what your thoughts were about the ideas. Are there any that stand out to you?*
> **HCP8:** *I would say all of the above. For some people, meeting other patients would be hell, for some it would be great… **all** of these things are very valuable but there isn't one size that fits all.*
> **HCP1:** *It's tailoring it. Like you say, some people wouldn't engage, some don't like digital technology, but they'd like the face-to-face. It's finding what fits.*

Interestingly, similar language around the need to 'tailor' support during the transfer of responsibility was evident in the other focus group:

> *What's striking about the list of ideas - they're all great, but any one young person might choose one or two of those. It's individually tailoring to what that young person wants, what that family wants or needs to be able to best progress.* (HCP17)

This sense that individualised support was needed for the process of *shifting responsibilities* to happen reinforced the idea discussed in section 5.2 that the transfer of responsibility was completely individualised to each family.

This section, 7.3, has discussed the actions and interactions that were perceived to sustain the parent-to-child transfer of self-management responsibility. Although there were many similarities between young people, parents and HCPs about what they believed facilitated the process of *shifting responsibilities*, some tensions appeared to be evident. In particular, the formation of partnerships between HCPs and young people, that excluded parents, seemed to cause conflict between young people, parents and HCPs. The following section will explore the actions and interactions that were perceived to disrupt the transfer of responsibility.

7.4 Disrupting the transfer of responsibility

Following the initiation of *shifting responsibilities*, the transfer process could be disrupted if young people disengaged from assuming self-management responsibility. For some families, the transfer process was disrupted only temporarily but then it would resume. However, for other families, the disruption could be longer-lasting. When disruption occurred, young people's, parents' and HCPs' accounts suggested trust had been lost. Young people, parents and HCPs made changes to their actions and interactions in an attempt to reinitiate the transfer process. At times this seemed to be effective; however, for

some families where trust had been lost, it was unclear whether the transfer process would recommence or whether the process had come to an end.

7.4.1 Disengaging

Young people, parents' and HCPs' accounts revealed situations where young people who had already started to assume responsibility began to disengage from self-management. A range of influences appeared to shape young people's motivation and decision-making around their engagement in self-management. Young people described the difficulties of consistently performing self-management, in particular remembering to take medication, following a renal diet and limiting their fluid intake:

> *I was a bit naughty. I used to go over [fluid restriction]. It was so hard, I couldn't do it.* (YP5, 16 year old girl)

Other young people reflected on how their lack of understanding of the seriousness of their condition, and the consequences of disengaging from self-management, meant they prioritised other activities such as school work or playing with friends. Although some young people were aware of the implications of not engaging in self-management - they described the visible changes to their bodies (e.g. being 'puffy' after exceeding fluid restrictions) - many were unaware how their decisions not to perform self-management tasks impacted on their health. There was a sense that some young people's actions and the consequences of their actions were happening 'below the surface'. This was evident in a young person's account as she described having a rejection episode of her transplanted kidney due to not following her treatment regimen:

> *Another thing the doctor said which opened my eyes was, 'If you don't take your tablets, you are hurting your kidney, but you don't see that because it's not a physical thing, your arm's not going to drop off'. You don't see the change, but there is a change and it is affecting your body whether you see it or not. It makes it hard. When I wasn't having my tablets, I didn't feel any different, I felt fine but my blood results weren't showing that.* (YP1, 14 year old girl)

The perception that the transfer of responsibility could be disrupted by young people's decisions to disengage from self-management was evident in parents' and HCPs' accounts. A HCP described how some young people on dialysis decided to engage in some aspects of self-management but not others, due to their understanding of the short- and longer-term consequences:

> *They're bothered about their fluid overload because that creates time. Their potassium, it's like, 'You keep telling me something will happen but it never does.' There's a fluid implication, dialysis for longer, extra sessions, whereas potassium, you don't get an implication until something bad happens, it'll send you into an arrhythmia, it could be at any point. All they hear is us, 'Potassium's high.' 'So what? Nothing ever happens to me.'* (HCP3)

As the quotation suggests, there was a perception that young people were prepared to take risks based on whether their actions resulted in consequences that were explicit and immediate, such as a longer session on dialysis, or more subtle, harder to detect and occurring at an uncertain point in the future. This sense that some young people disengaged from self-management due to limited understanding of the consequences of their actions on their health was also evident in parents' accounts. Despite sometimes being 'naughty' around her fluid restrictions, YP5's parent described how increased understanding of her condition supported her to re-engage in self-management:

> *She doesn't think, 'I'm going to be naughty this week,' because she understands that if she's going to get a transplant tomorrow, then she needs to be as healthy as she can, and her numbers need to be as good as they can…so for months now, she's been excellent.* (Parent5, 16 year old girl)

As the data extracts highlight, young people seemed more likely to disengage from self-management when they had limited understanding of their condition and the consequences of not following their treatment regimen. When the transfer process had been temporarily disrupted, developing understanding and learning from mistakes (discussed in section 7.3.7), appeared to support the transfer process to resume. However, as the following section explores, some young people's disengagement from self-management could be longer-lasting, disrupting the transfer process and impacting on trust.

7.4.2 Losing trust

Young people's, parents' and HCPs' accounts highlighted how trust between a young person and their parent seemed instrumental to parents' feeling able to 'let go'. When trust was lost, often as a result of their child disengaging from self-management, parents tended to reassume responsibility and an increased level of control. One young person, who had experienced a rejection episode of her transplanted kidney due to not taking her medication and reaching her fluid target, described the impact this had on the relationship she had with her parents:

If there's something wrong with my medication, or I'm not drinking properly, my dad will be, 'That's it. I'm going to give you the water'. He'll come and check on me. 'You've got to trust me a little bit, you know?' After my rejection, my dad's constantly nagging me. (YP14, 16 year old girl)

Parents' accounts also revealed how the transfer of responsibility was disrupted when they found trusting their child increasingly difficult. Parents adjusted their actions when their child struggled with self-management, such as closer monitoring or discreet checking of what their child was doing. Although parents seemed to view monitoring as a protective measure whilst their child was initially assuming responsibility, it also suggested parents did not feel ready to relinquish responsibility, as they did not trust their child to independently manage their condition:

It's to keep an eye on what he's doing. When they get to a certain age, they know how to play things and say, 'I'm taking them [tablets],' and not do it. I say, 'You do your injection,' and when he's done it, I'll say, 'Show me where you've done it'. There will be a spot, or a bit of blood, that's when I know he's done it. It's easy for them to say, 'I'm doing it,' and squirt it, not into him, maybe into the air or onto the floor. It's happened before in the past, so now I know I need to keep checking. (Parent4, 14 year old boy)

Once we pulled the fridge out to clean behind it and that's where he had been chucking tablets. I confronted him, he said, 'I haven't put them there.' We had to watch him then, how much he'd taken. He doesn't think I'm watching him I reckon, but I watch what he takes out, and if he takes it. We've a wall across the kitchen, he tries to shut that door a bit, goes in the back of the cupboard to get juice and he thinks, 'She won't be able to see me.' I push the door a bit further out in the open, and watch that he's taking it. (Parent10, 16 year old boy)

HCPs described how they adjusted their interactions when the transfer of responsibility was disrupted due to parents not feeling ready to relinquish control. A HCP described how he approached the issue indirectly through his interactions with the young person:

*I say to a child, 'I understand your parents are worried about this,' but when I think it's too much I tell the child in front of the parents, 'You know how mothers are, they always worry. That's partly why we've got mothers –', to try to not **accuse** her, but telling her, that both the child and I think that the mother worries too much, but trying not to put the blame on her for that. I hope that I sow a little seed in that mother's brain, 'Perhaps this is something I should try to work on.'* (HCP6)

There appeared to be some ambivalence, however, amongst HCPs around whether indirect or subtle interactions with young people and parents were sufficient when the transfer of responsibility had been disrupted. Some HCPs' accounts suggested they thought more explicit, direct interactions were sometimes beneficial if parents found it difficult to 'let go':

Maybe we do need to be more explicit in the conversation. I sat in the clinic with a mother and her son, and we actually had this conversation about her letting go and how difficult that is. I was saying I thought she's struggling to let go and allow him some freedom to do his care, and she was complaining that he hadn't cut his fingernails, they were too long and he looked like a girl. We used that as an example to think about whose choice that was, and what did it matter. Out of that, we did have an explicit conversation about how difficult it is to let go. (HCP18)

There was a perception that young people's actions around self-management could also lead to the loss of trust between young people and HCPs, and therefore disrupt the process of young people assuming responsibility. A HCP described how some young people's decision not to be honest about their dialysis care resulted in HCPs' increased monitoring as they were unable to trust the young person:

They learn to manipulate it more, getting to know what they can get away with and what they can't. We've had kids lie about their weights once they've started to weigh themselves, 'That's a bit high, that's going to keep me on [dialysis] for too long, I'll tell them a different weight.' So we have to go down a stage where we've had to watch weights. (HCP3)

When the transfer of self-management was disrupted and trust in the young person was lost, HCPs' accounts revealed how they responded. It seemed that the way a HCP decided to act was influenced by various issues such as the type and level of concern about the young person's management, MDT discussion and the HCP's discipline. One HCP described how the initial response, when a young person had disengaged from self-management, might be to discuss HCPs' concerns with the young person and parent and explore possible solutions:

You end up noticing those things if they come in with repeated infections, or their bloods are off. You question are they getting their medications. You say, 'What's your role?' and try to establish what is happening in the home, what their day-to-day routine is like and what they can do. They could have dosette boxes, and if the parents aren't working on the Sunday, on the Sunday together they could put all the medicines in the dosette box for the week. (HCP10)

HCPs' accounts revealed how different members of the MDT could become involved if there were concerns that a young person was not engaging in self-management. There was a sense that involving disciplines, such as social work, psychology and play/youth work that utilised different approaches, could potentially facilitate the continuation of the transfer of responsibility:

Sometimes, the doctors or nurses want more of a shock factor. They want me to go heavy, with the [young person] learning that if you don't meet your fluid target, your creatinine is going to increase, you might need a biopsy, and it's because you

haven't drunk your fluids. We'll say, 'This is your fluid allowance, 600ml'. We'll have different cups. I'll get them to guess, and then we check it. I'll have a big jug, we put in their allowance, then put in their sneaky drinking, and watch everything spilling over the top. I'd explain, 'That extra fluid would be in your body and your heart would be having to pump a lot harder.' I don't know if it has much effect, because it's done as a last ditch attempt to get some compliance. (HCP4)

The language in the above data extracts, such as 'sneaky drinking', 'manipulate' and 'lie' highlights how HCPs were losing trust in young people. Despite increased HCP involvement to encourage the young person to reassume self-management responsibility, at times the disruption to the transfer process would continue. HCPs' accounts revealed the rare situations where there were ongoing concerns around a young person's health, and HCPs had lost trust in both the young person's and parent's management of the condition. At these times, MDT discussion would explore how HCPs should act, which could include admitting young people to hospital and implementing safeguarding procedures. However, as discussed in section 5.5.3, there were sometimes 'grey areas'. Issues around parental responsibility and a young person's competency and capacity to make decisions around self-management appeared to increase the complexity of HCPs' decision-making in this area. This was evident in HCPs' accounts, as they described how the MDT responded when young people disengaged from self-management and the transfer process was disrupted:

> *There are lots of MDT discussions. There are social workers, psychology, dietitians, lots of direct support, and consideration, does this fall in a safeguarding category? It's difficult to measure omission of care in parental responsibility in these situations. If the parents aren't doing anything that would cause direct harm, then you are supporting the child to remain in the family home.* (HCP9)

As the quotation suggests, it could be difficult for HCPs to gain a clear picture of what was happening when trust between young people, parents and HCPs had been lost. In these situations, there appeared to be conflicting views amongst HCPs around how to respond, for example, whether the situation warranted safeguarding. A HCP described some of the difficulties that arose due to the different disciplinary perspectives, especially when there were potential safeguarding concerns:

> *It's tricky working within a medical model, sometimes we have conflicting-, when we're doing our [disciplinary] assessments, our ethos is to keep families together. The last thing we want is to remove the child, unless they're being harmed in a way that is unacceptable and, it's obviously a safeguarding concern… sometimes with the complex families where there are lots of things going on, the doctors might say, 'We think this is safeguarding, you're not taking it seriously enough,' but I'm, 'We're trying to support them, we're trying to move forward and, hopefully, that's going to work.'* (HCP5)

As the quotation suggests, and was evident in other HCPs' accounts, the different approaches amongst the MDT could cause conflict around how to act, interact and respond to young people and parents when the disruption to the transfer of responsibility was longer-standing and trust was lost. However, despite the uncertainty around whether the transfer process had ended prematurely, the above data extract suggests some HCPs remained hopeful that young people would reassume self-management responsibility. The importance of hope, when the process of *shifting responsibilities* was disrupted and trust had been lost, was also evident in two parents' accounts whose children were currently disengaged from self-management at the time of the study:

> *I wouldn't say she's being responsible at the moment, but I hope that she will settle down a bit, hopefully.* (Parent7, 16 year old girl)

> *I'm hoping that he's going to be able to do it himself, because I'm not going to be there when he gets a girlfriend and moves out. He needs to do it for himself.* (Parent10, 16 year old boy)

The two young people referred to in the above data extracts did not participate in interviews, and data generation occurred at one point in time. Therefore, it is unclear whether the transfer process had been disrupted from the young people's perspective, or whether *shifting responsibilities* reinitiated and their parents' hope was fulfilled.

7.5 Summary

This chapter has examined the second sub-category, *making changes,* which explained how young people, parents and HCPs adjusted their actions and interactions during the transfer of responsibility. Actions and interactions could initiate, sustain or disrupt the transfer process and influenced how responsibility moved backwards and forwards, shifting between young people, parents and HCPs. The ambiguity around how to initiate the transfer process was explored. Parents' decisions to start transferring responsibility were mostly based on practicalities, which meant their initial focus was on their child's actions and the self-management activities their child could 'do'. In contrast, HCPs identified that a young person was ready to assume responsibility when the young person had demonstrated their self-management knowledge during interactions. The chapter discussed the actions and interactions that sustained the parent-to-child transfer of responsibility: promoting a gradual transfer of responsibility; encouraging partnership; developing a routine; fostering positivity; building and maintaining trust; connecting with others with CKD; learning from mistakes; and individualising support. Finally, it was explained how actions and interactions could also

disrupt the transfer of responsibility. When young people disengaged from self-management, this could temporarily disrupt the transfer process. Through making changes to actions, such as young people developing understanding, the transfer of responsibility seemed to resume. However, for other families, the disruption to the transfer process was longer-lasting. Parents and HCPs lost trust in young people when they disengaged from self-management, and when more significant disruption occurred, HCPs appeared to lose trust in both young people and parents. At these times, and despite the uncertainty around whether the process of *shifting responsibilities* would resume or whether it had come to an end, it seemed that some parents and HCPs remained hopeful that change would result.

7.6 Conclusion to findings chapters

Chapters 5, 6 and 7 have presented the findings from this study's exploration of the parent-to-child transfer of self-management responsibility for CKD. These findings chapters as a whole described the grounded theory, *shifting responsibilities*, that was constructed from the narratives.

Chapter 5 examined the core category, *shifting responsibilities*, that captures and explains the main process that occurs as young people assume self-management responsibility and parents relinquish control. This category linked all the findings chapters; as illustrated by Figure 8, it was central to the transfer process and integrates the two sub-categories, *developing independence* and *making changes*. Chapter 5 described how responsibilities shifted along a continuum between parental-led management, and young person-led management. Although the process was always fluid and bidirectional, it was characterised by multiple ambiguities: who should be involved, when it started, when it was completed, and ultimately, what the endpoint of the process was. Many of these conflicts seemed to arise from how young people, parents and HCPs constructed the transfer process; with young people viewing the transfer of responsibility within a broader context of developing independence in daily activities and HCPs framing the process within the narrower context of the transition to adult health services.

The next two chapters presented the two sub-categories, that mutually influenced how and when responsibilities shifted. The first sub-category, *developing independence,* which provided the context for the transfer of responsibility, was examined in chapter 6. For young people and parents, young people assuming self-management responsibility was seen as a natural extension of the 'normal' process, where becoming older and growing up involved

increased independence. However, young people, parents and HCPs were aware that the risks associated with developing independence were intensified for young people with CKD. Consequently, there was tension around encouraging young people to assume responsibility, while balancing protection and risk. The chapter also discussed how contextual issues, such as the young person, parents and family, health condition, and environment interacted and mutually influenced how responsibilities shifted between parents and young people.

Chapter 7, the final findings chapter, described the second sub-category, *making changes*. This sub-category explained how as result of young people, parents and HCPs adjusting their actions and interactions, the transfer of responsibility was initiated and then either sustained or disrupted. The conflict around whether to take a 'doing' or 'knowing' approach when initiating the transfer process was explored. Next, the chapter revealed the actions and interactions that were perceived to sustain the process of young people assuming responsibility from their parents. When young people disengaged from self-management this disrupted the transfer process. Whether the disruption was temporary or lasting, parents and HCPs could lose trust in young people. Through making changes to actions and interactions, the transfer process would mostly resume following a disruption. However, for some families, when there was uncertainty around whether shifting responsibilities would continue or had come to a premature end, parents and HCPs tried to remain hopeful.

The next chapter discusses the findings in relation to the current literature, the study's contribution to knowledge, its limitations and strengths, and the arising implications for policy, practice and future research.

8. DISCUSSION

8.1 Introduction

This study aimed to: 1) explore young people's, parents' and HCPs' views on the parent-to-child transfer of self-management responsibility of CKD; 2) identify young people's, parents' and HCPs' perceptions of families' support needs during this transfer of responsibility; and 3) develop a grounded theory to understand and explain the processes that occur during the transfer of self-management responsibility. Data were generated through: individual interviews with young people with CKD, parents and HCPs; dyadic interviews with young people and their parents; and focus groups with HCPs. An emergent theory of *shifting responsibilities* was constructed from the narratives that explained processes that occur during transfer of self-management responsibility. The theory represents the differences between young people's, parents' and HCPs' constructions of the transfer of responsibility, the contextual factors that shaped their constructions, and the actions and interactions that initiated, sustained or disrupted the process.

The aim of this chapter is to discuss the significance of the study and its contribution to knowledge. The first section will discuss the study findings in relation to the current literature. Next, the strengths and limitations of the study will be considered. The originality of the study and contribution to research knowledge are also explored. The chapter will examine the implications the findings have for policy, practice and education. Finally, recommendations for future research will be made.

8.2 Review of the main findings in relation to the existing literature

This section will discuss the study's key findings in relation to the existing theory and literature. The ways in which the theory, core category (*shifting responsibilities*), and two subcategories (*developing independence* and *making changes*) compare with, and extend, existing research in the field of children's LTCs and self-management will be explored.

8.2.1 Shifting responsibilities

As both the theory and core category, *shifting responsibilities* explained the main processes that occurred during the transfer of responsibility.

8.2.1.1 A fluid process

During the transfer of self-management responsibility, responsibilities appeared to shift along a continuum between parental-led management and young person-led management. The transfer of responsibility was not linear, but fluid and bidirectional, as responsibilities shifted backwards and forwards between young people and parents. There was a strong sense that this transfer was a process: it consisted of 'unfolding temporal sequences in which single events become linked as part of larger whole. Thus temporal sequences are linked in a process and lead to change' (Charmaz, 2014 p. 344). Current conceptualisations of young people assuming self-management responsibility have also been presented as a process, rather than an event (Reed-Knight et al., 2014; Hanna and Decker, 2010), that involves 'shifting, shared responsibility between children/adolescents and their parents' (Schilling et al., 2002p. 91). However, unlike these conceptualisations, which were based on reviewing existing literature, the theory in this study was constructed from narratives; therefore, it represents the differing ways that young people, parents and HCPs understood, and assigned meaning to the transfer process. By being 'grounded' in data, this theory has potential to be further developed and used to design interventions to support young people, parents and HCPs involved in the process of *shifting responsibilities* (Starks and Trinidad, 2007).

As illustrated by Figure 8, there was a sense that management responsibilities shifted along a continuum. Change occurred very gradually, yet the extremes on the continuum were quite distinct. This finding supports existing research that modelled the transfer process in other LTCs, including type 1 diabetes and cystic fibrosis, as a continuum where young people's and parents' roles and responsibilities regularly changed (Chilton and Pires-Yfantouda, 2015; Williams et al., 2007). Interestingly, a key difference in this study's findings is the end point of the continuum; whereas Williams et al (2007) and Chilton and Pires-Yfantouda (2015) both described the end point of the continuum as a position where young people are independent in self-management, and parents have no involvement, this study suggested that parents continued to have some involvement in managing their child's CKD, despite their child having assumed responsibility. This new finding about the process endpoint will be discussed in more detail.

The finding that young people and parents in this study found the process of *shifting responsibilities* difficult supports existing research. Although young people with CKD accepted that they needed to assume responsibility as they became older, similar to young people with other LTCs, they found the process stressful and experienced

misunderstandings and frustration with their parents (Ersig et al., 2016; Meaux et al., 2014; Castensoe-Seidenfaden et al., 2017). Parents viewed the transfer of responsibility as a process; they often wanted their child to take an increased lead in managing their CKD, but also struggled with 'letting go'. Parents' fear and belief that they needed to remain vigilant, due to concerns about the consequences if their child struggled with self-management, resonated with findings from research exploring other childhood LTCs (Babler and Strickland, 2015; Schilling et al., 2006; Heath et al., 2017). As Dallimore et al (2018) found, the 'struggle' between young people assuming more responsibility, and parents wanting to retain control, was a 'key battle'.

8.2.1.2 Defining roles

By including HCP participants, one of the unique contributions of this study was providing HCP perspectives on transfer of responsibility. Similar to young people and parents, HCPs also found the process difficult, experiencing uncertainty regarding their role in supporting young people to develop independence in managing their condition. The difficulties of defining roles during the transfer of responsibility was highlighted by this study. In parents' constructions of their parental role, they thought it was their responsibility to support their child to develop independence as they became older; therefore, it was mostly parents who initiated the transfer process. This finding supports previous research that suggested parents either adopted a planned approach, where they explicitly started to transfer responsibility for specific self-management tasks (Thomsen et al., 2019; Williams et al., 2007), or decided to initiate the process in response to external events, such as their child starting secondary school (Rankin et al., 2018; Newbould et al., 2008).

The sense that young people's and parents' roles shifted, as young people developed independence in managing their CKD, supports existing primary (Thomsen et al., 2019; Meah et al., 2010) and secondary (Heath et al., 2017; Betz et al., 2015) research in other childhood LTCs. However, by including HCPs, this study has extended understanding of HCP roles and how they adjusted their actions and interactions with young people and parents during the transfer process. Although HCPs believed it was their role to support young people to assume self-management responsibility, there was ambivalence among young people and parents around whether the transfer process was primarily a family concern or whether HCPs should be involved. For the HCPs in this study, their main focus was on supporting the young person, rather than the young person-parent dyad. Only a few HCPs, mainly from clinical psychology and social work, appeared to believe their role involved helping parents to relinquish responsibility; this contributed to the lack of clarity around whether HCPs' approach should be young person- or family-centred. This finding is

interesting as both research and the theoretical literature recommend HCPs' interventions are family-focused (Lerch and Thrane, 2019; Ryan and Sawin, 2009) and should involve 'empowering parents to embrace a loss of control over their child's health care routines as it is about empowering the adolescent to take on greater responsibility as they mature into an adult' (Sawyer et al., 2007a p. 626). However, as will be discussed, HCPs' constructions of the transfer of responsibility, within the context of transition between child and adult services, meant HCPs tended to exclude parents from the process, focusing on developing partnerships with young people, rather than the evolving young person-parent dyad.

8.2.1.3 Differing temporal landscapes

The study findings add to the existing literature regarding the timeframe of the transfer of self-management responsibility and highlighted how different understandings existed around when the process started and when it finished. Although Charmaz described how some processes 'may have identifiable markers with clear beginnings and endings and benchmarks in between', other processes 'may be much more diffuse and less visible but nonetheless evident when comparisons are made over time' (2014 p. 344). In this study, there was a sense that different temporal landscapes existed for young people, parents and HCPs. Young people and parents appeared to view the transfer process more diffusely, constructed within a broader context of developing independence in everyday activities, whereas HCPs framed the process within the narrower context of the transition to adult health services, with a sense that there was a starting and finishing point.

Interestingly, young people's and parent's understanding of the transfer process appeared to align more closely with the framework proposed by Kieckhefer and Trahms (2000); this emphasised the role of parents in promoting child-parent shared management from early childhood and highlighted that the child's developmental stage, rather than a specific age, should guide the process. In contrast, HCPs' tendency to start the transfer process when a young person was approximately 13 years old aligned with alternative frameworks that identified adolescence as the critical timeframe for the transfer of self-management responsibility (Modi et al., 2012; Grey et al., 2015). This misalignment between young people's, parents' and HCPs' timeframes for the transfer process resonates with findings from previous research that concluded young people with CKD wanted holistic support with transition to adulthood over a longer period of time (Dallimore et al., 2018). As Sattoe et al (2014 p. 138) stated, the challenge for HCPs is to 'move beyond the focus on medical management and to consider young people's developmental tasks when coaching them into adulthood'. This suggests that support from HCPs could be beneficial if HCPs framed the

transfer process in a way that more closely aligned with how families constructed the process – an extension of the 'normal' process of developing independence that occurs throughout childhood. This finding is in line with recently developed guidance that recommends HCPs support children to engage in developmentally appropriate self-management, from the age of two through to 20 years old (Saxby et al., 2020). Although, as discussed in chapter 1, there are limitations in the methods used to develop this guidance, this finding still warrants further investigation.

8.2.1.4 Conflicting endpoints

In addition to the differing constructions around when the transfer process started, there were conflicting understandings around the endpoint of the transfer of responsibility. This was linked to the different meanings young people, parents and HCPs assigned to self-management. Young people and HCPs focused on daily self-management activities such as fluid intake, whereas parents considered other activities such as ordering medication. Despite their contrasting understandings, the focus was predominantly on medical management of CKD, such as taking medication and managing a renal diet (Lorig and Holman, 2003). Although young people in the study were developing the core self-management skills identified by Lorig and Holman (2003) including problem solving, decision making, forming partnerships with HCPs, resource utilisation and taking action, they were also acquiring other skills, including developing routines and learning from mistakes. The significance of these additional skills will be discussed in section 8.2.3. Interestingly, the ways young people, parents and HCPs were defining self-management appeared to resonate more closely with the domains of self-management suggested by Saxby et al (2020). By focusing on division of responsibility and autonomy, Saxby et al's (2020) framework may be more relevant when considering the transfer of responsibility rather than Lorig and Holman's (2003) conceptualisation of self-management.

The ambiguity around how to define self-management and what it meant to be responsible supported existing research that found young people and parents had different understandings around what was required to maintain health (Babler and Strickland, 2015) and be fully responsible (Hanna and Guthrie, 2000a; Meah et al., 2010). However, this study's findings extend the literature as there was also uncertainty amongst HCPs around what was 'acceptable' self-management and how to identify if a young person had assumed responsibility. HCPs adjusted their expectations around what they perceived to be optimal self-management as they acknowledged that young people were likely to make mistakes (Sawyer and Aroni, 2005). Although conceptualisations of self-management identify

outcomes of 'effective' self-management, such as 'disease control' and 'health behaviours' (Grey et al., 2015; Schilling et al., 2002), these seem to be based on concepts of adherence and potentially fail to reflect both the complexity and uncertainty around the endpoint of the transfer process. The outcomes of young people with diabetes assuming self-management responsibility, that include condition management, health outcomes, quality of life and young people's belief in their abilities, seem to be a more useful way to frame the study's findings (Hanna and Decker, 2010). However, as this study has highlighted, there were also consequences for parents from their child assuming responsibility, such as their own increased independence and freedom. Although this has been explored empirically (Hanna and Guthrie, 2000b), none of the conceptualisations incorporate parental outcomes, suggesting scope for further theoretical development.

The lack of clarity around what being responsible meant, and how much responsibility young people were expected to assume, resulted in conflict between young people, parents and HCPs. Parents' and HCPs' constructions around responsibility meant they seemed to perceive it was young people's 'obligation' to assume responsibility, yet they were also attempting to value, promote and respect the young person's emerging independence and autonomy. This tension between responsibility and autonomy potentially increased the uncertainty around what was expected of young people as they assumed responsibility (Snelling, 2012). Linked to this was the uncertainty around accountability and who had responsibility for a young person's health. In contrast to previous research (Strand et al., 2019), young people in this current study did not seem to perceive that becoming involved in managing their condition would mean they would be held responsible if they made a mistake. As the young people in this study were aged 13-17 years old, rather than 16-18 years old as in Strand et al's study (2019), this difference may be influenced by age or reflect different conceptualisations of children's rights and responsibilities in Norway and the UK. Interestingly, some young people and HCPs perceived that HCPs would always be partially accountable for managing the young person's CKD, which meant the young person would never have absolute responsibility. This new finding extends the debate around what self-management responsibility means and highlights an area for further research.

HCPs' perception that parents were accountable for their child's health supported existing research that found parents were blamed by HCPs if their child's condition deteriorated, while also being criticised for not 'letting go' (Williams, 1999; Meah et al., 2010). The difficulties experienced by parents in maintaining a supervisory role while supporting their child to develop independence in managing their condition, and continuing to be legally

responsible for their child's health, has previously been recognised by Sawyer and Aroni (2005). However, limited empirical research has examined this issue. Although parents in Sullivan-Bolyai et al's (2014) study were warned of social services involvement if they did not remain involved in managing their child's LTC, this study found HCPs were aware there were 'grey areas' and therefore had a more nuanced understanding around parental responsibility. This was evident in the ways HCPs adjusted their actions when the process of shifting responsibilities was disrupted, trust was lost and there were potential safeguarding concerns. Section 8.2.3 will discuss this finding further.

The uncertainty in this study around the endpoint of the transfer process supports the existing literature. Although many young people aimed for complete independence in managing their condition (Babler and Strickland, 2015; Buford, 2004), parents were more ambivalent, with some viewing shared management with their child as the goal (Auslander et al., 2010; Meah et al., 2010). Dallimore et al (2018) found that, because of individual characteristics and comorbidities, some young people with CKD were not able to assume complete responsibility and many parents found it difficult to relinquish control regardless of the age of their child. HCPs who viewed the transfer of responsibility as part of the transition between children's and adult services aimed for young people to be independent in managing their CKD by the time they transferred to adult services. Other HCPs, however, experienced uncertainty around whether this was a realistic goal. This finding extends research and theoretical literature in this area. Although parents sharing management with their child tended to be viewed as a 'bridge to full independence' (Heath et al., 2017 p. 89), some parents and HCPs questioned whether young people could or should have assumed full self-management responsibility by the time they were 18 years old. This uncertainty around the endpoint was reinforced by parents' belief that they would continue to have some involvement in managing their child's condition beyond their transition to adult services. As none of the young people in this current study were independently managing their LTC, it is difficult to conclude what the endpoint of the transfer of self-management responsibility was.

The ambiguity around the endpoint of the transfer process, apparent in this study and previous research, is in line with uncertainty in the theoretical literature. Hanna and Decker (2010) identified the goal of the transfer of responsibility as the young person having 'ownership' of their health care, which included both 'behavioural and decision-making autonomy'. This suggested parents would have fully relinquished control. In contrast, Saxby et al (2020) recommended that parents should continue to act as advocates, 'offering support and guidance as needed' (p. 578). This highlights the conflicting views about the

roles of parents beyond the endpoint of the transfer process and the transition to adult services, and suggests further research is needed.

8.2.2 Developing independence

Developing independence provides the context for how and why responsibilities shift between the parent and the young person.

8.2.2.1 Extending the 'normal' process

Figure 8 illustrates how *shifting responsibilities* was influenced by the wider context, *developing independence.* Supporting the findings of previous studies, young people assuming self-management responsibility was viewed by young people and parents as a natural extension of the 'normal' developmental process, where becoming an adult was associated with attaining independence and autonomy (Strand et al., 2019; Karlsson et al., 2008). This finding is in line with the theoretical literature that situated assuming responsibility within the context of adolescent development, where young people developing independence in 'typical' adolescent activities was thought to help prepare them for managing their condition (Hanna and Decker, 2010; Reed-Knight et al., 2014). However, the focus in the literature on adolescence as the developmental stage when young people become involved in self-management contrasts with this study's findings, that found some young people engaged in self-management while at primary school. Recently, there has been increasing attention on 'developmentally appropriate healthcare' (DAH) (Farre et al., 2015; Farre et al., 2016) that 'recognises the changing biopsychosocial developmental needs of young people and the need to empower young people by embedding health education and health promotion in consultations' (Colver et al., 2020 p. 76). Rather than framing the transfer of responsibility as part of transition to adult service, viewing the transfer process through a DAH lens shifts focus onto the young person's development. However, DAH's emphasis on adolescence as the developmental stage when HCPs should support young people to develop self-management skills (Farr et al., 2016) means the timing of HCPs' involvement continues to be misaligned with young people's and parents' constructions of the transfer process.

Although HCPs in the study appeared aware of the wider context of child and adolescent development, they tended to focus on self-management as a separate activity to other everyday activities where young people were developing independence. This is a new finding and it suggested HCPs tended to decontextualise self-management. HCPs' understandings of the transfer process were in contrast to those of young people and

parents, who viewed the process within a wider context that incorporated school, spending time with friends and other meaningful activities the young person engaged in. This supports existing research that found HCPs working with young people with CKD tended to have a narrow view of health, focusing on how the young person engaged within the clinical environment, rather than the 'broader developmental journey into adulthood' that is shaped by social, family and societal relationships (Dallimore et al., 2018). Although the literature describing DAH recommends HCPs should be 'holistic' and assess a young person's biopsychosocial development, it does not explicitly address how HCP involvement could support young people to integrate self-management into their daily lives (Farre et al., 2016, Colver et al., 2020).

Although assuming self-management responsibility was viewed as part of the 'normal' process, the risks associated with developing independence were heightened for young people with CKD. Parents and HCPs were aware of the potential consequences if a young person disengaged from self-management; consequently, many parents struggled with balancing protection and risk when supporting their child to develop independence. This tension experienced by parents was evident in studies exploring the transfer of responsibility in other childhood LTCs, including diabetes (Hanna and Guthrie, 2000b) and cystic fibrosis (Williams et al., 2007). This highlights how despite the specific challenges and risks associated with CKD self-management, such as a renal diet, fluid restrictions, dialysis and transplant loss (Sattoe et al., 2014), parental conflict between promoting their child's autonomy while remaining a protective parent was an experience shared with parents of children with other LTCs (Heath et al., 2017).

8.2.2.2 Influences on the transfer of responsibility

Contextual issues, such as the young person, parents and family, the health condition and the environment, influenced the parent-to-child transfer of self-management responsibility. These findings support and extend existing research and theoretical literature that identify the factors that influence, facilitate or act as a barrier to self-management. Young people and parents associated the young person becoming older with increased independence in self-management, often linking this with significant milestones such as starting secondary school. The young person's age was found to influence the transfer of responsibility in other studies (Alderson et al., 2006; Lindsay et al., 2011; Leeman et al., 2015; Meaux et al., 2014) and in both condition-specific and generic conceptualisations of young people's LTC self-management (Mammen et al., 2018; Modi et al., 2012; Reed-Knight et al., 2014). Parents and HCPs in the study acknowledged that a young person's developmental stage, in

addition to their chronological age, influenced the transfer process. This included the young person's cognitive and emotional maturity, which impacted on the young person's readiness to assume responsibility and parents' willingness to relinquish control. Readiness was related to a young person's motivation, independence in other everyday activities and knowledge of their LTC (Hanna and Decker, 2010; Heath et al., 2017), although as discussed in section 8.2.3, there was ambiguity amongst parents and HCPs around how to identify whether a young person was ready to assume responsibility.

Although the young person's gender was identified as an influence on the transfer of responsibility in previous studies (Lindsay et al., 2011) and the theoretical literature (Schilling et al., 2002; Modi et al., 2012), it was rarely mentioned in this study. Similar to previous studies (Rhee et al., 2009; Williams, 1999), there was a suggestion that boys potentially struggled more than girls with assuming responsibility; however, it was unclear how other factors, such as age and treatment regimen, interacted with gender to influence the transfer process. Interestingly, although the young people participating in the study were ethnically diverse, there was no discussion around how ethnicity impacted on the transfer process. A few previous studies had found young people from Black and Hispanic backgrounds experienced more difficulties with assuming responsibility (Rhee et al., 2009; Auslander et al., 2010), but ethnicity was rarely identified in the theoretical literature as influencing self-management. The exception is Modi et al (2012) who suggested young people from ethnic minority backgrounds tended to have poorer health outcomes. However, they acknowledged it was unclear whether this was associated with difficulties with self-management or whether other factors, such as the family's socio-economic status, could interact and impact on young people assuming responsibility.

A young person's parents and family were found to impact on the transfer of responsibility. This finding supported existing literature that identified the family as an influence on when and how self-management responsibilities shifted. The structure of the family, including the presence of siblings, and whether a family member had the same LTC, impacted on young people's motivation to assume responsibility. Similar findings have been reported in studies exploring the transfer process with young people with other LTCs (Akre and Suris, 2014; Leeman et al., 2015; Lindsay et al., 2011). The family has consistently been identified in theoretical literature as impacting on self-management (Modi et al., 2012; Reed-Knight et al., 2014). Both Ryan and Sawin (2009) and Grey et al (2014) linked individual self-management with family management, in recognition of the pivotal influence the family has on an individual's ability to manage their LTC. Although there is acknowledgement that the role of

family varies over the life cycle, for young people, the family and, in particular, parents are 'intimately linked' (Grey et al., 2014). Theoretical literature focused on specific childhood LTCs, including diabetes (Hanna and Decker, 2010; Schilling et al., 2002) and asthma (Mammen et al., 2018), suggest parental expectations and support, and young person-parent interactions, could influence the transfer process. Section 8.2.3 will discuss how this study found specific actions and interactions could either sustain or disrupt the transfer of responsibility.

Study findings indicated that different aspects of CKD, including the age of diagnosis, CKD stage and type of treatment, influenced the transfer of self-management responsibility. Similar to existing research in other children's LTCs, there was ambivalence around whether being diagnosed with CKD antenatally, or during childhood or adolescence, meant young people were either more able or struggled to assume responsibility (Meaux et al., 2014; Spencer et al., 2013). As CKD is a progressive LTC, its stage and level of stability impacted on how young people developed independence in managing their condition. This finding supports previous studies that found the transfer process was influenced by the young person's health and the extent to which young people and parents linked stability with engagement in self-management (Leeman et al., 2015; Heath et al., 2017).

Although none of the theoretical literature is CKD-specific, generic frameworks identified that the complexity and severity of the LTC could be risk or protective factors (Grey et al., 2014; Ryan and Sawin, 2009) and influenced parents' willingness to transfer responsibility (Kieckhefer et al., 2009). For some young people in this study, the progression of their CKD was a risk as it seemed to disrupt their self-management, whereas for other young people it appeared protective, prompting them to realise the seriousness of their condition, and increased their motivation to assume responsibility. As highlighted by the diabetes literature, the complexity of the treatment modality for CKD impacted on young people assuming responsibility and parents relinquishing control (Schilling et al., 2002; Hanna and Decker, 2010). CKD-specific treatment regimens, such as dialysis, appeared to have a significant impact on young people developing independence in managing their condition. The transfer process appeared more challenging for this group, potentially due to the significant demands associated with dialysis, including the time required for dialysing, and extreme fluid and diet restrictions (Sattoe et al., 2014; Dallimore et al., 2018). The sense that young people on dialysis appeared to struggle more with assuming responsibility due to the uncertainty around their future extends existing research that found young people on dialysis occupied a 'renal space', where waiting and hoping for a transplanted kidney was a 'lengthy and

emotionally demanding process' (Lindsay Waters, 2008 p. 3108). This highlights how the unique aspects of CKD self-management could shape the transfer process and supports the suggestion that a LTC-specific approach is needed when studying how young people assume responsibility (Hanna and Decker, 2010).

Similar to research with young people with type 2 diabetes, co-morbidities were found to influence the transfer of responsibility for CKD (Mulvaney et al., 2006; Mulvaney et al., 2008). However, unlike previous studies that found the transfer process more difficult as self-management became more complex when young people had more than one LTC, (Auslander et al., 2010; Grey et al., 2014), some young people in this current study found managing their CKD less challenging than managing their other health conditions. It seemed that this was associated with the severity, complexity, predictability and visibility of young people's other LTCs compared to their experience of living with CKD (Kayle et al., 2015; Karlsson et al., 2008).

Environmental factors were found to influence how and when young people assumed responsibility for their CKD and parents relinquished control. Similar to previous research, some young people found it challenging to engage with self-management while at school (Chilton and Pires-Yfantouda, 2015; Meah et al., 2010). School environments are identified in the theoretical literature as presenting potential barriers to young people self-managing due to the dietary, activity and medication requirements of many self-management routines (Modi et al., 2012; Mammen et al., 2018). Young people with CKD experienced similar difficulties, although some were CKD-specific, such as the need to meet a fluid target. The mixed findings in this current study about peers both supporting and disrupting young people assuming responsibility were in line with previous research. While some young people with CKD found self-management conflicted with 'fitting in' (Dashiff et al., 2011) others found that once they had disclosed their condition, the emotional support provided by friends helped with assuming responsibility (Ersig et al., 2010; Lindsay et al., 2011).

8.2.3 Making changes

During the parent-to-child transfer of self-management responsibility, young people, parents and HCPs made changes to their actions and interactions. As illustrated by Figure 8, these changes could initiate, sustain and disrupt the process of *shifting responsibilities*.

8.2.3.1 Initiating the transfer of responsibility

The ambiguity around how to initiate the transfer process was evident in parents' initial focus on the self-management activities their child was 'doing', whereas HCPs initial focus was on the young person's demonstration of self-management knowledge. This new finding extends existing research. Previous studies explored the transfer of responsibility from young people and parents' perspectives; therefore the focus was on self-management activities, such as managing medication (Schilling et al., 2006; Buford, 2004). By involving HCPs, this current study revealed the distinction between parents' 'doing' approach, and HCPs' 'knowing' approach, highlighting further how families' and HCPs' constructions around the transfer process differed.

The focus on 'doing' reflected how parents made pragmatic decisions to transfer self-management responsibility as their child spent increased time away from home at school or with friends (Heath et al., 2017). In contrast, as this current study revealed, HCPs adopted a 'knowing' approach as it was considered 'objective' and 'testable', compared with assessing a young person's ability to engage in self-management. Interestingly, this dichotomy between doing and knowing has been reflected in guidelines and checklists to support young people's self-management. Despite guidance recommending education to transfer 'knowledge, skills and abilities', assessment is limited to young people's 'knowledge of their condition and treatment' (Saxby et al., 2018). This gap in the literature around assessing young people's self-management skills is evident in a recently developed list of developmentally appropriate self-management for children and young people with LTCs (Saxby et al., 2020). Although the list highlights the importance of knowledge and self-management 'behaviours' ('doing' self-management), recommendations around identifying whether a young person had assumed responsibility focused on HCPs assessing knowledge. The emphasis on young people needing to 'pass' HCPs' 'tests' of their knowledge to demonstrate they have assumed self-management responsibility is evident in most transition checklists, including 'Skills for Growing Up' (Sattoe et al., 2014) and 'Ready Steady Go' (Nagra et al., 2015), which was used in Site A in this study. Although it has been recommended '*researchers* need to test when a child/young person can actually perform each self-management task' (Saxby et al., 2020 p. 580), this study has highlighted how more importantly, *HCPs* need to assess young people's skills and engagement in self-management, alongside their knowledge.

8.2.3.2 Sustaining the transfer of responsibility

Key findings about the actions and interactions that sustained the transfer of responsibility both support and extend the existing literature. The process of *shifting responsibilities* tended to occur very gradually over time as young people developed independence and parents' involvement in managing their child's condition reduced (Karlsson et al., 2008; Dashiff et al., 2011). Theoretical literature also outlined how 'ideally' the transfer of responsibility would occur incrementally (Reed-Knight et al., 2014; Kieckhefer and Trahms, 2000; Ryan and Sawin, 2009); therefore reinforcing this study's finding that actions promoting a gradual transfer sustained the process. As HCP involvement in the transfer of responsibility mostly occurred between young people becoming 13 years old and their transfer to adult services, some parents and HCPs believed HCP support over a longer time frame could be beneficial. By starting when the child was younger (and aligned with parents' initiation of the transfer process), and extending involvement beyond young people's transfer to adult services, HCPs could support a gradual process. However, as discussed previously, this could require HCPs to adjust how they contextualised the transfer of responsibility – instead viewing children on a trajectory of developing self-management skills from a young age, in line with developing independence in other areas of their life.

Actions and interactions that encouraged the formation of partnerships sustained the transfer of responsibility. This finding supported previous research that suggested a collaborative young person-parent dyad was key as young people were more likely to learn self-management from their parents, rather than HCPs (Christian et al., 1999; Dallimore et al., 2018; Kirk, 2008). During the transfer process, HCPs formed partnerships primarily with young people, rather than the young person-parent dyad, as they perceived this supported the assumption of responsibility, and parents' relinquishing of control. As HCPs' involvement in the transfer of responsibility was contextualised through a service transfer lens and shaped by transition guidance, young people were encouraged to attend clinic appointments without their parents (NICE, 2016; DoH, 2006b; DoH, 2008). Similar to previous research, young people in this study valued meeting with HCPs on their own, as they felt more able to talk openly without their parents present (Dallimore et al., 2018). While some parents were positive about their child attending appointments without them, others struggled with being excluded and wanted to be kept informed (Thomsen et al., 2019). The conflicting views among HCPs about whether parents were a facilitator or barrier to the transfer process, and parents' ambivalence about their inclusion or exclusion from consultations, extend the debate around whether HCP involvement should be child- or family-centred (Coyne et al., 2016). Although it has been recommended that triadic collaboration is fostered between

young people, parents and HCPs during the transfer of responsibility (Saxby et al., 2018; Colver et al., 2020) only a few HCPs in this study viewed parents as supporting the assumption of responsibility and, as a result, worked collaboratively with the young person-parent dyad. The uncertainty around how HCPs balance child- and family-centred care during the transfer process indicates further research is needed.

Similar to the findings from previous studies, structure and the development of routines were perceived by young people, parents and HCPs to sustain the transfer of responsibility (Strand et al., 2019; Castensoe-Seidenfaden et al., 2017; Sawyer et al., 2007). In this current study, practical strategies, such as testing out different water bottles and using dosette boxes, were found to support young people to adopt new habits and integrate self-management activities into their daily routines (Babler and Strickland, 2015; Meaux et al., 2014). Young people used technology, such as mobile phones and mobile applications (apps), to develop independence in managing their condition. Interestingly, families sought out apps for themselves, without the input of HCPs. Previous research has suggested apps support young people's self-management through 'knowledge development and by providing and collecting information in an accessible, convenient, and interactive way' (Majeed-Ariss et al., 2015 p. 2). However, the young people in this study mostly used apps to develop new habits and routines, in particular around medication and self-catheterisation, and to monitor their fluid intake. This finding highlights a potential area for intervention development.

A key finding in the current study was that trust sustained the parent-to-child transfer of self-management responsibility. This is supported by previous research that found parents needed to trust their child to relinquish control (Hanna and Guthrie, 2000b; Babler and Strickland, 2015). By exploring HCPs' perspectives, this study extends our current understanding about the importance of trusting relationships between young person-parent dyads and HCPs during the transfer process. Sullivan-Bolyai et al (2014) found parents lost trust in HCPs when HCPs believed the deterioration in young people's health was a consequence of parents' transferring responsibility to the child before they were ready. The inclusion of HCPs in this study revealed trust was two-way: that young people-parent dyads needed to trust HCPs, and HCPs needed to trust families. Section 8.2.3.3 will discuss how the loss of trust in young people, and HCPs losing trust in families, disrupted the transfer of responsibility.

Some young people in the study believed they needed be able to trust themselves to assume self-management responsibility. This sense that self-management required young

people to develop confidence and belief in their own ability aligns with the concept of self-efficacy (Bandura, 1998). Although the theoretical literature suggested enhancing self-efficacy can facilitate young people assuming responsibility (Hanna and Decker, 2010; Modi et al., 2012; Reed-Knight et al., 2012; Schilling et al., 2002), there is limited empirical research to support this. Colver et al (2020) suggest HCPs should encourage self-efficacy during the transfer process and recommend further research 'to identify the most effective and efficient ways to promote young people's knowledge and confidence in the management of their LTC' (p. 77). It is interesting that the emphasis is on 'knowledge' as the findings of this study suggest it is what young people are 'doing', not their knowledge of their condition, that improves young people's self-efficacy. By identifying actions that helped young people believe in their self-management ability, such as keeping positive and connecting with others with CKD, this study contributes to our knowledge of what supports young people to assume self-management responsibility.

The finding that connecting with other people who had CKD could support young people with assuming responsibility supports existing research (Castensoe- Seidenfaden et al., 2017: Mulvaney et al., 2006; Mulvaney et al., 2008) and is line with recent NHS guidance that advocates peer support (NHS England, 2019). However, as previously reported in relation to other childhood LTCs, some young people with CKD were reluctant to meet others with the same condition (Sullivan-Bolyai et al., 2014). The conflicting findings in this study, about young people's interest in meeting peers or having a role model, is supported by a systematic review, which found some young people with CKD valued sharing experiences with support networks, whereas others prioritised having 'normal' friends (Dallimore et al., 2018). Evaluations of peer support for young people with CKD found young people gained informational and emotional support, and their self-management and self-efficacy increased (Nicholas et al., 2009; Sattoe et al., 2013). Most interventional studies have focussed on peer support for young people; however, this study found that some parents valued meeting other parents who had a child with CKD. Existing literature recommends parents require support with the transfer of responsibility (Heath et al., 2017) and research in other LTCs found parents' skills and confidence in supporting their child to assume self-management responsibility increased following participation in a peer support group (Akre and Suris, 2014). As there is limited evidence regarding peer support for parents of adolescents with a LTC, further research is indicated.

Similar to findings from previous research, some young people in the current study learnt from making mistakes with self-management (Chilton and Pires-Yfantouda, 2015; Spencer

et al., 2013). Parents and HCPs were aware, however, that some mistakes could have a significant impact on the young person's health and, as a result, parents were cautious about relinquishing control (Akre and Suris, 2014). Although the existing literature recommends HCPs increase opportunities for experiential learning so young people can learn through trial and error (Sawyer and Aroni, 2005; Sullivan-Bolyai et al., 2014), there is limited evidence to suggest HCPs have utilised this strategy. Potentially due to including HCP participants, this study extends knowledge in this area, finding that HCPs discussed with parents the benefits of their child making mistakes 'safely'.

HCPs believed that individualised support that reflected the specific needs of young people and parents facilitated the transfer of responsibility. Interestingly, young people and parents who took part in the study did not perceive this as a factor that sustained the transfer process, potentially due to their ambivalence about HCP involvement and their perception that the process was primarily the family's concern. Although guidance emphasises the importance of HCPs adopting individualised or personalised approaches (NHS England, 2019; Saxby et al., 2020), there is lack of evidence in previous literature around how HCPs used these approaches to support the transfer of responsibility. This limited evidence base reflects how very few studies included HCP participants and suggests that individualised support is a concept valued by HCPs, but it potentially has little meaning for young people and parents. Further research to explore how HCPs construct and implement individualised support to sustain the transfer process is needed.

8.2.3.3 Disrupting the transfer of responsibility

As illustrated by Figure 8, young people, parents and HCPs making changes to their actions and interactions could disrupt the parent-to-child transfer of self-management responsibility. Study findings extend our understanding of young people disengaging from self-management and, in particular, the impact of this disruption on trust.

In line with existing research in CKD, the young people in this study attributed their disengagement to: forgetfulness; changing priorities; and risk-taking, due to limited understanding of their condition and the consequences of their actions (Dallimore et al., 2018). Research with young people with sickle cell disease suggested the invisible nature of symptoms could impact on self-management, resulting in young people not seeking help from parents or HCPs and managing their symptoms on their own (Kayle et al., 2016). In contrast, the invisibility of CKD symptoms meant some young people disengaged from self-management, deciding not to follow HCPs' recommendations when the consequences were

hidden or might occur at some uncertain point in the future. Although LTC symptoms have been recognised in the theoretical literature as impacting on self-management (Grey et al., 2014; Mammen et al., 2018; Schilling et al., 2002), the focus is mostly on condition-specific symptoms, such as hypo- or hyperglycaemia in diabetes, rather than the nature of symptoms. However, as other LTCs, like CKD, have 'invisible' symptoms or complications, which may only become visible in the longer term (Silverstein et al., 2005), this finding may be relevant to understanding young people with other LTCs who struggle with assuming self-management responsibility.

Actions and interactions that built and maintained trust were key to sustaining the transfer of responsibility; therefore when trust was lost, the transfer process was disrupted. When parents' trust in their child to engage in self-management had been broken, responsibilities shifted back along the continuum as parents reassumed responsibility for managing their child's condition. As reported in previous studies, parents used a range of overt and covert strategies to monitor their child when trust had been lost (Mulvaney et al., 2006; Ness et al., 2018; Meah et al., 2010). By including HCP participants, this study has enhanced our understanding of the importance of trust between young people, parents and HCPs, revealing how disruptions to the transfer process were associated with a loss of trust between families and HCPs. When trust was lost, HCPs adopted similar strategies to parents, such as increased monitoring of young people's self-management. However, this study revealed the other strategies adopted by HCPs including: subtle and explicit conversations with young people and parents; joint problem solving; and, when there were significant concerns and it seemed that trust could not be retrieved, implementing procedures. Although studies highlighted how parents had previously been threatened with social services involvement when HCPs had concerns about parents relinquishing control prematurely (Sullivan-Bolyai et al., 2014), this current study found HCPs were aware of the ethical and legal complexities associated with the transfer of responsibility. Consequently, the implementation of safeguarding procedures during the transfer process was always a MDT decision. As the transfer of responsibility was currently disrupted for two young people with CKD in this study, and there was uncertainty around whether the transfer process would resume, further longitudinal research is needed to enhance understanding of this phenomenon. Section 8.6 discusses recommendations for future research in more detail.

This section, 8.2, has discussed the study findings in relation to the current literature. The study's contribution to knowledge has been highlighted, although this will be explored in more detail in section 8.4. Next, the strengths and limitations of the study will be examined.

8.3 Strengths and limitations of the study

This section will discuss the strengths and limitations of the study. The context in which the study was conducted will be considered, including the implications for how study findings should be interpreted.

8.3.1 Study strengths

The main strengths of this study were: the methodology; the setting, sampling and recruitment; methods; and PPI. These will be discussed below. Denzin and Lincoln's (2011) criteria for assessing the quality and rigour of qualitative research have been considered in relation to this study in section 4.10. As described in section 3.7, the criteria developed by Charmaz (2014) for grounded theory studies will be used in this section to reflect on this study's credibility, originality, resonance and usefulness.

The application of grounded theory methodology and specifically the strategies described by Charmaz (2014) ensured rigour in the conduct of this study and theory construction. Multi-method, in-depth and iterative data collection enhanced the comprehensiveness of data and credibility of the study findings. Interactions between participants in the dyadic interviews and focus groups generated rich data. Examples of this distinctive data have been presented throughout the findings chapters. Combining this data, generated through individual and dyadic interviews, and focus groups, strengthened study findings and assisted with gaining a deeper understanding of the transfer process. In integrating these different approaches, this study has demonstrated the use of innovative methods in generation and analysis of data.

Conducting the study at two children's kidney units that covered wide geographical areas, in north and south England, ensured variation in the sample. The use of purposive sampling at the two sites resulted in a diverse sample of participants, especially in relation to young people's age, sex, ethnicity and CKD stage/treatment, and HCPs' discipline. Furthermore, as described in section 4.2, the two sites adopted different models of care for supporting young people with CKD; this enabled inclusion of a wider range of perspectives, ensuring comprehensiveness and variation in data.

This study demonstrated originality as it is the first grounded theory study exploring the views of young people with CKD, parents and HCPs on the transfer of responsibility. The

limited number of studies that have explored HCPs' perspectives on young people assuming responsibility have mostly involved nurses. Therefore, by extending the range of HCPs' narratives, this study has made a unique contribution to our understanding of the transfer process. The use of strategies such as detailed coding, constant comparison, searching for negative cases, memo-writing, and diagramming supported the construction of categories that offered new insights and a novel theory, *shifting responsibilities*. By discussing how study findings support and extend the existing research and theoretical literature, section 8.2 has highlighted the originality and significance of this current study.

Having patient and public involvement (PPI) and an advisory group to advise on the design and conduct of the study was a major strength. Conducting PPI throughout the study improved the quality and relevance of the findings, and, as section 4.3.2.2 discussed, had a significant impact on the study and the author of this thesis. In particular, discussing study findings, and the emergent categories and theory with PPI contributors, suggested *shifting responsibilities* resonated with their own experiences of the transfer of CKD self-management responsibility. The sense that exploring this topic was important and resonated with participants was evident during research encounters. For example, some participants discussed how the process of participating in the study had prompted them to reflect on, and discuss, the transfer of responsibility, for the first time. Other participants commented how they valued having an opportunity to reflect on their experience and be listened to. Finally, through its contribution to knowledge, implications for policy and practice and recommendations for future research, this study has demonstrated its usefulness (Charmaz, 2014). Sections 8.4, 8.5 and 8.6 will discuss these three areas.

8.3.2 Study limitations

The study has a number of limitations, in relation to the sample and methods. However, conducting the study was a learning process and, with hindsight, there are aspects which might have been carried out differently.

Clinicians in the two renal teams were responsible for identifying and approaching potential study participants. Although a diverse sample participated in the study, reliance on gatekeepers for recruitment may have introduced intentional or unintentional selection bias; this could potentially impact on transferability of study findings. It is also recognised that the realities constructed during data generation with young people, parents and HCPs were constructed within a particular context and time. This should be taken into account when considering whether study findings have applicability to other contexts.

The sample recruited to the study had a number of limitations. The parents in the sample were mostly mothers, perhaps because they were more likely to have management responsibility for their child's CKD than fathers. However, as the perspectives of fathers could be distinctive from those of mothers, the study findings may have been strengthened if more fathers had participated. In hindsight, adapting the sampling approaches to specifically focus on inviting fathers to participate may have been beneficial. Importantly, the sample included young people who struggled with assuming responsibility and parents reluctant to relinquish control. However, the two young people who were currently disengaged from self-management unfortunately did not participate in the study, which meant the data generated was solely from their parents. Including the perspectives of young people where the transfer of responsibility was presently, rather than historically, disrupted, may have provided a deeper understanding of the transfer process.

A potential methods limitation was the use of single interviews or focus groups as the primary approach to data generation. Relying on these retrospective accounts limited the analysis to a single point in time, potentially reducing development of a fuller understanding of how the process of *shifting responsibilities* evolved over time. Conducting a longitudinal study, where multiple research encounters occurred with participants over a period of time, may have enhanced the research. In particular, generating data through a series of interviews with young people and parents who were struggling with the transfer of responsibility may have contributed to theory development regarding the temporal aspect of *shifting responsibilities*, and whether the process would always reinitiate following disruption, or whether it had come to an end.

The methods used in this study to collect data relied on participants' self-reports and how they chose to present themselves during research encounters. Therefore, the theory developed reflected what participants were able to recall, what they considered relevant and what they were willing to share. The findings may have been strengthened by the author completing observations, for example of young people completing self-management or of interactions between young people, parents and HCPs during clinic appointments. However, as the findings suggested, the transfer of responsibility occurred over a long period of time, and primarily within the family home, so conducting observations would have been challenging within the confines of the study's timeline and resources. Conducting dyadic interviews and focus groups provided an opportunity for observing interactions between young people-parent dyads, and between MDT members. As the data extracts and

discussion in the findings chapters illustrate, the data generated through these interactions contributed to a richer understanding of the transfer of responsibility.

Finally, the study findings were based on the author's analysis and interpretation of young people's, parents' and HCPs' accounts. It was acknowledged throughout the study that my views, ideas, knowledge, experiences, background and assumptions shaped the research process and outcomes. Reflexivity was key to recognising that the outcome of the study would be an 'interpretative portrayal' rather than an 'exact picture' of the transfer of self-management responsibility. The reflexive stance taken during this study was discussed in section 4.11.

8.4 Contribution of the study to knowledge

This study has contributed to knowledge in terms of its topic area and methods. The overall aim of this study was to enhance understanding of the parent-to-child transfer of self-management responsibility for CKD 3-5. This is the first grounded theory study, either in the UK or internationally, that has explored: how young people with CKD assume self-management responsibility; how parents relinquish control; and the role of HCPs during this transfer process. The study findings have produced new practical and theoretical insights into young people's, parents' and HCPs' experiences, and families' support needs during the transfer of responsibility. A grounded theory of *shifting responsibilities* has been developed that explains the processes that occur, including what initiates, sustains and disrupts the transfer of responsibility, and the contextual influences that impact on when and how responsibilities shift.

One of the key contributions this study has to offer is greater understanding of how young people, parents and HCPs constructed the transfer of self-management responsibility. As the first study that has had an equal focus on young people's, parents' and HCPs' perspectives of the transfer process, and included HCPs from six different disciplines, it has extended knowledge around HCPs' roles. Most significantly, by including HCPs, the study found young people's, parents' and HCPs' constructions around the transfer process differed. Although there were some similarities in how young people, parents and HCPs viewed the process, tensions were evident between: young people and parents; young people-parent dyads and HCPs; and also different HCPs in the renal MDT. The differences manifested in how many aspects of the process were perceived, including: when young people started to assume responsibility; who initiated and was subsequently involved in

supporting the transfer process; how and why the process was initiated; what aspects of self-management were transferred; what sustained and disrupted the process; how the transfer process aligned with young people gaining independence in other areas of their life; when the process was completed; and what the outcome was for young people and parents. As a potential consequence of these differing constructions, there was ambivalence among young people and parents around the HCP's role in supporting the transfer of responsibility.

This study also demonstrated originality in its methods. It is the first known grounded theory study to use a combination of individual and dyadic interviews, together with focus groups, for data collection. Using methods that explicitly generate data as a result of interaction between participants was considered to be compatible with constructivist assumptions as it enabled young people, parents and HCPs to co-construct their understandings of the transfer process. Rich data were generated, in particular around how young people and their parents, and HCPs as both individuals and members of the MDT, constructed and negotiated the transfer of responsibility. This study used a novel approach to analysing data, in its integration of grounded theory analytic strategies, with an established method to explicitly analyse how interaction had shaped data generation in the dyadic interviews and focus groups. This unique combination of focus group data with data from individual and dyadic interviews assisted with gaining a deeper understanding of the transfer of self-management responsibility.

Finally, the professional background of the author of this thesis contributed to this study's originality. As an occupational therapist (OT), with clinical experience in both children's and adult's services, novel insights have been gained by viewing the transfer of responsibility through an OT lens. The following sections, in discussing implications for policy, practice and education, and recommendations for future research, explore how OT could further contribute to the area of self-management.

8.5 Implications for policy, practice and education

Several issues arise from this study that have implications for policy, practice and education.

8.5.1 Policy

A significant finding from this study was the difference in how the transfer of responsibility was contextualised. Young people and parents viewed the transfer process within a broader, developmental context. Parents mostly initiated teaching their child to perform self-

management during early childhood. In contrast, HCPs viewed the transfer of responsibility within the context of transition between children's and adult's services. By following national guidance for transition (NICE, 2016; DoH, 2006; DoH, 2008), HCPs' involvement in the transfer of responsibility started when the young person was around 13 years old. The difference between the timing of HCP involvement and when the process started for the family contributed to young people's and parents' ambivalence around the HCP's role during the transfer of responsibility.

Recently, transition literature has started to emphasise 'developmentally appropriate healthcare' (DAH) as the central concept that should underpin all health care services for young people, and especially those in transition (Colver et al., 2020, Farre et al., 2015). A key aspect of DAH is that families should be supported with the parent-to-child transfer of self-management responsibility (Farre et al., 2016). However, DAH's focus on adolescence, as the developmental stage when HCPs should start facilitating 'graded opportunities to develop self-management skills' (Colver et al., 2020 p. 77), does not recognise that young people have already started developing self-management skills, often during early childhood, in line with acquiring independence in other daily activities.

Recent guidance that is underpinned by the concept of developmentally appropriate self-management recognises that children are on a trajectory of developing self-management skills that can begin in early childhood (Saxby et al., 2020). In contrast to the transition and DAH literature which focus solely on adolescence, Saxby et al (2020) recommend how HCPs can support self-management from infancy through to 20 years of age. As a result, this guidance more closely aligns with how young people and parents in this study constructed the transfer of responsibility. However, by failing to integrate self-management with other daily activities where young people are developing independence, the guidance does not recognise that young people's and parents' motivations to initiate and sustain the transfer process are affected by wider contextual issues. Other limitations of this guidance have been discussed in chapter 1. Therefore, further development of guidance is recommended based on the findings of the current study, and the acknowledgement that self-management skills are developed in conjunction with gaining independence in other everyday activities throughout childhood.

Findings from this study also suggested tensions between how parents and HCPs approached the transfer of responsibility. Parents adopted a 'doing approach'; their focus was on their child's performance of self-management activities. In contrast, HCPs employed

a 'knowing' approach, focused on the young person's knowledge of their condition and treatment. Young people demonstrating their knowledge was viewed by HCPs as 'objective' or 'testable', whereas parents repeatedly observed their child complete a self-management activity until they felt confident in their child's independence and safety. Although existing guidance suggests HCPs' assessment of young people's ability to self-manage is critical, the emphasis is on testing young people's knowledge, rather than their performance of self-management tasks (Saxby et al., 2020; Nagra et al., 2015; Sattoe et al., 2014). Therefore, further development of guidance and checklists is recommended based on this study's findings. These would incorporate the need for HCPs to complete ongoing assessment of young people's engagement in and actual performance of self-management throughout the developmental trajectory.

8.5.2 Practice and education

Several implications for clinical practice and HCP education arise from this study. As discussed previously, extending the timeframe of HCP involvement could help the transfer of responsibility to occur more gradually over time. In line with recent guidance (Saxby et al., 2020), HCP input from the earliest possible point after CKD diagnosis through to young adulthood may be useful in supporting children to develop self-management skills appropriate to their developmental stage. To implement this in practice, HCPs may require further training around DAH.

Young people and parents may also benefit from HCPs considering self-management alongside other daily activities where young people are developing independence. Through taking into account these other activities, HCPs would gain enhanced understanding of young people's motivations, priorities, habits and routines, and how they impact on their readiness to assume self-management responsibility. Additionally, HCPs could obtain a more accurate and holistic picture of a young person's readiness, through assessing a young person's independence in other everyday activities and observing their actual performance of self-management activities, rather than solely relying on young people's demonstrations of knowledge.

To incorporate this wider, more holistic approach, the renal MDT could benefit from the involvement of other disciplines that have this expertise in 'doing'. The discipline of occupational therapy focuses on 'occupations' or activities people need and want to do as part of their daily life (RCOT, 2015). Using assessments and interventions centred on 'doing', or engaging in occupations, occupational therapists' (OT) core area of expertise is

supporting people's participation in everyday activities. Underpinning OT is the profession's core assumption that 'doing' can be used to cause a positive change (Pentland et al., 2018). Despite increasing recognition of the contribution OT could make in supporting young people with LTCs to develop self-management skills (Cahill et al., 2016), attention to self-management in OT literature, and the potential role of OTs in supporting self-management in the wider literature, is virtually non-existent (Pyatak, 2011). Although OTs are part of the MDT in adult renal services, there is significant variation across the UK and none of the UK children's kidney services include OT (Blank et al., 2005). This study's findings suggest the inclusion of OTs in the renal MDT to support young people to assume self-management responsibility, in conjunction with developing independence in other everyday activities, would be beneficial. Alternatively, training for existing members of the renal MDT, that is underpinned by OT theory and models of practice, would support HCPs to think more holistically about the transfer process.

This study's findings about the actions and interactions that initiated, sustained and disrupted the transfer of responsibility have implications for practice and education. Importantly, HCP involvement was supportive when it: promoted a gradual transfer of self-management responsibility; encouraged partnership; developed routines; fostered positivity; built and maintained trust; facilitated connections with others with CKD; enabled learning from mistakes; and was individualised to young people's and parents' preferences and needs. Young people and parents would benefit if HCPs received training and were supported in practice to adjust their involvement so it more closely aligned with young people's and parents' support needs and preferences identified in this study.

Developing partnerships helped facilitate the transfer of responsibility and clear, tangible HCP actions were found to promote this, including: directing communication primarily at young people rather than parents; exploring young people's concerns and their motivation to assume responsibility; joint goal-setting; findings solutions together; and, through acting as an advocate for the young person, helping them to negotiate with their parents around the transfer of responsibility. Alongside utilising these strategies, it would be beneficial if HCPs recognised parents were central to supporting young people to assume responsibility. Contrary to transition guidance, this study found that parents' exclusion from consultations was not critical to enabling the transfer process to occur. Parents' difficulties with relinquishing control suggests parents themselves would benefit from support with transferring responsibility to their child. This could include HCPs advising parents on how to gradually engage their child in developmentally appropriate self-management (Heath et al.,

2017; Saxby et al., 2020) and guide their child as they become increasingly involved in managing their own condition (Buford, 2004; Christian et al., 1999; Sullivan-Bolyai et al., 2014). Having opportunities to connect with other parents of adolescents with CKD, combined with HCP support and reassurance about their child's self-management ability, could benefit parents, especially those struggling to 'let go' (Dashiff et al., 2011; Heath et al., 2017). To adjust their practice, HCPs may require further training and guidance around how to balance family-centred with child-centred care, and how this interacts with transition guidance and DAH.

Building and maintaining trust was identified as key to sustaining the transfer of responsibility. When trust was lost, the transfer process was disrupted. HCPs adjusting their actions and interactions to support trust to develop between young people and their parents, and between families and HCPs, would be beneficial. For example, HCPs creating or identifying opportunities where parents witnessed their child being responsible for managing their condition (Heath et al., 2017), such as following their renal diet when eating at school or out with friends, could reassure parents that they can trust their child.

A range of strategies will be used to inform policy, practice and education of this study's findings. These will include:

- publication in peer-reviewed journals. For example, papers reporting on study methods and findings, will be submitted to child/adolescent health, qualitative health research and occupational therapy journals;
- presentations at conferences, the British Association of Paediatric Nephrology Clinical Study group, the two sites that participated in the study, and more widely to NHS Trusts that have children's kidney units;
- dissemination of findings to study participants, and the wider community of renal patients and their families via Kidney Research UK, and other charities, organisations and renal patient groups. Advice from PPI contributors will be sought to ensure findings are shared via relevant routes and using plain English.

8.6 Recommendations for future research

This is the first study, either in the UK or internationally, that has explored the parent-to-child transfer of self-management responsibility for CKD; therefore, more research is required to build on and extend this work. Based on the findings from this study, further research from

both theoretical and clinical perspectives is recommended to develop understanding and practice in this complex area of health care.

Further qualitative research is recommended to build on the theory of *shifting responsibilities*. This study focused on how young people aged 13-17 years old, their parents and HCPs experienced the transfer of responsibility. However, as the transfer process was initiated in some families when the child was starting primary school, examining this process from early childhood through different developmental stages would contribute to understanding around how, when and why children assume self-management responsibility, and how this process aligns with children gaining independence in other areas of their life. Observations of interactions between parents and their child, and between child-parent dyads and HCPs, would help with gaining insight into how children start 'doing' self-management. Exploring how HCPs frame the transfer process when it is no longer situated within the context of transition to adult services would enhance understanding.

None of the young people in this study had assumed full self-management responsibility; parents continued to have responsibility for managing some aspects of their child's condition. This meant uncertainty remained around the outcome of the process of *shifting responsibilities*. Research with young adults is recommended to extend understanding of how the transition to adult health services impacts on the transfer of responsibility, the role parents have and the outcome of the transfer process. Related to this question around outcomes, some young people, parents and HCPs suggested that being fully responsible for self-management was neither realistic nor desired; they perceived that, in adulthood, some people with CKD continued to share management with others, including family members and HCPs. Further research to explore how these concepts of self- and shared-management and responsibility are constructed would be useful and potentially enhance understanding of how these constructs impact on the transfer of responsibility. Finally, the theory of *shifting responsibilities* was developed from data generated from young people with CKD; it would be worthwhile to investigate whether the theory is relevant to young people with other LTCs such as diabetes or asthma.

Clinical research is also recommended. Young people's, parents' and HCPs' perspectives on what supported young people and their parents during the transfer of responsibility were identified. Ideas were generated for interventions that could sustain the transfer process, including digital technology to support young people with creating and maintaining self-management routines, and connecting with others affected by CKD, through peer support or

role models. The development of interventions that are occupation-focused, and based on OT theory and models, are also recommended, especially as exploring the role of OT in supporting self-management was recently identified as one of the UK's top 10 OT research priorities (RCOT, 2020). It is recommended that any future research to develop and evaluate interventions is underpinned by the evidence-base and theoretical literature, involves young people, parents and HCPs as key stakeholders and utilises a recognised approach, such as the MRC framework (Craig et al., 2013).

8.7 Conclusions

This study has contributed to knowledge by exploring and presenting young people's, parents' and HCPs' experiences of the parent-to-child transfer of self-management responsibility for CKD. A grounded theory, *shifting responsibilities*, was constructed from the narratives, which explained the main process occurring as young people assumed self-management responsibility and parents relinquished control. Through equally focusing on HCPs' perspectives, alongside those of young people and parents, this study revealed how young people's, parents' and HCPs' constructions of the transfer process differed. Whereas young people and parents viewed the transfer of responsibility within a broader context of developing independence in daily activities, HCPs framed the process within the narrower context of the transition to adult health services. Transition guidance and the concept of developmentally appropriate health care underpinned HCPs' decision making around their involvement in the transfer process. This meant the timing of HCP involvement was service-led, rather than based on family's needs, and conflicted with HCPs' beliefs that support needed to be individualised. These different constructions contributed to the uncertainty around the role of HCPs, when the process started and was completed, and, importantly, whether the endpoint of the process was young people's self-management or young person-parent shared management.

The study highlighted the contextual issues that influenced how and when responsibilities shifted. The assumption of responsibility was viewed by young people and parents as a natural extension of the 'normal' process, where becoming older and growing up involved increased independence. However, parents and HCPs were aware the risks associated with developing independence were heightened for young people with CKD. Consequently, there was tension around encouraging young people to assume responsibility, while balancing protection and risk. Young people's, parents' and HCPs' actions and interactions resulted in the transfer process being initiated, and then either sustained or disrupted. The tension

between parents taking a 'doing' approach and HCPs a 'knowing' approach when initiating the transfer of responsibility, was revealed. The study has enhanced understanding of the actions and interactions that both sustained and disrupted the process of young people assuming responsibility. Trust between young people and parents, and between young people-parent dyads and HCPs, was critical to the transfer process; when trust was lost as a result of young people disengaging from self-management, there was uncertainty around whether the transfer of responsibility would resume or had come to a premature end.

The implications of this study for policy, practice and education, and recommendations for future research, have been identified. It is hoped that this study will contribute to HCPs' knowledge and understanding of how young people and parents construct the transfer of self-management responsibility and, through doing this, will inform and enhance future support provided to families.

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APPENDICES

Appendix 1: Literature search strategy

Example of the search strategy used in MEDLINE

#	Searches
1	child*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
2	teenager*.mp.
3	adolescen*.mp.
4	young person.mp.
5	young people.mp.
6	youth.mp.
7	juvenile.mp.
8	p*ediatric.mp.
9	*Pediatrics/
10	exp Adolescent/
11	exp Child/
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13	exp Self Care/
14	self manag*.mp.
15	self-manag*.mp.
16	self care.mp.
17	self-care.mp.
18	self help.mp.
19	self-help.mp.
20	collaborative care.mp.
21	collaborative manag*.mp.
22	shared manag*.mp.
23	self medicat*.mp.
24	disease manag*.mp.
25	parent to child transfer.mp.
26	parent to child transition.mp.
27	transition to adulthood.mp.
28	exp Transition to Adult Care/

29	transition to adult care.mp.
30	health care transition.mp.
31	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
32	exp Chronic Disease/
33	chronic disease*.mp.
34	chronic condition*.mp.
35	chronic illness*.mp.
36	long term condition*.mp.
37	long-term condition*.mp.
38	diabet*.mp.
39	exp Diabetes Mellitus/
40	exp Asthma/
41	asthma.mp.
42	exp Cystic Fibrosis/
43	cystic fibrosis.mp.
44	exp Epilepsy/
45	epilep*.mp.
46	Renal Insufficiency, Chronic/
47	chronic kidney disease.mp.
48	chronic renal disease.mp.
49	Kidney Failure, Chronic/
50	chronic kidney condition.mp.
51	chronic renal condition.mp.
52	CKD.mp.
53	chronic kidney failure.mp.
54	32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53
55	12 and 31 and 54
56	limit 55 to (english language and humans and yr="1995 -Current")

Appendix 2: Included studies

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Akre and Suris (2014)	To look at parents of adolescents with chronic illness to: 1) identify their needs and preoccupations in dealing with their child's autonomy acquisition 2) determine whether mothers and fathers coped differently.	Qualitative. Focus groups. Thematic analysis.	Switzerland. 30 parents, 5 focus groups (18 mothers in 3 focus groups, 12 fathers in 2 focus groups). Parents of 20 adolescents aged 14-19 with range of chronic illness.	Mothers more involved, fathers let child make mistakes. Disparity between child and parents re: giving and taking on autonomy. Varying degrees of autonomy in how children handled their treatment and how parents reacted. Parents concerned re: potential future consequences as a result of child making self-management mistakes.	None reported.	None reported.
Auslander et al (2010)	1) What are adolescent and mother perceptions of resources and barriers to self-management among African American youths with type 2 diabetes? 2) To what extent do adolescents and mothers share views self-management?	Qualitative. Individual interviews. Modified grounded theory approach to text analysis.	USA. 10 African American adolescents (9 females), aged 15-18 with type 2 diabetes, and their mothers.	Resources: mother's role as primary support; gaining self-efficacy and coping over time; recognition of the seriousness of diabetes - family stories about diabetic relatives used to motivate children; supportive peers. Barriers: comorbidity; dietary and other regimen challenges; fitting in with peers; financial concerns.	Used strengths perspective. Discussed findings in relation to Health Belief Model.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Babler and Strickland (2015)	To gain an understanding of the adolescent's perspective, of their experiences in living with diabetes, their challenges and management issues and to build a theoretical paradigm to create future interventions.	Qualitative. Grounded theory. Individual interviews. Constant comparison analysis.	USA. 11 adolescents aged 11-15 with type 1 diabetes.	Major task for adolescents is separating from parent and independently managing diabetes. 3 aspects identified 1) Taking over care e.g. slow process, affected by parents' willingness to let go of care 2) Experiencing conflict with parents 3) Realising diabetes is hard. Key component in normalising is how adolescent is able to manage taking on the burden of care.	Theoretical model developed from findings based on concept of normalising.	None reported.
Buford (2004)	To explore the process for transfer of asthma management from parents to their school-age children.	Qualitative. Grounded theory. Indepth individual interviews.	USA. 14 children with asthma, aged 8-13, 14 adults (11 mothers, 2 fathers, 1 grandmother).	Transfer of responsibility is complex process and involves identifiable stages. Central concept underlying process 'controlling the situation': has 3 discrete states (out of control, autopilot, letting go) and 2 transitional stages (gaining control and empowerment). Families have unique characteristics e.g. health beliefs, parenting styles. Progression to autopilot stage was antecedent to beginning transfer of responsibility.	Theoretical model for parent-child transfer of asthma responsibility emerged from data.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Castensoe-Seidenfaden et al (2017)	To explore and describe the experiences of adolescents and their parents living with type 1 diabetes, to identify their needs for support to improve adolescents' self-management skills in the transition from child- to adulthood.	Qualitative. Explorative, using visual storytelling. Individual interviews. Thematic analysis.	Denmark. 9 adolescents aged 15-19 with type 1 diabetes, 13 parents (7 mothers, 6 fathers).	4 themes: 1) striving for safety - parents and friends as a 'safety net', parents lacked trust and wanted to maintain control to reduce risks 2) striving for normality – young people took time off self-management to feel normal, parents felt sorry for child and supported them when needed time off; others had integrated/accepted it as part of lives 3) striving for independence - both young people and parents wanted young person to be independent 4) worrying about future.	None reported.	None reported.
Chilton and Pires-Yfantouda (2015)	To understand how adolescents adapt to their self-management requirements from diagnosis to the point of successful self-management.	Qualitative. Social constructivist version of grounded theory. Semi-structured individual interviews. Constant comparative analysis.	UK. 13 young people aged 13-16 with type 1 diabetes.	Framework consists of self-management continuum with success at one end, and difficulties at the other. Transitional phases located within the continuum (e.g. impact of diagnosis, turning point, acceptance, distancing). Process mechanisms facilitate transition between phases - dynamic nature of adaptation across the continuum.	Developed conceptual framework re: how participants self-manage diabetes during adolescence.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Christian et al (1999)	To explore the meaning of the chronic illness experience for adolescents with diabetes in relation to taking on responsibility for their own care.	Qualitative. Grounded theory approach. Individual interviews. Constant comparison method used for data analysis.	USA. 4 adolescents, aged 14-18, with insulin dependent diabetes mellitus.	Process of learning self-responsibility began at around 12 years old. Gradual transition from dependence to independence. Worked with parents as partners, learned to share responsibility and gradually became less dependent. Gaining freedom as gaining self-responsibility. Child's cognitive and emotional readiness impact on acceptance of self-responsibility.	Develop-mental theory.	None reported.
Dashiff et al (2011)	To describe the experiences of parents of 16-18 year olds with type 1 diabetes in transitioning self-management to their adolescent.	Substudy of larger study. Qualitative data presented in paper. Individual interview or joint interview if both parents participated. Qualitative content analysis.	USA. 40 participants from 23 families, range of family structures including grandparents, stepparents. All had child, aged 16-18 with type 1 diabetes.	Parents' described positive and negative experiences. Positive: support from school and HCPs; parents tried to enhance adolescents' ability to problem solve. What worked: reminding child, noticing positive aspects of child's self-management. Negative: worried about when and how to let child take on responsibility without compromising glycaemic control. What didn't work: nagging, getting emotional.	None reported.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Ersig et al (2016)	To identify stressors of adolescents with type 1 diabetes, and their parents, relevant to the impending transition to adulthood.	Qualitative. Semi-structured telephone interviews. Qualitative descriptive analysis.	USA. 15 teenagers (aged 12-18, 11 female, 4 male) and 25 parents (15 mothers, 10 fathers) representing 16 families. All Caucasian.	Primary concern for teenagers was around ineffective self-management, turned to parents for support but over time relied less on parents. Parents' involvement in care differed, some wanted to retain control of management, others resumed responsibility when child made mistake, others viewed child's self-management as part of trial and error process. Parents concerned about short and long-term adverse outcomes.	None reported.	None reported.
Hanna and Guthrie (2000a)	What are adolescents' perceived benefits and barriers related to assuming diabetes management from their parents?	Qualitative descriptive study. Semi structured interviews. Content analysis.	USA. 16 adolescents aged 11-18 (56% female, 94% Caucasian)	Benefits for adolescents: having knowledge of, or confidence in self-management abilities; having more freedom; having approval of others. Benefits for parents: relief from responsibility, stress and worry. Barriers for adolescents': burden of responsibility. Barriers for parents: worry and guilt; loss of control.	Health Belief Model. Developmental theory.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Hanna and Guthrie (2000b)	What are parents' perceived benefits and barriers to transferring diabetes management during adolescence?	Qualitative descriptive study. Semi structured interviews. Inductive content analysis.	USA. 17 parents of adolescents with type 1 diabetes, 76% mothers, 88% Caucasian.	Benefits for parents: relief from burden; pride in child's abilities. Benefits for adolescents: confidence in abilities, freedom, independence. Barriers for parents: loss of control, authority and supervision; dealing with consequences. Barriers for adolescents: burden of responsibility. Parents struggling with balancing burden of diabetes management between themselves and child.	Health Belief Model. Develop-mental theory.	None reported.
Hanna and Guthrie (2001)	To identify positive and negative dimensions of support related to adolescents' assumption of diabetes management responsibility from the perspectives of adolescents and parents.	Qualitative. Individual interviews. Deductive content analysis, based on identified dimensions of support.	USA. 16 pairs of adolescents, aged 11-18, with type 1 diabetes (56% female, 94% Caucasian) and their parents (12/16 mothers).	Parents' views of helpful behaviours: direct commands, reminding, discussions. Non-helpful behaviour: reminding too early; physical help when not wanted by child. Adolescents' views of helpful behaviours: financial support, negotiating, encouragement. Non-helpful behaviours: physically helping when it's not needed. Dynamics of parent-child relationship and parenting style important.	Theoretical literature on support.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Husted et al (2014)	To explore and illustrate influenced developing life skills in adolescents with diabetes, when supported by their parents and health professionals.	Qualitative realistic evaluation Recorded sessions of adolescent-parent-HCP triads. Interviews with adolescents, parents and HCPs. Data analysed both deductively and inductively.	Denmark. 13 adolescents aged 13-18 with type 1 diabetes (7 female, 6 male); 17 parents (2 parent couples, 7 mothers, 1 father); 8 HCPs.	Process of developing life skills launched by involving adolescents first, and parents second in decision-making and problem-solving. Adolescents and parents completing reflection sheets was beneficial, and HCPs advanced communication skills useful to focus on difficulties perceived as important by adolescents and alleviate tension when adolescent-parent conflicts occurred.	Methods based on RE - theory driven approach that evaluates how expected changes occur.	None reported.
Jedeloo et al (2010)	To explore the attitudes of adolescents with chronic conditions towards health care delivery and self-management.	Mixed methods. Q-methodology. By-person factor analysis of Q-sorts.	Netherlands. 31 adolescents, aged 12-19 (mean age = 15.3) with variety of chronic conditions.	Identified 4 distinct preference profiles 1) Conscious and compliant: high level of involvement with disease management 2) backseat patient: less mature, lean more on their parents 3) self-confident and autonomous: don't feel they need help from HCPs or parents in managing their care 4) worried and insecure: welcome support from HCPs in learning how to manage disease.	None reported.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Karlsson et al (2008)	To elucidate lived experiences, focusing on the transition towards autonomy in diabetes self-management among teenagers with type 1 diabetes.	Qualitative. Ideas from Vancouver School of Phenomenology used in data collection and analysis.	Sweden. 32 teenagers, aged 13-17 with type 1 diabetes.	Some willing to take full responsibility, others too immature. Hovering between separating from parents and retaining parental support resulted in unclear responsibility. Transition towards autonomy affected by growth through individual self-reliance (e.g. self-determination, psychological maturity, motivation) and growth through confirmation of others.	None reported.	None reported
Kayle et al (2016)	To explore and describe the challenges faced by adolescents with sickle cell disease (SCD) and their parents, and the work they engage in to shift from parent-to-independent adolescent self-management.	Qualitative. Focus groups. Content analysis. Provisional codes based on Adaptive Leadership Framework for Chronic Illness.	USA. 14 adolescents aged 11-18 with SCD, 14 parents/carers.	Adolescents' challenges: mastering symptom management, communicating about SCD. Adolescents' work to address challenges: pushing back at parents, defaulting back to parent care, learning about SCD. Parents' challenges: giving over management, balancing protection and risk with fostering independence. Parents' work to address challenges: engaging child in dialogue, co-managing with child.	Adaptive Leadership Framework for Chronic Illness.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Kirk (2008)	Wider study - to investigate young people's experiences of living with medical technology. Focus of paper: how young people with complex healthcare needs experience different transitions.	Qualitative. In depth interviews. Constant comparative method of analysis.	UK. 28 young people, aged 8-19, using range of health care technologies. 9 children unable to participate in interview, so parents were key informants on their children's experiences.	Learning to manage therapies/devices: gradual process, moving from parental to shared responsibility to self-care, different activities transferred at different times. Parents had 'coaching' role. Individualised process, negotiated between young person and parent, and initiated by either. Not necessarily determined by age or cognitive ability.	None reported.	None reported.
Meah et al (2010)	To explore how the distribution of responsibilities for asthma self-care is negotiated between children aged 7-12 and their parents.	Qualitative. Individual interviews. Framework analysis.	UK. 18 children with asthma aged 7-12, and their parents.	Asthma self-management responsibilities viewed within context of children's everyday lives. Is a negotiated, complex process. Changing role for parents. Children have different understandings of their bodies and asthma, so view being responsible differently to their parents. Responsibility as the exercise of agency by children rather than compliance with adults' instructions and prescriptions.	Feminism. Sociology.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Meaux et al (2014)	To explore how adolescents and their parents perceive self-management, and how adolescents navigate the transition to independent self-management.	Qualitative. Computer mediated focus groups. 3 focus groups for younger adolescent, older adolescent and parents. Thematic analysis.	USA. 4 adolescents, aged 13-21 who had a heart transplant, 6 parents (4 mothers, 2 fathers).	Managing medications: Parents' role modelling/ teaching, child involved in preparing medication but parents had overseeing role. Responsibility increased with age. Time since transplant and development of complications also influential. Child viewed managing medication as 'normal' as had become part of their routine. Concerns about consequences of non-adherence to medication.	None reported.	None reported.
Mulvaney et al (2006)	To ask parents to describe barriers to, and facilitators of adolescent self-management, and their own experiences of caring for an adolescent child with type 2 diabetes.	Qualitative. Focus groups. Framework approach to data analysis.	USA. 27 parents/ guardians, 89% women, 63% African American. Average age of child = 15.2 years. 56% of parents also had diabetes.	Domains which influenced self-management: others with diabetes; parenting skills (e.g. monitoring, reminding); perceived lack of normalcy (e.g. peer relations); environment (e.g. lack of experiential learning at clinic); typical adolescent development (e.g. limited awareness of long-term consequences, conflict). Child's autonomy varied, some needed watching, others independent.	None reported.	Focus group questions refined in cognitive interviewing with volunteer families.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Mulvaney et al (2008)	To explore perceptions of self-care activities among adolescents with type 2 diabetes, including barriers to and facilitators of self-management.	Qualitative descriptive study. Focus group interviews. Framework approach to data analysis.	USA. 24 adolescents, aged 13-19 (mean age = 15.2) with type 2 diabetes. 62 % female, 71% African American.	Domains that affected self-management: adolescent psychosocial development (e.g. lack of normalcy, rebellion, denial/future orientation, peers); role of others with diabetes (e.g. family member); environment (e.g. school, parenting behaviours); child's problem-solving and coping skills.	None reported.	Focus group questions refined in cognitive interviewing with volunteer families.
Ness et al (2018)	To gain understanding of maternal experiences of transitioning their emerging adult with type 1 diabetes to college.	Qualitative descriptive study. Individual interviews. Thematic analysis, using Revised Self and Family Management Framework.	USA. 9 mothers of high school seniors (aged 17-18) with type 1 diabetes.	4 themes 1) concern for health & safety at college: child's ability to manage diabetes, level of preparedness of child & readiness of parent for change 2) emerging roles: relationships & roles changing, need to relinquish control, parents as safety net 3) changing communication: YP frustrated with parents involvement 4) need for support systems.	Interview guide & data analysis based on Revised Self and Family Management Framework.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Newbould et al (2008)	To examine the partnerships between young people and their parents in the management of medication for 2 chronic conditions - diabetes and asthma.	Qualitative. Semi-structured interviews with both structured and open questions. Qualitative and quantitative data analysis.	UK. 69 young people, aged 8-15 (43 with asthma, aged 8-12; 26 with diabetes, aged 8-15). 78 parents (65 mothers, 13 fathers).	Transfer of responsibilities from parent to child often happened without prior planning but in response to specific occasions (e.g. starting secondary school). Seen as natural process of growing up. A few parents reported transfer as part of a strategy or longer term goals, and adopted a more planned approach. Only few parents spoke with HCPs about transfer as felt HCPs not interested in being involved.	None reported.	None reported.
Olinder et al (2011)	To gain insight into and generate theoretical knowledge about the processes involved when insulin pump-treated adolescents take or miss taking their bolus doses.	Qualitative interview study. Grounded theory. Constant comparison method used for data analysis.	Sweden. 12 adolescents aged 12-19 with diabetes (5 boys, 7 girls). 4 parents. 1 paediatric diabetes specialist nurse.	Lack of responsibility is main reason for missed bolus doses/insufficient self-management. Responsibility for self-management discussed rarely, child doesn't think about this or discuss it with parents or HCPs. Optimal if responsibility moves gradually from parent to child. Need to clarify responsibility for self-management in continuous negotiations between child/parent.	Developed theory and model around responsibility for self-management	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Rankin et al (2018)	To understand and explore the challenges pre-adolescents encounter self-managing diabetes, & the factors and considerations which motivate & enable them to take on new self-management tasks.	Qualitative. In-depth interviews. Thematic approach informed by method of constant comparison.	UK. 24 children with type 1 diabetes, aged 9-12.	1) Barriers: over reliance on parents; lacking maths skills to count carbs & calculate insulin doses; accessing difficult to reach injection sites. 2) Motivations: minimise pain when injections administered by others; alleviate parent burdens; becoming more autonomous; starting secondary school. 3) Enablers: strategies to minimise need to perform complex maths; using technology & mobile phones.	None reported.	None reported.
Rhee et al (2009)	1) To assess the common types of barriers perceived by adolescents with asthma 2) To examine the associations between barrier perception and psychosocial factors.	Quantitative. Cross sectional study. Used range of standardised and non-standardised measures. Data analysed using descriptive statistics, factor analysis and hierarchical regression.	USA. 126 adolescents, aged 13-20 (mean age = 15.5) with asthma. 40.5% male. Diverse ethnic groups in sample.	Barriers: negativity towards providers and medication regimen; cognitive difficulty; peer/family influence; denial. Psychosocial factors accounted for 32% of variance in total barrier perceptions, especially self-efficacy. Cognitive difficulties as a barrier more often reported by non-white and those with disadvantaged socio-economic status. Males reported higher levels of barriers.	Health Belief Model.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Schilling et al (2006)	To describe the a) division of labour in illness management between parents and youth, and b) state of transfer of management responsibility from parents to youth.	Qualitative. Individual interviews. Qualitative content analysis.	USA. 22 youth with type 1 diabetes, aged 8-19 (mean age: 14.5). 22 parents (17 mothers, 5 fathers).	Youth have increased responsibility as get older, parental involvement reduces. Parents took active steps to transfer responsibility to child (e.g. educating, explaining consequences of decisions). Importance of developmental readiness. Identified 3 patterns of self-management, primarily relating to age (e.g. parent-dominant, transitional, adolescent-dominant).	Develop-mental theory. Concept analysis of self-management of type 1 diabetes in youth.	None reported
Spencer et al (2013)	To explore the lived experiences of adolescents with type 1 diabetes and their parents.	Qualitative approach, underpinned by interpretative phenomenology	UK. 20 adolescents (9 male, 11 female), aged 13-16. All white British. 27 parents (7 male, 20 female).	Some adolescents felt education they received from HCPs didn't always translate into real life, tried to apply clinical knowledge into practice through trial and error; learnt valuable lessons through their mistakes. Parents negotiated finding a balance between letting child manage independently and helping with self-management tasks. Experiential learning was prerequisite to development of adolescent independence.	None reported.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Stinson et al (2008)	To explore 1) self-management needs of adolescents with juvenile idiopathic arthritis (JIA), and 2) the acceptability of a web-based programme of self-management.	Qualitative. Individual and focus group interviews. Thematic analysis.	Canada. 36 adolescents with JIA, aged 12-19.	Developed strategies to better manage their disease which centred on parents and professionals 'letting go', and 'gaining control' of managing JIA independently. Strategies used to assist this process: acquiring knowledge and skill to manage the disease (e.g. listening to, and challenging HCPs, acquiring skills to communicate with HCPs); experiencing understanding through social support.	Discusses findings in relation to self-efficacy and empowerment.	None reported.
Strand et al (2018)	To describe how adolescents perceive the transition from being dependent on their parents towards managing their own type 1 diabetes treatment.	Qualitative. Phenomenography. Individual interviews.	Sweden. 18 adolescents with type 1 diabetes, aged 16-18.	3 categories: 1) taking responsibility for own diabetes is a natural process; expectations from parents and HCPs change with age 2) taking responsibility was dependent on coping; feeling proud to handle own diabetes; taking responsibility means it's your fault if you make mistakes 3) its demanding to take responsibility; requires knowledge and skills; its time-consuming; it's like being examined everyday.	Interview guide based on Meleis' transitions theory. Findings discussed in relation to Meleis, Reigel's theory around self-care, and behaviour change models (e.g. COM-B).	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Sullivan-Bolyai et al (2014)	To describe the perspectives of teens and their parents about self-management knowledge, behaviours and resources used to manage type 1 diabetes.	Qualitative focus group design. 4 focus groups segmented by the teen's HgA1c value, concurrent teens and parent groups. Note-based qualitative content analysis.	USA. 10 teenagers (6 boys), aged 13-17. 13 parents (3 fathers, 10 mothers). 80% of teens had lower HgA1c, 20% had higher levels.	Teens: Age of diagnosis affected when got involved in management .Thought HCPs shouldn't be involved in helping parents let go. Parents: engaged child in management depending on age of diagnosis. Felt it was their job to make sure child self-sufficient in management but felt pressure from professionals to physically do care and threatened with social services involvement.	Self and family management behaviours framework.	None reported.
Williams (1999)	To explore the ways gender impacts on the meanings and management of diabetes during adolescence.	Qualitative. In depth interviews. Grounded theory approach.	UK. 20 adolescents (10 male, 10 female) aged 15-18. 20 mothers.	Girls incorporated diabetes into their identities, viewed as important; boys tended to hide it - implications for management. Mothers of sons more likely to be involved in care - blamed by HCPs for being overprotective; girls more likely to take on responsibility, and actively encouraged by professionals. Girls were expected to be self-caring, reluctant to ask for support, sometimes led to secret non-adherence.	Medical sociology theories e.g. gender, identities, chronic illness /health, stigma.	None reported.

Author	Research aim	Study design	Setting/Participants	Main findings	Theory	PPI
Williams et al (2007)	1) What are the roles of family members in the initiation and implementation of home exercises and how do these vary? 2) How is the responsibility for physiotherapy exercises transferred from parent to child, and what factors help this process?	Qualitative. In depth individual interviews. Framework analysis.	UK. 32 children, aged 7-17 with cystic fibrosis. 31 parents.	Level and nature of involvement varied along a continuum of responsibility. Roles/responsibilities changed over time. Factors influencing role adoption and progression: perceived wellness, episodes of illness, performance uncertainty, family routines. Transfer seen as gradual, taken for granted process over time. Physiotherapists viewed as playing a key role in process.	Kleinman's concept of explanatory models. Levanthal's notion of illness representation. Health belief model.	None reported.

Appendix 3: Critical appraisal tool

1. Abstract and title: Did they provide a clear description of the study?	
Good	Structured abstract with full information and clear title.
Fair	Abstract with most of the information.
Poor	Inadequate abstract.
Very Poor	No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?	
Good	Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.
Fair	Some background and literature review. Research questions outlined.
Poor	Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.
Very Poor	No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?	
Good	Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
Fair	Method appropriate, description could be better. Data described.
Poor	Questionable whether method is appropriate. Method described inadequately. Little description of data.
Very Poor	No mention of method, AND/OR method inappropriate, AND/OR no details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?	
Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
Fair	Sample size justified. Most information given, but some missing.
Poor	Sampling mentioned but few descriptive details.
Very Poor	No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?	
Good	Clear description of how analysis was done. Qualitative studies: Description of how themes derived/respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed.
Fair	Qualitative: Descriptive discussion of analysis. Quantitative.
Poor	Minimal details about analysis.
Very Poor	No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?	
Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above (i.e., these issues were acknowledged).
Poor	Brief mention of issues.
Very Poor	No mention of issues.
7. Results: Is there a clear statement of the findings?	
Good	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.
8. Transferability or generalisability: Are the findings of this study transferable (generalisable) to a wider population?	
Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very Poor	No description of context/setting.
9. Implications and usefulness: How important are these findings to policy and practice?	
Good	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very Poor	None of the above.

Appendix 4: Quality assessment

Key: [shaded box] = overall study quality is fair   [empty box] = overall study quality is good

Paper	Abstract /title	Introduction /aims	Method /data	Sampling	Data analysis	Ethics /bias	Results	Transferability or generalisability	Implications and usefulness
Akre and Suris (2014)	Good	Good	Fair	Poor	Fair	Poor	Fair	Poor	Fair
Auslander et al (2010)	Good	Fair	Fair	Poor	Fair	Poor	Good	Poor	Good
Babler and Strickland (2015)	Fair	Good	Fair	Poor	Fair	Poor	Fair	Poor	Fair
Buford (2004)	Fair	Fair	Good	Good	Good	Fair	Good	Fair	Good
Castensoe-Seidenfaden et al (2017)	Fair	Good	Fair	Fair	Good	Fair	Good	Fair	Fair
Chilton and Pires-Yfantouda (2015)	Good	Fair	Good	Fair	Good	Good	Good	Fair	Good
Christian et al (1999)	Good	Good	Good	Fair	Fair	Fair	Good	Fair	Good
Dashiff et al (2011)	Good	Good	Fair	Fair	Good	Poor	Good	Fair	Fair
Ersig et al (2016)	Good	Good	Good	Fair	Fair	Fair	Good	Fair	Fair
Hanna and Guthrie (2000a)	Good	Fair	Fair	Poor	Fair	Fair	Fair	Poor	Good
Hanna and Guthrie (2000b)	Good	Fair	Fair	Poor	Poor	Poor	Fair	Poor	Fair
Hanna and Guthrie (2001)	Fair	Good	Fair	Fair	Good	Fair	Good	Fair	Good
Husted et al (2014)	Fair	Fair	Good	Fair	Good	Fair	Good	Fair	Poor

Paper	Abstract /title	Introduction /aims	Method /data	Sampling	Data analysis	Ethics /bias	Results	Transferability or generalisability	Implications and usefulness
Jedeloo et al (2010)	Good	Fair	Fair	Fair	Fair	Poor	Good	Fair	Good
Karlsson et al (2008)	Good	Good	Good	Fair	Good	Fair	Good	Fair	Fair
Kayle et al (2016)	Good	Good	Good	Fair	Fair	Poor	Good	Fair	Good
Kirk (2008)	Good	Fair	Fair	Fair	Fair	Fair	Good	Fair	Fair
Meah et al (2010)	Good	Good	Fair	Poor	Fair	Poor	Fair	Poor	Good
Meaux et al (2014)	Good	Good	Good	Poor	Good	Poor	Good	Poor	
Mulvaney et al (2006)	Good	Good	Poor	Poor	Fair	Poor	Fair	Poor	Fair
Mulvaney et al (2008)	Good	Fair	Poor	Poor	Fair	Poor	Poor	Poor	Fair
Ness et al (2018)	Fair	Fair	Fair	Fair	Fair	Poor	Fair	Poor	Fair
Newbould et al (2008)	Fair	Fair	Fair	Fair	Fair	Poor	Good	Fair	Fair
Olinder et al (2011)	Good	Good	Fair	Fair	Good	Good	Fair	Fair	Good
Rankin et al (2018)	Good	Good	Fair	Fair	Fair	Poor	Good	Fair	Good
Rhee et al (2009)	Good	Good	Fair	Fair	Good	Poor	Fair	Fair	Good
Schilling et al (2006)	Good	Good	Fair	Poor	Fair	Poor	Good	Poor	Good
Spencer et al (2013)	Good	Good	Good	Fair	Fair	Poor	Good	Fair	Fair
Stinson et al (2008)	Good	Good	Good	Fair	Good	Poor	Good	Fair	Fair
Strand et al (2018)	Good	Fair	Fair	Fair	Fair	Poor	Fair	Fair	Poor
Sullivan- Bolyai et al (2014)	Good	Good	Good	Fair	Fair	Fair	Good	Fair	Good
Williams (1999)	Good	Good	Poor	Poor	Fair	Fair	Good	Poor	Fair
Williams et al (2007)	Good	Good	Good	Fair	Good	Good	Good	Fair	Good

Appendix 5: Participant information sheet (young people)

UNIVERSITY OF LEEDS

School of Healthcare

NHS

Supporting 13-18 year olds to become independent at managing their chronic kidney disease: Phase 1.
Information for young people aged about 13-15 years old

We would like to ask you to take part in a research study.
Before you decide, it is important for you to understand what it is about, and what will happen if you take part.
Please read this leaflet and talk about it with others if you like. Please ask us about anything that you do not understand. Take your time to decide if you would like to take part.

1. What is the study about?

Developing independence is part of growing up. We want to learn how to help teenagers with chronic kidney disease (CKD) become more independent at looking after their health.

We are asking patients, parents and health care staff to be in the project.

2. Why have I been invited?

We are asking young people to take part who are being treated at [name of hospital] for a chronic kidney condition.

The project will involve other young people like you.

3. Do I have to take part?

No, you do not have to take part; it is up to you to decide. Nobody will mind if you don't want to take part.

If you decide not to take part it will not affect how the kidney team supports you. You can change your mind at any time without saying why.

4. What will happen if I say yes?

You will meet the researcher Ruth, known to the children's kidney team, who will tell you more about the study and answer your questions.

Ruth will invite you to talk about how you and your family look after your health at home. This could be on your own or with your parents/carers, you can say which you would like best. Ruth would like to audio-record what you talk about so we can remember what is said. These tapes will be kept in a safe, lockable place. After the tapes have been typed up, they will be destroyed.

5. Will the information you gather about me private?

Yes, any information you give us will be private. We won't use any real names when we write or talk about the project. We can use a number instead of your name or you can choose a nickname that we can use when writing a report about the project. The report might include quotes from people who have taken part in the study, though anything which could identify you will be taken out. This means no-one will know the information is about you. You can tell your family and friends about taking part in the study if you want to.

6. What are the good things that can happen from this project?

We can't promise that taking part will help you, although we hope you like having the chance to share your reviews. We will use what we learn to develop a tool which could help young people become more independent in looking after their CKD as they get older. A gift voucher will be offered to young people who take part.

7. Are there any bad things that can happen from this project?

No, we don't think so.

8. Is this like a test?

No, we are not testing anyone; we only want to learn from you the best ways we can help teenagers to begin taking charge of their own health.

9. Will anyone else be told about what is said?

We will not tell anyone else that you are taking part in the project. We will not tell anyone what is said. All information will be stored safely either on a password protected computer or in a locked filing cabinet. Any information with your name on it will be destroyed after 12 months, and all other information will be destroyed five years after the project ends.

10. What if there is a problem?

If you have a concern about any part of this project, please speak to the researchers or kidney team who will do their best to answer your questions.

11. Who is organising and funding the research?

The University of Leeds and staff from the kidney team at [name of hospital] are organising the project. It is paid for by Kidney Research UK.

12. Who has allowed the project to happen?

All research in the NHS is looked at by a group of people, called a Research Ethics Committee to check the research is fair. Leeds University has also said we can do this project.

Who should I contact if I have any questions?

If you would like to speak to one of the project team before deciding please contact:

Ruth Nightingale   [name/contact of local PI]
Kidney Research UK PhD Fellow
Great Ormond Street Hospital/
University of Leeds
07825 098844
hcrn@leeds.ac.uk

Ruth is supervised by:

Professor Veronica Swallow	Professor Gretl McHugh	Professor Susan Kirk
University of Leeds	University of Leeds	University of Manchester
07866 975124	0113 343 1365	01613067872
v.m.swallow@leeds.ac.uk	G.A.McHugh@leeds.ac.uk	sue.kirk@manchester.ac.uk

Appendix 6: Participant information sheet (HCPs)

UNIVERSITY OF LEEDS

NHS

School of Healthcare

**Supporting 13-18 year olds to become independent at managing their
chronic kidney disease: Phase 2.**
Information about the research (for health care professionals)

We would like to invite you to take part in a research project funded by Kidney Research UK. Before you decide please read this information and talk to others about it if you wish. Please ask one of the researchers (details below) if anything is unclear or you want more information before deciding to take part.

What is the purpose of the project?
Developing independence can be challenging for young people, particularly if they have chronic kidney disease (CKD). Health care professionals can encourage young people to begin taking charge of their health care and parents to begin 'letting go' but there is limited evidence about how families can best be supported with this process.

We want to find out how 13-18 year olds with CKD can be supported to take on responsibility from their parents for managing their health condition. We are asking teenagers with CKD, parents and health professionals for their views on how we can do this.

Why have I been invited?
You have been invited because you have experience of working with patients with CKD and we would value your opinion on how teenagers can be helped to take on responsibility for managing their health condition. We are inviting young people, parents and professionals to take part in the research. If after reading this you are happy to take part in the research please complete the enclosed consent form and post it back to us in the enclosed, stamped addressed envelope or hand it to the nurse in clinic by [Date]. Ruth, the researcher will contact you to arrange a date/time/place to answer any questions you have. If after that you do agree to take part you are free to withdraw at any time without giving a reason.

What will happen if I take part?
Once we have received the completed consent form, Ruth will contact you to find out when you would be available to take part in a discussion. This could either be as part of a small group with other health professionals working with children with CKD or a one-to-one interview. Ruth will arrange a combination of group discussions/individual interviews which will be either face-to-face or virtual (e.g. by phone or videoconferencing) at different venues, these will be based on your personal preferences and what is convenient. Ruth will be flexible and sensitive to how each person is able to contribute to the group's discussions.

We would like to hear your views on whether you think families need more help with encouraging teenagers to take on responsibility from their parents for managing their health condition. We will ask for suggestions about the types of support that would be helpful. Our aim is then to use these ideas to develop a resource or programme that would help families with the handover of responsibility for CKD from parents to their child. The discussion is likely to last between 45 and 90 minutes and will be audio-recorded so we can remember what is said.

Do I have to take part?
No, you do not have to take part. Participation is completely voluntary and even if you say yes now, you are free to stop at any time, without giving a reason.

What are the possible consequences of taking part?

What you tell us during the discussion will be used to develop a resource to help families with the handover of responsibility for CKD from parents to their child. Taking part will mean giving up some time to talk about your experience. It is unlikely that there will be any risks in taking part in this study but if you felt upset in any way we would stop the discussion. If at the end of the discussion you were still feeling upset, Ruth would advise you on where you could access support.

Will my taking part in the project be kept confidential?

Yes. We will follow ethical and legal guidance and all information about you will be handled in strict confidence. We will not disclose answers given by patients, parents or professionals to anyone else. If we share any results, these will be kept anonymous, which means that you will not be able to be identified. After the discussion, a Great Ormond Street Hospital/ University of Leeds approved commercial transcription company will be used to type up the recordings and any information that could identify people will be removed. Once typed up, the original recording will be destroyed. The only reason we would break confidentiality and share any information is if we felt concerned about the safety of any children you talked about.

How will be data be stored?

All paper information, like signed consent forms, will be stored securely in a locked filing cabinet. This is located in a research office at Great Ormond Street Hospital/ University of Leeds [delete as appropriate] only accessible by a swipe card. Electronic data will be stored on a password protected University of Leeds computer accessible only to Ruth and her PhD supervisors. At the end of the study, personal data (e.g. names, contact details) will be stored and accessed for up to 12 months and research data will be stored for 5 years. These will be stored securely on a password protected University of Leeds computer accessible to Professor Veronica Swallow, Ruth's main supervisor. All data will be destroyed five years after the project ends.

What will happen to the results of this research?

The results will be used to help us develop a resource to help families with the handover of responsibility for CKD from parents to their child. A report will be produced for the funders. This will present the findings and may include anonymous quotations with any person-identifiable information removed. A summary report will be sent to all who take part in the project; a full report will be available to those who request it.

What will happen if I don't want to carry on with the project?

You are free to withdraw from the project at any time without giving a reason. If you wish, we will destroy all the information you give us up to the point that your contributions to discussions were added to the other anonymised information collected.

What if there is a problem?

If you have a concern about any aspect of this study, please ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact Clare Skinner, Faculty Head of Research and Innovation Support, Faculty of Medicine and Health at the University of Leeds by email to governance-ethics@leeds.ac.uk. Alternatively you can contact the Patient Advice and Liaison Service (PALS) at [name of hospital] on [phone number] or by email to [email address].

Who has reviewed the project?

All NHS research is looked at by an independent group of people, a Research Ethics Committee, to protect participants' interests. The Yorkshire & The Humber - Sheffield

Research Ethics Committee has approved the project and the University of Leeds is sponsoring it.

How will the study sponsor manage data?

The University of Leeds is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Leeds will keep identifiable information about you for 12 months after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information at http://www.leeds.ac.uk/secretariat/data_protection.html.

Who is organising and funding the research?

This project is part of a PhD/doctorate which is being funded by Kidney Research UK.

Who should I contact for further information?

If you would like to speak to one the research team before deciding please contact:

Ruth Nightingale   [name of local PI]
Kidney Research UK PhD Fellow
Great Ormond Street Hospital/
University of Leeds
07825 098844
hcrn@leeds.ac.uk

Ruth is supervised by:

Professor Veronica Swallow   Professor Gretl McHugh
University of Leeds   University of Leeds
07866 975124   0113 343 1365
v.m.swallow@leeds.ac.uk   G.A.McHugh@leeds.ac.uk

Professor Susan Kirk
University of Manchester
0161 306 7872
sue.kirk@manchester.ac.uk

Appendix 7: Assent form (young people aged under 16 years)

UNIVERSITY OF LEEDS

NHS

Supporting 13-18 year olds to become independent at managing their chronic kidney disease: Phase 1

ASSENT FORM

(to be completed by the young person under 16 years, and their parent/guardian)

Young person (or, if unable, parent on their behalf) to circle all they agree with:

Have you read (or had read to you) the information about this study?	Yes/No
Has a researcher explained this study to you?	Yes/No
Do you understand what this study is about?	Yes/No
Have you asked all the questions you want to?	Yes/No
Have you had all of your questions answered so you understand?	Yes/No
Do you understand that it's OK to stop taking part at any time?	Yes/No
Are you happy for what you tell the researcher to be recorded?	Yes/No
Are you happy that what you tell us will be written down but your real name won't be used so no one else will know who said it?	Yes/No
Are you happy to take part in this study?	Yes/No

If you don't want to take part, **DON'T** sign your name.

If you **DO** want to take part, please write your name and today's date below:

Your name_____

Date_____

Your parent/guardian must write their name too if they are happy for you to take part:

Print _____

Sign _____

Date_____

The researcher who explained this study to you also needs to write their name:

Print _____

Sign _____

Date_____

When completed, original for participant; 1 copy for researcher file, 1 copy for medical file.

CKD study: YP under 16 assent form. Phase 1. V1. 12.4.18. IRAS: 226365

Appendix 8: Consent form (parents)

UNIVERSITY OF LEEDS

School of Healthcare

NHS

PARENT CONSENT FORM

TITLE OF PROJECT: Supporting 13-18 year olds to become independent at managing their chronic kidney disease: Phase 2

If you agree with the following statements please put your initials in the relevant box and sign below:

1. I confirm that I have read and understand the information sheet dated ____ (Version __) for parents of young people with CKD taking part in the above project.	
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
3. I understand that I am free to withdraw at any time without giving any reason and without [name of young person]'s care or legal rights being affected.	
4. I understand that anonymised quotations during tape recorded interviews or group discussions may be used in reporting the study.	
5. I understand that relevant sections of my child's medical notes and data collected during the study, may be looked at by individuals from the research team, from regulatory authorities, the University of Leeds or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my child's records.	
6. I agree to the interview/group discussions being audio recorded.	
7. I understand that my anonymous data may be used to support other research in the future, and may be shared anonymously with other researchers.	
8. I agree to take part in the above project.	

Name of parent ………………………………………………………………..
Signature of parent …………………………………………………………
Date…………………..

Name of researcher obtaining consent …………………………………...
Signature of researcher……………………………………….......................
Date………………………….

When completed, original for participant; 1 copy for researcher file.

Appendix 9: Initial topic guide (young people)

1. Could you tell me about a typical school/college day – what kind of things are you doing, starting when you get up?
- How does having a kidney condition affect your day?
- How are things different at the weekend?

2. What do you do to take care of your kidney condition? e.g. medication, food, drink, sleep, exercise.
- What other things do you do to keep healthy?

3. How do you find it taking care of your kidney condition?
- What is easy/difficult?
- What else would help you take good care of yourself?

4. How do your parents help you to take care of your health?
- What are they doing?
- Who else helps you? e.g. other parent, other family members, friends, school, HCPs.

5. Could you mark on the line how much you are responsible for looking after your kidney condition?
- Why did you put the mark there?
- What do you think being 'fully responsible' means?
- What works/doesn't work about sharing responsibility with other people?

6. With looking after your health, how has it changed over time?
- When did you start to take over care for your kidney condition?
- How did you begin to take over care?
- What prompted you to start taking over care?

7. As you have become more in control of looking after your health, what/who has helped you?
- What wasn't been helpful?

8. What has your experience been like with health professionals from the kidney team?
- Were they involved in helping you become more in charge?
- How?
- How could things be improved?
- [Have you attended a transition clinic? How have you found this? How is it different to the clinic you went to when you were younger?]

9. As you have started to take control of your health, are there other areas in your life where you have become more independent? e.g. at home, school/college

10. How do you feel about taking/being in control of your health?

11. With looking after your health, how will things change as you get older?

12. Is there something else you think I should know about how teenagers take over care for their kidney condition?

Appendix 10: Revised topic guide (young people)

1. Could you tell me about a typical school/college day – what kind of things are you doing, starting when you get up?
- How does having a kidney condition affect your day?
- How are things different at the weekend?

2. With looking after your health, how has it changed over time?
- When did you start to take over care for your kidney condition?
- How did you begin to take over care?
- What prompted you to start taking over care?

3. As you have become more in control of looking after your health, what has helped you?
- Who has helped you? e.g. family, health professionals, friends, teachers
- How did they help you?
- What other things might have been helpful?
- What hasn't been helpful?

4. Would you like more help with learning to take over care for your condition?
- If yes, can you tell me about what would be helpful? *[Use prompt cards, ideas from earlier interviews with young people, what do they think?]*
- What kind of help?
- Who could provide this help?
- When? e.g. at certain times – change in condition/treatment; changing schools
- Where? e.g. hospital, home, school etc
- If no, can you tell me your reason for not wanting more help?

5. How do you think your parents felt as you became more involved in your care?

6. Do you think your parents would like help with letting go of doing the care?
- If yes, can you tell me about what would be helpful?
- What kind of help?
- Who could provide this help?
- When?
- Where?
- If no, can you tell me your reason for not wanting more help?

7. What advice would you give to another teenager with a kidney condition who was going to become more in control of looking after their health?

8. Is there anything else I should know about how teenagers and parents could be helped with handing over care for their kidney condition?

Appendix 11: Completed lines

Young person 1/Parent 1:

Not responsible   Parent   Young Person   Fully responsible
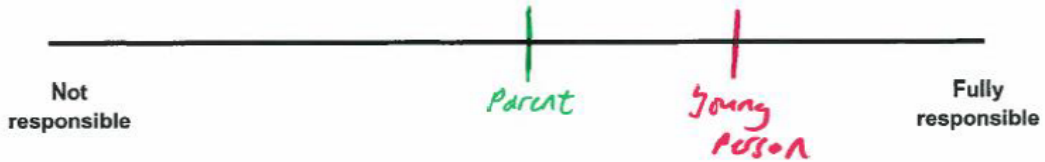
Young person 2/Parent 2:

Young Person   Parent

Not responsible   Fully responsible

Young person 3/Parent 3:

Young Person   Parent

Not responsible   Fully responsible

Young person 4/Parent 4:

Parent

Young Person

Not responsible   Fully responsible

Young person 5/Parent 5:

Young
Person

Parent

Not
responsible

Fully
responsible

Young person 6/Parent 6:

Parent

Young
person

Not
responsible

Fully
responsible

Parent 7:

Parent / Carer

Not
responsible

Fully
responsible

Young person 8/Parent 8:

Parent

Young Person

Not
responsible

Fully
responsible

Young person 9/Parent 9:

Young person

Parent

Not
responsible

Fully
responsible

Parent 10:

Parent

Not
responsible

Fully
responsible
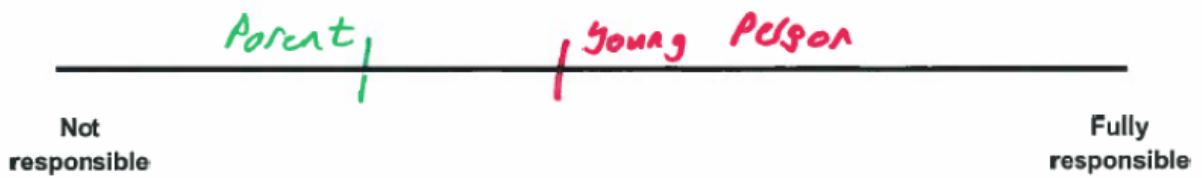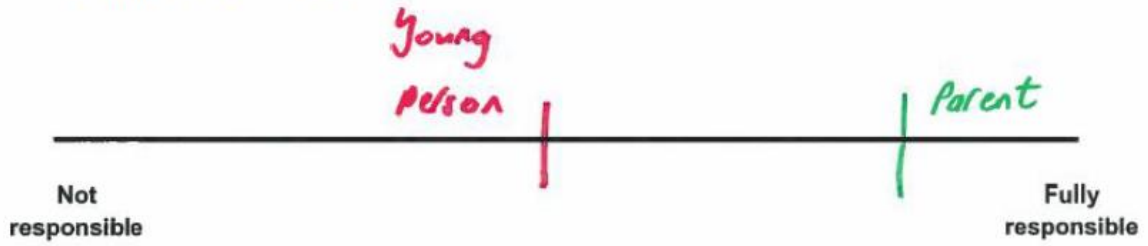
Young person 11/Parent 11:

Young Person

Parent

Not
responsible

Fully
responsible
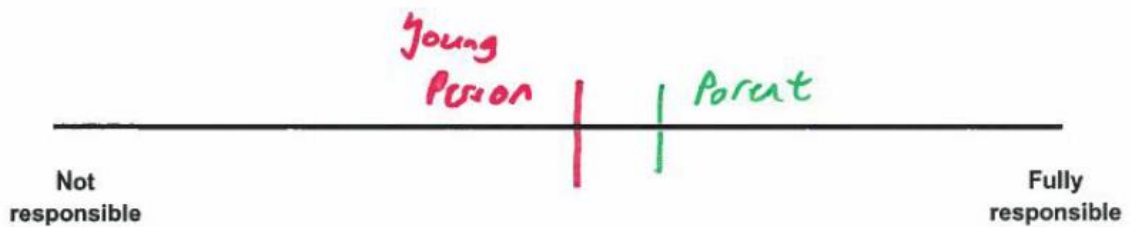
Appendix 12: Tool to clarify self-management responsibility

Total own responsibility

Own responsibility

The adolescent's indicated responsibility

This lack needs to be covered by parents or others

Responsibility of parents or others

No own responsibility

Total responsibility
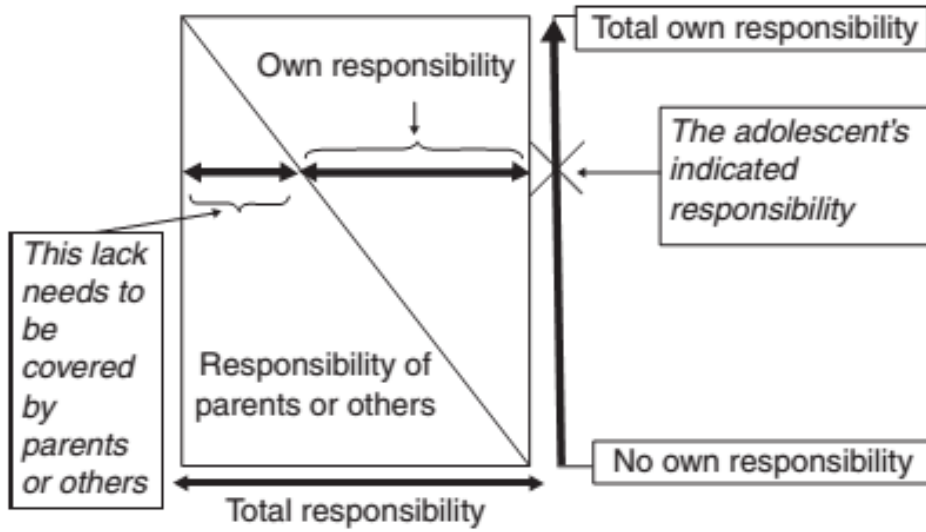
Appendix 13: Ideas presented during interviews with young people and parents

Practical things **e.g. finding the right water bottle**	**Solving problems together with parents and/or health professionals**
Using mobile phone to record information	**Talking with other young people with kidney conditions**
Health professionals listening to your opinion	**Learning from mistakes**
Information	**Having a role model**
Achievable goals	**Encouragement**
Motivation	**Believing in yourself**
Making gradual changes	**Having a routine**
Digital technology	**Group work**
More help for young people with developing independence	**More help for parents with handing over care**
Meeting other young people with kidney conditions	**Getting involved in own health care at a younger age**
Meeting other parents	**Help outside of the hospital**

Appendix 14: Ideas presented during HCP focus groups

Digital technology e.g. apps
Start to develop independence at an earlier age
Meeting other young people with kidney conditions
Meeting other parents
Group work
Role models
Interventions outside of hospital e.g. at home, school
Increased opportunities for young person to be seen on their own

Appendix 15: Focused coding in NVivo

A) HCP Focus Group 2
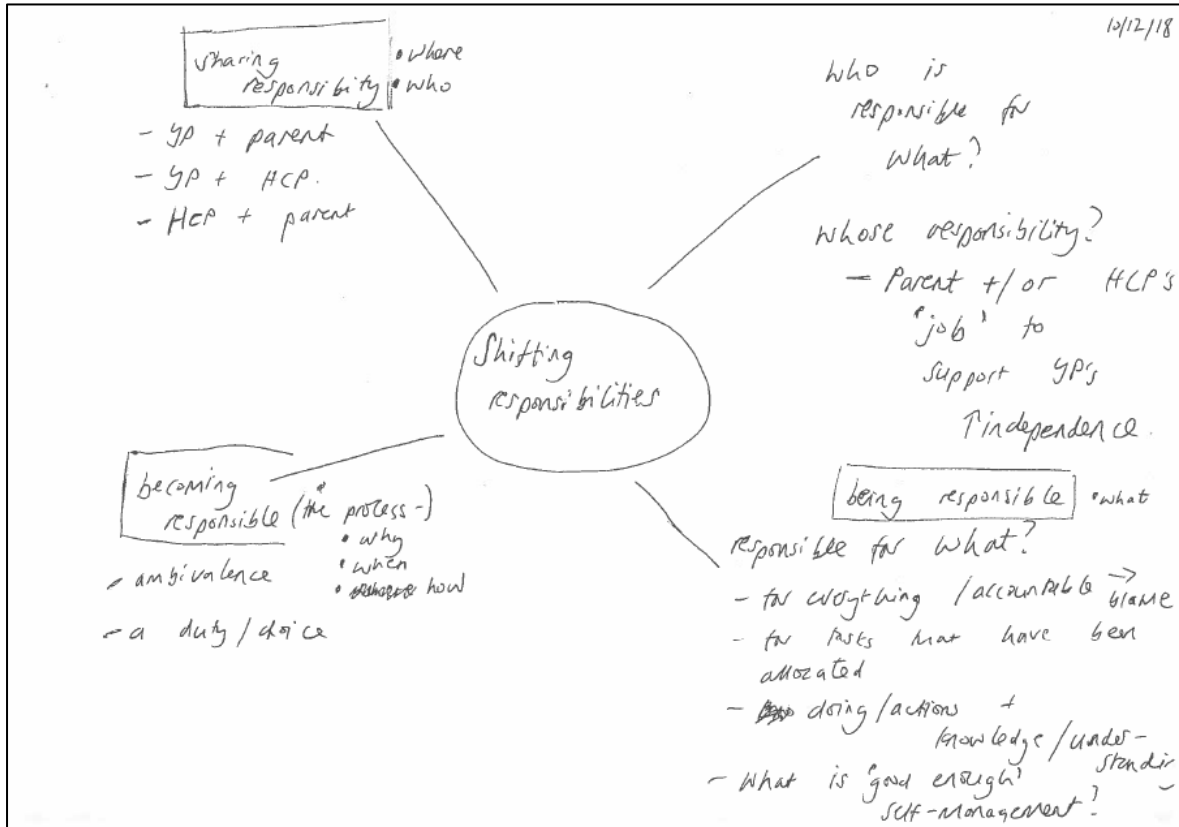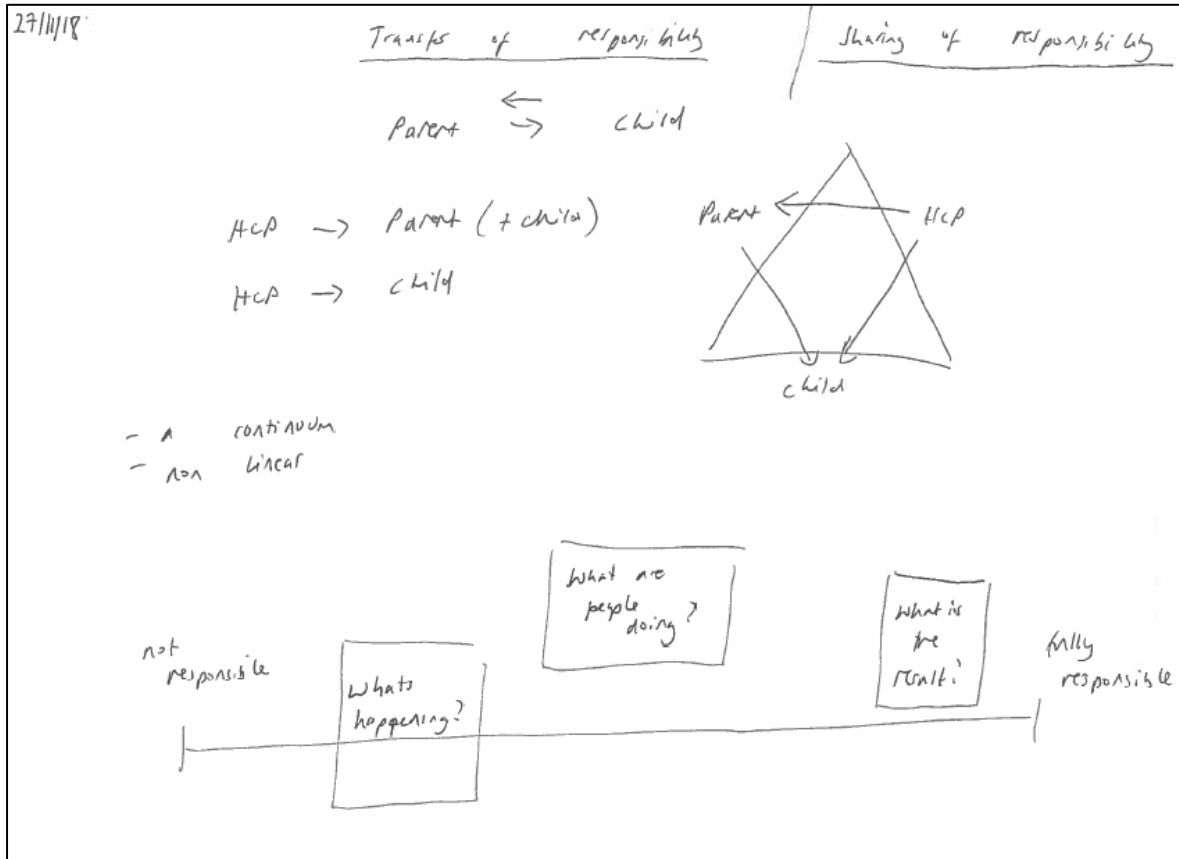

B) YP8 & Pnt8

Appendix 16: NVivo node structure

Nodes\\Developing independence, gaining autonomy

Nodes\\Developing independence, gaining autonomy\being a crashlander

Nodes\\Developing independence, gaining autonomy\being seperate

Nodes\\Developing independence, gaining autonomy\comparing to peers

Nodes\\Developing independence, gaining autonomy\finding motivation

Nodes\\Developing independence, gaining autonomy\finding motivation\prioritising other things

Nodes\\Developing independence, gaining autonomy\finding motivation\realising its serious

Nodes\\Developing independence, gaining autonomy\getting older, growing up

Nodes\\Developing independence, gaining autonomy\growing up in the system

Nodes\\Developing independence, gaining autonomy\having no choice

Nodes\\Developing independence, gaining autonomy\living with CKD

Nodes\\Developing independence, gaining autonomy\living with CKD\seeking solace in God

Nodes\\Developing independence, gaining autonomy\putting it in context

Nodes\\Making changes

Nodes\\Making changes\acknowledging strengths

Nodes\\Making changes\adopting new habits

Nodes\\Making changes\avoiding conflict

Nodes\\Making changes\being a role model

Nodes\\Making changes\bending the rules

Nodes\\Making changes\finding it hard

Nodes\\Making changes\finding solutions

Nodes\\Making changes\fitting around other daily activities

Nodes\\Making changes\getting annoyed

Nodes\\Making changes\getting help from others

Nodes\\Making changes\learning from mistakes

Nodes\\Making changes\making changes gradually

Nodes\\Making changes\making judgements

Nodes\\Making changes\MDT working

Nodes\\Making changes\needing parental help

Nodes\\Making changes\needing structure & routine

Nodes\\Making changes\parent being an anchor, a prop

Nodes\\Making changes\parents monitoring

Nodes\\Making changes\seeing the evidence

Nodes\\Making changes\seeing the evidence\picking up on clues

Nodes\\Making changes\working collaboratively

Nodes\\Shifting responsibilities

Nodes\\Shifting responsibilities\defining responsibilities

Nodes\\Shifting responsibilities\getting help from HCP

Nodes\\Shifting responsibilities\HCP expectations

Nodes\\Shifting responsibilities\parent letting go

Nodes\\Shifting responsibilities\taking ownership

Nodes\\Shifting responsibilities\timing HCP intervention

Appendix 17: Theoretical memo

Defining/understanding responsibility and 'effective' self-management: 16.10.18

- Differing understandings of what it means to be 'fully responsible' – is this the aim? Is it realistic? Is it what YP/parents want?
- Defining a goal – being a good OT. Are people on the same page? (HCP1)
- What does it mean if people have different understandings? Does this matter? Maybe if these aren't made explicit
- Are doing self-management tasks and being responsible different things (HCP1)? Sharing tasks/responsibility with YP & parent, YP-parent-HCP? Transfer of responsibility from HCP to family initially, and then from HCP to YP?
- Responsibility as accountability, liability – what happens when things go wrong? Interesting paper about responsibility & LTC (Snelling).
- Do things work better if responsibility is delineated? But it's always shifting
- Invisible/visible – tacit/explicit
- Is the line asking the right question? What would YP/parents/HCPs put on the line?
- YP5 – learning to do aspects of HD machine e.g. self-needling - it's like a job, being a nurse. Sharing care with nurses on HD – who is then responsible?
- Not just sharing care with parents, but also HCPs – YP2
- Young people on HD learning aspects of care that their parents don't learn?
- Who has ultimate responsibility in self-management? HCPs using competency books to sign off teenagers on HD – issues around liability, accountability & blame. Are standards for HCP education being applied to patient education? – See HCP3 interview field note
- HCP4 talking about different expectations of what is 'good enough' self-management
- YP1 reporting she had to work out herself what fluid target she needed to reach

Appendix 18: Analytic diagrams

27/11/18

Transfer of responsibility | Sharing of responsibility

Parent ⇄ child

HCP → Parent (+ child)

HCP → child

- a continuum
- non linear

not responsible

Whats happening?

What are people doing?

What is the result?

fully responsible

10/12/18

Sharing responsibility • where • who

- YP + parent
- YP + HCP
- HCP + parent

Shifting responsibilities

who is responsible for what?

whose responsibility?
— Parent +/or HCP's 'job' to support YP's ↑independence.

becoming responsible (the process -)
• why
• when
• how
- ambivalence
- a duty / choice

being responsible • what

Responsible for what?
- for everything / accountable → blame
- for tasks that have been allocated
- doing / actions + knowledge / understanding
- What is 'good enough' self-management?

Appendix 19: Analysis of interaction

A) Dyadic interview: YP4 & Pnt4

Contrasting researchers' purposes with those of the participants	
Who do participants represent when they speak?	Parent – herself, role of YP's older sibling in supporting self-management; YP - himself
What are the explicit purposes of participants?	Parent – still doing a lot, burden of self-management, impacts on whole family, worry continues whilst at work. YP – 'doing it on his own' / independence
What could be their implicit purposes?	Mum teaching - proud that YP now swallows tablets all together – when younger had not been able to swallow Is mum sending an implicit message to her son that she is keeping an eye on him?
To what extent to participants comply with the researchers cues or seek to foster discussion on other issues?	Stick to topic
What do participants' purposes tell us about the research topic?	People stick to the topic – does this mean participants value having the opportunity to talk about this?
Understanding interactions and what is shared as a result of relational positioning of participants	
What types of interactions occur among participants?	Interactions mostly with me rather than with each other. Is it the line that makes things shift? – they relax/start interacting with one another more. P12, first direct interaction with one another, mum asks YP a question P13 &14 &16, mum agreeing with son's telling of the story – listening to him P16 &17, mum asks YP to name a med, testing him so he can demonstrate his knowledge to me, & her skill as a teacher/parent P16, mum correcting YP on age, reminding him of interactions with consultants P17 – testing his knowledge, picks up that he forgets one, but remembers P21, mum talking about YP in third person, then switches directly to addressing him – to feel comfortable/ confidence to carry out self-management activities in front of peers (embarrassed about being different)
To what extent do these interactions reflect the broader social contexts?	Reflecting the nature of the relationship between mum & 14 year old son ?typical interaction
Which participants dominate the discussion? How does this affect the contribution of other participants?	Parent provides much more detail when she talks P12 mum clarifying details about when child younger
Which participants adopt a passive role? How do other participants respond to this position?	YP quieter, possibly feels unable to challenge mum

What do dominant and passive positions reveal about the topic at hand?	Mum is the boss – maybe mum needs to be the boss due to previous difficulties with self-management? P9 – doing the line, YP looks at what mum has done and puts his mark in the same place
What types of knowledge claims are endorsed and/or challenged by participants? On what basis?	Mum challenges YP claim of doing things on his own
Considering the extent to which researcher participates in the construction of participants views'	
How does the researcher set the tone at the beginning?	Non-judgemental, listener, typical' school day compared to the school holidays (** timing of data collection -useful when some of the interviews with YP/parents took place during school holidays) – encouraging YP to think about self-management integrated alongside other daily activities – co-construction of data
How does the researcher succeed in making room for each participant to contribute to the common ground?	Direct first question at YP, using name, asking follow up questions to YP. Ask about help, YP mentions mum, I then invite parent to talk P3, asking questions directly to YP – use his name, talk about mum in 3rd person
Do participants accept or challenge the leadership of the researcher?	Accepts me mostly P14, Mum laughs when responds to one of my questions, disagreement with my suggestion that transfer process happens in stages – mum views process as a continuum, it is constant, burden
How does the researcher respond to the validation or disputing of knowledge claims?	Co-construction of data. My focus on 'doing' – what does YP do? What does mum do? (vs knowing – making a joke about the memory test when mum is asking YP to list his medication, she is replicating at home, and in front of me what happens in clinic appointments (p17). Does she think I am a HCP?
What is the overall impact on the 'common ground'?	P2 Issues around trust – parent doesn't trust son ?why, p6 – trust, 'know how to play things' – needing to see evidence P2, Monitoring – discrete/hidden or explicit – parent makes it clear during the interview that she monitors son – YP not fully aware of what parents are doing, full extent of what it means to be responsible, p6 – keep an eye P3 – mutual benefits of YP taking on responsibility P3, parent making decisions about transfer, parent 'teaching', p18 P4 – forgetting, prioritising other things, motivation – YP decision-making, short term vs long term consequences, risk awareness P8 parent does organisational stuff – ordering meds

B) HCP focus group: FG1

Contrasting researchers' purposes with those of the participants	
Who do participants represent when they speak?	'We' vs 'I' – the individual, the discipline, the whole MDT, specific teams within the MDT (e.g. transition)
What are the explicit purposes of participants?	HCP8 & 15: Transition, to promote the need for colleagues to be talking about transition with families, the need for additional resources HCP5: parents
What could be their implicit purposes?	HCP8 – clinical experience/ expertise in working with YP
To what extent to participants comply with the researchers cues and seek to foster discussion on other issues?	HCP8: Shifts the topic to transition early on: do they view the parent-child transfer as part of transition?
Why do these issues matter? And to which participants?	HCP8 & 15: Particular interest in transition, opportunity to increase colleagues awareness of transition work
What do participants' purposes tell us about the research topic?	Do HCPs tend to view the parent-child transfer of responsibility as part of transition? Families don't –within a wider context

Understanding interactions and what is shared as a result of relational positioning of participants	
What types of interactions occur among participants?	HCP8 & 15 dominate conversation initially HCP5 – asking questions of colleagues, appealing to others HCP14 - ?the outsider (1st meeting with MDT), asks questions/raises challenge HCP11 challenging HCP8 – evidence vs experience
To what extent do these interactions reflect the broader social contexts?	HCP8 (male, oldest, most senior consultant, introduces himself as 'responsible for transition') HCP5 (the parent) HCP14 (older female, authority, the outsider) ?HCP5 &13 (female, ethnicity) HCP12: youngest, female, not professionally qualified
Which participants dominate the discussion? How does this affect the contribution of other participants?	HCP8 HCP15 – speaks first, puts her opinion on the line, often the first to break the silence. Very similar response to HCP19 speaking first in FG2 (early conversations) Do others feel inadequate, lacking skills & experience compared to the 'transition specialists'?
Which participants adopt a passive role? How do other participants respond to this position?	HCP16 doesn't speak, no one invites her to participate, leaves half way through discussion HCP1: first contribution on p8, listening to conversation - took part in interview – providing opportunity for others to speak (HCP5 & 8 also took part in interviews) HCP12: first contribution, p9
What do dominant and passive positions reveal about the topic at hand?	Dominant position - HCPs view transfer of responsibility within the context of transition between child and adult services

What types of knowledge claims are endorsed and challenged by participants? On what basis?	HCP8 – clinical knowledge and experience, age, a parent/father. Occupies multiple positions, sometimes contradictory – the expert vs own dependency on parents, own parenting HCP11 – 'evidence': does this prevent others from challenging him? HCP13 & 5 – drawing on examples from practice to support their claims, story-telling – the voice of the parent HCP5 – experience of being a parent HCP14 – research experience?, CYP typical development
What types of knowledge claims receive less support? Why?	HCP11 & evidence. Research/evidence base is viewed as less important than clinical experience?
Considering the extent to which the researcher participates in the construction of 'HCPs views'	
How does the researcher set the tone at the beginning?	Asking them to share their experiences p1– prompted further by asking them to reflect on their work p2. Introduced self as OT – a HCP too, but not part of the renal MDT Non-judgemental, loosely guiding conversation
How does the researcher succeed in making room for each participant to contribute to the common ground?	P3, repeating that topic of discussion is parent-child transfer: 1st question reworded to invite others to contribute P3, asking for an example – means others become involved (e.g. HCP5, p3)
Do participants accept or challenge the leadership of the researcher? How and when is acceptance or defiance manifested? How does the moderator respond?	Response when discussion shifting to transition by restating the topic through how question is phrased HCP8, p9: looking at list of ideas, not 1 stands out – all are valuable HCP14, p5 &10 Asking for specifics/examples vs. complexity, individual nature of input
Does the common ground remain stable over time?	Barriers to doing this work YP/parent/resources/ working within organisations based on chronological age, not developmental needs/specific NHS trust – trying to meet individual needs within confines of service provision. *'There isn't one size that fits all'* Inclusion/exclusion of parents – interdependence /independence Transition doesn't stop at transfer to adult services vs expectations , experiences, skills, interest amongst HCPs in adult services YP & parents support needs during the process

Appendix 20: REC favourable opinion letter

NHS

Health Research Authority

Yorkshire & The Humber - Sheffield Research Ethics Committee

NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Tel: 0207 104 8082

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

31 May 2018

Ms Ruth Nightingale
PGR office, Room 2.30, Baines Wing
School of Healthcare
University of Leeds, Leeds
LS2 9JT

Dear Ms Nightingale

Study title:	Preliminary co-design, development and evaluation of a self-management action plan: Supporting parent-to-child transfer of responsibility for chronic kidney disease (CKD)
REC reference:	18/YH/0210
Protocol number:	N/A
IRAS project ID:	226365

The Proportionate Review Sub-committee of the Yorkshire & The Humber - Sheffield Research Ethics Committee reviewed the above application on 28 May 2018.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk 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 management permissions from host organisations.

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

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 request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

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).

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").

Approved documents

The documents reviewed and approved were:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance]	v1	21 September 2017
Interview schedules or topic guides for participants [Phase 1 topic guide]	v1	09 April 2018
Interview schedules or topic guides for participants [Phase 2 topic guide]	v1	20 April 2018
IRAS Application Form [IRAS_Form_08052018]		08 May 2018
Letter from funder [Letter from Kidney Research UK]	v1	22 December 2016
Letter from sponsor [Email confirming sponsorship]	v1	30 April 2018
Letters of invitation to participant [Parent of young person participant]	v1	12 April 2018
Letters of invitation to participant [Parent participant]	v1	12 April 2018
Letters of invitation to participant [Health professionals]	v1	12 April 2018
Letters of invitation to participant [Young person 13-15]	v1	12 April 2018
Letters of invitation to participant [Young person 16-18]	v1	12 April 2018
Participant consent form [Phase 1 assent form]	v1	12 April 2018
Participant consent form [Phase 1 health professionals]	v1	12 April 2018
Participant consent form [Phase 1 parent of young person participant]	v1	12 April 2018
Participant consent form [Phase 1 parent participant]	v1	12 April 2018
Participant consent form [Phase 1 young person 16-18]	v1	12 April 2018
Participant consent form [Phase 2 assent form]	v1	12 April 2018
Participant consent form [Phase 2 health professionals]	v1	12 April 2018

Participant consent form [Phase 2 parent of young person participant]	v1	12 April 2018
Participant consent form [Phase 2 parent participant]	v1	12 April 2018
Participant consent form [Phase 2 young person 16-18]	v1	12 April 2018
Participant information sheet (PIS) [Phase 1 parent of YP participant]	v1	12 April 2018
Participant information sheet (PIS) [Phase 1 health professional]	v1	12 April 2018
Participant information sheet (PIS) [Phase 1 parent participant]	v1	12 April 2018
Participant information sheet (PIS) [Phase 1 young person 13-15]	v1	12 April 2018
Participant information sheet (PIS) [Phase 1 young person 16-18]	v1	12 April 2018
Participant information sheet (PIS) [Phase 2 health professionals]	v1	12 April 2018
Participant information sheet (PIS) [Phase 2 parent of young person participant]	v1	12 April 2018
Participant information sheet (PIS) [Phase 2 parent participant]	v1	12 April 2018
Participant information sheet (PIS) [Phase 2 young person 13-15]	v1	12 April 2018
Participant information sheet (PIS) [Phase 2 young person 16-18]	v1	12 April 2018
Referee's report or other scientific critique report [Kidney Research UK 1st review]	v1	20 October 2016
Referee's report or other scientific critique report [Kidney Research UK final feedback]	v1	09 January 2017
Referee's report or other scientific critique report [University of Leeds transfer panel report]	v1	28 February 2018
Research protocol or project proposal [Research protocol]	V1	13 April 2018
Summary CV for Chief Investigator (CI) [CI CV]	v1	19 April 2018
Summary CV for supervisor (student research) [Academic supervisor CV (VS)]	v1	26 April 2018
Summary CV for supervisor (student research) [Academic supervisor CV (GM)]	v1	24 April 2018
Summary CV for supervisor (student research) [Academic supervisor CV (SK)]	v1	01 May 2018

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sh

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Resear
Ethics Committees and complies fully with the Standard Operating Procedures for Research
Ethics Committees in the UK.

After ethical review

<u>Reporting requirements</u>

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 HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

18/YH/0210	Please quote this number on all correspondence

Yours sincerely

pp

Professor Basil Sharrack
Chair

Email: nrescommittee.yorkandhumber-sheffield@nhs.net

Enclosures: List of names and professions of members who took part in the review

                        "After ethical review – guidance for researchers"

Copy to: Faculty NHS   Research Ethics Officer
                        Anne Gowing, Leeds Teaching Hospitals NHS Trust

Appendix 21: HRA approval letter

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Ms Ruth Nightingale
PGR office, Room 2.30, Baines Wing
School of Healthcare
University of Leeds, Leeds
LS2 9JT

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

04 June 2018

Dear Ms Nightingale

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Preliminary co-design, development and evaluation of a self-management action plan: Supporting parent-to-child transfer of responsibility for chronic kidney disease (CKD)
IRAS project ID:	226365
Protocol number:	N/A
REC reference:	18/YH/0210
Sponsor	**University of Leeds**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of

IRAS project ID	226365

capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Tel: 0113 343 7587
Email: governance-ethics@leeds.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

IRAS project ID	226365

Your IRAS project ID is **226365**. Please quote this on all correspondence.

Yours sincerely

Laura Greenfield
Assessor

Email: hra.approval@nhs.net

Copy to: *Anne Gowing, [Lead NHS R&D Contact on behalf of Leeds Teaching Hospitals NHS Trust]*

IRAS project ID	226365