The Association between Illness Perceptions, Resilience, and Health Risk Behaviours in Young Adults with Congenital Heart Disease

Louise Johnson

Submitted in accordance with the requirements for the degree of Doctor of Clinical Psychology (D. Clin. Psychol.)
The University of Leeds
School of Medicine
Academic Unit of Psychiatry and Behavioural Sciences

May 2015
The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

© 2015 The University of Leeds and Louise Johnson
Acknowledgements

I would like to thank my supervisors Dr Cathy Brennan and Dr Maureen Twiddy for their continued support and encouragement to explore my ideas throughout this thesis. It has been a pleasure to work with you both. Thank you to Dr Sara Matley for being so helpful with recruitment and for keeping me motivated along the way. I'd like to thank all the congenital heart disease centres who have assisted with recruitment from the following hospitals; Alder Hey Children's Hospital, Glenfield Hospital, Leeds General Infirmary, Manchester Royal Infirmary, Queen Elizabeth Hospital Birmingham and the Royal Brompton Hospital. A special thanks to Dr Robert Johnson for going beyond the call of duty with recruitment.

A big thank you to all the young people who took part in this research. Without your time and efforts, this thesis would not be possible.

Thank you to Sarah, all my friends and to the clique for always making me smile. Thank you to Chris for listening to my endless psychology chat and for being a calming influence throughout training. Your love, kindness and support has been invaluable.

Finally I would like to dedicate this thesis to my parents, Sally and Alan. Thank you for always encouraging and inspiring me to achieve my goals. You truly are wonderful parents.
Abstract

Due to medical advances, the number of adults living with congenital heart disease (CHD) is growing. Individuals with CHD are advised to stay healthy in order to prevent cardiac complications. However, there is evidence to suggest that young adults with chronic health conditions engage in risky health behaviours, although few studies have explored possible theoretical explanations to help understand this.

This study aimed to (1) explore the health risk behaviours of young adults with CHD; (2) explore the illness perceptions they hold about their CHD and their resilience; and (3) explore the association between illness perceptions, resilience and health risk behaviours. Data from young adults (16-24 year-olds) with CHD were collected (n = 70). Participants completed validated measures of illness perceptions (Illness Perception Questionnaire - Revised), resilience (Resilience Scale), and health risk behaviours (Health Behaviour Scale-CHD). Correlation analyses and logistic regression models were used to explore associations between the variables.

Results showed that some participants report engaging in health risk behaviours, including binge drinking, drug taking, smoking, poor dental hygiene and a lack of physical exercise. Increasing age was associated with substance use and age was able to significantly explain some of the variance in reported binge drinking. Some illness perceptions (e.g. consequences, emotional perceptions and personal control) were found to be significant in explaining the variance in health behaviours. However, resilience was not found to be significant in explaining outcomes in health risk behaviours.

The study draws tentative conclusions that illness perceptions may play a role in explaining health risk behaviours. The limitations and clinical implications of the study are discussed.
# Table of Contents

Acknowledgements ..................................................................................................................... iii
Abstract ....................................................................................................................................... iv
Table of Contents ........................................................................................................................ vi
List of Tables ................................................................................................................................. ix
List of Figures ............................................................................................................................... x

## Introduction ............................................................................................................................... 11
   The dimensions of chronic illness ............................................................................................. 11
   Congenital Heart Disease ......................................................................................................... 13
      Classification .......................................................................................................................... 13
      Prognosis .............................................................................................................................. 14
      Complications ....................................................................................................................... 15
   Emotional wellbeing and quality of life in young adults with CHD ............................................. 15
   Challenges facing young adults with CHD ............................................................................... 16
   Young adulthood as a developmental stage ............................................................................. 17
   What are health risk behaviours? ............................................................................................. 18
      Definition .............................................................................................................................. 18
      Recommendations and guidelines ....................................................................................... 19
      Measuring health risk behaviours ......................................................................................... 21

## Literature review ..................................................................................................................... 23
   Search strategy .......................................................................................................................... 23
   Health risk behaviours and chronic illness ............................................................................... 24
   Health risk behaviours and CHD ............................................................................................. 27
   Theoretical models to understand health behaviours ............................................................... 30
      Social Cognition Models ...................................................................................................... 30
      Illness perceptions and the Self-Regulatory Model ................................................................. 31
   Research using the Self-Regulatory Model ............................................................................. 34
      Illness perceptions and adherence ....................................................................................... 34
      Illness perceptions and CHD ................................................................................................. 36
      Illness perception based interventions and self-management .............................................. 37
   Coping ...................................................................................................................................... 39
Definition ........................................................................................................... 39
SRM and coping ................................................................................................. 40
Resilience ........................................................................................................... 41
Defining resilience ............................................................................................. 41
Differences between coping and resilience ...................................................... 43
Theories of resilience ......................................................................................... 44
Measuring resilience ......................................................................................... 44
Resilience and chronic illness ........................................................................... 46
Summary of literature ....................................................................................... 51
Research aims .................................................................................................... 52
Research questions: .......................................................................................... 52
Method ............................................................................................................... 53
Design ............................................................................................................... 53
Participants ........................................................................................................ 53
Procedure .......................................................................................................... 54
Recruitment procedures ................................................................................... 54
Data collection .................................................................................................... 55
Measures ............................................................................................................ 55
Outcome variable ............................................................................................... 55
Health Behaviour Scale-Congenital Heart Disease (HBS-CHD) ...................... 55
Independent variables ...................................................................................... 56
Illness Perception Questionnaire-Revised (IPQ-R) ......................................... 56
The Resilience Scale (RS) ................................................................................. 58
Bristol Online Survey ........................................................................................ 59
Data analysis ....................................................................................................... 60
Sample size ......................................................................................................... 63
Ethical considerations ....................................................................................... 63
Prize draw incentive .......................................................................................... 64
Confidentiality and consent .............................................................................. 64
Results ............................................................................................................... 66
Introduction ....................................................................................................... 66
Participants ......................................................................................................... 66
Participant characteristics .............................................................................. 66
Descriptive statistics ......................................................................................... 68
Health risk behaviours ....................................................................................... 68
Substance use .................................................................72
Dental hygiene ..................................................................74
Physical activity ..................................................................75
Independent variables ..........................................................76
Illness perceptions ..................................................................76
Resilience ...........................................................................77
Associations between health risk behaviour summary scores, illness perceptions and resilience ...........................................78
Associations between specific health behaviours ..............................................79
Analytic statistics - Exploring the variance in health risk behaviours .................80
Logistic regression ..................................................................80
Selecting independent variables ..................................................80
Interpreting logistic regression output .............................................81
Drug use ...........................................................................81
Binge drinking ......................................................................82
Smoking ...........................................................................83
Annual visit to the dentist ..........................................................83
Physical activity ....................................................................84
Checking assumptions ...................................................................85
Discussion .............................................................................86
Introduction ...........................................................................86
Summary of health risk behaviour findings ..........................................86
Explaining the variance in health risk behaviours ......................................91
Age and substance use ................................................................91
Consequences, drug use, and binge drinking .......................................92
Consequences and physical activity ..................................................93
Emotional perceptions and binge drinking ..........................................95
Personal control and annual dentist visit ............................................96
Resilience and health risk behaviours ...............................................97
Resilience and consequences .......................................................98
Strengths ...........................................................................98
Limitations ............................................................................99
Recruitment and participants .........................................................99
Measures .............................................................................100
Study design and statistical limitations ..............................................102
List of Tables

Table 1: Information about the subscales from the questionnaires ........................................61
Table 2: Demographic and CHD-related characteristics of the sample ..................................67
Table 3: Mean, Median, range and SD for health risk behaviour summary scores ..............68
Table 4: Substance use in young adults with CHD ..........................................................72
Table 4 (continued): Substance use in young adults with CHD .........................................74
Table 5: Dental hygiene of young adults with CHD .........................................................74
Table 6: Means, SD and Cronbach's alpha for IPQ-R ....................................................76
Table 7: Correlation data between health risk behaviour summary scores, demographics, IPQ-R and RS .................................................................78
Table 8: Logistic regression model for drug use ...............................................................82
Table 9: Logistic regression model for binge drinking .......................................................83
Table 10: Logistic regression model for no annual visit to the dentist ...............................84
Table 11: Logistic regression model for physical activity .................................................85
List of Figures

Figure 1: Leventhal's self-regulatory model of illness behaviour........................................32
Figure 2: Substance use risk scores for sample .................................................................69
Figure 3: Dental hygiene risk scores for sample...............................................................69
Figure 4: Physical exercise scores for sample .................................................................70
Figure 5: Overall health risk behaviour scores for sample ..............................................71
Introduction

Since the age of 10, I have lived with a chronic health condition. As an adolescent, I can recall wanting to enjoy 'typical' teenage experiences and not wanting to miss out because of my condition. My beliefs about my illness at that time were different compared to the beliefs I now hold. Furthermore, my perception of my illness undoubtedly has influenced the way I choose to manage my condition. The concept of resilience has become of particular interest to me during my clinical practice, especially the ways in which many young people with various physical health conditions demonstrate an astounding ability to 'bounce back'.

The ideas behind this research study have developed from such experiences. The aim of this research is to better understand the health risk behaviours of young adults (16-24 year-olds) with congenital heart disease (CHD). The role of illness perceptions and resilience were investigated to see if there was an association between these psychological constructs and health risk behaviours in young adults with CHD. The following introduction sets this study in context with an overview of CHD and the implications of this condition for young adults. Subsequently a literature review of current understandings of health risk behaviour in young adults with chronic illnesses is discussed.

The dimensions of chronic illness

Chronic illness may be defined as enduring conditions that have a biological, psychological or cognitive basis; last for at least one year, and have the potential to impact upon daily functioning (Moss-Morris, 2013; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). There is a vast amount of research which has investigated the psychosocial impact of living with a chronic illness (Barlow & Ellard, 2006; de Ridder, Geenen, Kuijer, & van Middendorp, 2008; Sawyer, Drew, Yeo, & Britto, 2007). However, the issue of trying to make sense of the variation on psychosocial outcomes is complex. It has been argued that a large amount of this research into the psychosocial impact of living with a chronic illness is disease-specific, although recognising the similarities and differences between specific chronic illnesses and groups of illnesses may help to inform practice (Sawyer et al., 2007). A debate exists in the literature as to whether chronic illnesses should be considered as a 'group' or 'split' into individual conditions (Goodman, Posner, Huang, Parekh, & Koh, 2013). One viewpoint suggests that from a medical perspective, chronic illnesses are
different as they involve a variety of treatment regimes and therefore impact differently on individuals. This medical model of disease focuses on the idiosyncratic aspects of each chronic illness as being largely separate and distinct from each other.

Traditionally, the social model of disease holds an alternative perspective, suggesting that there are many similarities which exist across various chronic illnesses and this model focuses on the individual experience, rather than the specifics of the treatment (Pless & Pinkerton, 1975; Venning, Elliott, Wilson, & Kettler, 2008). It has been suggested that a non-categorical, rather than disease-specific, approach is most appropriate for investigating psychosocial issues related to chronic illness (Pless, Cripps, Davies, & Wadsworth, 1989; Stein & Jessop, 1982).

However, there are also times when illnesses stand out as individual from this perspective. For example, it does not make sense to look at CHD and asthma together due to key differences in diagnosis, prognosis and severity between these conditions. The nature of CHD is that it can be life threatening at birth and there is a need for complex surgery at a young age, which is not true of asthma. Empirical evidence has provided support for the concept that there may be adaptive tasks or illness stressors which relate to the specific illness (Bensing, Schreurs, de Ridder, & Hulsman, 2002), as well as common tasks across illness groups (Heijmans, Rijken, Foets, de Ridder, Schreurs, & Bensing, 2004).

Recently, a working model of adjustment to chronic illness has been proposed which gives consideration to illness specific factors and also factors which have found to be related to outcome across chronic illnesses (Moss-Morris, 2013). The model suggests that illness-specific factors have an effect on the way in which illness stressors impact on emotional wellbeing and quality of life (QOL). Background factors may determine how individuals adapt to illness stressors (e.g. personal, social and environmental factors).

Adjustment to illness stressors is also determined in part by the use of cognitive and behavioural strategies (e.g. self-efficacy, problem-focused coping strategies) which can be considered as relevant across illnesses (Moss-Morris, 2013). Therefore, both illness-specific factors and factors applicable to chronic illnesses more generally should be considered in a more unified way.

This research has chosen to look at complex CHD. Previously, CHD was an area which had been somewhat neglected in psychological literature (Tayebjee & Lip, 2003), however more recently this has begun to attract attention. Complex CHD is a chronic condition which requires further exploration into the specific psychosocial aspects and management of the condition. This group of individuals are likely to have undergone surgical interventions, require follow-up and are advised to adhere to certain lifestyle recommendations. Individuals with CHD have unique medical, emotional and social needs.
which warrant complex CHD conditions being investigated as a group of specific conditions.

Congenital Heart Disease

CHD is an abnormality of the heart that babies are born with and is the most common birth defect, with a worldwide prevalence of 9.1 per 1000 live births (van der Linde, Konings, Slager, Witsenburg, Helbing, Takkenberg, & Roos-Hesselink, 2011). The incidence rate for CHD is estimated to be 6.9/1000 in the United Kingdom or 1 in every 145 babies born (Webb & Williams, 2001). The precise prevalence for adults with congenital heart disease unknown. However, the British Cardiac Society Working Party (2002) estimated that in 2010 there were over 150,000 adults living with simple congenital heart disease in the UK and over 17,000 with complex CHD. Equal numbers of male and females are affected. The cause of CHD is unknown. However, associations include maternal prenatal rubella infection, maternal alcohol abuse, drug treatment and radiation, genetic and chromosomal abnormalities (Kumar & Clark, 2005).

CHD includes a wide range of simple, moderate and complex severity lesions (Hoffman, Kaplan, & Liberthson, 2004). Examples of simple CHD include heart conditions in which there is a hole between the chambers on the left and right side of the heart or a narrowed valve obstructing blood flow to the lungs or other parts of the body (National Heart, Lung, & Blood Institute, 2014). In contrast, complex CHD may include combinations of simple defects, the heart's blood vessels may not be in the correct place, or the way in which the heart develops may be problematic (National Heart, Lung, & Blood Institute, 2014). The treatment for CHD depends upon the specific type of defect. Many simple defects do not require any treatment. However, more severe defects usually require surgery and long-term monitoring of the heart throughout life (National Heart, Lung, & Blood Institute, 2014).

Classification

Cardiac lesions have been classified by incidence and by differentiation of cyanotic and acyanotic lesions (Jacobs, 2003). The classification into cyanotic and acyanotic refers to the general common physiology in the pure 'unoperated' form and describes the condition of the patient at a point in time, rather than the cardiac defect itself (Jacobs, 2003). Cyanosis is "a bluish discolouration of the skin and mucous membranes resulting from an inadequate amount of oxygen in the blood" (Oxford University Press, 2003, p.171). Cyanosis can evolve gradually with several lesions that are initially acyanotic becoming cyanotic (Jacobs,
The most commonly encountered 'cyanotic' cardiac lesions include; tetralogy of Fallot, transposition of the great arteries, tricuspid atresia, total anomalous pulmonary venous connection and truncus arteriosus (Rao, 2009). Common 'acyanotic' conditions include ventricular septal defect, coarctation of the aorta, atrial septal defect, and atrioventricular septal defect.

As there are various types of CHD which require different treatment and follow-up care, it was decided for the purposes of this study that the most commonly occurring 'cyanotic' conditions, as listed above, would be appropriate conditions. These conditions are considered as 'complex', as the majority of patients present as severely ill during the newborn phase (Hoffman & Kaplan, 2002). The treatment for these conditions is major surgery. Without surgery, most children will die before reaching adulthood. The timing and type of the surgery depends on the individual anatomy but is commonly carried out during infancy (British Heart Foundation, 2008a). When patients become older, for example during adolescence, many patients will require further surgical intervention (British Heart Foundation, 2008a).

**Prognosis**

Although the outlook for these conditions is somewhat different, there are notable similarities between them. These conditions usually require surgery in childhood and all require follow-up into adulthood. It is also important to note that the surgery, often referred to as 'corrective' surgery, never makes the heart completely normal. Consequently, there are some important long-term health implications for this population which are discussed later. It is recommended that patients with these conditions should have periodic (typically annual) cardiac follow-up in a specialised CHD centre in order to monitor the heart and identify any complications (Baumgartner et al., 2010).

With the exception of tricuspid atresia, the outlook following surgical intervention for the selected conditions is largely good. In general tricuspid atresia, being a 'univentricular heart' (i.e. one circulatory system), cannot be repaired surgically and can only be palliated. Life expectancy with this condition is generally reduced and patients may die in their teens or more commonly as young adults (British Heart Foundation, 2008b). Previously CHD was considered as a paediatric specialty, but as approximately 90% of children born with CHD now reach adulthood (Moons, Bovijn, Budts, Belmans, & Gewillig, 2010), the number of adults treated for this condition outnumber children (Fox, Devendra, Hart, & Krasuski, 2010). It is difficult to estimate the life expectancy of someone with CHD as it depends on the individual. Estimates are approximately 35-40 years for complex CHD and 55 years for
moderate CHD (Reid et al., 2006). However, many individuals with complex CHD are now living beyond such estimates due to medical advances.

**Complications**

For some types of CHD, (notably tetralogy of Fallot and truncus arteriosus), there are almost always sequelae (conditions resulting from the heart condition) which require reoperation in childhood and adult life. Some heart defects will require replacement valves in the future. A common problem as patients get older is the development of arrhythmias (abnormal heart rhythms) which have the potential to be serious and even fatal (Roos-Hesselin, Perlotro, McGhie, & Spitaels, 1995). Other complications include pulmonary hypertension (raised blood pressure within the pulmonary arteries). This is a serious condition as it can affect the heart's ability to pump blood around the body and get oxygen to the blood.

Individuals with CHD are at risk of endocarditis. Infective endocarditis is an infection of the inner membrane which lines the heart. Without treatment (intravenous antibiotics), endocarditis is very dangerous and mortality approaches 100% (Kumar & Clark, 2005). The condition can be caused by bacteria in the blood stream. There are certain activities that increase the risk of introducing infection into the blood supply that are recommended to be avoided. Injecting recreational drugs, body piercing and tattooing all carry a risk of endocarditis (British Heart Foundation, 2012). As endocarditis may be caused by infections of the teeth or gums, it is recommended that patients visit the dentist regularly and maintain good oral hygiene (National Institute for Health and Care Excellence (NICE), 2008).

**Emotional wellbeing and quality of life in young adults with CHD**

The findings of studies which have investigated emotional wellbeing and QOL in young adults with CHD are mixed. Some studies have reported poor emotional adjustment (i.e. high levels of anxiety and depression) and low self-esteem among adolescents and young adults with CHD (Freitas et al., 2013; Spurkland, Bjornstad, Lindberg, & Seem, 1993; Utens et al., 1993). Studies have found that patients with CHD, including young adults, are disadvantaged in terms of QOL (Landolt, Valsangiacomo Buechel, & Latal, 2008; Schwimmer, Burwinkle, & Varni, 2003; Spijkerboer et al., 2006).

In contrast, other studies indicate that adolescents and adults with CHD perceived their QOL and health status to be as good as that of matched healthy peers (Immer, Althaus, Berdat, Saner, & Carrel, 2005; Moons et al., 2006a). A systematic review investigated QOL
and psychological adjustment in children and adolescents with CHD following cardiopulmonary bypass surgery and found that a significant proportion experienced psychological maladjustment (Latal, Helfricht, Fischer, Bauersfeld, & Landolt, 2009). However, the authors found notable variation in the methodological quality of such studies, for example, some studies included measures which may not have been suitable for use with the population (Latal et al., 2009).

A recent cross-sectional study explored QOL, psychosocial adjustment and psychiatric morbidity of 150 adolescents and young adults (12-26 years) with CHD and also investigated which variables (demographic, clinical and psychosocial) were important in buffering stress and promoting resilience (Areias et al., 2013). It was found that overall CHD patients reported better QOL compared to the healthy population. The authors suggested that this may due to the presence of some buffer variables, such as family environment and social support (Areias et al., 2013).

Overall, there would appear to be a lack of consensus as to the long-term psychological adjustment and QOL of adults with CHD. This may be largely due to limited research (Green, 2004; Pike et al., 2007), no clear consensus about the exact determinants of QOL (Moons et al., 2006a), differences in study designs and the use of various measures (Shearer, Rempel, Norris, & Magill-Evans, 2013).

Interestingly, it has been repeatedly found that psychological adjustment, in children and adults with CHD, is not associated with the severity of the cardiac defect (Brandhagen, Feldt, & Williams, 1991; DeMaso et al., 1991; Karsdorp, Everaerd, Kindt, & Mulder, 2007; Moons, Van Deyk, De Geest, Gewillig, & Budts, 2005). Although a recent review of the evidence suggests that the relationship between disease severity and QOL is not clear-cut (Apers, Luyckx, & Moons, 2015). Nevertheless, it is essential to consider the individual's own subjective experience and coping process for their condition given that psychosocial factors (e.g. beliefs about illness) are important influences (Apers, Luyckx, & Moons, 2015; Sable et al., 2011).

Challenges facing young adults with CHD

Young adults with CHD face several additional challenges in terms of developmental tasks, compared to healthy peers. A model by Foster et al., (2001) highlights unique developmental tasks and issues for adolescents and adults with CHD, which are organised around various domains, including social, emotional, physical, medical and health behaviours. In terms of social and emotional implications, social support for issues related to CHD may reduce as young adults become independent from the family (Foster et al., 2001). Decision making around life partner and reproduction may raise additional issues for
young adults with CHD, especially in cases where there may be risks associated with pregnancy. In order to maintain emotional wellbeing, young adults with CHD may have to manage anxiety related to medical procedures and arrhythmias (Foster et al., 2001).

Young adults with CHD may face gradual or abrupt decreases in physical functioning, including potentially subnormal level of exercise tolerance (Foster et al., 2001; Prapavessis, Maddison, Ruigrok, Bassett, Harper, & Gillanders, 2005). As the transition from child to adult care begins, young adults take responsibility for their health. This requires a greater need for young adults to have knowledge around diagnosis, prognosis and associated health behaviours (Foster et al., 2001).

As discussed, CHD increases an individual's vulnerability to the development of arrhythmias, endocarditis, ventricular dysfunction and premature mortality (Brickner, Hillis, & Lange, 2000a, 2000b). In order to prevent such complications, patients are advised to engage in health promoting behaviours (Goossens et al., 2013). Such behaviours include moderating the intake of alcohol, avoiding cigarette smoking and recreational drugs, maintaining excellent oral hygiene, engaging in adequate exercise and eating a healthy diet (Sable et al., 2011).

There is a need for increased awareness amongst medical professionals of some of the issues described above, which face individuals who are surviving into adolescence and adulthood with CHD (Kumar & Clark, 2005). It has been argued that some of the physical and psychosocial implications for young adults with CHD are uncertain and require future research (Shillingford & Wernovsky, 2010).

**Young adulthood as a developmental stage**

This research is interested in 16-24 year-olds with CHD; an age group which falls within the developmental stage between adolescence and adulthood. As discussed above, during this important transition period, young adults with CHD may have different experiences from healthy peers. A number of theories consider this developmental stage to be characterised by emerging independence and a time during which experimentation is likely (Arnett, 2000; Erikson, 1950, 1968). Adolescents with chronic illnesses are expected to go through similar developmental stages as their healthy peers, such as leaving home, developing relationships and defining their role in society (Hallum, 1995). However, there is research to suggest that young adults with chronic illnesses may find this developmental stage challenging (Maslow, Haydon, McRee, Ford, & Halpern, 2011) and follow atypical developmental patterns, compared to their peers (Verhoof, Maurice-Stam, Heymans, & Grootenhuis, 2012).

A challenge that young adults face with chronic illness face is related to experimental
behaviour. Testing the boundaries is common and can be associated with 'experimenting' behaviours, including smoking tobacco, use of recreational drugs and alcohol (Chen & Jacobson, 2012; Staff et al., 2010). Such behaviour is central during young adulthood and therefore health risk behaviours may be more likely to occur during 'emerging adulthood' (Arnett, 2000). These behaviours may be understood as an important aspect of developmental transition associated with identity explorations (Schulenberg, Maggs, & Hurrelmann, 1999) and risk behaviours may reflect a desire to obtain a wide range of experiences before settling down into the responsibilities of adult life (Arnett, 2000; Schulenberg & Maggs, 2002). Young adults can pursue such experiences freely as they are less likely to be monitored by parents and constrained by roles (Arnett, 2000).

Longitudinal evidence has shown how in the general population substance use rises to a peak in the early twenties, declines sharply following marriage and declines further following the entry to parenthood (Bachman, Wadsworth, O'Malley, Johnston, & Schulenberg, 2013). This research suggests that risk behaviours typically feature during young adulthood, although it is not clear whether this would apply to those young adults who decide not to marry and have children. Nevertheless, given that there is an increased likelihood of health risk behaviours during young adulthood, this may have important health consequences for young adults with CHD and requires further investigation.

**What are health risk behaviours?**

*Definition*

As discussed above, young adulthood is typically a time for experimenting with certain behaviours that may be considered as 'health risk behaviours'. However, it is important to define what is meant by 'health risk behaviours' and recognise that these may be different from 'experimenting' behaviours.

Health risk behaviours have been defined as behaviours with potentially negative effects on health, such as substance use, risky driving, or disordered eating (Surís, Michaud, Akre, & Sawyer, 2008). However, this definition is rather broad and does not make reference to the frequency or intensity of 'risky' behaviours. Furthermore, one-off behaviours, such as taking drugs once during adolescence/young adulthood, may be considered as 'experimenting' behaviours. A more specific definition which makes reference to frequency and intensity of a health risk behaviour is; any activity undertaken by individuals with an intensity or frequency that increases the risk of disease or injury (Steptoe & Wardle, 2004). Another consideration when defining health risk behaviours is that what is considered to be a health risk behaviour in the literature has changed over time.
in response to new evidence, advice and recommendations, e.g. smoking (Morrison & Bennett, 2009). Thus definitions of health risk behaviours often change with new recommendations.

There are some definitions of specific health risk behaviours which exist, in particular for smoking and alcohol use (Hernandez & Blazer, 2006). With regards to tobacco use, the behavioural definition of smoking used in most prevalence studies is having smoked more than 100 cigarettes in one’s lifetime and currently smoking every day or most days (Centers for Disease Control and Prevention, 2010). This definition makes reference to the frequency of smoking behaviour and is clear as to what constitutes as smoking behaviour.

Similar to smoking, alcohol use and defining risky drinking has changed over time. Binge drinking is a fairly new conceptualisation and before then guidance was given in terms of total units consumed in a week. The definition of binge drinking can often have different interpretations, with few references to a numerical value. For example, parliamentary publications often refer to the impact of binge drinking but only use a vague definition of "the consumption of excessive amounts of alcohol within a limited time period" (Parliamentary Office of Science and Technology, 2005, p.1). A more precise definition of binge drinking is the consumption of eight or more units in men and six or more units in women in a single sitting (House of Commons Science and Technology Committee, 2012).

However, such definitions are not consistently applied in the literature and what is meant by health risk behaviours varies, making measurement of such behaviours inconsistent. The lack of formal definitions of health risk behaviours means that measures may struggle to operationalise health risk behaviours with various measures using different cut-off values, making comparisons across studies difficult. Therefore, conclusions about health risk behaviours across studies may be unclear and vary to a large extent.

**Recommendations and guidelines**

In order to help differentiate between 'risky' and 'non-risky' health behaviours, it can be useful to consider the recommendations or guidelines for certain health behaviours. The recommendations and guidelines for smoking, alcohol, dental hygiene and physical exercise will now be discussed, for both the general population and where applicable for individuals with CHD. Recommendations for smoking within the general population and CHD population are for complete cessation of smoking given the vast evidence which has demonstrated the health risks associated with smoking (e.g. Benowitz & Gourlay, 1997;
Kapoor & Jones, 2005; McBride & Ostroff, 2003). There is no recommendation of a ‘safe’ amount of smoking, hence the introduction of national programmes such as the National Health Service (NHS) Stop Smoking campaign. Although there are no specific guidelines for CHD patients, the same guidelines for the general population to cease smoking apply. Furthermore, there is some evidence that this recommendation is more important for those with CHD, given the cardiac associated risks (Engelfriet et al., 2008).

Recommendations for safe use of alcohol are not clear-cut. Guidelines for safe alcohol consumption for the British population were updated in 1995 with the 'Sensible Drinking Report' recommending that men consume no more than 21 units of alcohol per week and women 14 units (Department of Health, 1995). However, these guidelines have undergone several amendments to discourage periodic heavy alcohol consumption with recommendations from the Royal College of Physicians that the British population should aim to abstain from alcohol for three days of the week (House of Commons Science and Technology Committee, 2012). There are no guidelines specifically for individuals with CHD, suggesting that the guidelines for the general population apply. Some have suggested that individuals with CHD are at no greater risk than the general population with regards to alcohol use (Moons et al., 2001) and the lack of guidance by the British Heart Foundation and the American Heart Association on this matter would appear to back up this assumption.

Many drugs are illegal to take due to the associated risks, although the risks from illicit drug use are contested (Nutt, King, & Phillips, 2010). The 'Just Say No' campaign provides recommendations for the general population which advises against taking drugs. However, this campaign was introduced in the 1980s and may be outdated. It may not be the case that all drugs are equally as dangerous (Nutt et al., 2010), although this is often not differentiated in recommendations provided by campaigns such as 'Just Say No'.

In terms of drug use and CHD, intravenous use is specifically contraindicated due to the risk of development of infective endocarditis (British Heart Foundation, 2008a). Certain other drugs are known to have an impact on the heart, which can be particularly detrimental for those with CHD. For example, cocaine use causes increase in blood pressure and cardiac output, which increases the demand on the heart. Whilst increasing the demand of the heart it also causes constriction of the coronary arteries, thereby reducing oxygen supply to an overworked myocardium. This increases risk of cardiac arrest, angina chest pain and arrhythmias (Schwartz, Rezkalla, & Kloner, 2010). Therefore, whilst the recommendations for both the general population and those with CHD are to avoid taking drugs, there may be increased cardiac risks associated with some drugs (e.g. cocaine) for those with CHD.

With regards to dental hygiene, NICE guidelines recommend patients receive routine follow-up from as regularly as three months extending to two years depending on
the patients dental health (NICE, 2004a). Advice from the British Heart Foundation about dental hygiene in patients with CHD is non-specific with regards to frequency of dental check up. Patients are advised to attend regular check-ups with a dentist (British Heart Foundation, 2008a), but what is considered as 'regular' is not stated in these recommendations and therefore open to individual interpretation. According to the NICE guidelines (NICE, 2004a), this could range between three months and two years, as it is for the general population.

Recommendations for physical exercise in adults over the age of 16 are for participation in at least 150 minutes of exercise per week that leads to an increased heart rate and breathing rate, such as brisk walking (Department of Health, 2011). Alternatively, participation in vigorous exercise such as running may be sufficient for a minimum period of 75 minutes per week (Department of Health, 2011).

Advice for individuals with CHD is to encourage physical exercise and very few CHD conditions require the abstinence of physical activity (Sable et al., 2011). The British Heart Foundation provides advice for children and adolescents in line with national guidelines and that patients should exert themselves up to a point of breathlessness at which they are still able to speak in full sentences (British Heart Foundation, 2011). For individuals with CHD who take medication to thin their blood (e.g. warfarin), contact sports, such as rugby, are advised against (British Heart Foundation, 2011). Recent guidelines recommend that adolescents and adults with CHD are encouraged to participate in physical activities and three to four and a half hours per week is suggested, although this depends on individual conditions (Budts et al., 2013). This is somewhat more than the recommendations for the general population. Typically individuals are advised about exercise based on their anatomical lesions (Takken et al., 2012), but this can become complex when calculating recommended exercise (Budts et al., 2013). In summary, the guidelines for physical exercise and CHD do not appear straightforward and perhaps there is confusion both for patients and healthcare professionals about which to apply.

More generally, the way in which guidelines and recommendations change over time highlights some of the complexities of trying to define and measure health risk behaviours. As discussed, there are a lack of guidelines and recommendations for individuals with CHD in terms of various health behaviours. It is therefore unclear what are 'safe' levels of certain behaviours for this population.

Measuring health risk behaviours

In order to try and improve public health, it is important to measure the prevalence of health behaviours in the general population to help identify trends and areas in need of
public health interventions (Mokdad & Remington, 2010). There are various methods in which health risk behaviours are measures, such as postal, face-to-face, telephone, or on the internet and often the method chosen is based on time and cost (Mokdad & Remington, 2010). Furthermore, different populations may respond better to certain methods, e.g. young people may prefer online surveys. There are various national surveys which measure health risk behaviours, such as the Behavioural Risk Factor Surveillance System which is a state-based system of health surveys (Centers for Disease Control and Prevention, 2015a). Another measure of health risk behaviours among young adults is the Youth Risk Behaviour Surveillance System (Centres for Disease Control and Prevention, 2015b). Such national surveys allow trends to be measured across time.

Health risk behaviours are usually measured by questionnaires that assess retrospective self-reports about engaging in various health risk behaviours (Brener, Billy & Grady, 2003). However, difficulties with such measures are that the truthfulness and accuracy of such self-reports are questionable given that it may be difficult to remember accurately and also due to the sensitive nature of such questions. There may be both under- and over-reporting of certain behaviours, depending on social desirability of reporting certain behaviours (Brener et al., 2003). Social desirability may also be influenced by the perceived anonymity and confidentiality of the questionnaire. It has been suggested that young adults may under-report smoking behaviour due to infrequent and episodic smoking which does not lend itself to a clear description of a usual pattern of smoking (Brener et al., 2003; Pokorski, Chen, & Bertholf, 1994).

Problems when asking questions about physical activity, are that a reference period is usually given (e.g. within a week) and individuals are asked to recall such activities that may not be memorable (e.g. climbing up the stairs). Furthermore, the intensity and duration of activities are often asked about which again may be difficult to remember. Individuals may also have to make judgements regarding which categories their behaviour fits into, such as moderate or physical activity (Brener, et al., 2003). The questions used in measures may not correspond to the recommendations/guidelines for certain behaviours as discussed above, making it difficult to accurately assess the level of ‘risky’ behaviour.

A literature review of health risk behaviours and chronic illness will now be presented, with a focus on CHD. Following this, literature which may be useful in understanding why young adults with CHD may engage in health risk behaviours is discussed.
Literature review

Search strategy

A number of literature searches were conducted in order to review the extent to which chronic illness (more specifically CHD), health risk behaviours, resilience and illness perceptions are reported and discussed in the literature. Search strategies were constructed using Web of Science and PsychInfo. Three separate searches were run (see Appendix A) to identify literature on; (i) chronic illness and health risk behaviours, (ii) chronic illness and illness perceptions, and, (iii) chronic illness and resilience. For searches (ii) and (iii) as the initial search did not return sufficient papers, additional key terms (names of various chronic illnesses) were included. A search limited to 1970 to 2015 was used. This timeframe was used to ensure that original key papers were included. Studies were selected based on the following criteria.

The inclusion criteria were:

- Primary research
- Reviews of primary research
- Peer-reviewed
- English language
- Studies which included an 'adolescent' or 'young adults' population, recognising that this definition is not fixed and may range between 12-30 years.

The exclusion criteria were:

- Case studies and opinion papers.
- **Relevance**: Studies were excluded if they were not relevant to the population to be studied. Studies which included young children (0-11 years) or older adults (50+ years) were excluded. Studies which did not include a population who had an illness were excluded.
- **Quality**: Studies which were considered to be of poor quality were excluded. Relevant questions from the Critical Appraisal Skills Programme (CASP) tools were used as a checklist for quality assurances (CASP, 2014). For example, the studies were assessed on whether the outcome was accurately measured to minimise bias and whether confounding factors had been taken into account.
Titles and abstracts were screened for eligibility. Full texts of articles which were not excluded at this stage were obtained and screened. The reference lists of published studies included in the literature review were scrutinised to identify other relevant publications not returned from the electronic search. Data were then synthesised into a narrative review.

**Health risk behaviours and chronic illness**

There has been an increasing interest into health risk behaviours in young adults with chronic illnesses. Whilst risk behaviours are of concern for healthy young people, there are additional concerns for young people with chronic conditions as certain health risk behaviours may have an adverse impact on their condition (Sawyer et al., 2007). Research which has investigated substance use in young adults with chronic illnesses has found inconsistent findings (Sawyer et al., 2007). The use of tobacco has been found to be at least as common in young adults with asthma and diabetes as in healthy young adults (Precht, Keiding, & Madsen, 2003; Wakefield, Ruffin, Campbell, Roberts, & Wilson, 1995). Given that smoking has major health consequences for those with asthma and diabetes, this is concerning. A cross-sectional study of 1,887 adolescents with asthma and 20,688 controls found that more adolescents with asthma smoked daily than without asthma (Precht et al., 2003). Furthermore, the group with asthma smoked significantly more cigarettes compared to the control group. Boys with asthma started smoking at an earlier age compared to boys without asthma (Precht et al., 2003). However, participants were recruited from schools in Denmark and only 59% of schools participated, therefore the sampling bias may have occurred. In addition, the diagnosis of asthma was self-reported and it is unknown whether asthma preceded smoking or whether asthma developed as a result of smoking (Precht et al., 2003).

In a survey of 116 adolescents (12-19 year-olds) with cystic fibrosis and 205 with sickle cell disease, it was found that substance use (tobacco, marijuana, and alcohol) occurred in both groups, but this was more common in the healthy control group (selected from 2760 in-school adolescents) matched for age, sex, and race (Britto et al., 1998). Among those who reported to have used alcohol and marijuana, the age at first use for both substances was older in those with cystic fibrosis and sickle cell disease (Britto et al., 1998). This was also true for the age of first use of tobacco, but only significant for those with sickle cell disease. The authors suggest that this difference may be due to the smaller sample size for cystic fibrosis (Britto et al., 1998).

In terms of explaining the differences between the findings of Precht et al., (2003) and Britto et al., (1998), there are key distinctions between the chronic conditions included
in the samples. Cystic fibrosis and sickle cell disease are both conditions which individuals are born with, whereas asthma is a condition which develops. This may relate to the disease versus dimensions debate of chronic illness discussed earlier and it could be argued that the disease-specific differences between the chronic illnesses explains the difference in health risk behaviours. For example, considering that the age of onset for engaging in health risk behaviours was later for those with cystic fibrosis and sickle cell disease, suggests that perhaps there is delayed pubertal maturation as a result of these conditions which impacts on typical development and adolescents with such conditions are likely to spend periods of time in hospital (Britto et al., 1998). This is unlikely to be the case for those with asthma.

Another study has compared the frequency of health risk behaviours between chronically ill/disabled (n = 760) and healthy (n = 6,788) young adults (Surís et al., 2008). The authors analysed data from the 2002 Swiss Multicenter Adolescent Survey on Health database. This is a nationally representative survey of 7548 adolescents aged 16 to 20 years. The findings revealed that after controlling for age, gender, academic track and parents’ education level, adolescents with a chronic condition were significantly more likely to smoke, use cannabis and to have performed violent or antisocial acts (e.g. attacking an adult, vandalism). It was also found that young adults were significantly more likely to report three or more risk behaviours, after controlling for all other potential confounders (Surís et al., 2008). Such findings suggest that having a chronic condition was an additional risk for engaging in health risk behaviours.

A limitation of this study is that only a proxy measure of socioeconomic status was used in this study (parents’ education level). It may be that this was not adequately controlled for and therefore influenced the results as socioeconomic status is associated with a higher prevalence of risk behaviours (Hanson & Chen, 2007). Furthermore, recruitment included only those young people who attended school and those who were too unwell to attend school, were home schooled, attended special schools, or who had dropped out of school, were not included. Therefore, the finding may be biased towards those with milder health conditions and the results may not be a true reflection of health risk behaviours of young adults with chronic illness.

A recent cross-sectional, school-based, self-report questionnaire study found that Portuguese adolescents with a chronic illness (n = 643) were as likely to engage in risky behaviours (drunkenness, physical fighting and self-harm) as their healthy peers (n = 2,635) (Santos, Ferreira, Simoes, Machado, & de Matos, 2014). Furthermore, adolescents with a chronic illness who reported that their chronic illness affected participation and attendance at school (18.7%) were found to report more risky behaviours, compared to those who felt their chronic illness did not affect school (81.3%). The authors conclude that adolescents with chronic illnesses may be a vulnerable group and engage in risky behaviour, however,
protective factors may include family, peers and school (Santos et al., 2014).

Type one diabetes involves some similar considerations as CHD in terms of lifestyle choices potentially impacting upon prognosis. Risk behaviours in adolescents with type one diabetes can have detrimental effects on health outcomes, and adolescents often have a lack of understanding of their personal risk related to consumption of alcohol, cigarette smoking, illicit drug use, unprotected sex and disordered eating behaviours (Jaser, Yates, Dumser, & Whittemore, 2011).

A cross-sectional, self-report questionnaire study of 215 adolescents (12-18 years) with type one diabetes found that participants were as likely to engage in risky health behaviours (e.g. smoking, drinking alcohol, illicit drug use), compared to a healthy control group (n = 464) (Scaramuzza et al., 2010). Males with type one diabetes were significantly more likely to report a higher rate of tobacco use compared to the control group. Females with type one diabetes reported significantly higher rates of illicit drug and alcohol use. Furthermore, amongst those with type one diabetes those who engaged in risky behaviours reported a higher rate of treatment mismanagement, defined as the reporting of false glycaemic or urine stick results, purposefully avoiding insulin injection and eating sugary foods (Scaramuzza et al., 2010). This suggests that health risk behaviours may be associated with mismanagement of the health condition, both of which may have detrimental health consequences.

Although there is evidence to suggest that young adults with chronic conditions are more likely to engage in health risk behaviours to at least similar, if not higher rates, as young adults without such conditions (Surís & Parera, 2005), this is inconclusive given the contradictory findings. Such inconsistent findings may reflect differences in the way in which health risk behaviours in various studies are defined and measured. When comparisons are made across studies, any difference in how health risk behaviours are defined become important as this may affect valid comparisons from being made. There is a need for future studies to address some of the limitations of previous research. Recommendations include recruiting a cohort of sufficient size to allow multivariate modelling, using standardised and validated measures and to assure confidentiality to participants regarding reporting risk behaviours (Bender, 2006). Furthermore, it is important to expand on recent work which is focussed on investigating explanatory and potentially protective factors against health risk behaviours. This research study intends to address previous limitations and investigate possible explanatory factors. Current research which has explored health risk behaviours in individuals with CHD will now be discussed.
Health risk behaviours and CHD

As with many other chronic illnesses, engaging in health risk behaviours can result in health consequences for young adults with CHD. The risk of developing cardiac-related complications, such as hypertension and coronary artery disease, can be reduced by lifestyle changes (Jackson, Tierney, Daniels, & Vannatta, 2015). For example, engaging in positive health behaviours, such as physical activity and eating a diet low in saturated fats, may be beneficial in reducing the development of such complications (Sable et al., 2011). Therefore, it is perhaps more important for this population to be as healthy as possible, compared to their peers.

Recently, there has been increased interest into health risk behaviours of adolescents and young adults with CHD, although research on this topic still remains scarce (Goossens et al., 2013; Janssens et al., 2014, Jackson et al., 2015). In a study involving 328 patients with moderate and complex CHD, it was found that over one quarter of adolescents (16-18 years-old) and over half of the young adults (19-20 years-old) reported significant substance use, defined as; smoking cigarettes on more than two days, using marijuana or other illicit drugs at least once or binge drinking during a period of 30 days (Reid, Webb, McCrindle, Irvine, & Siu, 2008). Substance use levels were comparable to samples of similar aged peers. However, when considering the general definition of smoking behaviour (i.e. having smoked more than 100 cigarettes in one’s lifetime and currently smoking every day or most days; Centers for Disease Control and Prevention, 2010), smoking on more than two days during a period of 30 days, may not classify someone as a smoker.

Only about 15% of patients with CHD report 'excellent' oral hygiene, defined as annual cleaning by the dentist, and daily flossing and brushing of teeth (Reid et al., 2008) Although again, the NICE guidelines (NICE, 2004a), for dental hygiene are more lenient suggesting that routine dental appointments should be between three months extending to two years, and not necessarily annually. Nevertheless, such results reflect previous findings on the oral hygiene of this population (Chen et al., 2007). The authors concluded that a significant proportion of young adults with CHD are engaging in behaviours that may be impacting on their health and this requires further research (Reid et al., 2008). Although the rates of health risk behaviours were found to be comparable to similar aged peers without CHD (Reid et al., 2008), the issue here is why young adults with CHD are not following advice, as opposed to CHD being a risk factor for health risk behaviours.

A recent study has investigated the health risk behaviours of young people (14-18 years) with CHD (n = 429) and explored the relationship between disease-related knowledge and health risk behaviours (Janssens et al., 2014). As part of the i-DETACH project (Information technology Devices and Education programme for Transitioning
Adolescents with Congenital Heart Disease), data was collected using a four-wave descriptive longitudinal study over three years. Using self-report questionnaires, the Leuven Knowledge Questionnaire for CHD was used to assess disease-related knowledge (Moons et al., 2001). Health risk behaviours were assessed using the Health Behaviour Scale-CHD (HBS-CHD) which measures: i) use of alcohol ii) use of tobacco and illicit drugs iii) oral hygiene and iv) physical activity (Goossens et al., 2013).

This study found moderate to good overall health behaviour as defined by the summary health risk behaviour scores (i.e. substance use, oral hygiene and physical activity) (Janssens et al., 2014). However, more detailed analysis revealed that only a small proportion of patients performed excellent oral health behaviours and most never flossed their teeth which was found to be the most prevalent health risk behaviour (Janssens et al., 2014), which is in line with previous findings (Chen et al., 2007; Reid et al., 2008). Substance use rates were found to be similar to previous studies, with alcohol being reported as the most frequently used substance (Reid et al., 2008). Interestingly, a previous study which used the same sample of patients, found that substance use was significantly lower in adolescents with CHD compared to matched controls (Goossens et al., 2013). Disease-related knowledge was reported to be poor (regarding knowledge about diagnosis, cardiovascular risk factors, signs of deterioration, reproduction, and endocarditis) and there was little evidence to suggest a relationship between disease-related knowledge and health risk behaviours (Janssens et al., 2014).

In a recent cross-sectional study, adolescents and adults (15-39 years) with CHD (n = 200) completed measures of risk knowledge accuracy, perceived risk for developing complications, levels of physical activity and saturated fat intake (Jackson et al., 2015). It was found the majority of participants reported poor risk knowledge (only 9% correctly identified all of the cardiac conditions that they were at risk of developing) and consumed high-fat diets (mean score of 30.36 out of 45, which indicated high levels of saturated fat consumption). Adolescents (15-18 years) and emerging adults (19-25 years) had the lowest risk knowledge scores, compared to the older participants (26-39 years). Participants reported to engage in physical activity at the recommended level, although this was self-reported data and not objectively measured.

Greater risk knowledge and perceived risk for developing complications were significantly associated with a lower saturated fat diet, after controlling for age and education level. Interestingly, perceived risk was significant in predicting exercise (controlling for age and education level) with participants who reported that they expected fewer complications being more likely to report exercising more (Jackson et al., 2015). However, this study was cross-sectional which make difficult to ascertain any inferences about the relationship between disease knowledge, risk perception and health behaviours.
Despite this, the study is interesting in that it explores possible factors which may influence health behaviours of individuals with CHD.

Although the benefits of physical activity have been extensively documented, it has been found that approximately one-quarter of young people with CHD do not perform any physical activity (Janssens et al., 2014; Lunt, Briffa, Briffa, & Ramsay, 2003). Such findings may reflect misconceptions about safe and desirable levels of exercise for this population (Swan & Hillis, 2000). The prognosis for young adults has improved, so the recommended physical activity levels have changed over time, but advice given to patients may not have kept up with this. As discussed, there are now guidelines about recommended physical activity for individuals with CHD (Budts et al., 2013; Takken et al., 2012), although it is unclear whether these are routinely used by healthcare professionals.

Research has investigated physical activity in adolescents and young adults. For example, a retrospective study of 1,976 adults with CHD analysed data collected on smoking, physical activity, blood pressure, body mass index and diabetes, which are considered to be cardiovascular risk factors and compared this sample to the general population (Moons, Van Deyk, Dedroog, Troost, & Budts, 2006). It was found that males had significantly higher prevalence of smoking and high blood pressure, compared to females. Conversely, females engaged in less physical activity and were more likely to be obese (Moons et al., 2006b). Although this may be a mirror of population differences more generally. The CHD sample reported less smoking and more physical activity, compared to the general population sample.

In contrast, another cross-sectional study of 61 adults with CHD assessed physical activity over one week using two accelerometers (Dua, Cooper, Fox, & Stuart, 2007). One measured total activity volume (the Actigraph) and the other measured energy expenditure in physical activity (the Caltrac). In addition, patients were asked to complete an exercise self-efficacy questionnaire. The authors found that those with simple CHD (n = 26), engaged in physical activity similar to a sedentary reference group and those with moderate CHD (n = 18) and severe CHD (n = 17) engaged in significantly lower physical activity than recommended guidelines (Dua et al., 2007). However, the questionnaire responses suggested that individuals were willing to participate in physical activity but had concerns around the safety or benefits of exercise.

The contradictory findings from the two studies described above (Moons et al., 2006b; and Dua et al., 2007) may be explained by the differences in methodology. Moons et al., (2006b) used self-reported measures which may be subject to socially desirable responding, in contrast Dua et al., (2007) used objective measures of habitual physical activity, albeit over a short period of time. Furthermore, there were large differences between the sample sizes in each study, and the small sample size in the second study (Dua
et al., 2007) may affect the reliability of the findings.

In summary, the findings from current research indicate that some young adults with CHD engage in risky health behaviours. Much of the research to date has investigated health behaviours without exploring possible factors associated with such behaviours. This study intends to build on the existing research and attempt to understand why young adults with CHD may participate in health risk behaviours. Theoretical models which may be helpful in understanding this will now be discussed.

**Theoretical models to understand health behaviours**

*Social Cognition Models*

Health psychology offers a number of models that attempt to better understand factors that explain how people manage their health (Byrne, Walsh, & Murphy, 2005). Social Cognition Models which describe key cognitions and their inter-relationships in the regulation of behaviour, have been applied to understanding health behaviours (Conner & Norman, 2005). In particular, the use of such models has been applied to predict adherence in chronically ill patients. Understanding adherence to treatment or health behaviours is important given that it is estimated that 50% of patients with a chronic condition do not adhere to their treatment regime (DiMatteo, Haskard-Zolnierek, & Martin, 2011; Kane & Robinson, 2010). Furthermore, understanding cognitions provides possible targets for behaviour change and hence improved health outcomes.

One of the most widely used of the Social Cognition Models is the Theory of Planned Behaviour (TPB) (Ajzen, 1991). TPB suggests that behavioural intentions (BI) are the best predictor of later behaviour and BI is the outcome of a combination of several beliefs (Ogden, 2007). TPB states that the intention to perform certain behaviours is determined by two forms of beliefs; behavioural beliefs (attitudes towards a behaviour) and normative beliefs (beliefs concerning the likely approval or disapproval of others towards performing a behaviour) (Ajzen & Madden, 1986). Perceived behavioural control is also important. According to TPB, these factors predict behavioural intentions, which are then linked to behaviour (Ogden, 2007).

The TPB is widely used in understanding health behaviour. There were 15,700 citations of TPB in Google Scholar between 2006 and 2010 (Ajzen, 2012). The TPB has been widely applied in the context of understanding and predicting behaviour and meta-analyses for the TPB have focused on health behaviours (Godin & Kok, 1996), such as exercise (Hagger, Chatzisarantis, & Biddle, 2002; Kelley & Abraham, 2004), alcohol use (Johnston & White, 2003) and smoking cessation (Bledsoe, 2006). However, limitations to this model include that the TPB suggests that attitudes and beliefs determine behaviour.
Unfortunately most studies using the TPB have employed correlational designs which do not allow this causal assumption to be tested. A meta-analysis found the average intention-behaviour correlation was 0.53 (Sheeran, 2002), suggesting that intention does not necessarily result in actual behaviour. In addition, TPB does not consider emotional variables which may influence behaviour (Conner & Norman, 2005).

**Illness perceptions and the Self-Regulatory Model**

An alternative approach has suggested that the way in which individuals with chronic conditions perceive their illness might serve to regulate health behaviour (Ross, Walker, & MacLeod, 2004). Leventhal and his colleagues defined illness perceptions or illness representations/cognitions, as a patient's own common sense perceptions about their illness (Leventhal, Meyer, & Nerenz, 1980; Leventhal & Nerenz, 1985). It has been suggested that patients form these illness perceptions based on three sources of information (Leventhal et al., 1980; Leventhal, Nerenz & Steele, 1984; Hagger & Orbell, 2003): i) 'Lay' information which has come from previous social communication and cultural knowledge about the illness, ii) 'External' social environment, such as perceptions of significant or 'authoritative' others about the illness and iii) Individual's 'current' experience with the illness. Using interviews with patients experiencing a variety of different illnesses, Leventhal and his colleagues identified five cognitive dimensions of illness perceptions (Leventhal et al. 1980; Leventhal and Nerenz 1985): i) **Identity**: refers to the label given to the illness and the symptoms experienced, ii) **Cause**: beliefs regarding the possible causes of the illness, iii) **Timeline**: refers to the patients beliefs about how long the illness will last, iv) **Consequences**: the patient's perceptions of the possible effects of the illness on their life, v) **Curability or controllability**: patients represent their illness in terms of whether they believe that the illness can be treated and cured and the extent to which the outcome of their illness is controllable.

Leventhal and colleagues incorporated their work into illness perceptions into the Self-Regulatory Model (SRM) or 'Common Sense Model' of illness behaviour (Leventhal et al., 1984). This model suggests that illness perceptions, influence a range of illness coping behaviours and outcomes (Leventhal et al., 1984; Kaptein et al., 2008; Rozema, Völlink, & Lechner, 2009). The model proposes that there are three stages involved in regulating behaviour. These are: "i) the cognitive representation of the health threat, ii) the action plan or coping stage, iii) the appraisal stage, in which coping and progress are assessed, leading to modification of the representation and/or coping behaviours" (Harvey & Lawson, 2009, p.7). This makes it a dynamic model, but it is difficult to assess the predictive abilities of the model. The model considers interaction between these three stages and the 'parallel
processing’ (cognitive and emotional processes) that may operate independently, although typically there is an interaction (Leventhal & Cameron, 1987). Emotional perceptions are feelings that are triggered by the illness (Diefenbach & Leventhal, 1996; Leventhal, Diefenbach, & Leventhal, 1992). Figure 1 shows a diagrammatic form of the SRM.

![Diagram of the SRM](image)

**Figure 1:** Leventhal's self-regulatory model of illness behaviour (taken from Ogden, 2007, p.53)

Although Leventhal and colleagues originally used interviews to assess illness perceptions, most studies have operationalised illness perceptions using questionnaires, such as the Illness Perception Questionnaire (IPQ) and the revised version of the Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002; Weinman, Petrie, Moss-
Whilst the TPB has often been used as a framework for predicting health behaviour, the SRM may be more useful in accounting for variance in health behaviour. For example, a study which compared the utility of the SRM and the TPB in explaining help-seeking intention of 546 women for symptoms of breast cancer, found that the cognitive component of the SRM accounted for approximately 22% of the variance in help-seeking intention (Hunter, Grunfeld, & Ramirez, 2003). Inclusion of the components of the TPB accounted for an additional 7% of the variance (Hunter et al., 2003). This suggests that both models can help explain some of the variance in health behaviours, although SRM accounted for slightly more. In addition, this study did not examine the emotional component of the SRM which is likely to have explained more of the variance (Hunter et al., 2003).

However, for the hierarchical multiple-regression analysis, the theories were entered in a logical temporal sequence which may explain the difference in the amount of variance explained (SRM was the first step, TPB was the second). This was based on the assumption that women may first draw on their beliefs/knowledge of breast cancer (as outlined in the SRM) and then consider beliefs about help-seeking behaviour (outlined in the TPB) (Hunter et al., 2003). However, it is interesting to note that components from the SRM and TPB were significantly correlated and therefore some of the variance accounted by the SRM in the first step may also have been explained by the TPB. Although breast cancer is a very different illness to CHD, this study illustrates the point to some extent that the SRM may be useful in understanding variance in health behaviours.

In summary, the SRM is different to previous models as it takes into consideration the emotional response to illness and also highlights the importance of coping mechanisms (Harvey & Lawson, 2009). There are limitations to the SRM. For example, it is often not operationalised as intended as researchers tend to focus on one part of the model and often ignore coping. The model suggests that illness perceptions are constantly changed based on how well the coping strategy has addressed the outcome of concern, with the aim to return to homeostasis. This makes the model difficult to refute due to its cyclical design. In addition, the effect sizes are similar to those of other psychological models. Many of the research studies are often cross-sectional in design, as opposed to longitudinal, and therefore they do not test whether the model is actually predictive of outcomes or not. However, as the association between illness perception and health risk behaviours in young adults with CHD has not been explored to date, cross-sectional research is an appropriate and important first step. Despite the limitations outlined above, there is significant research support for the SRM across various illnesses which will now be discussed.
Research using the Self-Regulatory Model

Illness perceptions and adherence

There appears to be two main areas of interest with regards to SRM research. One is research which is focussed on the association between illness perceptions and QOL/emotional wellbeing (e.g. Cartwright, Endean, & Porter, 2009; Edgar & Skinner, 2003; Sawicki, Sellers, & Robinson, 2011; Vaughan, Morrison, & Miller, 2003). The second is related to illness perceptions and health behaviours, of which there is much research across various illnesses and health-related behaviours, in particular adherence (e.g. Abubakari et al., 2011; Broadbent, Donkin, & Stroh, 2011; Bucks et al., 2009; Chen, Tsai, & Chou, 2011; Horne & Weinman, 2002; Kaptein, Klok, Moss-Morris, & Brand, 2010). Adherence may be defined as the extent to which patients follow recommended treatment or health behaviours (Brandes & Mullan, 2013; DiMatteo et al., 2011; Kane & Robinson, 2010).

A recent meta-analysis by Brandes and Mullan (2013) explored whether illness perceptions were able to predict adherence behaviour, including adherence to medication, exercise and diet, across 12 different chronic illnesses. The majority of studies included used the IPQ (Weinman et al., 1996), IPQ-R (Moss-Morris et al., 2002), or Brief Illness Perception Questionnaire (BIPQ) (Broadbent, Petrie, Main, & Weinman, 2006) as a measure of illness perceptions. Correlations from the individual studies were meta-analysed using a random-sized effect model (Brandes & Mullan, 2013). The effect sizes for the different illness perceptions and adherence constructs ranged from -0.02 to 0.12, suggesting a very weak relationship. Furthermore, many of the studies included used a cross-sectional design, which makes it difficult to identify causal relationships (Brandes & Mullan, 2013).

It was hypothesised that the type of chronic illness may have moderated the relationship between illness perceptions and adherence. However, due to the large variation in types of chronic illnesses included in the study, moderator analysis was unable to be performed. It was found that for all illness perceptions, except for coherence, the residual heterogeneity was significant, which suggests that another moderator may have influenced the effect sizes (Brandes & Mullan, 2013). The authors suggest this could have been disease duration, in terms of those who had experienced chronic illness for longer may have been less likely to adhere. However, there was insufficient data on illness duration to perform a moderator analysis on this. The authors concluded that the SRM may be more useful in understanding why patients do not adhere, as opposed to predicting adherence.

Despite the findings from the above meta-analysis, there is some research (some studies which were included in the above meta-analysis) which suggests that illness
perceptions are associated with adherence behaviour among individuals experiencing a chronic illness (Broadbent et al., 2011; Griva, Myers, & Newman, 2000; Kaptein et al., 2010). For example, an exploratory study examined the association between illness perception, personality and adherence behaviours of 97 adolescents and young adults (13-23 years) with hypertension (Žugelj et al., 2010). Similarly to complex CHD, there is no cure for hypertension and patients are advised to follow lifelong non-pharmacologic regimes (e.g. healthy diet, weight reduction and regular physical activity), and sometimes pharmacologic treatment regimes. Using self-report measures, participants completed demographic measures, the BIPQ (Broadbent et al., 2006), the Inventory of Child/Adolescent Individual Differences (Halverson et al., 2003) and the Medical Outcomes Study Adherence Questionnaire (DiMatteo et al., 1993). The authors found that conscientiousness was a significant predictor of general adherence behaviour and was related to lower levels of risky behaviour and higher levels of self-care behaviour (Žugelj et al., 2010). In terms of illness perceptions, treatment control beliefs accounted for a significant amount of the variance in general adherence and specific adherence. For adherence to specific treatment regimes, illness perceptions were more predictive than personality dimensions (Žugelj et al., 2010). This research suggests that personality aspects may influence adherence behaviours, but illness perceptions perhaps play a more important role.

Research into adherence considers not only beliefs about illness, as suggested by the SRM, but also beliefs about treatment behaviours (Horne, 2003; Horne & Weinman, 2002). A cross-sectional study involving 38 adolescents (11-17 year-olds) with cystic fibrosis, investigated the relationship between illness perceptions (as measured by the IPQ), beliefs about treatment (Beliefs About Medicines Questionnaire-Specific (Horne, Weinman, & Hankins, 1999), and reported adherence to treatment (Cystic Fibrosis Treatment Questionnaire, adapted from Myers & Horn, 2006), and reported non-adherence (Medication Adherence Report Scale; Horne & Weinman, 2002) (Bucks et al., 2009). It was found that treatment control beliefs and beliefs about chronicity (timeline) were predictive of health behaviour, and 50% of the variance in reported adherence was explained by adolescents’ illness perceptions (Bucks et al., 2009). Limitations to this study include the small sample size, cross-sectional design and use of self-report measures.

A recent study with 257 adults with type two diabetes examined the beliefs about self-management behaviours (as measured by Beliefs about Medication Questionnaire; Horne et al., 1999), illness perceptions (as measured by the IPQ-R; Moss-Morris et al., 2002), and self-reported measures of adherence to medication, physical activity and diet (French, Wade, & Farmer, 2013). The study design was a cohort analysis of data from a previous open, randomised, three-arm parallel group; which aimed to determine whether there was
any significant difference between the HbA1c levels of diabetic patients who were receiving one of three allocated interventions (Farmer et al., 2009). The study found that illness perceptions and beliefs about behaviour were predictive of health-related behaviours at one year. The authors concluded that beliefs about treatment behaviours are at least as important as illness perceptions in predicting health-related behaviours in those with type two diabetes (French et al., 2013). However, some self-reported measures behaviours used were brief and the measures for physical exercise and diet were not standardised or validated measures. Therefore, the conclusions which can be drawn from this study need to be treated with caution.

In summary, there is empirical support for the use of the SRM as a way of understanding various adherence health-related behaviours. Although it is difficult to make any firm conclusions due to limitations of studies, including small sample size and inadequate measures of various health-related behaviours. This study intends to address some of these previous limitations.

**Illness perceptions and CHD**

There is very little research which has explored the role of illness perceptions in individuals with CHD and more research is needed (Apers, Luyckx, & Moons, 2015). Illness perceptions and QOL have been studied within a CHD population (Schoormans et al., 2014). A longitudinal study involving 845 adults with CHD, asked patients to complete three questionnaires: the IPQ-R (Moss-Morris et al., 2002) and two years later the SF36-Health Survey (Ware & Sherbourne, 1992) and a CHD adult quality of life measure (TNO/AZL Adult Quality Of Life-CHD; Kamphuis et al., 2004) (Schoormans et al., 2014). Using linear regression analyses, it was found that patients with complex defects and poor functional status were more likely to report negative illness perceptions. In addition, negative illness perceptions, such as a strong belief that illness has severe consequences, was predictive of poor future quality of life, independent of patient characteristics (e.g. sex, age, disease severity and functional status) (Schoormans et al., 2014). This suggests that illness perceptions held by individuals with CHD may impact upon their future wellbeing. However, there may have been other factors which influenced quality of life and illness perceptions, such as individual attributes (Schoormans et al., 2014). The authors hypothesised that sense of coherence may mediate the relationship between illness perceptions and quality of life.

This study is supported by the recent findings of O'Donovan, Painter, Lowe, Robinson, & Broadbent, (2015). In a cross-sectional study design, 110 adults with CHD completed measures on depression, anxiety, QOL and illness perceptions. Regression
analyses revealed that illness perceptions were associated with depression, anxiety and QOL. Disease severity and illness course were not (O’Donovan, et al., 2015).

A search identified no literature which has investigated the role of illness perceptions and health behaviours in individuals with CHD. As discussed, individuals with CHD may not necessarily require medication, but certain lifestyle factors and health behaviours are considered important. These include good dental hygiene, regular exercise, moderate alcohol intake and avoidance of smoking and drug use (Sable et al., 2011). It has been suggested that to obtain a good understanding of illness perceptions and health behaviours, the measurement should be tailored to the specific patient population and the specific adherence behaviour (Linn, Vervloet, van Dijk, Smit, & Van Weert, 2010). The present study intends to focus on this. Previous research has indicated that the SRM may be useful in understanding health-related behaviours in chronic illness and therefore the SRM was chosen as one of theoretical underpinnings for this study.

Illness perception based interventions and self-management

It is important for healthcare professionals to recognise the significance of illness perceptions and how these may guide patients’ preferences for treatment and health behaviours (Hale, Treharne, & Kitas, 2007; Leventhal, Leventhal, & Breland, 2011). Indeed the findings from research have been used within clinical settings, for example, to inform management plans (Theunissen, de Ridder, Bensing, & Rutten, 2003). Given that research indicates that there is a link between the beliefs people hold about their illness and their behaviour, researchers have started to investigate whether using illness perceptions as a foundation for self-management interventions can help change patients’ behaviours (Broadbent, Ellis, Thomas, Gamble, & Petrie, 2009; Petrie, Perry, Broadbent, & Weinman, 2012). Much research into this area has been investigated within a cardiac population.

Many self-management groups are built on the idea that cognitions which people form about their illness can be changed (Barlow, Wright, Turner, & Bancroft, 2005). Thus, cognitive-behavioural interventions have been found to help influence the self-management of chronic illnesses (Evers, Kraaimaat, van Riel, & de Jong, 2002; Goodman, Morrissey, Graham, & Bossingham, 2005; Petrie, Cameron, Ellis, Buick, & Weinman, 2002; van Kouil et al., 2010).

One study used the IPQ to help distinguish prospectively between those individuals who had experienced myocardial infarction (MI) who frequently attend at cardiac rehabilitation and those who rarely or never attend (Whitmarsh, Koutantji, & Sidell, 2003). It was found that those who attended cardiac rehabilitation perceived a greater number of symptoms to be associated with their illness (identity), stronger beliefs about the negative
consequences of their illness (consequences) and experienced more emotional distress, compared to non-attenders (Whitmarsh et al., 2003). Understanding the role illness perceptions may have on self-management and health behaviours can help to inform interventions which alter maladaptive illness perceptions in order to try to improve health behaviours.

A randomised controlled trial, has investigated whether an illness perception intervention is effective for MI patients (Broadbent et al., 2009). Patients who had been admitted with acute MI, were randomly allocated to two groups; one was a standard care control group (n = 51) and the other was an intervention group (n = 52). Those in the intervention group received four half-hour individual sessions which were tailored according to the individual's baseline illness perception questionnaire responses. The authors found that the intervention significantly improved how quickly individuals' returned to work of return compared to the control group (Broadbent et al., 2009). Furthermore, the intervention lowered anxieties about returning to work. Interestingly the intervention changed patients sense of coherence about their illness and this remained to be the case at six months. In addition, patients in the intervention group were found to have significantly strengthened causal-attributions for the heart attack compared to the control group. This suggests that an early illness perception intervention may be beneficial to patients and have positive effects both in terms of targeting maladaptive perceptions and helping individuals to return to work (Broadbent et al., 2009).

A more recent study has looked at the effectiveness of a text message intervention designed to modify illness perceptions and treatment beliefs in 216 adults with asthma (Petrie et al., 2012). In a randomised study, over a period of 18 weeks participants either received individually tailored text messages based on their illness perceptions and treatment belief (intervention group) or no text messages (control group). Illness perceptions and treatment beliefs were assessed at baseline and at 18 weeks. Telephone calls were made to participants at 6, 12 and 18 weeks and at 6 and 9 months, to assess adherence to asthma preventer inhaler (Petrie et al., 2012). The authors found that at 18 weeks, the intervention group had significantly increased their rating of the perceived necessity of the preventer medication, the chronicity of the condition (timeline), and their perceived control (control) over their condition, compared to the control group. Furthermore, there was significantly improved adherence to medication in the intervention group over the follow-up period, compared to the control group (Petrie et al., 2012). However, there was significant drop-out to the study, which limits its generalisability.

In summary, such findings described above suggest that tailoring self-management programmes based on patients perceptions of their illness should be considered as a means of promoting self-management of those with chronic illnesses. Therefore, the SRM as a
framework may have important clinical application. It is important to consider that whilst much research related to the SRM has focused on illness perceptions, coping forms a central part of the SRM. This will now be discussed.

**Coping**

*Definition*

There are many definitions of coping which have changed over time (Latack & Havlovic, 1992). The definition proposed by Lazarus and Folkman (1984) is one of the most well known and widely used definitions. They define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). There are two main ways in which coping has been viewed; i) the dispositional view of coping focuses on specific coping styles that have been considered to help people cope across situations, whereas, ii) the situational view of coping considers coping as a process and as something that is specific to stressful situations (Jones & Bright, 2001). The dispositional view considers stable individual differences and looks at the extent to which different coping styles are effective in terms of resulting in positive outcomes. However, others suggest that it is the stressful situation, rather than individual disposition, that shapes the coping response. These responses can change in response to different stressful situations and hence coping is viewed as a process (Jones & Bright, 2001).

The transactional theory of coping brings both of these views together (Lazarus & Folkman, 1984). This transactional theory of coping does not consider coping to be an enduring personality trait, but rather as a dynamic process which consists of cognitive and behavioural strategies used in stressful situations (De Ridder, 1997). Appraisal (evaluation of the stressor) is an important part of the transactional theory of coping. Two types of appraisal are primary and secondary (Lazarus & Folkman, 1984). Primary appraisal is the process in which the potential loss, harm or challenge of the stressor is evaluated (Jones & Bright, 2001). Secondary appraisal refers to the process where the coping options are evaluated to see what can be done to overcome the stressor (Jones & Bright, 2001). Depending on the way in which the situation is appraised, will impact upon the chosen coping strategy and emotional response (Jones & Bright, 2001).

Although the transactional model is a widely used model to explain coping, it does have some limitations. Some of the main concepts of the model are not sufficiently defined. For example, there is no particular timeframe stated for coping efforts (Stone, Greenberg, Kennedy-Moore, & Newman, 1991). Furthermore, the way in which coping is
considered to be a reaction to stressors ignores the effect of other determinants of coping, such as social resources which may also influence coping (Moos & Schaefer, 1993).

Coping has been operationalised in a variety of ways (Davey, Eaker, & Walters, 2003). Whilst there are many measures of coping, there is little consensus on the focus of measures, for example, trait and process measures exist (De Ridder, 1997). Furthermore, there are various ways in which coping strategies have been categorised, such as 'problem-focused' and 'emotion-focused' (Folkman & Lazarus, 1980), and 'avoidant' and 'approach' forms of coping (Krohne, 1993). However, many researchers have used different names to describe the same strategies or the same name to describe different strategies and hence there does not appear to be a consistent approach to categorising coping strategies (Roesch & Weiner, 2001). Another consideration is whether measures (e.g. Ways of Coping and COPE Scale) are assessing coping behaviours or coping strategies, although it is unclear whether such measures can accurately measure either. It is argued that these measures are based on a too narrow conceptualisation of coping which results in a framework that forces individuals to use a framework that may not be appropriate for them (Coyne & Gottlieb, 1996; Jones & Bright, 2001).

It has been suggested that difficulties in measuring coping are not limited to issues regarding the psychometric quality of measures (e.g. validity and reliability), but also reflects underlying conceptual problems (De Ridder, 1997). The numerous coping questionnaires, each assessing various coping dimensions, suggest a lack of consensus around the basic properties of the concept (De Ridder, 1997). Despite these limitations, there is a great deal of research into coping and chronic health conditions and coping forms part of the SRM. This will now be discussed.

**SRM and coping**

The SRM makes explicit links between illness perceptions and coping mechanisms, although coping is often not operationalised in studies (Harvey & Lawson, 2009). There is some empirical and longitudinal research which has found that illness perceptions have an effect on coping behaviour in proportion with the perceived severity of the illness (Kemp, Morley, & Anderson, 1999; Moss-Morris, Petrie, & Weinman, 1996).

There is evidence from recent studies that coping strategies may contribute to psychosocial outcomes in those with illness. For example, in a correlational study of 207 patients with atrial fibrillation (irregular heart rate), illness perceptions were found to contribute the most to psychological distress followed by coping strategies, and symptom frequency (McCabe & Barnason, 2012). Illness perceptions about atrial fibrillation as having serious consequences, a psychological cause, and poor understanding of the
condition, contributed more to total mood disturbance, compared to coping by focusing on emotion or symptom frequency.

In a cross-sectional study of 87 adults with Huntington's disease, it was found that certain illness perceptions predicted psychological distress (Arran, Craufurd, & Simpson, 2013). In particular identity, treatment control and timeline cyclical were found to be independent predictors of anxiety. Illness perceptions which were found to be independent significant predictors of depression were those of identity and perceiving the cause to be related to chance. The coping strategy of seeking instrumental support was also an independent significant predictor of depression. The self-report clinical variables of pain and role functioning related to physical difficulties were found to be independent significant predictors of anxiety and depression, respectively (Arran et al., 2013). Whilst coping was found to explain some of the variance in the outcome, this was more apparent for depression than anxiety.

It has been suggested that the relationship between illness perceptions, coping response and health outcomes represent a 'mediational model' (Baron & Kenny, 1986), in which coping mediates the effects of illness perceptions on health outcomes (Hagger & Orbell, 2003; Rutter & Rutter, 2002). However, many studies have found little evidence to support the 'mediation hypothesis' (e.g. Dorrian, Dempster, & Adair, 2009; Edgar & Skinner, 2003; Heijmans, 1999; Kemp et al., 1999). Such studies found significant impact of illness perceptions on health outcomes, with very little impact on adding coping behaviours (Hagger & Orbell, 2003). As Hale et al. (2007) suggest, it is likely that other factors, such as the role of significant others, influence the pathway from illness perception to outcome and these should be considered. Given that the findings between coping, illness perceptions and outcomes are mixed, perhaps coping is a too narrow construct. Resilience is related to coping but is a more comprehensive construct that perhaps can add explanatory value.

Resilience

Defining resilience

Over recent years there has been growing interest in resilience across psychology and health due to the increase in popularity of positive psychology and asset versus deficit approaches to health and wellbeing (Yi-Frazier et al., 2010). There is not one generally accepted definition of resilience and the way in which empirical studies have operationalised resilience varies (Luthar, Cicchetti, & Becker, 2000). Resilience may be defined as "a psychosocial construct referring to an individual's capacity to maintain psychological and physical wellbeing in the face of adversity" (Yi, Vitaliano, Smith, Yi,
However, this is just one of many different definitions of resilience, which are discussed below. There are various ways of conceptualising resilience either as a personality characteristic, as an outcome, or as a multidimensional process (Aherne, Kiehl, Sole & Byers, 2006). As a result of differences in the way in which resilience has been defined (i.e. trait, outcome or process), it is difficult to measure. This is similar to the discussion above around the difficulties with measuring coping due to conceptual problems.

Some researchers suggest that resilience should be considered as a personality characteristic/trait (Stewart, Reid & Mangham, 1997; Wagnild & Young, 1993). According to the literature, there are certain characteristics/personal resources that are considered to be associated with resilience (Davey et al., 2003). These include high self-worth, coping skills, and personality traits, such as agreeableness, openness and conscientiousness (Rutter, 1985; Werner, 1994). However, some would argue resilience and personality are very similar (Garmezy & DeVine, 1984; Parkes, 1994) and that personality may be a proxy for resilience (Davey et al., 2003).

Others consider resilience as an outcome (Masten, 2001; Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). An outcome definition of resilience is "children who have good outcomes in spite of serious threats to adaptation" (Masten, 2001, p.228). Most definitions of resilience make reference to the experience of some level of risk and achieving positive outcomes (Masten & Powell, 2003), which are often conceptualised in terms such as 'risk' (increased chance of negative outcome) and 'adversity' (situations that may threaten adaptation) (Wright, Masten, & Narayan, 2013).

Commonly identified risk factors for negative outcomes include low socioeconomic status, traumatic life events (e.g. death of family member), and mental illness (Kaplan, 1999). It has been suggested that resilience helps to 'protect' individuals and act as a buffer against psychological and physical health problems during difficult times (Rutter, 1985; Yi et al., 2008). Protective factors are characteristics of the individual (e.g. high self-worth, conscientiousness) and their environment (e.g. supportive social network) which help to reduce or buffer against the possible negative effects of the risk factor (Braverman, 2001).

Other definitions suggest that resilience is a process and occurs within a specific context, for example, "a dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar, Cicchetti, & Becker, 2000, p.543). The suggestion that resilience should be considered as a process, is a more recently recommended approach for viewing resilience. Resilience research tends to focus now on risk and protective processes, as opposed to factors. The reason for the use of the term 'processes' is because 'factors' only provide a name for the feature (e.g., social support) whereas 'processes' provide a more descriptive explanation of how these factors work (Luthar et al., 2000). For
example, the reason why social support may lead to resilient outcomes, may be due to processes involved with social support, such as feelings of acceptance and belonging. Support for resilience as a process comes from evidence of those who demonstrate competence despite being in a high-risk environment (Luthar & Cicchetti, 2000; Masten & Coatsworth, 1998). Furthermore, support from longitudinal studies have found that individuals can fluctuate in terms of unsuccessful to successful adaptation and vice versa at various stages of their lives (Werner, 2000; Werner & Smith, 1982), which suggests resilience is a dynamic process.

**Differences between coping and resilience**

Whilst research has emphasised ‘coping’ as being one aspect of understanding of how individuals manage with chronic conditions (Compas, Jaser, Dunn, & Rodriguez, 2012), resilience implies more than ‘coping’ with a certain situation. Resilience has been considered as an adaptive process in response to a stressor, whereas coping refers to the set of cognitive and behavioural responses used by an individual to manage or diminish the demands of stressful situations (Davey et al., 2003; Folkman & Moskowitz, 2004; Luthar et al., 2000). Coping is one aspect of a resilient individual, however resilience is broader in that it considers wider resources which an individual can draw on in the face of adversity (Masten, Best, & Garmezy, 1990). Coping is reactive and implies there is something to cope with and strategies are needed, whereas resilience implies not needing to cope and strategies may not need to be used (Masten et al., 1990).

Indeed, resilient individuals may have more coping strategies at their disposal but less of a need to use them as they experience a less negative reaction to supposed stressors due to the buffering effect of resilience between coping and stressful situations. Furthermore, individuals who are resilient may not need to rely on coping skills because they have other intra- and inter-personal resources (Davey et al., 2003). It has been suggested that individuals who have positive personality attributes may not need to rely on coping skills as they have other intrapersonal resources (e.g. higher self-worth, conscientiousness) and therefore some argue that resilience and coping are different constructs (Davey et al., 2003). Nevertheless, it is important to acknowledge that distinguishing between coping and resilience is complex and the convergent and discriminant validity of such constructs is still not fully understood. The current study considers coping and resilience to be separate, but related, constructs.
Theories of resilience

Early theories of resilience emphasised identification of child characteristics (e.g. temperament) associated with positive outcomes in the face of adversity (Rutter, 1985; Werner & Smith, 1982). Early approaches to resilience research were based on children who were exposed to risk and as a consequence expected to experience psychopathology but remained healthy (e.g. Anthony, 1987; Rutter, 1985; Werner & Smith, 1982). This approach focused on individual protective factors as it was suggested that these children had unique qualities which enabled them to overcome adversity (Anthony, 1987).

However, later research argued that resilience was not a ‘magic’ but ordinary system of human adaptation in which all children had the ability to overcome adversity (Masten, 2001). This change of perspective was the result of evidence that resilient children were not invincible and with continued risk, all children are vulnerable to negative outcomes (Howard, Dryden & Johnson, 1999; Sameroff & Rosenblum, 2006). Evidence started to show that vulnerable children who faced adversity were able to demonstrate positive outcomes/resilience when certain resources were in place (Ungar, 2001).

Such research later expanded to include external protective factors that may promote resilience, such as effective schools and relationships with supportive adults (Luthar et al., 2000). Consequently, there have been many possible risk and protective processes identified at various levels (Alvord & Grados, 2005; Kelly & Emery, 2003). For example, one framework for resilience includes internal processes, which may be biological (e.g. gender, genetic disposition) or psychological (e.g. coping, personality characteristics), and external processes that relate to the family (e.g. home environment, parenting) or wider community (e.g. peers, social services) (Mandleco & Peery, 2000).

Therefore, although the concept of resilience has been around for some time in the literature, it has changed in how it is defined over time and hence the measurement of resilience is far from straightforward.

Measuring resilience

Whilst acknowledging that there are conceptual difficulties, there is research evidence to support the construct validity of a hypothetical concept of ‘resilience’ (Luthar et al., 2000; Masten et al., 1990; Werner, 1990). This is in terms of synchronous evidence relating to many correlates of resilience (e.g. protective factors, such as positive connections with wider community) across several studies, which have used a number of different measurements (Luthar et al., 2000).
However, there are differences within this evidence in terms of how resilience is conceptualised and the type of 'risk' and 'protective' factors measured vary somewhat. The 'risk' aspect of resilience has been defined in a number of ways (Masten, 2001). For example, risk factors may include socioeconomic measures, divorce, and low birth weight. Similarly, protective factors which also form part of resilience theory have been categorised in terms of individual, family, social or other contextual factors (Haase, 2004). However, researchers have found that different assets are correlated with various risk and outcomes (Crosnoe, Erickson & Dornbusch, 2002; Gutman, Sameroff, & Eccles, 2002) and this makes it difficult to identify universal protective factors (Zolko & Bullock, 2012).

One problem with the lists of risks and protective processes identified is that these can become prescriptive and evidence suggests these are not universal processes as different factors influence their impact (Luthar et al., 2000). For example, the context, individual who experiences risk, the type of risk and resources available are all important (Gladstone, Boydell, & McKeever, 2006; Ungar, 2004). Studies have shown that it is not possible to apply risk and protective processes universally. For example, although internal locus of control is often considered to be a protective factor in resilience (Cryder, Kilmer, Tedeschi, & Calhoun, 2006; Greeff & Van der Merwe, 2004), it can be both a protective process and a risk process. One study found that adolescents with an internal locus of control who were exposed to risk (e.g., alcoholism, divorce) had significantly better mood, self-esteem, and grades (Grossman et al., 1992). However another study, found that maltreated children with an internal locus of control had significantly worse outcomes in peer friendships and academic and social competence (Bolger & Patterson, 2003). This suggests that risk and protective processes are dependent upon numerous factors which relate to the context.

When measuring resilience, it has been suggested that it is important to highlight what is being measured (Windle, Bennett, & Noyes, 2011). Psychosocial resources such as self-efficacy, self-esteem and optimism are often used in studies involving resilience (Cederblad, Dahlin, Hagnell, & Hansson, 1994; Cicchetti, Rogosch, Lynch, & Holt, 1993; Rutter, 1985; Vedhara & Nott, 1996; Wagnild & Young, 1993) and this can avoid the issue of circularity, e.g. when each individual variable is a measure of the same construct, such as that of 'resilience' (Yi et al., 2008). Other researchers have defined and measured resilience in terms of an outcome in response to stress, either a positive or poor outcome (McCubbin, 2001). However, criticisms of this approach include the fact that there is much variation in the types of outcomes as discussed above (Olsson et al., 2003) and there are few validated measures to examine outcomes of resilience (Ahern, 2006).

Other difficulties with measuring resilience is that researchers do not often distinguish between factors that define resilience and those that promote or hinder resilience (Kinard, 1998). It is therefore important to be clear when deciding which aspect of resilience will be
measured, how it will be measured and to acknowledge the limitations to the measurement. There is no 'gold standard' of resilience (Windle, Bennett, & Noyes, 2011) and therefore measurement should be selected based on the chosen definition of resilience and research question.

For the purposes of this research, individual characteristics which are considered to be protective factors in the resilience literature, are measured using a psychological measure of resilience (Wagnild & Young, 1993). It is important to acknowledge that 'psychological resilience' is one facet of resilience; there is much more fruitful discussion of resilience from a multi-faceted approach, with psychological resources being only one type. As discussed above, this includes other resources that are available (extrinsic variables), such as wider social support and family (Masten & Garmezy, 1985; Werner & Smith, 1982, 1992). Although these facets are linked as it is about the individual utilising wider sources of support as well as the issue of social capital in and of itself.

The focus of the majority of research into resilience is with children (Luthar et al., 2000), but there is a need for additional work on resilience with a focus on at risk individuals at other developmental stages (Egeland, Carlson, & Sroufe, 1993; Masten et al., 1990). It is important to acknowledge that individuals respond differently to various developmental opportunities and challenges; this becomes particularly prominent around periods of transition, i.e. adolescence to adulthood (Murray, 2003). In addition, little is known about resilience in populations with chronic illness and further research is needed in this area (Yi et al., 2008). The existing literature on resilience and chronic illness will now be discussed.

**Resilience and chronic illness**

There is some research which has focused on the notion of resilience in adolescents with chronic illnesses to explain why many manage the challenges of adolescence, despite the possible risks which they might face (Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003; Resnick, 2000). Physical illness could be considered as an adversity and resilience may explain why some individuals do better despite the same challenges (Johnston et al., 2015). Children born with congenital defects have been identified as being 'at risk' of failing to achieve their full potential as adults (Rak & Patterson, 1996). However, certain 'protective factors' are considered to support and enhance resilience (Alvord & Grados, 2005; Fergus & Zimmerman, 2005). For example, sense of competence and self-efficacy (individual), close bond with family (family) and peer contact (community).

A relevant study by Blum, Kelly, and Ireland (2001) has examined risk and protective factors associated with young people (aged 12-18) with learning disabilities,
emotional behavioural difficulties, and mobility impairments (n = 5,503), as well as those without such disabilities (n = 15,689). It was found that young people with disabilities were significantly more likely to engage in health compromising behaviours (i.e. suicide attempts, sexual intercourse before the age of 12 years), regular cigarette smoker, alcohol and marijuana use). For example, young people with disabilities were significantly more likely to report regular cigarette smoking compared to their peers. This was not the case for marijuana use, in which only those in the emotional behavioural difficulties group were more likely to report having used marijuana, compared to the comparison group (Blum et al., 2001).

However, protective factors were considered to reduce the likelihood of engaging in health compromising behaviours. These included aspects of resilience such as individual characteristics (e.g. high self-esteem), experiences within families (e.g. family connectedness) and experiences within school (e.g. high attainment) (Blum et al., 2001). Although high attainment is also considered as an outcome for resilience rather than an explanatory variable, such factors could be considered as important attributes which help build resilience and protect against engaging in health compromising behaviours. This study considers resilience as an outcome and investigated protective factors associated with resilience. The study helps to provide support for factors which may help to protect against health risk behaviours.

It has been suggested that resilient young adults tend to engage in adaptive behaviour, including areas of health (Wagnild & Young, 1993). Therefore, it is important to consider research which has investigated whether resilience acts as a protective buffer against engaging in health risk behaviours. A recent study has investigated which factors may serve to protect against health risk behaviours in adolescents with chronic conditions (Nylander, Seidel, & Tindberg, 2014). In a cross-sectional, school-based study, 3786 adolescents (aged 15 and 17) completed a questionnaire which included questions about gender, socioeconomic background, lifestyle, school results, experimenting behaviour and social network. Protective factors related to personal (e.g. optimism), family (e.g. feeling able to talk to parents) and community aspects (e.g. enjoying school) were also measured. The protective factors were identified based on the questions from the 'Life and Health in Youth' questionnaire and variables were created from these questions. Of the 3786 adolescents, 459 reported that they had a chronic condition. All those with chronic illness were more likely to report two, three, or four or more risk behaviours compared to their health peers. It was found that having a chronic condition and a low number of protective factors was associated with increased reporting of clustered health risk
behaviours (Nylander et al., 2014). This study does not directly define these protective factors as being an outcome measure of resilience. However, there is reference to this in the discussion, suggesting that strengthening protective factors will help to ensure resilience. Therefore, it is not clear whether the authors consider the protective factors to be an outcome of resilience and therefore no clear conclusions regarding the role of resilience can be drawn. Furthermore, adolescents with severe chronic conditions may not have been able to attend school and hence not been included which may have influenced the results. For example, it is unclear whether individuals with more severe chronic conditions may have engaged in as many risk behaviours.

A recent systematic review found that resilience was associated with factors specific to physical illness, such as self-care, adherence with recommended treatment, exercise adherence, illness perception and physical outcomes (Stewart & Yuen, 2011). However, the quality of the studies included in this review was variable, with many studies omitting details on selection criteria, statistical analyses and sources of bias. Nevertheless, this review provides some support that resilience may play a role in understanding the health behaviours of those with chronic illnesses and future research should explore this further.

Research has investigated the effects of resilience on self-care behaviours of those with diabetes. In a longitudinal design study, 111 individuals' with diabetes completed surveys and had their glycated haemoglobin (HbA1c) assessed at baseline and at 1-year follow-up (Yi et al., 2008). The study used measures of self-esteem, self-efficacy, optimism and self-mastery to form a composite resilience factor. In addition, diabetes-related distress and self-care behaviours were assessed. The authors found that baseline resilience levels, diabetes-related distress and their interaction predicted individuals' physical health (as measured by HbA1c levels) at one year (Yi et al., 2008). Low resilience was associated with fewer self-care behaviours when there was increased diabetes-related distress. The authors concluded that resilience might serve as a buffer against the impact of diabetes-related distress on self-care behaviours and glycaemic control.

Resilience in this study was considered as more of a personality characteristic, rather than a process. The above study used existing measures of closely related psychosocial resources to create a measure of resilience. This measure was derived from personal and protective resources which have been used to define or associated with resilience (Yi-Frazier et al., 2010). This is not a validated measure of 'resilience' and in terms of psychological resilience, there may be other factors that have not been measured that are part of psychological resilience, such as equanimity (Wagnild, 2009). However, the authors suggest that in using the chosen measures of psychosocial resources, it avoids the problems of circularity, e.g. when each individual variable is a measure of the same construct, such as that of 'resilience' (Yi et al., 2008). This could be considered as an effective way of trying to help define and operationalise resilience. A limitation to the study
is that there was attrition of the sample (23%) at the 1-year follow-up which may have influenced the results. Those who did not attend for a follow-up appointment may have had worse diabetic control and hence the sample may have been biased towards a better-functioning sample than the general diabetes population (Yi et al., 2008).

An extension of this research into resilience and the management of diabetes, investigated coping as a potential mechanism of resilience (Yi-Frazier et al., 2010). It could be argued that there is circularity inherent in definitions of resilience and coping. However, there is research which supports the premise that coping style may contribute to resilience (Rose, Fliege, Hildebrandt, Schirop, & Klapp, 2002; Yi-Frazier et al., 2010). A study of 145 individuals with diabetes found that all the maladaptive coping subscales (e.g. anger, impatience, anxiety, denial, self-blame, distraction, behavioural disengagement, and venting) were significantly and negatively associated with resilience (Yi et al., 2010). Interestingly, in terms of the adaptive coping scales, only emotional support, acceptance and pragmatism were significantly and positively associated with resilience (Yi-Frazier et al., 2010). Other adaptive coping subscales, such as active coping, instrumental support, positive reframing, planning and stoicism were not. This research suggests that although coping and resilience may be related constructs, they are not the same.

Furthermore, the concept of adaptive versus maladaptive coping mechanism is problematic as there is evidence that a repertoire of strategies is most effective (Brennan, Hugh-Jones, & Aldridge, 2013). What may be most important is the right choice of strategy at the right time. For example, siblings of children with a life-limiting condition, participated in a longitudinal, mixed method study which investigated coping and adjustment (Brennan et al., 2013). It was found that strategies such as 'compartmentalising life' allowed siblings to cope with their concern for their ill sibling and create a sense of normality for themselves that seemed positive for them at that time. Whilst this may be considered as an avoidant coping strategy, for siblings in this study it appeared to be adaptive in the short term. However, it has been argued that for long-term coping, reliance on avoidant strategies may be ineffective (Seiffge-Krenke & Klessinger, 2000).

Yi-Frazier et al., (2010) findings suggest that coping strategies may not necessarily be as critical for those with higher resilience. This is a well-designed longitudinal study which provides evidence to support the argument that there is a difference between resilience and coping. However, the study did not find any association between resilience or coping and glycemic control and therefore it is unclear whether resilience is important for self-management of chronic illness over time. This differs from the earlier study which found that resilience predicted change in glycemic control over time (Yi et al., 2008). This was a different type of study design in that it employed a longitudinal design as opposed to cross-sectional and may account for the difference. Nevertheless, both of these studies are interesting in that they provide support that psychological resilience, as defined by self-
esteem, self-efficacy, self-mastery and optimism, may contribute to the management of chronic illness.

There are few studies which have investigated the association between resilience and CHD. A cross-sectional study of 231 adolescents (13-18 years) with CHD found that those who had higher levels of resilience had lower levels of depression (Moon et al., 2009). Resilience in this study was defined and operationalised as a multidimensional construct with a number of associated protective factors (i.e. resilience as an outcome), intrapersonal (e.g. positive self-concept and self-understanding), coping (e.g. resourcefulness) and interpersonal (e.g. positive relationships with others and intimacy) domains (Kim, 2002). These aspects of resilience were included in a 32 item self-report scale that was designed for school-aged children and adolescents with chronic diseases in Korea (Kim, 2002). Each item was scored on a 5-point scale; total scores range from 32 to 160. A higher score indicates higher resilience. This measure of resilience has been shown to have good internal consistency (Cronbach’s alpha 0.92) and test–retest reliability (range; 0.86-0.66).

Despite this, this measure of resilience is very broad in that it encompasses a number of factors within one measure and it is questionable as to whether all such aspects can be accurately measured within a 32-item questionnaire. Depression was measured using the Child Depression Inventory (Beck, 1967) which is a 27-item self-report measure which assesses symptoms of depression. Parental attitude was assessed using a revised version of from Schaefer’s Maternal Behaviour Research Instrument (MBRI), which is a 24 item measure of parenting attitude. All domains of resilience (intrapersonal and interpersonal) were significantly negatively correlated with depression. The multiple regression analysis from this study found that 62% of the variance in depression could be explained by resilience, parental attitude, and CHD functional class (severity), when all other variables were controlled for (Moon et al., 2009).

A limitation of this study is that resilience and parental attitude were found to be significantly positively correlated and hence multicollinearity could have influenced the findings of the multivariate analysis. The cross-sectional study design does not allow for cause-and-effect to be established. Although this study was interested in a psychological outcome i.e. depression, rather than a behavioural outcome, i.e. health risk behaviours, it provides some support that resilience may be important for certain outcomes for those with CHD.

A more recent cross-sectional study explored the health-promoting behaviour and resilience of three groups of chronic kidney disease (CKD) patients (high risk CKD, early CKD and pre-end stage renal disease)(Lu, 2013). Face to face interviews were carried out (n = 150) in which information was collected about the demographic and disease characteristics of the sample. The CKD Health to Promote Lifestyle Scale (Chen, Chou,
Shiau, Wang, Chiou, & Liang, 1997) and Resilience Scale (Wagnild & Young, 1993) were also administered. The CKD Health to Promote Lifestyle Scale comprises of items to assess nutrition, health responsibility, self-actualisation, interpersonal support and stress management and has been found to be a validated and reliable measure. The Resilience Scale is a validated and reliable measure which consists of 25-items which asks questions relating to the psychological resilience, such as acceptance and meaning of life. The study found that those with pre-end stage renal disease had lower resilience compared to the high-risk or early stage CKD groups (Lu, 2013). A significant positive correlation was found between health promoting behaviour and resilience in all groups.

However, these findings are associations and do not imply causality, but do show that better health behaviours are associated with higher resilience scores. In addition, the way in which health behaviours were measured were based on 'promoting' behaviours, some of which included items associated with resilience, such as interpersonal support, and it could be argued that these are not necessarily behaviours and more protective resilience factors. Another limitation is that the sample was recruited from one outpatient setting and therefore may not be generalisable to the wider CKD population.

Despite some of the above limitations, such studies indicate that resilience may be important in understanding health risk behaviours of young adults with chronic illness. This has not yet been explored in young adults with CHD and therefore requires further investigation.

**Summary of literature**

Despite the fact that many children born with CHD are now surviving well into adulthood, there is little research into health risk behaviours of young adults with CHD (Goossens et al., 2013). This has been highlighted as an important area which warrants further investigation as what findings there are seem to be inconsistent (Reid et al., 2008; Sawyer et al., 2007). Young adulthood as a developmental stage is typically characterised by exploration and experimentation, including participation in health risk behaviours (Arnett, 2000).

Whilst the association between illness perceptions and various psychosocial outcomes, including health behaviours, is well reported in the literature for a number of chronic illnesses (Brandes & Mullan, 2013; Hagger & Orbell, 2003), this is somewhat neglected for CHD. The concept of resilience and the impact this may have on outcomes in those individuals who have a chronic illness has empirical support in the literature (Wagnild & Young, 1993; Yi-Frazier et al., 2010), but has not been explored in young adults with CHD.
Young adults with CHD have added stressors in respect to their illness and engaging in health risk behaviours may be one sign that such individuals are struggling with their illness. It may be that illness perceptions and psychological resilience both play a role in influencing whether young adults with CHD engage in health risk behaviours. In terms of clinical application, it is important for healthcare professionals to understand possible associations between psychosocial and physical variables within this population. This can help to inform treatment, management and tailored interventions through a biopsychosocial perspective (Yi et al., 2008).

Research aims

The aims of this study are to explore the health risk behaviours, illness perceptions and resilience of young adults with CHD. Both the SRM and resilience theory provide two possible explanations for understanding health risk behaviours. Therefore, an additional aim is to investigate whether these are useful in understanding the variance in health risk behaviours in young adults with CHD. It may be that, individually, these theories predict health risk behaviours. Alternatively, there may be an interaction between illness perceptions and resilience in terms of better explaining the variance in outcome (i.e. health risk behaviours). Therefore, the aim is to explore the association between illness perceptions, resilience and health risk behaviours in young adults aged 16-24 years with CHD.

Research questions:

- Do young adults with CHD engage in health risk behaviours?
- What kind of illness perceptions do young adults with CHD hold?
- What is the resilience of young adults with CHD?
- Is there an association between illness perceptions and health risk behaviours?
- Is there an association between resilience and health risk behaviours?
- Can an interaction between illness perceptions and resilience better explain the variance in health risk behaviours in young adults with congenital heart disease?
Method

Design

A cross-sectional, online questionnaire based study was used to explore the association between illness perception, resilience and health risk behaviours in young adults with CHD. This is an exploratory study because little is known about this topic. This design allows for a large sample size to be targeted in a straightforward and timely manner. Cross-sectional designs are most commonly used in research which has investigated the association between illness perceptions and various health-related behaviour outcomes (Brandes & Mullan, 2013). Although a cause and effect relationship cannot be established, associations between the variables of interest can be explored using the proposed design. Interesting findings can then be followed up with further experimental or longitudinal studies.

Participants

The sample included participants aged 16-24 years with CHD. This age group (16-24 years) are considered as 'young adults' (Office for National Statistics, 2012). As discussed, CHD encompasses a variety of different conditions, ranging from mild to severe conditions. To reduce the variance in severity of condition within the recruited sample, this study chose to focus on individuals with complex CHD conditions who are likely to require operations from birth and follow-up throughout adulthood. The inclusion criteria included young adults aged 16-24 years who had one of the following types of CHD; tetralogy of Fallot, transposition of the great arteries, tricuspid atresia, total anomalous pulmonary venous connection or truncus arteriosus. The exclusion criteria included anyone without the listed cardiac conditions, those who did not fall into the age-range (16-24 years), those with other genetic abnormalities (such as 22q11 deletion), those without access to the internet and those who were unable to understand written English.
Procedure

Recruitment procedures

As the response rate for online surveys is approximately 30% (Watt, Simpson, McKillop, & Nunn, 2002), in order to recruit sufficient participants it was decided that recruitment for this study would be across multiple National Health Service (NHS) CHD centres. This was a multi-site study and participants were recruited via NHS CHD centres in England. A total of eight NHS CHD centres were identified, following advice received from the CHD centre at Leeds General Infirmary. The researcher made contact with all centres, either via email or telephone. Two centres refused to participate due to time constraints. The other six centres agreed to be involved and act as participant identification sites. Recruitment took place over nine months, between March - December 2014.

In order to protect patient confidentiality, potential participants were identified by a member of the NHS team (i.e. Clinical Psychologist, Consultant, or Nurse) working as part of the local congenital heart service. Participants were identified either via the service database or as participants attended clinic appointments. If participants were identified via a database, a member of the team posted all potential participants who met the inclusion criteria an information pack about the study. If participants were identified via clinics, a member of staff handed out the information packs to all potential participants who met the inclusion criteria, when they came into clinic appointments during the recruitment period.

The recruitment method used was dependent upon the individual service. The preferred method was for services to send information packs in the post which allowed for many packs to be sent at once. This method required CHD services to have an up to date database of patient diagnoses and demographics. This recruitment method was used by five out of six of the CHD centres. One recruitment site did not have a database and therefore potential participants were given the information packs by the nurse via the CHD clinics. This latter method was dependent on eligible patients attending clinics during the timeframe of the study and relied on nurses to hand out the research packs. Although nurses were asked to ensure packs were distributed to all eligible patients, there is no data available as to how many patients were eligible and how many were given packs and therefore selection bias may have occurred. In terms of the number of participants CHD services estimated to meet the inclusion criteria from those services who had a database, this ranged between approximately 50-150 participants per service, but as discussed it was unknown as to how accurate these databases were.

Each information pack contained an invitation letter signed by the lead Consultant or research nurse (Appendix B) and a participant information sheet (Appendix C) which
included the website address to access the survey. Participants who decided to take part in the study went to the online website address and completed the questionnaires.

Data collection

Measures

Participants were asked to complete an 'About You' questionnaire (Appendix D) which was designed to assess demographic information (e.g. age, gender, education level) and CHD-related characteristics (e.g. type of condition, number of operations and how often they attend clinic appointments) in order to help situate the sample. The remaining three validated questionnaires assessed the study related variables. In order to ensure that the study measured the intended constructs, only validated and reliable measures were considered.

Outcome variable

*Health Behaviour Scale-Congenital Heart Disease (HBS-CHD)*

The HBS-CHD is a comprehensive, validated tool for measuring potential health compromising behaviours in individuals with CHD (Goossens et al., 2013). The measure was developed, in part, from existing measures of health behaviour in adolescents and adults (Babor, Higgins-Biddle, Saunders, & Monteiro, 2001; Baecke, Burema, & Frijters, 1982; Brener, Collins, Kann, Warren, & Williams, 1995; Florindo et al., 2006; Kolbe, 1990; Reid et al., 2008; Saunders, Aasland, Amundsen, & Grant, 1993; Saunders, Aasland, Babor, De La Fuente, & Grant, 1993).

The HBS-CHD consists of 15 questions and enables four summary risk scores to be calculated. The risk scores are: i) substance use risk score, ii) dental hygiene risk score, iii) physical exercise score and iv) overall health risk score. Examples of the questions include the following: 'Do you smoke cigarettes occasionally or regularly?' and 'Have you been to the dentist in the past year?' Depending on the responses given to each question, the respondent may be asked to answer additional questions about a particular health risk behaviour. For example, if respondents answer 'yes' to 'Do you consume alcohol from time to time?' further questions ask about the frequency and amount of alcohol consumed (Appendix E).

From the HBS-CHD, there are four summary health risk behaviour scores that can be calculated: substance use risk score, dental hygiene risk score, physical exercise score and overall health risk score. Substance use risk score (range 0-3) is calculated based on: i)
binge drinking at least monthly, ii) smoking of cigarettes and iii) the use of one or more predefined drugs at least once a month in a 12 month period. The higher the score, the more risky substance use behaviour. Dental hygiene risk score (range 0-3) is calculated based on; i) if the participant does not attend annual dentist visits ii) participant does not brush their teeth on a daily basis and iii) participant does not floss their teeth. The higher the score, the more risky dental hygiene behaviour. The physical exercise score (range 0-∞) is calculated based on the usual time spent per week (in hours) in various types of physical exercise, multiplied by the average energy expenditure per unit of time (MJ/h), as derived from Baecke (Baecke et al., 1982). The higher the score, the higher levels of physical exercise. Finally the overall health risk score (range 0-7) is calculated based on the respective substance use risk score, the dental hygiene risk score and the absence of participation in physical activities. The substance use risk score, dental hygiene risk score, and overall health risk score are transformed to a scale from 0 (no risk) to 100 (maximum risk), in order to ease interpretation and comparison (Goossens et al., 2013).

Although there are other measures of health risk behaviours of individuals with CHD (Chen et al., 2007; Reid et al., 2008; Van Deyk, Moons, & Budts, 2005), the HBS-CHD was considered the most comprehensive in terms of assessing a wide range of relevant health risk behaviours which are specifically relevant to the population to be studied (Goossens et al., 2013). This is different from previous measures which only measure some aspects of relevant health behaviour, such as substance use and oral hygiene (Reid et al., 2008).

The psychometric properties of the HBS-CHD have been assessed and tested with 429 adolescents with CHD (Goossens et al., 2013). Overall 86.3% of the items had good to excellent content validity. The averaged scale content validity index (0.81) and the multi-rater Kappa (0.78) were adequate. The Guyatt's Responsiveness Index showed good to excellent capacity of the HBS-CHD to detect clinical changes in the health behaviour over time (Goossens et al., 2013). As this questionnaire is published in American English, it has had minor changes approved by the author into UK English.

Independent variables

Illness Perception Questionnaire-Revised (IPQ-R)

Illness perceptions were assessed using the revised version of the Illness Perception Questionnaire (IPQ) (Weinman et al., 1996; Moss-Morris et al., 2002). The IPQ-R is a self-report questionnaire which asks individuals to rate a series of 70 statements about their illness (Moss-Morris et al., 2002). These statements reflect the dimensions of 'identity' (14 items), 'timeline acute/chronic' (6 items), 'timeline cyclical' (4 items) 'causes' (18 items), 'personal control' (6 items), 'treatment control' (5 items), 'consequences' (6 items), 'illness
coherence' (5 items) and 'emotional perceptions' (6 items). The questionnaire has three sections. The first part measures the 'identity' dimension. From a list of 14 commonly occurring symptoms, participants are asked as to whether they; i) experience the symptom and ii) if they consider it to be related to their CHD condition (Appendix F).

The IPQ-R can be adapted to any medical condition and the authors encourage the 'identity' dimension to be adapted to include symptoms specific to the condition being studied. Although there is an adapted version of the IPQ-R for a CHD population, this is in Dutch (Schoormans et al., 2014). The author of this adapted version was contacted and informed the researcher about the adaptation. From this information and discussions with local Cardiologists, there were four additional symptoms, specific to CHD which were included: cyanosis, palpitations, difficulty breathing and fluid retention. Therefore, there were a total of 18 items on the 'identity' dimension.

The second part of the IPQ-R consists of 38 items and using a 5-point likert scale (from strongly disagree to strong agree) participants are asked to state where they stand in relation to a number of statements, such as 'My illness will last a short time' and 'I don't understand my illness'. The final part of the questionnaire assesses causal attributions in the format of 18 standard items using the same 5-point likert scale. As there was no appropriate cause for CHD listed as a causal attribution in the standard IPQ-R, the researcher included 'genetic abnormality' as a possible cause, which made a total of 19 items for the final section. As suggested by the authors, the word 'illness' was replaced with 'CHD' throughout the questionnaire.

In terms of the scoring for the IPQ-R, for the items on the 'identity scale', a 'yes' response is coded as '1' and a 'no' response is coded as '0'. The total 'identity' score is calculated by the sum of the 'yes' responses in the second column i.e. this symptom is related to my illness. The coding for the second part of IPQ-R (38 items) is as follows; strongly disagree = 1, disagree = 2, neither agree or disagree = 3, agree = 4, strongly agree = 5. However, for the following items this scoring system is reversed; IP1, IP4, IP8, IP15, IP17, IP18, IP19, IP23, IP24, IP25, IP26, IP27, and IP36. High scores on the 'identity', 'timeline acute/chronic' 'timeline cyclical', and 'consequences' dimensions, represent beliefs which are strongly held about the number of symptoms attributed to the illness, the chronicity and cyclical nature of the illness, and the negative consequences of the illness. High scores on the 'personal control', 'treatment control', and 'illness coherence' subscales represent positive beliefs about controlling the condition and a personal understanding about the condition.

High scores on the 'emotional perceptions' subscale represent a more negative emotions associated with CHD. For the final part of the questionnaire, the 'causes' items are not analysed as a scale, rather they are grouped together (i.e. those who do/do not believe in a specific causal factor). The authors of the IPQ-R, suggest that with a sample size of 85+, it
is possible to use factor analysis to identify groups of causal beliefs (e.g. lifestyle, stress) which can then be used as subscales (Moss-Morris et al., 2002).

The IPQ-R was developed as a way of operationalising the SRM. Although the revised version of the IPQ includes three additional subscales (timeline cyclical, emotional perceptions and illness coherence) which do not form part of the original SRM, the inclusion of these additional subscales was based on both psychometric (i.e. improved measurement properties of the cure/control and timeline subscales) and theoretical justification. Research has shown that emotional perceptions and illness coherence are predictive of outcomes (Moss-Morris et al., 2002). The brief version of the IPQ-R (BIPQ) (Broadbent et al., 2006) was considered, although it was felt this was too brief (total of nine items) to be able to explore all the aspects of illness perceptions in any detail.

The IPQ-R is a validated questionnaire which has good evidence for both the internal reliability of the subscales (Cronbach alpha's ranged from 0.79 to 0.89) and the short (three week) and longer term (six month) retest reliability (correlations ranging from $r = 0.46$ to $r = 0.88$) (Moss-Morris et al., 2002). The IPQ-R has sound discriminant, known group and predictive validity. Whilst beliefs about illness have been assessed using a variety of methods including interviews (Schmidt & Fröhling, 2000), the majority of research has made use of the IPQ/IPQ-R, in order to test the SRM.

The Resilience Scale (RS)

As resilience can be difficult to define and operationalise, it was important to use a validated and reliable measure. However, there is no 'gold standard' for measuring resilience (Leontjevas, de Beek, Lataster, & Jacobs, 2014; Windle et al., 2011). As a result of the lack of clarity regarding the resilience concept itself, there are many measures of resilience, which measure the construct differently. Following a literature review of measures of resilience (Windle et al., 2011), it was felt the Resilience Scale (RS) was the most appropriate measure for this study (Wagnild & Young, 1993) (Appendix G). The RS has been used with a wide age range, including young adults (Black & Ford-Gilboe, 2004; Salazar-Pousada, Arroyo, Hidalgo, Perez-Lopez, & Chedraui, 2010) and adolescents with chronic illness (Winsett, Stender, Gower, & Burghen, 2010). Therefore, the measure chosen for the purposes of this study measures psychological resilience, which focuses on an individual's resources. Although resilience is not just about the resources an individual has to offer and encompasses other aspects such as social capital, to date, there is no suitable measure which can reliably measure all aspects of resilience.

The 25-item RS measures the degree of individual resilience through five components: equanimity, perseverance, self-reliance, meaningfulness and existential
aloneness. From factor analysis, it has been found that the RS has two factors: i) Personal Competence (with 17 items that suggested self-reliance, independence, determination, invincibility, mastery, resourcefulness and perseverance) and ii) Acceptance of Self and Life (with eight items that represented adaptability, balance, flexibility and a balanced perspective of life (Wagnild & Young, 1993). It is derived from a qualitative study of interviews with 'resilient' individuals and measures personal attributes associated with resilience (Wagnild & Young, 1990). Participants are asked to rate 25 statements that best indicate their feelings about that statement, using a 7-point likert scale, from 'strongly disagree' to 'strongly agree'. Examples of the statements include, 'I am determined' and 'I keep interested in things'.

A total score is calculated by adding all the choices made on the 25 items from the seven-point likert scale. All items are positively worded and a higher score indicates higher resilience, with possible scores ranging from 25-175. According to the RS manual, scores greater than 145 indicate moderately high to high resilience, scores from 116 to 144 indicate moderately low to low levels of resilience and scores of 115 and below indicate very low resilience (Wagnild, 2009).

The RS has good internal consistency ($r = 0.91$) and good test-retest reliability (correlations ranging from 0.67 and 0.84) (Wagnild & Young, 1993). There is also support for concurrent validity as shown by modest correlations of the RS with well established validated measures of constructs linked with resilience and outcomes of resilience, specifically depression ($r = -0.37$), life satisfaction ($r = 0.30$), morale ($r = 0.28$) and health ($r = -0.26$) (Wagnild & Young, 1993; Wagnild, 2009).

**Bristol Online Survey**

An online survey which included all of the measures described above, was created using Bristol Online Survey (BOS). BOS is an inexpensive method of collecting large amounts of data and responses are also submitted immediately to the researcher, so response rates can be monitored. Furthermore, BOS is a very secure and safe way of collecting and storing data, in contrast to other online survey sites. The BOS encryption (Secure Sockets Layer) ensures that data cannot be intercepted by third parties and that access to the site is secure. It was decided that an online survey would be appropriate for this study, as opposed to a postal survey, for reasons of convenience and possibility increased response rate. An online survey could be widely accessed with relative ease as many young people have access to the internet via computers, smart phones or tablets. The Office for National Statistics (2011) found that 77% of households have access to the internet in the UK. In
addition, 91% of 16-24 year-olds said that they took part in social networking sites on the internet (Office for National Statistics, 2011).

There is a question around whether the psychometric properties for online surveys hold true, as many validated questionnaires are validated using pen-and-pencil versions (Ritter, Lorig, Laurent, & Matthews, 2004). However, research suggests that internet surveys appear to be as reliable and answered similarly as when such questionnaires are administered via traditional mailed paper format (Ritter et al., 2004). In addition, advice was sought from the developer of the IPQ-R who advised that they have used the IPQ-R in this context to good effect. The RS has also been used online to collect data (Wagnild, 2009). The order of the questionnaires were administered as follows; i) IPQ-R, ii) RS, iii) HBS-CHD and iv) About You questionnaire. The survey would not allow participants to continue to the next section until all questions had been answered.

Data analysis

Data was analysed using IBM Statistical Package for the Social Sciences (SPSS) (version 22.0 for windows). As the survey required a response for every question before it could be submitted, there was no missing data to consider. However, as there may have been some inappropriate data (i.e. participants just filling in questions arbitrarily), exploratory statistical tests were carried out to check for this. Initially the data was screened as recommended by Field (2009) and Tabachnick and Fidell (2013) and explored using histograms, Q-Q plots and estimates of skewness and kurtosis to help identify outliers and to assess the distribution of the data. Table 1 provides information about the types of variables and subscales included in the analysis.
Table 1: Information about the subscales from the questionnaires

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Subscale</th>
<th>Type of variable (range of scores)</th>
</tr>
</thead>
<tbody>
<tr>
<td>HBS-CHD</td>
<td>Overall health risk score</td>
<td>Ordinal (0-7)</td>
</tr>
<tr>
<td></td>
<td>Substance use risk score</td>
<td>Ordinal (0-3)</td>
</tr>
<tr>
<td></td>
<td>Dental hygiene risk score</td>
<td>Ordinal (0-3)</td>
</tr>
<tr>
<td></td>
<td>Physical exercise score</td>
<td>Ordinal (0-∞)</td>
</tr>
<tr>
<td>IPQ-R</td>
<td>Identity</td>
<td>Continuous (0-18)</td>
</tr>
<tr>
<td></td>
<td>Timeline acute/chronic</td>
<td>Continuous (6-30)</td>
</tr>
<tr>
<td></td>
<td>Consequences</td>
<td>Continuous (6-30)</td>
</tr>
<tr>
<td></td>
<td>Personal control</td>
<td>Continuous (6-30)</td>
</tr>
<tr>
<td></td>
<td>Treatment control</td>
<td>Continuous (5-25)</td>
</tr>
<tr>
<td></td>
<td>Illness coherence</td>
<td>Continuous (5-25)</td>
</tr>
<tr>
<td></td>
<td>Timeline cyclical</td>
<td>Continuous (4-20)</td>
</tr>
<tr>
<td></td>
<td>Emotional perceptions</td>
<td>Continuous (6-30)</td>
</tr>
<tr>
<td></td>
<td>Causes</td>
<td>Categorical</td>
</tr>
<tr>
<td>RS</td>
<td>Total score</td>
<td>Continuous (25-175)</td>
</tr>
</tbody>
</table>

The mean (M) score for the identity, timeline acute/chronic, consequences, personal control, treatment control, illness coherence, timeline cyclical and emotional representations dimensions were calculated. For the IPQ-R, the scores for the subscales were divided by the number of items which make up the subscale, so that they could be compared to each other on the same scale (1-5). Whilst the authors of the IPQ-R do not include this as part of their scoring guide, previous research has often done this for comparison reasons (e.g. Schoormans et al., 2014). The identity subscale is scored using a summative scale. For the causes domain, items were analysed separately using descriptive statistics to identify trends. It has been suggested that with a sufficient sample size (n = 85 or more), factor analysis can be carried out to identify groups of causal beliefs which may be used as a subscale (Moss-Morris et al., 2002). The internal consistency (Cronbach's alpha) for the IPQ-R and the RS was calculated. Cronbach's alpha was not calculated for the items from the HBS-CHD, following the advice stated by the authors that it is not appropriate nor permitted to use, given that the items on the HBS-CHD are not intended to measure one common concept (Goossens et al., 2013).

In order to examine the association between the variables, initially correlations were carried out. As the health risk behaviour summary scores are ordinal data, Kendall's Tau (τ) was used to explore the associations between the health risk behaviour summary scores (HBS-CHD), illness perceptions (IPQ-R), resilience (RS) and demographic variables (age and frequency of clinic appointments). Kendall's Tau was chosen as opposed to Spearman's coefficient because it has been suggested that Kendall's Tau is a better estimate of the correlation for smaller sample sizes (Howell, 1997). Associations between gender and the
health risk behaviour summary scores were evaluated using the Mann-Whitney U-test.

Correlations were carried out to explore associations between the various illness perceptions and resilience. For normally distributed IPQ-R and RS variables, Pearson’s correlation coefficient ($r$) was used and for non normally distributed correlations, Kendall’s Tau ($\tau$) was used.

To explore the associations between specific health behaviours (smoking, drug use, binge drinking, annual dental visit and physical activity), Fisher’s exact test was used as this method is able to compute the exact probability of the chi-square statistic for smaller sample sizes (Field, 2009).

As the outcome variable (health risk behaviour summary scores) is ordinal, it was not possible to use linear regression. Therefore, binary outcomes derived from the HBS-CHD questionnaire were used in logistic regression models to help establish which independent variables were significant in explaining the variance in health behaviours. There was no statistically or theoretically appropriate way to split the HBS-CHD health risk behaviour summary scores to create binary outcomes and the dichotomisation of variables is not recommended (MacCallum, Zhang, Preacher, & Rucker, 2002). However, some of the questions in the HBS-CHD are binary, for example, ’have you been to the dentist in the last year’? required a response of either ‘yes’ or ‘no’ and so these were used in the analysis.

Initially independent variables (i.e. illness perceptions, resilience score and demographic variables) were examined univariately in each logistic model to see which were significantly associated with various health risk behaviours (e.g. smoking, drug use, binge drinking, annual dentist visit and exercise participation). An alpha level of 0.05 was considered appropriate. Independent variables were entered into multivariate logistic regression models for each health behaviour in order to assess which independent variables accounted for any of the variance in the different health risk behaviour outcomes.

Logistic regression is popular within the field of health sciences and has been used to good effect in research which has explored the association between illness perceptions and health behaviour, such as adherence and health risk behaviours (Sjölander, Eriksson, & Glader, 2013; Van De Ven, Engels, Otten, & Van Den Eijnden, 2007). Logistic regression does not require assumptions of linearity, normality or homoscedasticity to be met (Field, 2009; Katz, 2006; Tabachnick & Fidell, 2013). Binary logistic regression assumes that the outcome variable is a dichotomy (two categories) and that a linear relationship exists between any continuous independent variables and the logit of the outcome variable (Field, 2009). This latter assumption was tested by investigating whether the interaction between the independent variable and its log transformation is significant (Hosmer & Lemeshow, 1989, Field, 2009). Logistic regression also requires independent variables not to be too highly correlated to avoid multicollinearity (Field, 2009).
Multivariate statistics are popular techniques that are widely used for analysing complex data sets (Tabachnick & Fidell, 2013). Multivariate statistics provide analysis when there are many independent variables and/or dependent variables which correlate with each other to different degrees (Tabachnick & Fidell, 2013). However, multivariate results can be sensitive to which analytic strategy is chosen and do not always protect against statistical errors. It is important to consider the number of variables that will be included in the multivariate analysis. In order to get the best solution, this is typically done with the fewest variables (Tabachnick & Fidell, 2013). Including more variables may increase the variance that can be explained in the outcome, although overfitting needs to be considered. The more variables which are included may impact upon the precision of the model, unless there is a sufficient sample size (Tabachnick & Fidell, 2013).

**Sample size**

As it was unknown what the potential strength of any associations between illness perceptions and/or resilience with health risk behaviours, no formal sample size calculation was carried out. However, the following algorithm has been suggested when conducting multiple regression analyses: $104 + p$ (where $p$ is the number of independent variables) (Tabachnick & Fidell, 2013). As there were 10 possible independent variables (as given by the measures used; IPQ-R and Resilience Scale), this would suggest a minimum sample size of 114 participants was required.

**Ethical considerations**

The study met the criteria for Proportionate Review and was granted favourable ethical opinion by the National Research Ethics Service, North West - Preston Research Ethics Committee (REC reference: 13/NW/0883; Appendix H). Approval was received from all six NHS Trust Research and Development departments which granted permissions for the identified centres to act as participant identification sites.
Prize draw incentive

Following the completion of the questionnaires, there was the opportunity for all participants who completed the online survey to enter into a prize draw to win £50 worth of Amazon vouchers. This required participants to enter their email address on a separate form on BOS and it was made clear that this email address was kept separate to their responses. The advantages of including incentives for surveys include the possibility of increasing the response rate. Incentives may also demonstrate appreciation for participants’ time and efforts in completing the survey. Some of the disadvantages may include the issue of coercion, in terms of participants' feeling obligated to complete the survey in order to gain financial reward. However, the incentive used in this survey was to enter into a prize draw to win a £50 Amazon voucher. Therefore, not all participants were financially rewarded. Furthermore, entry into the prize draw was optional.

Confidentiality and consent

All surveys were completed anonymously and no patient identifiable information was collected. Only staff members of the NHS CHD centres had access to the names of those participants who were sent an information pack. Once participants received the information packs to inform them about the project, it was their choice as to whether or not they decided to complete the online questionnaires. At the start of the online survey there was another copy of the participant information sheet (Appendix C). This was followed by a consent form which stated that participants understood what was involved and to click 'continue' if they were happy to take part (Appendix I). The consent form made it clear that because data is anonymous, once the questionnaires have been completed online, it was not possible to remove any responses.

Risks and burdens

This study was potentially a sensitive area which asked young people to think about their illness, in terms of the beliefs they hold and ways in which they cope with their illness. Therefore, it could have caused psychological distress to participants. Participants may have felt uneasy about disclosing their health risk behaviours. In the unlikely event of psychological distress, there were plans in place in order to effectively manage such distress. At the end of the survey, there was a thank you page and a link to the CHD UK support website, should participants have experienced any concern following completion of the survey. If any participant contacted the chief investigator with concerns as a
consequence of completing the questionnaires, Dr Sara Matley (Consultant Clinical Psychologist, Leeds congenital heart service) agreed to support the chief investigator in identifying the appropriate action. This may have involved liaising with the participant's local psychology services with consent from the participant. The questionnaires took no longer than 20 minutes to complete to reduce participant burnout.

Data protection

Data was securely stored by BOS. Only the researcher had access to the data collected and email addresses. The data collected, including email addresses, was securely stored in an access controlled folder on the University computers. Once the survey ended, it was closed on BOS and deleted. A prize draw winner was selected at random and contacted via email. The file containing the email addresses was then permanently deleted from the University computers.
Results

Introduction

This chapter describes and explores the results from this study. The sample and demographic data are described first, followed by descriptive results from the HBS-CHD, IPQ-R and RS. This section concludes by examining the association between the independent variables (illness perceptions, resilience, and demographic variables) and health risk behaviour outcomes. An exploration of how measures of illness perceptions and resilience are associated with various health risk behaviours are explored using correlation and logistic regression analyses. The research questions were as follows:

- Do young adults with CHD engage in health risk behaviours?
- What kind of illness perceptions do young adults with CHD hold?
- What is the resilience of young adults with CHD?
- Is there an association between illness perceptions and health risk behaviours?
- Is there an association between resilience and health risk behaviours?
- Can an interaction between illness perceptions and resilience better explain the variance in health risk behaviours in young adults with congenital heart disease?

Participants

The final sample consisted of a total of 70 participants (45 female; 25 male) aged 16-24 years with CHD. It is estimated that a total of 500 research packs were posted out, given an approximate response rate of 14%. The one centre which handed out research packs, handed out a total of 15 research packs, suggesting that this method was more problematic in terms of recruitment. The limitations of this in terms of bias are discussed in the final chapter.

Participant characteristics

Table 2 provides the details of the demographic and CHD-related characteristics of the sample.
Table 2: Demographic and CHD-related characteristics of the sample (n = 70)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16-17</td>
<td>18</td>
<td>(26)</td>
</tr>
<tr>
<td></td>
<td>18-19</td>
<td>23</td>
<td>(33)</td>
</tr>
<tr>
<td></td>
<td>20-21</td>
<td>21</td>
<td>(30)</td>
</tr>
<tr>
<td></td>
<td>22-24</td>
<td>8</td>
<td>(11)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>25</td>
<td>(36)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>45</td>
<td>(64)</td>
</tr>
<tr>
<td><strong>Geographical location</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yorkshire and the Humber</td>
<td>22</td>
<td>(31)</td>
</tr>
<tr>
<td></td>
<td>North West</td>
<td>19</td>
<td>(27)</td>
</tr>
<tr>
<td></td>
<td>West Midlands</td>
<td>10</td>
<td>(15)</td>
</tr>
<tr>
<td></td>
<td>South East</td>
<td>8</td>
<td>(11)</td>
</tr>
<tr>
<td></td>
<td>Wales</td>
<td>4</td>
<td>(6)</td>
</tr>
<tr>
<td></td>
<td>South West</td>
<td>3</td>
<td>(4)</td>
</tr>
<tr>
<td></td>
<td>North East</td>
<td>2</td>
<td>(3)</td>
</tr>
<tr>
<td></td>
<td>East Midlands</td>
<td>2</td>
<td>(3)</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>GCSE/NVQ</td>
<td>25</td>
<td>(36)</td>
</tr>
<tr>
<td></td>
<td>A-level</td>
<td>29</td>
<td>(41)</td>
</tr>
<tr>
<td></td>
<td>University</td>
<td>14</td>
<td>(20)</td>
</tr>
<tr>
<td></td>
<td>Post-graduate</td>
<td>2</td>
<td>(3)</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Student</td>
<td>32</td>
<td>(46)</td>
</tr>
<tr>
<td></td>
<td>Full-time paid work</td>
<td>13</td>
<td>(18)</td>
</tr>
<tr>
<td></td>
<td>Part-time work</td>
<td>9</td>
<td>(13)</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>9</td>
<td>(13)</td>
</tr>
<tr>
<td></td>
<td>Unable to work due to ill health</td>
<td>4</td>
<td>(6)</td>
</tr>
<tr>
<td></td>
<td>Voluntary work</td>
<td>2</td>
<td>(3)</td>
</tr>
<tr>
<td></td>
<td>Self-employed</td>
<td>1</td>
<td>(1)</td>
</tr>
<tr>
<td></td>
<td>Homemaker</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Transposition of the great arteries</td>
<td>37</td>
<td>(53)</td>
</tr>
<tr>
<td></td>
<td>Tetralogy of Fallot</td>
<td>21</td>
<td>(30)</td>
</tr>
<tr>
<td></td>
<td>Total anomalous pulmonary venous</td>
<td>7</td>
<td>(10)</td>
</tr>
<tr>
<td></td>
<td>connection</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tricuspid atresia</td>
<td>3</td>
<td>(4)</td>
</tr>
<tr>
<td></td>
<td>Truncus arteriosus</td>
<td>2</td>
<td>(3)</td>
</tr>
<tr>
<td><strong>Frequency of CHD service clinic appointments</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>At least every 3 months</td>
<td>0</td>
<td>(0)</td>
</tr>
<tr>
<td></td>
<td>At least every 6 months</td>
<td>8</td>
<td>(11)</td>
</tr>
<tr>
<td></td>
<td>At least every year</td>
<td>40</td>
<td>(57)</td>
</tr>
<tr>
<td></td>
<td>At least every 5 years</td>
<td>11</td>
<td>(16)</td>
</tr>
<tr>
<td></td>
<td>When needed</td>
<td>11</td>
<td>(16)</td>
</tr>
</tbody>
</table>
Table 2 shows that the majority of the participants were female (64%). The mean age was 19 years (SD = 2.09), with most of the sample (80%) aged between 16-20 years. Exploratory data analysis found age was normally distributed. The largest proportion of the sample was located in Yorkshire and the Humber (31%) and the North West of England (27%). The majority of the participants were students (46%). Transposition of the great arteries was the most commonly reported diagnosis (53%). All participants had undergone at least one surgical operation, with the majority reporting 1-2 operations (83%) and most commonly participants attended CHD service clinic appointments at least every year (57%).

Descriptive statistics

Health risk behaviours

Table 3 shows the health risk behaviour summary scores for substance use risk scores, dental hygiene risk scores, physical exercise scores and overall health risk behaviour scores. For substance use, dental hygiene and overall health risk scores, higher scores are an indication of more risky behaviours. For physical activity, the score is calculated based on the usual time spent per week (in hours) in various types of physical exercise, including walking or cycling to and from school or work, multiplied by the average energy expenditure per unit of time (MJ/h), as derived from Baecke (Baecke et al., 1982). Higher scores indicate higher levels of physical exercise.

Table 3: Mean, Median, range and SD for health risk behaviour summary scores

<table>
<thead>
<tr>
<th>HBS-CHD risk scores (range)</th>
<th>Mean</th>
<th>Median</th>
<th>Sample range</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance use risk score (0-100)</td>
<td>20.44</td>
<td>0.00</td>
<td>0-100</td>
<td>30.23</td>
</tr>
<tr>
<td>Dental hygiene risk score (0-100)</td>
<td>22.29</td>
<td>33.00</td>
<td>0-67</td>
<td>23.22</td>
</tr>
<tr>
<td>Physical exercise score (MJ/h) (0-∞)</td>
<td>5.68</td>
<td>2.27</td>
<td>0-32</td>
<td>7.56</td>
</tr>
<tr>
<td>Overall health risk score (0-100)</td>
<td>25.13</td>
<td>29.00</td>
<td>0-71</td>
<td>18.65</td>
</tr>
</tbody>
</table>

From Table 3, the mean (M) and median scores for the dental hygiene risk score (M = 22.29, Median = 33.00, SD = 23.22), suggest that the majority of the sample scored higher risk for dental hygiene compared to substance use risk. Generally participants reported what is considered 'moderate to good' overall health risk behaviours and these are comparable to other studies which have used the HBS-CHD (Goossens et al., 2013). However, the SD and range is large for all the subscales suggesting wide variability within the scores. Figures 2-5 illustrate the large distribution of the scores for all four health risk behaviour summary scores.
Figure 2 shows that the majority of the sample (n = 43, 61%) scored 0 on the substance use risk score, which was also the case for the dental hygiene risk score (n = 32, 46%) (Figure 3). For both the substance use risk scores and dental hygiene risk scores, the majority of the participants scored at the lower end of the scale indicating relatively low risk behaviours (n = 58, 82% and n = 61, 87%, respectively). In real terms what this means for substance use risk scores is that a score of 0, indicates that there was no reporting of any of the following; i) binge drinking (drinking six glasses or more of alcohol on one occasion) at

Figure 2: Substance use risk scores for sample (n = 70)

Figure 3: Dental hygiene risk scores for sample (n = 70)
least monthly, ii) smoking cigarettes occasionally/regularly and iii) the use of one or more predefined drugs at least once a month in the last 12 months (Goossens et al., 2013). A score of 33, indicates one out of three of these health behaviours were reported, a score of 67 indicates that two of these behaviours were reported and a score of 100 indicates that all three of these substance use risk behaviours were reported. For the dental hygiene risk scores, a score of 0 indicates that there was no reporting of any of the following: i) no annual visit to the dentist, ii) no daily brushing of teeth and iii) no flossing of teeth (Goossens et al., 2013). As with the substance use risk scores, a score of 33 indicates one out of three of these health behaviours were reported, a score of 67 indicates that two of these behaviours were reported and a score of 100 indicates that all three of these dental hygiene risk behaviours were reported.

Figure 4: Physical exercise scores for sample (n = 70)

Figure 4 shows large variability in the physical exercise scores. Whilst almost a third of participants scored 0 (i.e. reported no physical exercise) on the physical exercise score (n = 21, 30%), the majority (n = 49, 70%) exerted at least an hour of energy (MJ/h) per week as derived by Baecke algorithm (Baecke et al., 1982).
Figure 5 shows that the majority of the overall health risk behaviour scores (n = 50, 71%) were less than or equal to 29 out of a possible total of 100, again suggesting relatively low overall health risk behaviours. For the overall health risk behaviour score, a score of 0 indicates that there was no reporting of any of the following behaviours; i) binge drinking at least monthly, ii) smoking cigarettes occasionally/regularly, iii) the use of one or more predefined drugs at least once a month, iv) no annual visit to the dentist, v) no daily brushing of teeth, vi) no flossing of teeth or vii) the absence of participation in physical activities (Goossens et al., 2013). A score of 14 = 1 behaviour, 29 = 2 behaviours, 43 = three behaviours, 57 = four behaviours, 71 = five behaviours and 100 = six or more behaviours.

Exploratory data analysis showed that overall health risk behaviour score appeared to be normally distributed. The substance use risk score was non-normally distributed and was significantly positively skewed, as was the dental hygiene risk score and physical exercise score. The distribution for this sample indicates that such subscale scores were on the lower side for the health risk behaviours, i.e. participants were relatively healthy. Furthermore, it is not surprising that these subscales were non-normally distributed given that they are not continuous variables.

The way in which the HBS-CHD calculates each health behaviour risk score provides a global score and does not provide specific details regarding individual health risk behaviours. Therefore it was considered important to explore the breakdown of the data from the HBS-CHD further to identify any trends in health risk behaviours. This is outlined below.
Table 4 shows the reported use of various substances; alcohol, tobacco and drugs. In terms of substance use, the majority of participants consumed alcohol from time to time (n = 54, 77%) and 18 (26%) reported to engage in binge drinking (i.e. consumed six glasses of alcohol on one occasion at least once a month). Only 9 participants (12%) smoked cigarettes occasionally or regularly and 16 participants (23%) reported using at least one type of the listed drugs, at least once a month. The most frequently used drugs were cannabis, and then sleeping pills, sedatives, or tranquilisers. With regards to Table 4, it is important to note that some participants reported taking more than one of the listed drugs and this explains the discrepancy between number of participants reported as using at least one of the listed drugs once a month or more within 12 months (n = 16) and the breakdown of each individual drug type.
Table 4: Substance use in young adults with CHD (n = 70)

<table>
<thead>
<tr>
<th>HBS-CHD item</th>
<th>n ( %)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alcohol</strong></td>
<td></td>
</tr>
<tr>
<td>Yes consume alcohol from time to time</td>
<td>54 (77)</td>
</tr>
<tr>
<td>If yes, how often do you drink six glasses or more on one occasion?</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>16 (23)</td>
</tr>
<tr>
<td>Less than monthly</td>
<td>20 (29)</td>
</tr>
<tr>
<td>Monthly</td>
<td>12 (17)</td>
</tr>
<tr>
<td>Weekly</td>
<td>6 (9)</td>
</tr>
<tr>
<td>Daily or almost every day</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Tobacco</strong></td>
<td></td>
</tr>
<tr>
<td>Smoking cigarettes occasionally or regularly</td>
<td>9 (12)</td>
</tr>
<tr>
<td>If yes, during the last 30 days, on how many days did you smoke cigarettes?</td>
<td></td>
</tr>
<tr>
<td>1-2 day(s)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>3-5 days</td>
<td>1 (1)</td>
</tr>
<tr>
<td>6-9 days</td>
<td>0 (0)</td>
</tr>
<tr>
<td>10-19 days</td>
<td>2 (3)</td>
</tr>
<tr>
<td>20-29 days</td>
<td>3 (4)</td>
</tr>
<tr>
<td>All 30 days</td>
<td>2 (3)</td>
</tr>
<tr>
<td><strong>Drug type</strong></td>
<td></td>
</tr>
<tr>
<td>How often in the last 12 months did you take the following drugs?</td>
<td></td>
</tr>
<tr>
<td><em>Cannabis</em></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1 (1)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>2 (3)</td>
</tr>
<tr>
<td>≥2 × per month</td>
<td>68 (97)</td>
</tr>
<tr>
<td><em>Ecstasy</em></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≥2 × per month</td>
<td>68 (97)</td>
</tr>
<tr>
<td><em>Cocaine</em></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>2 (3)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≥2 × per month</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
Table 4 (continued): Substance use in young adults with CHD (n = 70)

<table>
<thead>
<tr>
<th>HBS-CHD item</th>
<th>n ( %)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hallucinogenic mushrooms</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>69 (99)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>1 (1)</td>
</tr>
<tr>
<td>2-4× per month</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≥2× per week</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Speed</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>70 (100)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>0 (0)</td>
</tr>
<tr>
<td>2-4× per month</td>
<td>0 (0)</td>
</tr>
<tr>
<td>≥2× per week</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>Sleeping pills, sedatives or tranquillisers</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>66 (94)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>2 (3)</td>
</tr>
<tr>
<td>2-4× per month</td>
<td>2 (3)</td>
</tr>
<tr>
<td>≥2× per week</td>
<td>0 (0)61</td>
</tr>
<tr>
<td>[ ]</td>
<td>(87)</td>
</tr>
<tr>
<td><strong>Other drugs</strong></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>6 (9)</td>
</tr>
<tr>
<td>≤1× per month</td>
<td>0 (0)</td>
</tr>
<tr>
<td>2-4× per month</td>
<td>3 (4)</td>
</tr>
<tr>
<td>≥2× per week</td>
<td></td>
</tr>
</tbody>
</table>

Dental hygiene

Table 5 shows that in terms of the dental hygiene of the sample; annual dental visits, teeth brushing and flossing. Thirteen participants (19%) do not attend an annual visit to the dentist. The majority of the sample brush their teeth at least once a day or more (n = 69, 99%), although the majority (n = 67, 96%) reported that they 'never' or 'now and then' floss their teeth.
Table 5: Dental hygiene of young adults with CHD (n = 70)

<table>
<thead>
<tr>
<th>HBS-CHD item</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No visit to the dentist in the past year</td>
<td>13 (19)</td>
</tr>
<tr>
<td>How often do you brush your teeth?</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Now and then</td>
<td>1 (1)</td>
</tr>
<tr>
<td>1× per day</td>
<td>24 (35)</td>
</tr>
<tr>
<td>2× per day</td>
<td>44 (63)</td>
</tr>
<tr>
<td>3× per day</td>
<td>0 (0)</td>
</tr>
<tr>
<td>&gt;3× per day</td>
<td>1 (1)</td>
</tr>
<tr>
<td>How often do you floss your teeth?</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>32 (46)</td>
</tr>
<tr>
<td>Now and then</td>
<td>35 (50)</td>
</tr>
<tr>
<td>1× per day</td>
<td>2 (3)</td>
</tr>
<tr>
<td>2× per day</td>
<td>1 (1)</td>
</tr>
<tr>
<td>3× per day</td>
<td>0 (0)</td>
</tr>
<tr>
<td>&gt;3× per day</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Physical activity

In exploring the data further regarding physical activity, it was found that 30 participants (43%) reported that they walked or cycled to school or their place of work and 37 participants (53%) stated that they regularly practice a sport. Of those who stated that they regularly practiced a sport, closer examination of the data revealed the majority of the sample stated this was zero hours per week for physically demanding sports (n = 44; 63%), moderately physically demanding sports (n = 41; 59%) and for minimal demanding physical activity (n = 51; 73%). These figures suggest that whilst the majority of the sample reported they practiced a sport, for many this was less than an hour per week. For those who reported that they walked or cycled to school or their place of work and/or regularly practiced a sport, the majority reported that they took part in at least one of these activities (n= 51; 73%), compared to 19 participants (27%) who reported that they did not participate in either.
Independent variables

Illness perceptions

Table 6 shows the means, SD, and Cronbach's alpha for the IPQ-R variables.

<table>
<thead>
<tr>
<th>IPQ-R Scale (range)</th>
<th>Sample range</th>
<th>Mean</th>
<th>SD</th>
<th>Cronbach's alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity (0-18)</td>
<td>0-12</td>
<td>3.71</td>
<td>3.12</td>
<td>N/A</td>
</tr>
<tr>
<td>Timeline acute/chronic (1-5)</td>
<td>2-5</td>
<td>4.10</td>
<td>0.83</td>
<td>0.89</td>
</tr>
<tr>
<td>Consequences (1-5)</td>
<td>1-4.5</td>
<td>2.56</td>
<td>0.91</td>
<td>0.86</td>
</tr>
<tr>
<td>Personal control (1-5)</td>
<td>1.8-4.5</td>
<td>3.14</td>
<td>0.58</td>
<td>0.62</td>
</tr>
<tr>
<td>Treatment control (1-5)</td>
<td>1.6-4.6</td>
<td>3.23</td>
<td>0.63</td>
<td>0.67</td>
</tr>
<tr>
<td>Illness coherence (1-5)</td>
<td>1.4-5</td>
<td>3.81</td>
<td>1.00</td>
<td>0.92</td>
</tr>
<tr>
<td>Timeline cyclical (1-5)</td>
<td>1-5</td>
<td>2.22</td>
<td>1.02</td>
<td>0.89</td>
</tr>
<tr>
<td>Emotional perceptions (1-5)</td>
<td>1-5</td>
<td>2.57</td>
<td>1.09</td>
<td>0.92</td>
</tr>
</tbody>
</table>

From Table 6, illness identity scores ranged from 0 to 12 with a mean of 3.71 (SD = 3.12), suggesting that participants did not hold a particularly strong illness identity, i.e. believed there to be few symptoms associated with their condition. The symptoms most frequently reported as being related to CHD were 'palpitations' (60%), 'breathlessness' (54%) and 'cyanosis' (40%), which are medically recognised symptoms for CHD. Few participants reported symptoms which are not typically associated to CHD as being related, for example, 'headaches' (11%), 'stiff joints' (4%) and 'sore eyes' (3%).

The other IPQ-R subscales scores ranged from 1 to 5 with higher scores being indicative of a stronger belief in that illness perception. The strongest held belief was that for the timeline chronic/acute subscale (M = 4.10; SD = 0.83), with higher scores indicating that participants considered their condition to be chronic, rather than acute. The second strongest held illness perception was that of illness coherence (M = 3.81; SD = 1.00), which suggests that participants have a moderate to good personal understanding about their condition.

For the consequences subscale, a mean score of 2.56 (SD = 0.91) suggests that participants tended to view their condition as having mild to moderate negative consequences for their life. For personal control and treatment control subscales, the mean scores were 3.14 (SD = 0.58) and 3.23 (SD = 0.63) respectively. This suggests that participants believed they had a moderate amount of control over their condition, although felt that their condition may be better controlled by treatment as opposed to their personal actions. The least strongly held illness perception was for the timeline cyclical subscale (M = 2.22; SD = 1.02), which indicated that participants viewed their CHD as a relatively stable
condition, as opposed to fluctuating. The emotional perceptions subscale suggests that participants experienced a mild to moderate, negative emotional response (e.g. anxiety, depression) to their CHD ($M = 2.57; SD = 1.09$).

As there were less than 85 participants in the sample, the authors of the IPQ-R do not recommend examining the causal items using factor analysis (Moss-Morris et al., 2002). Therefore this data was analysed descriptively. The most commonly reported causes were 'chance or bad luck' (73%), followed by 'genetic abnormality' (64%) and then 'hereditary' (23%). This suggests that large majority of participants were able to identify reasonable possible causes of their CHD.

The reliability (Cronbach's alpha) for the IPQ-R variables ranged between 0.62 and 0.92. There are suggested guidelines on the alpha levels which have been categorised as: $\geq 0.90$ excellent, $\geq 0.80$ good, $\geq 0.70$ acceptable, $\geq 0.60$ questionable, $\geq 0.50$ poor and $<0.50$ unacceptable (George & Mallery, 2002). For the majority of subscales the alpha levels are considered to be 'good' or 'excellent' (George & Mallery, 2002). The only subscales which were 'questionable' were the IPQ-R personal control and treatment control subscales. Removing specific items from these subscales did not improve the internal reliability of the scale. However, these alpha levels are similar to those found in previous research using the IPQ-R (Bucks et al., 2009; Byrne et al., 2005; French et al., 2013) and were included in the analyses. Identity is not usually treated as a scale in the same way as the other illness perceptions and therefore the alpha level was not calculated.

Exploratory data analysis revealed that the IPQ-R variable identity was not normally distributed and was significantly positively skewed. This suggests that the sample did attribute a high number of symptoms to their condition. The IPQ-R subscale timeline acute/chronic was not normally distributed and was significantly negatively skewed, indicating that the sample considered their CHD to be chronic. Illness coherence from the IPQ-R was also found to be non normally distributed and was negatively skewed, indicating that the majority of the sample believed they understood their illness. The other IPQ-R variables (i.e. consequences, personal control, treatment control, timeline cyclical and emotional perceptions) were found to be normally distributed. Due to the assumptions of the statistical tests employed, it was not necessary to transform the non-normally distributed IPQ-R variables to improve normality.

**Resilience**

In terms of the scoring of the RS, a score of 25-100 = very low resilience, 101-115 = low resilience, 116-130 = on the low end, 131-145 = moderate resilience, 146-160 = moderately high resilience and 161-175 = high resilience (Wagnild, 2009). The mean total
resilience score was 134.44 (SD = 19.75) which is considered as being a 'moderate' level of resilience (Wagnild, 2009). However, there is a large distribution of scores (SD = 19.75, range = 91-175), suggesting large variability amongst the total resilience scores. The reliability (Cronbach's alpha) was 0.88 suggesting good internal consistency (George & Mallery, 2002). The total resilience score was found to be normally distributed, indicating a spread of resilience scores across the sample.

**Associations between health risk behaviour summary scores, illness perceptions and resilience**

Table 7 shows the correlation data (Kendall's Tau (τ) correlations) between health risk behaviour summary scores, various demographic variables, IPQ-R variables and total resilience score. Age was found to be significantly positively correlated to overall health risk behaviour scores, (τ = 0.23, p < 0.01) and substance use risk scores, (τ = 0.26, p < 0.01). This suggests that older participants reported overall more health risk behaviours and higher substance use. From the Mann-Whitney U-test, physical exercise scores of males (median = 5.86) significantly differed from physical exercise scores of females (median = 0.95), (U = 359.50, z = -2.51, p = < 0.01, r = -0.30). This indicates that males reported significantly more physical exercise than females. There were no other significant differences between males and females found on any of the other health risk behaviour summary scores.

**Table 7: Correlation data between health risk behaviour summary scores, demographics, IPQ-R and RS**

<table>
<thead>
<tr>
<th></th>
<th>Overall health risk score</th>
<th>Substance use risk score</th>
<th>Dental hygiene risk score</th>
<th>Physical exercise score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.23**</td>
<td>0.26**</td>
<td>0.07</td>
<td>-0.05</td>
</tr>
<tr>
<td>Frequency of clinic appointments</td>
<td>0.08</td>
<td>-0.01</td>
<td>0.12</td>
<td>0.18</td>
</tr>
<tr>
<td>Identity</td>
<td>-0.09</td>
<td>-0.12</td>
<td>-0.14</td>
<td>-0.16</td>
</tr>
<tr>
<td>Timeline acute/chronic</td>
<td>0.07</td>
<td>-0.13</td>
<td>0.13</td>
<td>-0.18*</td>
</tr>
<tr>
<td>Consequences</td>
<td>-0.06</td>
<td>-0.17</td>
<td>-0.05</td>
<td>-0.23**</td>
</tr>
<tr>
<td>Personal control</td>
<td>0.10</td>
<td>0.13</td>
<td>0.15</td>
<td>0.04</td>
</tr>
<tr>
<td>Treatment control</td>
<td>-0.07</td>
<td>0.01</td>
<td>-0.10</td>
<td>0.04</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>-0.14</td>
<td>-0.03</td>
<td>-0.17</td>
<td>0.03</td>
</tr>
<tr>
<td>Timeline cyclical</td>
<td>-0.04</td>
<td>-0.01</td>
<td>-0.10</td>
<td>-0.11</td>
</tr>
<tr>
<td>Emotional perceptions</td>
<td>-0.10</td>
<td>-0.18*</td>
<td>-0.07</td>
<td>-0.14</td>
</tr>
<tr>
<td>Total RS score</td>
<td>-0.01</td>
<td>0.03</td>
<td>0.05</td>
<td>0.22**</td>
</tr>
</tbody>
</table>

*significant at p < 0.05
**significant at p < 0.01
Table 7 shows the majority of the correlations between illness perceptions and health risk behaviour summary scores were found to be non-significant. A more chronic timeline (timeline acute/chronic) was negatively associated to the time spent exercising (\( \tau = -0.18, p < 0.05 \)). Illness consequences were negatively associated with physical exercise scores, (\( \tau = -0.23, p < 0.01 \)). This suggests that for example, strong beliefs about the negative consequences of CHD, was associated with less reported physical exercise. Emotional perceptions were negatively associated with substance use risk scores, (\( \tau = -0.18, p < 0.05 \)), for example, feeling worried about CHD was associated with less reported substance use.

As these are correlations, it could also be that the opposite is true, for example, not being worried about CHD was associated with more reported substance use. Such findings suggest that some illness perceptions may play a role in explaining the variance in health risk behaviour summary scores, although this is correlational data and does not infer causality.

The total resilience score was significantly positively correlated with physical exercise scores, (\( \tau = 0.22, p < 0.01 \)), for example, higher resilience scores were associated with more reported physical activity. The total resilience score was not found to be significantly correlated with any other health risk behaviour summary scores.

**Associations between specific health behaviours**

Given the small sample size, Fisher’s exact test was carried out to explore the associations between specific health behaviours. Smoking was significantly associated with both drug use (\( p < 0.05 \)) and binge drinking (\( p < 0.05 \)). There was a significant association between no annual dental visit and participation in physical activity (\( p < 0.01 \)). There were no other significant associations between the health behaviours.

**Correlations between illness perceptions and resilience**

Correlations were carried out for illness perceptions (IPQ-R) and resilience (RS) (see Appendix J for the correlation matrix). Several of the IPQ-R variables were found to be correlated with each other. However, many of the significant correlations were only relatively modest, suggesting weak associations. Illness identity was significantly associated with; timeline acute/chronic, (\( \tau = 0.32, p < 0.01 \)), timeline cyclical, (\( \tau = 0.28, p < 0.01 \)), consequences, (\( \tau = 0.48, p < 0.01 \)) and emotional perceptions, (\( \tau = 0.22, p < 0.05 \)).

Timeline acute/chronic was significantly positively associated with consequences, (\( \tau = 0.32, p < 0.01 \)), and negatively associated with treatment control, (\( \tau = -0.34, p < 0.01 \)). Consequences was significantly positively correlated with timeline cyclical, (\( r = 0.43, p < 0.01 \)), and emotional perceptions, (\( r = 0.48, p < 0.01 \)). Consequences was significantly
negatively correlated with treatment control, \((r = -0.27, p < 0.05)\), suggesting that for example, perceiving there to be more consequences linked with CHD was associated with strongly held beliefs that treatment was less able to control CHD. Personal control and illness coherence were both significantly positively correlated with treatment control, \((r = 0.24, p < 0.05, \text{ and, } \tau = 0.21, p < 0.05, \text{ respectively})\). Illness coherence was significantly negatively associated with emotional perceptions, \((\tau = -0.18, p < 0.05)\). Timeline cyclical was significantly positively associated with emotional perceptions, \((r = 0.35, p < 0.01)\).

The only IPQ-R variable significantly associated with resilience was consequences, in which there was a significant negative correlation, \((r = -0.27, p < 0.05)\), with higher resilience scores associated with lower consequences scores and vice versa.

**Analytic statistics - Exploring the variance in health risk behaviours**

*Logistic regression*

Logistic regression was used to explore whether illness perceptions and/or resilience were able to explain, in part, the outcome of various health behaviours. Some of the questions from the HBS-CHD produced a number of binary responses (i.e. yes/no) to questions about smoking, drug use, binge drinking, dental care and physical activity. The responses to such questions were used as the health risk behaviour outcome variables for the logistic regression analyses.

**Selecting independent variables**

Tabachnick & Fidel, (2013) suggest that fewer independent variables should be included in the model. The sample size helps to determines how many independent variables should be included. The sample size is based on the smaller number of the two groups (e.g. likelihood of event occurring, such as smoking). It is suggested that there should be at least 10 cases in the outcome that trying to explain, per independent variable (Katz, 2006; Peduzzi, Concato, Kemper, Holford, & Feinstein, 1996). Although the initial data analysis plan was to enter all independent variables into each logistic regression, it was necessary to make amendments to this strategy as a result of the lower than expected sample size. Due to the modest sample size, it was not possible to enter all independent variables into the model. Furthermore, there were no specified hypotheses about the order or importance of the independent variables as this is an exploratory study (Katz, 2006; Tabachnick & Fidel, 2013). Therefore, each independent variable (from the IPQ-R and RS)
was entered into the logistic regression model univariately with the outcome to investigate which were significant \((p < 0.05)\). This is the recommended and appropriate strategy for this situation (Katz, 2006).

The significant variables were then included into a multivariate logistic regression model using direct method in which they were entered simultaneously. Age was entered in all models regardless, as there is research to suggest age is associated with health risk behaviours (Spring, Moller, & Coons, 2012). The confidence intervals (CI) for the odds ratio were examined for two reasons. Firstly, the width of the CI was examined in order to assess the precision of the estimate. A wide CI could indicate an over- or under-estimation of the effect of the variable. Secondly, if the CI crosses 1 then the results are not significant as the true value could be 1 which indicates no effect.

*Interpreting logistic regression output*

In order to assess the significance of the model, the likelihood ratio test (referred to as the model chi-square) was used (Katz, 2006). If knowing the values of the independent variables is able to improve the model’s fit better than would be expected by chance, the value of the chi-square will be large with a small \(P\) value and the null hypothesis is able to be rejected (Katz, 2006). Logistic regression produces an odds ratio (OR) which is often presented as a percentage. The OR is the change in odds of being in one of the possible outcome categories when the independent variable value increases by one unit (Tabachnick & Fidell, 2013). The coefficients, \(B\), for the independent variables are the natural logs (logit) of the odds ratio; odds ratio = \(e^B\). A one unit change in the independent variable multiplies the odds by \(e^B\) (Tabachnick & Fidell, 2013). A positive coefficient indicates that as the variable increases, the logit also increases, therefore the OR would be 1 or above. In contrast, a negative coefficient indicates that as the variable increases, the logit decreases and the OR would be below 1 (Katz, 2006). The Hosmer-Lemeshow goodness-of-fit test assesses "how similar the estimated probability of outcome is to the observed probability of outcome" (Katz, 2006, pp.122-123). If the model is a good fit, the estimated probability will be close to the observed probability of outcome, resulting in a small chi-square and a non-significant \(P\) value (Katz, 2006).

*Drug use*

Drug use was operationalised as reported use of at least one of the listed drugs, at least once a month within a 12 month period. A total of 16 participants fulfilled the criteria for drug use. Age and consequences were entered into a logistic regression model (Table 8). A
test of the full model against a constant only model was statistically significant, indicating that the independent variables as a set were able to significantly distinguish between participants who reported drug use (n = 16) and those who did not (n = 54) (Model $X^2(2) = 7.90, p < 0.01$).

Table 8: Logistic regression model for drug use (reported drug use; n = 16, non reported drug use; n = 54)

<table>
<thead>
<tr>
<th>Variables included</th>
<th>OR</th>
<th>95% CI for OR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Lower</td>
</tr>
<tr>
<td>(Constant)</td>
<td></td>
<td>1.29</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td>1.29</td>
</tr>
<tr>
<td>Consequences*</td>
<td>0.88</td>
<td>0.78</td>
</tr>
</tbody>
</table>

*significant at $p < 0.05$

From Table 8, it can be seen that consequences made a significant contribution to reported drug use ($p < 0.05$). As participants perceived increased consequences of their CHD, the likelihood of reporting drug use decreased; for every increase in one on consequences scores, the odds of reporting drug use reduced by 12%. The CI indicate that the estimate is significant and is fairly precise. Hosmer and Lemeshow goodness of fit test statistic was non significant ($p = 0.82$), suggesting that the model prediction does not significantly differ from the observed. Therefore, the model is a relatively good fit.

**Binge drinking**

Binge drinking was operationalised as reported drinking of six glasses or more of alcohol on one occasion at least monthly. A total of 18 participants fulfilled the criteria for binge drinking. Age, consequences and emotional perceptions were entered into a logistic regression model (Table 9). A test of the full model against a constant only model was statistically significant, indicating that the independent variables as a set were able to significantly distinguish between individuals who reported binge drinking (n = 18) and those who did not (n = 52) (Model $X^2(3) = 22.75, p < 0.01$).
Table 9: Logistic regression model for binge drinking  (reported binge drinking; n = 18, non-reported binge drinking; n = 52)

<table>
<thead>
<tr>
<th>Variables included</th>
<th>OR</th>
<th>95% CI for OR</th>
<th>Lower</th>
<th>Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Constant)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age**</td>
<td>1.89</td>
<td>1.29</td>
<td>2.77</td>
<td></td>
</tr>
<tr>
<td>Consequences</td>
<td>0.61</td>
<td>0.27</td>
<td>1.42</td>
<td></td>
</tr>
<tr>
<td>Emotional perceptions*</td>
<td>0.42</td>
<td>0.19</td>
<td>0.92</td>
<td></td>
</tr>
</tbody>
</table>

*significant at p < 0.05  
**significant at p < 0.01

From Table 9, it can be seen that age and emotional perceptions both made a significant contribution to reported binge drinking (p < 0.01, p < 0.05, respectively). For every one year increase in age, the odds of reporting binge drinking increased by approximately twofold. As participants experienced more negative emotions associated with their condition, the likelihood of reporting binge drinking decreased; for every increase in 1 on emotional perception scores, the odds of reporting binge drinking reduced by 58%. The CI indicate that the estimates for age and emotional perceptions are significant and relatively precise. The Hosmer and Lemeshow goodness of fit test statistic was non-significant (p = 0.77), suggesting that the model prediction does not significantly differ from the observed. Therefore, the model is a relatively good fit.

**Smoking**

Smoking behaviour outcome was operationalised in terms of whether or not participants reported smoking cigarettes occasionally/regularly (reported smoking; n = 9, no reported smoking; n = 61). There were no significant independent variables (including age) found in the univariate analysis, likely due to the small numbers in the outcome. Therefore no logistic regression model was performed for smoking behaviour.

**Annual visit to the dentist**

Annual visit to the dentist was operationalised in terms of whether participants reported that they had visited the dentist in the last year or not. A total of 13 participants reported that they did not visit the dentist annually. Age and personal control were entered into a logistic regression model (Table 10). A test of the full model against a constant only model was statistically significant, indicating that the independent variables as a set were able to significantly distinguish between individuals who reported no annual visit to the
dentist (n = 13) and those who reported annual visits to the dentist (n = 57) (Model \(X^2(2) = 5.74, p < 0.05\)).

**Table 10:** Logistic regression model for no annual visit to the dentist (no reported annual visit to the dentist; n = 13; reported annual visit to the dentist; n = 57)

<table>
<thead>
<tr>
<th>Variables included</th>
<th>OR</th>
<th>95% CI for OR Lower</th>
<th>95% CI for OR Upper</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>1.27</td>
<td>0.93</td>
<td>1.74</td>
</tr>
<tr>
<td>Personal control*</td>
<td>3.14</td>
<td>1.02</td>
<td>10.01</td>
</tr>
<tr>
<td>(Constant)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*significant at \(p < 0.05\)

From Table 10, it can be seen that personal control made a significant contribution to no reported annual visit to the dentist \((p < 0.05)\). As participants experienced more personal control over their condition, the likelihood of reporting no annual visit to the dentist increased; for every increase in 1 on personal control scores, the odds of reporting no annual visit to the dentist increased by approximately three times. This suggests that those with lower personal control perceptions (i.e. felt in less control of their CHD) were more likely to go to the dentist. The CI indicate that the estimate for personal control is significant, but as the CI is rather large, the precision of the estimate questionable. The Hosmer and Lemeshow goodness of fit test statistic was non significant \((p = 0.68)\), suggesting that the model prediction does not significantly differ from the observed. Therefore, the model could be considered as a relatively good fit.

**Physical activity**

Physical activity was operationalised as reported walking or cycling to school or work and/or regularly practicing a sport. A total of 19 participants reported that they did not participate in either of these activities. Age, gender, consequences, identity, timeline acute/chronic and illness coherence were entered into a logistic regression model (Table 11). A test of the full model against a constant only model was statistically significant, indicating that the independent variables as a set were able to significantly distinguish between individuals who reported physical activity \((n = 51)\) and those who reported no physical activity \((n = 19)\) (Model \(X^2(8) = 21.82, p < 0.01\)).
Table 1: Logistic regression model for physical activity (reported physical activity; n = 51, no reported physical activity; n = 19)

<table>
<thead>
<tr>
<th>Variables included</th>
<th>OR</th>
<th>95% CI for OR</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Constant)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.92</td>
<td>0.67 - 1.27</td>
</tr>
<tr>
<td>Gender</td>
<td>0.22</td>
<td>0.04 - 1.12</td>
</tr>
<tr>
<td>Consequences*</td>
<td>0.38</td>
<td>0.15 - 0.96</td>
</tr>
<tr>
<td>Identity</td>
<td>0.92</td>
<td>0.71 - 1.19</td>
</tr>
<tr>
<td>Timeline acute/chronic</td>
<td>0.69</td>
<td>0.23 - 4.81</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>0.57</td>
<td>0.26 - 1.25</td>
</tr>
</tbody>
</table>

significant at p < 0.05

From Table 11, it can be seen that consequences made a significant contribution to reported physical activity (p < 0.01). As participants perceived increased consequences of their CHD, the likelihood of reporting physical activity decreased; for every increase in one on consequences scores, the odds of reporting physical activity reduced by 62%. The CI indicate that the estimate for consequences is significant and relatively precise. The Hosmer and Lemeshow goodness of fit test statistic was non significant (p = 0.59), suggesting that the model prediction does not significantly differ from the observed. Therefore, the model is a relatively good fit.

Checking assumptions

In line with the assumptions of logistic regression, it was necessary to check that the independent variables were linearly related to the log of the outcome variables and also to test for multicollinearity following logistic regression analyses (Field, 2009). To test for linearity of the logit, the logistic regression was run again, but included independent variables that are the interaction between each independent variable and the log of itself (Field, 2009; Hosmer & Lemeshow, 1989). This was run for all the above reported models. Any interaction found to be significant suggests that the assumption of linearity of the logit has been violated. There was no evidence that the assumption of linearity of the logit had been violated as all interactions had significance values greater than 0.05 (Field, 2009).

In order to test for multicollinearity, the tolerance and Variance Inflation Factors (VIF) were examined. There was no evidence of multicollinearity from these analyses, with tolerance values greater than 0.1 and VIF values less than 10 (Menard, 1995; Myers, 1990). The residuals were also examined in order to ensure the model is a good fit and to check that no residuals were having an excessive influence on the model (Field, 2009). There was no evidence of influential cases causing an effect on the models.
Discussion

Introduction

This chapter summarises the general findings of this study in relation to health risk behaviours of young adults with CHD. The pertinent findings are discussed in detail and some possible explanations are explored. The chapter concludes with a discussion of the clinical implications of the presented research, strengths and limitations, and potential future research directions.

Summary of health risk behaviour findings

One of the main aims of this study was to explore health risk behaviours in young adults with CHD. This population is at risk of complications relating to their condition as they get older. Such complications include the development of arrhythmias, endocarditis and ventricular dysfunction which ultimately may result in premature mortality (Brickner et al., 2000a, 200b). Therefore, it is suggested that patients engage in health promoting behaviours to help prevent such complications (Goossens et al., 2013). Such behaviours include moderating the intake of alcohol, avoiding smoking and recreational drugs, ensuring that maintain good oral hygiene, and engaging in adequate exercise (Sable et al., 2011).

Health risk behaviours, such as smoking, alcohol and drug taking are associated with risks of health complications for all young people, but these risks may be increased for young adults with CHD. The dental hygiene of young adults with CHD is important given that poor dental hygiene is associated with endocarditis (Strom et al., 2000). However, the relationship between flossing teeth and endocarditis is not straightforward (Crasta et al., 2009; Lockhart et al., 2009). Nevertheless, good oral hygiene which includes regular dental visits, brushing and flossing of teeth, is important for young adults with CHD (NICE, 2008). Similarly, the benefits of physical exercise are well documented (Thompson et al., 2007) and it is recommended that those with CHD engage in some form of regular exercise (Budts et al., 2013).

In this study, it was found that there was large variability amongst the scores for several types of health risk behaviours, suggesting that some young adults with CHD are engaging in health compromising behaviours. The variability amongst the overall health risk behaviour summary scores in this sample was larger than previous studies which have used the HBS-CHD (Goossens et al., 2013; Janssens et al., 2014). The mean substance use risk
summary score and overall health risk behaviour summary score were slightly higher compared to previous studies (Goossens et al., 2013; Janssens et al., 2014). However, the age of participants in this sample (16-24 year-olds) was older compared to this previous research (14-18 year-olds) and this may account for such differences. There is large amount of research, from both the general population and with young adults with CHD, which indicates that as age increases so does health risk behaviours (Goossens et al., 2013; Kolbe, 1990; Reid et al., 2008; Spring et al., 2012).

The findings from this study with regard to substance use are similar to previous research which has found that over one quarter of adolescents (16-18 years-old) and over half of the young adults (19-20 years-old) reported significant substance use defined as; smoking cigarettes on more than two days, using marijuana or other illicit drugs at least once, or binge drinking during a period of 30 days, (Reid et al., 2008). Similar to previous studies, alcohol was reported as the most frequently used substance (Janssens et al., 2014; Reid et al., 2008).

Reported binge drinking was higher in this sample (26%) than some studies have reported (Janssens et al., 2014), but lower than other studies (Reid et al., 2008). This may reflect cultural differences as Janssens et al., (2014) study was based in Belgium and Reid et al., (2008) was based in Canada. However, it was found that when the rates of alcohol consumption in the general population of Belgium, Canada and the UK were compared, Belgium and the UK were found to have similar rates which is 11.0 litres per capita of pure alcohol and 11.6 litres per capita of pure alcohol respectively, but this was found to be lower for Canada, at 10.2 litres per capita of pure alcohol (World Health Organisation, 2014). Interestingly in the young adult general population (15-19 years) binge drinking was found to be slightly higher in the Belgium (45.5%) compared to the UK (40.5%), but lower in Canada (33.2%) (World Health Organisation, 2014). This suggests that rates of alcohol consumption in the UK and Belgium general population are similar, but for Canada lower, suggesting that cultural differences may not provide an explanation for the differences in findings.

An alternative explanation for the differences in binge drinking of young adults with CHD may be the result of differences in the way each study has operationalised binge drinking. For example, the HBS-CHD defines binge drinking as consuming six or more glasses of alcohol on one occasion at least once a month (Janssens et al., 2014), whereas the measure used in the Canadian study (Reid et al., 2008) operationalised binge drinking as consuming five or more drinks of alcohol within a couple of hours at least once during the past 30 days, suggesting differences in the way binge drinking was measured. Given the lower number of drinks included in the binge drinking definition for the Reid et al., (2008) study, this may account for the higher rates of binge drinking found, compared to Janssens et al., (2014) and the present study.
The mean dental hygiene risk summary score was lower compared to previous research which has used the HBS-CHD to measure dental hygiene (Goossens et al., 2013; Janssens et al., 2014). For specific dental hygiene behaviours, such as brushing and flossing of teeth, participants were healthier than reported in previous research (Chen et al., 2007; Janssens et al., 2014; Reid et al., 2008). Although the differences are small and may simply be the result of discrepancies in the way excellent dental hygiene was defined and measured in each study, especially in those studies which did not use the HBS-CHD (e.g. Chen et al., 2007; Reid et al., 2008).

A slightly higher percentage reported no annual visit to the dentist in this sample compared to previous research (Janssens et al., 2014). However, reported dental visits are higher than that reported in the general population, as according to the Adult Dental Health Survey in 2009, 35% of those aged 16-24 years in England, Wales and Northern Ireland, do not attend their annual dental check up (Health and Social Care Information Centre, 2011). Although given that NICE guidelines recommendations for routine follow-up range from three months to two years (NICE, 2004a), not attending annually may not actually be problematic. Reasons for not attending the dentist may be explained by the cost of dental treatment in England, which is not free of charge over 17 years of age, unless 18 years and in full time education (Health and Social Care Information Centre, 2011). As socioeconomic status was not measured it is difficult to assess whether the cost implications associated with dental visits may explain why some participants did not attend annual dentist visits.

In terms of physical exercise, the physical exercise summary score revealed large variability amongst participants scores. The median physical exercise score was lower in this sample compared another study which has used the HBS-CHD (Janssens et al., 2014), suggesting that young adults in the UK may not be as physically active as young adults with CHD in Belgium. Almost a third of participants in this study reported that they did not participate in physical activity, which is similar to findings from previous research (Dua et al., 2007; Janssens et al., 2014; Lunt et al., 2003). In the present study, males scored significantly higher on the physical exercise summary score compared to females, suggesting they are more active which is in keeping with previous findings (Moons et al., 2006b).

However, a national survey carried out in 2012 found that only 67% of men and 55% of women in the general population over the age of 16 achieved the recommendations for physical activity (i.e. 150 minutes of exercise per week that leads to an increase heart rate and breathing rate) (Health and Social Care Information Centre, 2015a). Although these figures cannot be compared directly to the findings of this study, due to differences in measurement, they do suggest that many people in the general population do not achieve the recommended amount of physical exercise.
A more general finding relating to the health risk behaviours of young adults with CHD was that risky behaviours were found to cluster, which is consistent with previous research (Jaser et al., 2011; Mistry, McCarthy, Yancey, Lu, & Patel, 2009; Spring et al., 2012). Clustering was apparent for risky health behaviours such as substance use, smoking, binge drinking and drug use, which were significantly positively associated. These behaviours tend to be clustered together, in that those that drink are more likely to smoke and take drugs (Spring et al., 2012). In this population, this may also be linked to perceived consequences and knowledge, which will be discussed in more detail below. Positive behaviours (dental hygiene and physical exercise) were significantly negatively associated. Therefore positive behaviours were not clustered in the same way as risky behaviours. Furthermore, there was no association found between positive behaviours and risky behaviours. Overall, the findings indicate that despite the health risk and probable advice received, some young adults with CHD still engage in risky health behaviours according to the way they are defined and measured by the HBS-CHD.

However, it is difficult to assess at what level behaviours become 'risky' to the health of young adults with CHD. This is due to the lack of clarity both from the HBS-CHD measure and the wider literature and guidelines around what constitutes 'risky' behaviour. In terms of the HBS-CHD measure, this measure does not provide clinical norms or cut-off points for which behaviours and frequency of behaviour puts someone with CHD at a health risk. It difficult to determine what score is 'healthy' or 'risky' using the HBS-CHD as the only broad indicator is higher scores are suggestive of more risky behaviours. The HBS-CHD suggests that engaging in any behaviour, such as using cannabis once a year, is risky. However, in reality this may not actually cause the same harm as someone who uses substances on a weekly basis (Nutt et al., 2010). The scoring of the HBS-CHD does not allow for differentiating between what could be considered as 'experimental' one-off behaviours and those who regularly engage in harmful risk behaviours. It has been suggested that experimentation with substance use during adolescence is considered as normative behaviour and may be an important part of this development stage (Newcomb & Bentler, 1988; Shedler & Block, 1990).

As well as the difficulties with defining and measuring substance use, measuring physical activity using the HBS-CHD is problematic. The physical activity subscale does not allow for the intensity, frequency, amount or type of physical activity to be scored in a meaningful way. This makes it difficult to assess the young adults with CHD included in this study were engaging in an appropriate level of physical activity as the scoring system does not allow for the physical exercise subscale to be compared with the recommended exercise guidelines for CHD (e.g. Budts et al., 2013). Furthermore, high levels of physical exercise may not be recommended to some individuals and therefore indicate 'risky' rather than 'healthy' levels.
The wider literature and guidelines also are unclear as to what constitutes as harmful health risk behaviour. For substance use (e.g. smoking, alcohol use, drug use), the degree to which such behaviours are considered 'risky' may depend upon the level or frequency of engagement. On the one hand, any illicit drug use might be viewed as risky (as it is for the HBS-CHD scale), although this does not necessarily mean it is 'risky' in the sense of causing significant harm. By contrast, for drinking and smoking, many draw a distinction between one-off experimentation and regular or excessive use (Department of Education, 2013). For example, a young person having a small alcoholic drink under parental supervision, would typically not constitute ‘risky’ behaviour in the same way that binge drinking would (Department of Education, 2013). Furthermore, some studies show that there is a positive effect from some exposure of drinking. For example, over 100 prospective studies have shown an inverse association between moderate drinking and risk of heart attack, stroke, and sudden cardiac death (Goldberg, Mosca, Piano, & Fisher, 2001). However, what is considered as 'moderate' drinking is debatable. Nevertheless, there seems to be ambiguity about what constitutes as ‘safe’ and 'risky' drinking.

Due to differences in the way in which health risk behaviours are measured in this study compared to those in the general population, direct comparisons cannot be made to see whether the trends found in this study represent those of the general young adult population. However, considering the prevalence of health risk behaviours of young adults in the general population can help to contextualise the study results. The prevalence of smoking within the age range of 16-24 year olds within the general population is 23% (Health and Social Care Information Centre, 2015b), which is less than those who reported smoking occasionally or regularly in this study (12%).

In a study on alcohol consumption in 2013, 18% of 16-24 year-olds had participated in binge drinking a week before the study interview (Health and Social Care Information Centre, 2013). This is less than was reported for binge drinking in this study (26%), although there are differences in the time period during which binge drinking was measured, which may account for the differences. In the general population the incidence drug use in young adults (aged 16-24) is approximately double the population average, with 18.9% having used illicit drugs within the last year (Health and Social Care Information Centre, 2014). In this study, 23% reported to have used a drug/drugs once in the last 12 months at least, however, this may be higher than that found for the general young adult population due to differences in the way drug use is operationalised.

In summary, although some individuals with CHD from this study reported engaging in potentially harmful behaviours, it is unclear from the HBS-CHD measure and indeed the general guidelines as to the extent to which these behaviours are risky and harmful.
Explaining the variance in health risk behaviours

Additional aims of this study were to explore possible variables which may help to explain the variance in reported health risk behaviours, in particular illness perceptions and resilience. The key independent variables from the logistic regression models (i.e. age, consequences, emotional perceptions, and personal control) which were found to be important in explaining some of the variance in health risk behaviour outcomes will now be discussed. It is important to note that this is a small exploratory study and these findings should be interpreted with caution given the small number of participants who reported certain health behaviours.

Age and substance use

In line with previous research with young adults with CHD, increasing age was associated with higher overall health risk summary scores and substance use risk summary scores (Goossens et al., 2013; Janssens et al., 2014). Furthermore, age was a significant independent variable when entered into the logistic regression model for reported binge drinking, suggesting that increasing age explained some of the variance in the outcome of reported binge drinking. This reflects findings from the general population, where longitudinal evidence has demonstrated that substance use rises to a peak in the early twenties and then declines (Bachman et al., 2013).

Such findings may be explained, in part, by more accessibility to such substances as adolescents age. However, considering the wider developmental context of this age group (16-24 year-olds) may help to explain this finding. A number of theories consider this developmental stage to be characterised by emerging independence and a time during which experimentation is likely (Arnett, 2000; Erikson, 1950, 1968). As a result of demographic shifts in the past half-century, the transition into adulthood has become less straightforward (Arnett, 2000). In modern society, more young adults are likely to go on to higher education and are choosing to get married and start families later (Office for National Statistics, 2012, 2013). It has been argued that such changes may have delayed the transition into adulthood, suggesting that this transition occurs later than previously (Arnett, 2000).

The notion of 'emerging adulthood' has been proposed as a theory of understanding development for the period from the late adolescence through the twenties, with a focus on ages 18-25 years (Arnett, 2000). As older adolescents enter into this stage, exploring and experimentation become more important (Arnett, 2000). Testing the boundaries is common and is often associated with 'experimenting' behaviours (Chen & Jacobson, 2012; Staff et al., 2010). During emerging adulthood, young adults are likely to leave the family home and
therefore be less constrained by parental influence and supervision. The notion of emerging adulthood, which has been theorised to start around the age of 18 years, is typically characterised by a period of experimentation and may therefore explain the finding that increasing age is associated with more reported substance use.

However, the theory of ‘emerging adulthood’ has been criticised as being culturally constructed, in that it may only apply to societies which allow delayed entry into adult responsibilities (Facio & Micocci, 2003). Nevertheless as the UK is part of a westernised culture, the research may be considered relevant and helpful in understanding the finding that increasing age is associated with more reported health risk behaviours. This suggests that the finding that increasing age is associated with health risk behaviours may reflect that of the general population. Although the consequences of experimentation for young adults with CHD may be more severe than that for young adults in the general population.

Consequences, drug use, and binge drinking

The way participants perceived the consequences of their illness was found to be associated with a number of health behaviours. Holding strong beliefs about the negative consequences of living with CHD was significant when explored univariately with reported drug use and binge drinking. Whilst consequences remained a significant independent variable in the multivariate logistic model for explaining outcome in reported drug use, it was no longer significant for binge drinking. This may be explained by shared variance with other independent variables included in the model for binge drinking, such as emotional perceptions, which may have resulted in consequences becoming non-significant. However, due to low sample sizes this hypothesis was not statistically tested.

Nevertheless, the findings suggests that believing CHD to be a serious condition and to have a likely serious impact on life could be considered as a protective factor against engaging in such health risk behaviours. The Health Belief Model suggests that when people are making decisions about whether to engage in a behaviour or not, they consider beliefs related to the perceived susceptibility (risk) of certain outcomes (Janz & Becker, 1984). This could explain why those who believe their illness already has negative consequences avoid risk behaviours through perceived risk of causing harm.

It could be posited that knowledge may be important in explaining why those with stronger beliefs about the consequences were less likely to engage in health risk behaviours, due to having a better understanding about the risks associated with this. However, knowledge was not measured in this study and recent research indicates that knowledge may not be important in determining health risk behaviours of young adults with CHD (Goossens et al., 2015; Janssens et al., 2014). It is therefore unclear whether knowledge would explain
this finding.

Previous research has found mixed results in terms of the association between consequences and health behaviours of those with chronic illnesses. For example, some studies have found that there is a higher dropout rate in cardiac rehabilitation programmes when individuals perceived there to be lower consequences of their illness (Yohannes, Yalfani, Doherty, & Bundy, 2007). This supports the findings of this study that stronger beliefs about the negative consequences of illness are associated with better health behaviours. However, the research by Yohannes et al., (2007) is about engagement in a positive behaviour (attending cardiac rehabilitation) and not about avoiding risky behaviours (e.g. substance use). Therefore, the similarities between the current study and Yohannes et al., (2007) is questionable.

In contrast, some studies have found no association between consequences and self-management behaviours in those with chronic illness (Law, Kelly, Huey, & Summerbell, 2002; Nouwen et al., 2009; Žugelj et al., 2010). However, self-management behaviours are usually about engaging in positive behaviours, rather than avoiding negative ones, which may account for the differences found. It may also relate to the different conditions included in these studies, e.g. diabetes and hypertension. These conditions may have varying consequences associated with different health behaviours, compared to those for individuals with CHD.

Consequences and physical activity

Those who held negative beliefs about the consequences of CHD were less likely to report engaging in physical activity. Consequences remained a significant independent variable when entered into the multivariate logistic regression model for physical activity. This suggests holding negative views about the consequences of CHD may have a negative impact on the engagement in positive health behaviours. This is in line with some previous research in type 1 (n=49) and type 2 (n=108) diabetic patients which found that those who reported lower perceived consequences were found to adhere to medication and dietary adherence (positive behaviours) (Broadbent et al., 2011). This supports the findings of this study that lower perceived consequence is associated with positive health behaviours (i.e. exercise). However, not all studies have found this association between consequences and positive health behaviours (e.g. Whitmarsh et al., 2003; Yohannes et al., 2007). Again, such differences found may be explained by the different types of conditions and behaviours involved in each study.

The association between negative views about consequences and less physical activity may be explained by patients’ misconceptions about exercise and safety and also a
lack of confidence (Dua et al., 2007; Swan & Hillis, 2000). Self-efficacy (feeling capable and confident in effectively performing a behaviour) has been found to be an important predictor of participation in physical activity in adolescents with CHD, suggesting that those with poor self-efficacy are less likely to participate in exercise (Bar-Mor, Bar-Tal, Krulik, & Zeevi, 2000; Moola, Faulkner, Kirsh, & Kilburn, 2008). Although in this study personal control, which could be considered as an aspect of self-efficacy, was not found to be associated with physical exercise. This suggests that the role of self-efficacy in determining physical activity may not be as clear-cut as previous research has suggested.

Interestingly, perceived risk in young adults with CHD has been found to be negatively associated with physical exercise, suggesting that those who do not consider there to be risks associated with CHD are more likely to exercise (Jackson et al., 2015). Jackson and colleagues suggest that this may be because those individuals who are already taking part physical activity may perceive themselves to be at less risk for future complications (Jackson et al., 2015). However, similar to consequences, this finding could be explained by those who consider their condition to have fewer consequences/future risks, felt safer and more able to engage in physical exercise.

Given that many young adults in this sample reported no or very little physical activity, this may reflect a lack of knowledge and understanding about the safety and importance of physical exercise. It has been suggested that many health care professionals do not spend sufficient time educating and encouraging young adults with CHD about the benefits of exercise participation (Longmuir et al., 2013), which could explain why fewer participants reported engaging in physical exercise. Information about positive behaviours may not be emphasised by healthcare professionals in the same way that the risks of negative behaviours are emphasised.

Recent guidelines recommend that adolescents and adults with CHD participate in physical activity and three to four and a half hours per week is recommended (Budts et al., 2013). The findings from this study indicate that the majority of participants in this study were not engaging in the recommended amount of exercise, although the HBS-CHD questions about exercise are not really able to assess this accurately. Only recently have such guidelines been developed and it has been hypothesised that previously young adults with CHD may have been advised differently in childhood regarding exercise (Dua et al., 2007).

The lack of reported physical activity may reflect the habits developed in childhood regarding lack of physical exercise. Poor health habits in childhood can lead to poor health habits in adulthood (Kemper & Verschuur, 1990). There is evidence from the general population that health risk behaviours, including physical activity, in young adulthood reflect such behaviours developed in childhood/adolescence (Paavola, Vartiainen, &
Therefore, young adults with CHD may not have been encouraged to participate in physical exercise when they were younger, due to parental, school, or personal fears about their CHD condition and sedentary behaviour has endured into early adulthood (Moola, Fusco, & Kirsh, 2011; Sable et al., 2011).

Considering the SRM as a framework may help to understand the lack of participation in physical activity. It has been suggested that illness perceptions are formed on three sources of information, one of which is the social environment (Leventhal et al., 1980, Leventhal et al., 1984; Hagger & Orbell, 2003). Therefore, individuals who have formed strong negative views about the consequences of their illness are likely to have done so over a long period of time and are likely to have been previously influenced by parents and healthcare professionals views. It has been found that there are social and contextual barriers to participation in exercise, for example, parental overprotection in that the parents of young adults with CHD may not have encouraged their children to participate in physical exercise, perhaps due to fear about their child's safety (Moola et al., 2008; Moola, McCrindle, & Longmuir, 2009).

The 'vulnerable child syndrome', in which parents of children with a chronic illness worry a great deal about their child and restrict the participation of physical activity, may be relevant to explain the findings (Moola et al., 2011). This may develop into a chronic sick role in which young people believing they are unable to exercise due to ill health (Wilkes et al., 2009). Such views may have influenced beliefs about the consequences held by children with CHD and these beliefs may be maintained into adulthood. Therefore, young adults with CHD may still consider physical activity to be unsafe and hence avoid participation.

**Emotional perceptions and binge drinking**

Emotional perceptions were significantly negatively associated with substance use summary scores and reported binge drinking. This suggests that strong negative emotional perceptions (i.e. feeling anxious and depressed about impact of CHD) may reduce the likelihood of engaging in risky behaviours, including not engaging in binge drinking.

One plausible explanation for this could be that individuals who experienced negative emotional responses associated with their illness were more likely to be anxious about engaging in health risk behaviours, in particular binge drinking through fear it may impact negatively on their condition. When feeling anxious, avoidance of behaviours that may further increase anxiety is a common behavioural response (Dymond & Roche, 2009). It has been suggested that in the context of health-related decision making, emotion has been found to play an important role in engaging in health behaviours, such as exercise (Salovey, Rothman, & Rodin, 1998). Furthermore, research has found that there are
situations in which worry, as opposed to risk judgements, are predictive of health behaviours (Diefenbach, Miller, & Daly, 1999; McCaul, Schroeder, & Reid, 1996). For example, worry about breast cancer (but not perceived risk) independently predicted an increased interest in genetic testing (Cameron & Diefenbach, 2001). This suggests that emotions, as well as cognitions, may play an important role in determining health behaviours of young adults with CHD, which is in line with the SRM suggesting that both are important (Leventhal & Cameron, 1987).

Previous findings which support the findings about the role of emotional perceptions and health risk behaviours are mixed. For example, a study with patients with coronary heart disease found that lower levels of emotional perceptions were associated with higher alcohol consumption (Byrne et al., 2005), which supports the findings of this study. Whereas, in contrast, other research has found that adolescents who reported a lower emotional burden associated with hypertension were more likely to adhere to their medication, compared to those who associated more negative emotions with their illness (Žugelj et al., 2010). Although this is about adhering to positive behaviours, not about avoiding health risk behaviours parallels could be drawn. For example, feeling anxious about adherence due to concerns about side effects for example, may result in avoidance of such positive health behaviours. Whereas feeling anxious about the effects of engaging in health risk behaviours, such as taking drugs, may result in the avoidance of negative health risk behaviours. Therefore, emotional perceptions might be useful in helping to explain both negative and positive health behaviours, but their influence differs depending on the behaviour. Other research has found no association between emotional perceptions and self-management behaviours in those with chronic illnesses (Bucks et al., 2009; Law et al., 2002), so this association needs further consideration.

**Personal control and annual dentist visit**

It was found that those with lower perceived personal control (i.e. felt they had less control of their CHD) were more likely to attend the dentist. However, the confidence intervals around the odds ratio for personal control were very large making the estimation imprecise and any assumptions are tentative.

Individuals who do not feel they have personal control over their illness may recognise that they require input from others to help with the management of their condition. The integrative model of behavioural prediction suggests that self-efficacy has a direct influence on behaviour (Fishbein, 2000). Therefore, this could indicate that for dental visits, not feeling confident about caring for ones teeth without professional input, may encourages young adults with CHD to attend the dentist.
In contrast to the findings of this study, some research has found that positive behaviours (e.g. attendance at cardiac rehabilitation) are associated with higher personal control beliefs (Tolmie et al., 2009). Although the cardiac rehabilitation population and young adults with CHD are very different. For example, the age of participants included in Tolmie et al., (2009) study were 65+ years, compared to 16-24 year-olds in this study and this may explain the differences. Young adults with CHD may feel as though they have less personal control over their illness as they may be more dependent upon parents or medical professionals in the management of their condition, than older adults. Other research has not found evidence for an association between personal control and self-management behaviours in young people with chronic conditions (Law et al., 2002; Žugelj et al., 2010). It is unclear as to whether personal control has an influence on engagement in health risk behaviours in young adults with chronic conditions and this requires further investigation.

Resilience and health risk behaviours

The overall mean RS score found in this sample is similar to previous studies which have used the RS with adolescents (Black & Ford-Gilboe, 2004; Hunter & Chandler, 1999). An unexpected finding was that resilience did not appear to be significant in explaining the variance in outcome of health risk behaviours. The lack of support for resilience as a significant independent variable may be explained by the measure used to assess resilience, which only measures one aspect of resilience (i.e. psychological resilience) (Wagnild & Young, 1993). However, previous studies which have used the RS have found higher scores to be associated with more positive health behaviours (Black & Ford-Gilboe, 2004; Lu, 2013; Rew, Taylor-Seehafer, Thomas, & Yockey, 2001), although not all these studies were with individuals with chronic conditions.

Furthermore, it is widely accepted in the literature that resilience is multidimensional construct and includes social influences e.g. family (Cicchetti, 2010; Luthar et al., 2000). Such aspects could have been important in explaining the variance in health behaviours. For example, research has shown that broader resilience factors, such as supportive parenting and parental supervision, may be important factors in protecting adolescent against smoking (Nowlin & Colder, 2007) and drinking (Petrie, Bunn, & Byrne, 2007). However, the findings are mixed, with some research finding that parental support was associated with increased odds of smoking in adolescents (Mistry et al., 2009). Nevertheless, such social influences were not explored in this study and it is possible these may have accounted for some of the variance in health behaviours.

The only health behaviour associated with resilience in this study was for the physical exercise summary score, with which resilience was found to be significantly
positively correlated. However, the correlation between resilience and physical exercise summary score was weak and when resilience was entered univariately into a logistic regression model with physical activity, it was not significant in explaining the variance in physical activity.

Tentative conclusions from the weak correlation found could suggest that resilience may be important in determining whether or not someone engages in physical activity, with higher resilience associated with physical activity. It would appear to make sense that resilience may serve as a protective factor in engaging in healthy behaviours, such as physical activity, as resilience can help people to cope with adversity (e.g. manage having a CHD condition) and continue to engage in 'normal' activities. This reflects previous findings which have found resilience to be associated with healthy behaviours in those with chronic illnesses (Stewart & Yuen, 2011; Yi et al., 2008).

Resilience and consequences

A further interesting finding was a significant negative correlation found between resilience and consequences. This suggests higher resilience is linked with less strongly held beliefs about the negative consequences of CHD, indicating resilience is a positive attribute. This is an expected correlation, given that strongly held consequences beliefs about the negative impact that CHD has on an individual's life suggest that individuals do not feel resilient in living with their illness. The RS on the other hand measures the way an individual deals and copes with difficult times. Therefore, higher resilience and strongly held negative beliefs perhaps counteract each. There may have been shared variance between the RS and the IPQ-R consequences domain but due to the modest sample size this not statistically tested for.

Strengths

A strength of this research is that it is the first UK study to use the HBS-CHD to measure health risk behaviours of young adults with CHD. The HBS-CHD is a comprehensive measure of a number of health risk behaviours developed specifically for research with individuals with CHD. In addition, this is one of few studies examining illness perceptions and resilience in this population and therefore adds to the limited literature in the area and hence contributes to the body of knowledge. Another strength is that participants were recruited from NHS CHD services across the country, as opposed to just in one area. This was an effective way of enhancing recruitment. Strengths of the measures used were that they were reliable and valid and had been used with similar samples in
previous research. Furthermore, data collection was anonymous which was designed to help enhance open responding. Given that the data did not fulfil the requirements for linear regression, logistic regression was an appropriate alternative (Field, 2009). The use of logistic regression was found to be a useful modelling technique for helping to explain the variance in health risk behaviours and has been used in similar studies (Van De Ven et al., 2007).

**Limitations**

*Recruitment and participants*

The representativeness of the sample included in this study should be considered in order to assess whether the findings are generalisable. According to national statistics there are more males than females born with the included CHD conditions, suggesting that females are over represented in the study sample (Office for National Statistics, 2010). In terms of the age range of the sample, there were fewer respondents in the older age range (22-24 years) and therefore the results may not be representative of this age range. The frequency of the type of conditions reflects the incidence of each condition in the general population, with transposition of the great arteries and tetralogy of Fallot being the most common type of CHD conditions included within this study, followed by truncus arteriosus, total anomalous pulmonary venous connection and tricuspid arteria (Hoffman & Kaplan, 2002). It is unknown whether the participants in the study had other health conditions, as this was not recorded. Other health conditions may impact the responses to the questionnaires, although it was made clear in the participant information sheet that the study was interested in CHD.

It is not clear as to whether the research packs posted out reached the intended participants. This was reliant upon the most current database from the individual NHS CHD service. Many of the young people recruited may have moved addresses since childhood and the accuracy of the databases is unknown. There may have been bias in terms of those participants who were recruited in clinics. Only those who attended clinic during the nine month recruitment period would have been approached and hence the sample may not be representative. It may be that those participants were health conscious and hence attended clinic appointments.

The estimated response rate is 14% which is relatively low for an online survey. However, this is only an estimate based on the number of packs (500 packs) sent out by the researcher to the individual NHS CHD services, not the number of packs distributed by staff or received by participants. Nevertheless a low response rate may make the representativeness of the sample questionable. There may have been an element of bias, in
that those who completed the online survey had an interest in their condition and did not engage in many health risk behaviours.

Ideally, a centralised database would have allowed for a follow-up mail out to be sent to participants. However, due to ethics and R&D restrictions, it was not possible to send reminders. As the survey was completed online it was possible to accurately measure the number of responses and this helped to inform the recruitment strategy. Additional services were recruited from in order to help increase the sample, but ultimately it was still reliant on members of staff posting out the information packs. Some services were more invested in the recruitment than others, due to links with research and this may explain the higher response rate from Yorkshire and the North West.

**Measures**

All questionnaires are limited because they are a proxy of what actually want to measure and therefore inherently inaccurate. Furthermore, all of the measures used in this research were self-report measures. It is unclear as to whether the responses accurately represent health behaviour. Participants may under or over report their health risk behaviours because they think they are socially undesirable or desirable (Brener, Billy, & Grady, 2003), which may limit the validity. Despite this, such self-report measures have been used in a large number of studies and were considered appropriate to address the research questions proposed in this study. The anonymity and secure use of the data was made clear to participants in order to reduce the likelihood of socially desirable responding and encourage open responding.

There were some limitations to the 'About You' (demographic) questionnaire. In this study, participants were aged 16 to 24 years, so educational attainment could just be proxy for age rather than educational attainment. For example, a 16 year-old could not have achieved higher than GCSE/NVQ level, but this does not mean that it is going to remain their highest level of education. Therefore there was no true measure of educational status. Furthermore, given that educational status was not an accurate measure, there were no questions which could be linked to socioeconomic status. The relationship between socioeconomic status and health risk behaviour is well established and socioeconomic status is associated with a higher prevalence of risk behaviours (Hanson & Chen, 2007). Therefore, it is likely that socioeconomic status may have explained some of the variance in health risk behaviours. Furthermore, low socioeconomic status has been found to be associated with low resilience and may have affected the RS scores (Thompson, Corsello, McReynolds, & Conklin-Powers, 2013).

There is no 'gold standard' measure of resilience (Windle et al., 2011) and the RS is a valid and reliable measure which was considered the most appropriate for this sample.
However, the RS only measures one aspect of resilience, psychological resilience, and therefore does not include other aspects of resilience such as peer and family influences. It is now accepted that resilience is a multidimensional process that includes internal and external resources (Luthar et al., 2000). However, the RS is a 'trait' measure rather than a 'process' measure of resilience and hence does not provide any understanding into the processes of resilience in individuals with CHD. The RS is a static measure, which does take into account that resilience is a process which changes over time. This would require the use of a different measure to assess the external processes and a longitudinal study design. Consideration was given to including questions about social support in the 'About You' questionnaire in order to incorporate the multidimensional nature of resilience. However, it was felt this would add significantly to the survey length. Furthermore, this study was specifically interested in psychological resilience, although it is accepted that there are limitations to this.

There are some significant limitations to the HBS-CHD measure as discussed earlier in this chapter. There were problems which became apparent when the scoring the measure. Although the HBS-CHD is a validated measure which comprehensively assesses a number of different health risk behaviours, there were problems which became apparent when scoring the measure. The HBS-CHD produces four subscale risk scores; i) substance use risk score ii) dental hygiene risk score iii) physical activity score, and, iv) overall health risk score. The way in which these subscale risk scores are calculated is problematic in that the scoring does not take into account the frequency or intensity of the way certain health behaviours are performed. For example, for drug use, an individual was included in the reported 'drug use' category even if they had only reported using one drug at least once a month or less in the last 12 months. This would include individuals who had used drugs once a year, in the same group who reported drug use every week. Thus the findings of reported drug use may not accurately reflect those who use drugs regularly and those who have experimented on a one-off basis. The way smoking behaviour is operationalised and measured is problematic. Smoking is defined by the HBS-CHD as those who smoke cigarettes 'occasionally or regularly', which are vague terms that are subjective regarding what someone considered to be occasionally or regularly smoking. Considering the definition of smoking behaviour having smoked more than 100 cigarettes in one’s lifetime and currently smoking every day or most days (Centers for Disease Control and Prevention, 2010), the scoring of the HBS-CHD does not operationalise smoking behaviour in a way which enables it to be distinguished as a health risk behaviour or not.

In addition, the HBS-CHD does not provide any clinical norms or cut-off points in terms of what is considered to be a 'healthy' or 'risky' level of behaviour, although this is true of many other measures of health risk behaviours. As a result of these measurement
limitations, it makes it difficult to accurately identify whether someone is engaging in health risk behaviours. Therefore, the face validity of the measure is questionable.

Another problem with the substance use subscale is that it does not distinguish between illicit and prescribed drugs. Interestingly in this study, sleeping pills, sedatives, or tranquilisers, were the second most commonly reported drugs in this sample. However, such drugs may have been prescribed and taken for medical reasons, such as for help with anxiety or sleep difficulties (British National Formulary, 2015; NICE, 2004b).

The physical activity subscale of the HBS-CHD asks about the amount of time spent per week on specific activities. However, participants may take part in physical exercise that is not included in the examples given and therefore the responses may not be accurate. The scoring of the physical activity subscale was also problematic. The way in which the questions were asked meant that it was difficult to ascertain the frequency and intensity of physical activity and the measurement of energy expenditure per hour was meaningless as there was no way of knowing whether this was the recommended amount of exercise or within the recommended guidelines, which is given in hours per week (Budts et al., 2013). Furthermore, more physical exercise does not necessarily imply 'healthy' behaviour as individuals may have been advised against engaging in such exercise. For example, the British Heart Foundation provides recommendations that young people should be able to speak still whilst exercising (British Heart Foundation, 2011). A further limitation of the measure is that the health risk behaviour scale does not ask about body piercings or tattoos which are strongly advised against due to the risk of endocarditis (British Heart Foundation, 2012). However, it could be argued that the HBS-CHD is measuring current health risk behaviours, not past behaviours of which piercings and tattoos could be considered.

**Study design and statistical limitations**

The study design was cross-sectional and therefore no conclusions about causality can be made. However, cross-sectional designs are an important first step when exploring a new area of research before conducting a longitudinal study. As the participants in this study generally reported healthy behaviours, there were low numbers in each outcome health behaviour risk group. For example, only 9 out of 70 participants reported smoking cigarettes occasionally/regularly. Therefore it was not possible to include all illness perceptions and resilience variables in each model and some significant predictors of certain health risk behaviours may have been missed. In addition, due to limited sample size, causes subscale of the IPQ-R could not be included as a separate variable in the models (Moss-Morris et al., 2002). As strongly held beliefs about the negative consequences of CHD were found to be significantly negatively correlated with resilience, there may have been an interaction
between consequences and resilience. An interaction between these two variables may have been better able to explain more of the variance in some health risk behaviours. It was not possible to explore this given the limited numbers in each of the risk outcome groups for each health risk behaviour.

Clinical implications

Addressing health risk behaviours

This research study and earlier research has shown that some young adults with CHD engage in potentially harmful health behaviours and this indicates that there is a need to address such issues (Janssens et al., 2014; Reid et al., 2008). With consideration to the discussion above regarding the uncertainty as to what is considered risky health behaviour for young adults with CHD, it is necessary for clear and consistent guidelines to be developed for substance use, dental hygiene and physical exercise. It may be that such guidelines/recommendations for individuals without CHD are applicable or it may be that separate guidelines for this population need to be developed. However, this is currently unclear. In providing clarity and clearer recommendations, individuals with CHD and indeed healthcare professionals would have a better understanding about what are 'safe' limits of experimenting behaviours and what behaviours put health at risk for this population.

In particular, there should be a greater focus on the physical activity guidelines for individuals with CHD. From this study and previous research (Dua et al., 2007; Janssens et al., 2014), many young adults reported not engaging in any exercise despite the evidence showing this is an important aspect of maintaining good health (Thompson et al., 2007). The current guidelines for patients with CHD should be made more available to patients (Moola et al., 2009; Sable et al., 2011). Although whilst guidelines do exist for individuals with CHD and physical exercise (Budts et al., 2013), these are not straightforward and hence in real life may be difficult to apply and measure. It is unclear what healthcare professionals are 'recommending' to young adults with CHD, perhaps due to the lack of clear guidelines and evidence-base. Healthcare professionals who work with young adults with CHD should seek to develop greater consensus regarding the existing guidelines for this population. Once healthcare professionals have greater clarity and understanding about what advice they should be recommending to young people with CHD, this should help to open up conversations about such topics with young adults.

Research has shown that health risk behaviours which occur during young adulthood may predict future health risk behaviours (McCarty et al., 2004; Paavola et al., 2004;
Willoughby, Chalmers, & Busseri, 2004) and so it is important to identify health risk behaviours early on in order to help prevent physical complications. Therefore, a measure of health risk behaviours could be used in clinical practice to help identify potentially harmful behaviours, in particular during the transition stage between paediatric and adult services when health risk behaviours may be more likely.

NHS England has recently proposed new service specifications for CHD services in the UK (NHS England, 2014). These standards emphasise the importance of carefully planned and personalised transition (between 12-18 years) to enable a seamless pathway of care (NHS England, 2014). The inclusion of information to prepare adolescents to take responsibility for their condition is essential (Jackson et al., 2015; Sable et al., 2011). It is important for health care professionals to encourage young adults to open up and to hold conversations with them about risky behaviour in order to help them proceed towards adulthood in a safe way (Scaramuzza et al., 2010). Young adults with complex CHD are a relatively new population and a shift in professional perspective about some of the challenges facing young adults may be necessary.

Findings from a qualitative study with children and young people (8-19 year-olds) with CHD identified that there was a need for better strategies of communication between children and young people with CHD and their wider social network, including healthcare professionals, about their condition (Birks, Sloper, Lewin, & Parsons, 2007). The present study has also identified that improved communication between healthcare professionals and individuals with CHD is needed. Healthcare professionals should consider that adolescence and young adulthood is a time for exploring and experimenting as this serves developmental needs (Santos et al., 2014). Therefore providing young adults with CHD with opportunities to discuss such behaviours is important in order to help promote a healthy development (Santos et al., 2014).

In addition, there is a need to encourage and educate young adults with CHD about health-promoting behaviours. There is evidence to suggest that individuals with CHD have poor understanding about risk factors of endocarditis, the risks of smoking and alcohol (Moons et al., 2001). Furthermore, there is evidence to suggest that risk knowledge may play a role in explaining engagement in health behaviour in young adults with CHD (Jackson et al., 2015). Patient education therefore should be delivered regarding the risks of engaging in certain behaviours. Given that health risk behaviours were found to cluster in this study and previous studies (Jaser et al., 2011; Spring et al., 2012), it may be a helpful preventative strategy to provide information to adolescents about the added harm associated with simultaneous use of alcohol, drugs and tobacco, as well as the individual risks of these behaviours (Briere, Fallu, Descheneaux, & Janosz, 2011; Leatherdale & Burkhalter, 2012).
Although this study did not investigate the association between knowledge and health risk behaviour, there is recent evidence to suggest that disease knowledge generally may not play a large role in determining whether or not individuals engage in health risk behaviours (Janssens et al., 2014). Whilst personal control relating to CHD was not found to influence individuals' behaviour in this study, it has been suggested that overall self-efficacy may have a direct influence on behaviour (Fishbein, 2000; Janssens et al., 2014). Therefore, techniques aimed to increase self-efficacy may be beneficial, such as motivational interviewing.

Motivational interviewing may be an appropriate technique to use with patients as this is aimed at addressing behaviour change (Miller & Rollnick, 2002). Using a collaborative approach, motivational interviewing aims to increase an individual's motivation and commitment to changing their behaviour. It is a helpful way of addressing ambivalence about making changes in a compassionate manner (Miller & Rollnick, 2002). There is emerging evidence to support the use of motivational interviewing as an effective way of helping people to make change their behaviour in order to improve health outcomes. For example, a recent systematic review and meta-analysis of randomised controlled trials (n = 48) has found motivational interviewing to be effective in medical settings, including chronic illnesses, in improving outcomes in dental hygiene, alcohol and tobacco use (Lundahl et al., 2013).

The role of clinical psychology

There is a clear role for clinical psychology within CHD services. Psychocardiology refers to the role of clinical psychology within cardiac settings and considers biopsychosocial factors which may be the result of living with CHD (Compare, Zarbo, & Bonaiti, 2015). Clinical psychology may be involved in the teaching and training of other staff working into CHD services, e.g. in motivational interviewing to encourage health behaviour change. In addition, clinical psychology can help with the assessment and identification of unhelpful illness perceptions, unhelpful coping strategies, low resilience, and health-risk behaviours, in order to help support the wellbeing of individuals with CHD. Furthermore, clinical psychologists could become involved raising the awareness of other professionals and indeed patients as to how psychological factors affect physical health e.g. illness perceptions and health behaviour. This would help to make it clear why it would be important to discuss illness perceptions with those with CHD.

The SRM could be considered as a useful framework for professionals to use with young adults with CHD. Through the use of the IPQ-R, an individual's underlying illness perceptions and self-regulation principles could be identified. It has been found that patients
are more satisfied when healthcare professionals address illness perceptions (de Ridder, Theunissen, & van Dulmen, 2007), suggesting that talking about illness perceptions is not only helpful for patients, but also valued by them. Assessing and addressing patients’ illness perceptions has been found to improve adherence to health behaviours, including prescribed diet and physical activity changes (McSharry, Moss-Morris, & Kendrick, 2011; Phillips, Leventhal, & Leventhal, 2012). Therefore using the SRM as a framework may help to improve adherence of healthy risk behaviours and reduce risky behaviours.

This study and previous research has found that some illness perceptions are associated with health risk behaviours. Therefore, understanding how these illness perceptions, including emotional perceptions, interact with decision making processes about engaging in certain behaviours is important. It has been suggested that one strength of using the SRM with patients is that it can help create an action plan for helping patients which is framed by the patient's model of their illness (Breland, Fox, Horowitz, & Leventhal, 2012). A cognitive-behavioural approach may be helpful in addressing maladaptive thoughts and behaviours, for example, avoidance of engaging in physical exercise due to mistaken beliefs about the consequences of exercise. For example, cognitive-behavioural therapy (CBT) helps to address causal attributions, and may be useful if a young person with CHD thinks that physical exercise will make their CHD worse leading them to avoid exercise. Sedentary behaviour is a potential risk factor for comorbid conditions, such as obesity which puts added stress on the heart, so it important that this is addressed appropriately with young adults with CHD.

Social context

It is important to consider the wider social context in which young adults with CHD are placed. In relation to this research, one reason for this is that the SRM suggests that illness perceptions are derived from personal experiences and the social environment (Leventhal et al., 1980; Leventhal et al., 1984). Therefore, it is important that the views of parents and peers are considered as these may impact upon illness perceptions. Furthermore, the social context is important in terms of resilience. Although not measured in this research, it has been suggested that protective factors which may help to foster resilience in young adults include social influences, e.g. family and friends (Nylander et al., 2014). Although this research only provides limited support that resilience influences healthy behaviours, previous research has found that resilience may play an important role in the participation of healthy behaviours (Stewart & Yuen, 2011). Interventions should therefore be based around strengthening protective factors in order to help build resilience which may
help to prevent health risk behaviours and encourage healthy behaviours (e.g. participation in physical activities) (Santos et al., 2014).

Areas for future research

Given that this study was exploratory, it is important to replicate these findings before any definitive conclusions can be made. This includes recruiting from a larger and more reliable sample. In addition, a better way of sampling could be considered, such as utilising GP records, for example, to identify and mail out to individuals with CHD. It would be beneficial to use a recognised database and to monitor and follow-up those who do not respond to the first invitation to take part. If funding was available, ideally a researcher could be placed within each CHD centre in England to assist with recruitment and handing out information packs in clinics. A larger sample size would also enable interactions between illness perceptions and resilience to be tested, as well as increasing the number of participants in each health risk behaviour category to improve the reliability of the logistic regression models.

A longitudinal study design would help to identify the direction of the relationship between illness perceptions and health risk behaviours, to see if illness perceptions can predict health risk behaviours over time.

Future research could use a measure socioeconomic status, such as a measure of area deprivation using postcode or a measure of parental employment, in order to assess whether this is a significant variable in determining the outcome of health risk behaviours. It would be interesting to measure a more multidimensional construct of resilience, to assess the influences of the social context in which young adults with CHD are integrated. However, the existing measures are limited and it may be better to develop and validate a measure of resilience for use with this population. As discussed, it is important to ensure the concept of resilience is clearly defined and operationalised accordingly. For example, if resilience is defined as an 'outcome', there needs to be a clear and consistent way of measuring this outcome. If resilience is considered as a process, then a longitudinal design should be used.

Given some of the difficulties with the measurement and scoring of health risk behaviours using the HBS-CHD, it would be worth developing and validating a health risk behaviour questionnaire for this population. This questionnaire would address some of the limitations of the existing measure, such as distinguishing between illicit and prescribed drugs, having a more valid scoring system, and developing clinical norms for this population. An alternative suggestion would be to consider the use of existing measures of health risk behaviours that are used for the general population on smoking, drug use, and
exercise. This could then be used to compare rates of health risk behaviours in the CHD population with the general population.

As the physical activity subscale of the HBS-CHD may not have been an accurate measure of physical activity, more objective measures of physical exercise should be considered in future research, such as accelerometer data (Dua et al., 2007). Other measures of physical activity used in the general population, such as the Health Survey England (Scholes & Mindell, 2012) should be considered. This self-reported questionnaire asks about activity levels in the four weeks prior to the survey completion and about four domains of activity; i) activities around the house, ii) walking, iii) sports and exercise, and, iv) occupational activity. There are sub-sections within these activities, enquiring about duration of activity and level of exertion. The quantification of self reported levels of physical activity are assessed against the recommendations set by the 2011 Department of Health (DoH) guidelines on activity (Health and Social Care Information Centre, 2015a). The current guidelines on activity advise a total of 150 minutes of moderated exercise per week or 75 minutes of vigorous exercise per week. This measure is therefore able to assess physical activity and compare this to the recommended guidelines, unlike the HBS-CHD. In addition, the health risk behaviour questionnaire should also include questions about tattoos and piercings, given these are risk factors for developing endocarditis (British Heart Foundation, 2012). In addition, further research could include a matched comparison group of young adults who do not have a chronic illness to enable comparisons to be made.

Future research could pilot and evaluate psychological interventions aimed at educating young people with CHD about health risk behaviours, which include the use of motivational interview techniques. In addition, interventions based on using the SRM as a framework understanding and changing unhelpful thought could be developed. Such interventions could be evaluated in a longitudinal, randomised-controlled trial to see whether such interventions have a positive impact on the engagement in health risk behaviours. Recent studies have started to explore this, although there is scope for further research (Broadbent et al., 2009; Goossens et al., 2015).

**Conclusion and summary**

To date, this is the first UK-based research study which has explored comprehensively a wide range of health risk behaviours (substance use, dental hygiene and physical activity) of young adults with CHD and considered possible variables to help explain health behaviours. Furthermore, the role of illness perceptions and resilience have been explored using logistic regression models as potential independent variables to explain participation in specific health behaviours. Despite the health risks associated, some young adults with
CHD are reporting to be engaging in potentially harmful behaviours. Although the sample size was small, tentative conclusions regarding the role of illness perceptions and resilience have been drawn. It is hoped that the findings from this study help to inform services about how best to support young adults with CHD in order for them to live as healthy a life as possible.
References


Cederblad, M., Dahlin, L., Hagnell, O., & Hansson, K. (1994). Salutogenic childhood factors reported by middle-aged individuals. Follow-up of the children from the Lundby study grown up in families experiencing three or more childhood psychiatric risk factors. *European Archives of Psychiatry and Clinical Neuroscience, 244*(1), 1-11.


Van De Ven, M. O., Engels, R. C., Otten, R., & Van Den Eijnden, R. J. (2007). A longitudinal test of the theory of planned behavior predicting smoking onset among


**List of Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>BI</td>
<td>Behavioural intentions</td>
</tr>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>BIPQ</td>
<td>Brief Illness Perception Questionnaire</td>
</tr>
<tr>
<td>BOS</td>
<td>Bristol Online Survey</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behavioural Therapy</td>
</tr>
<tr>
<td>CHD</td>
<td>Congenital Heart Disease</td>
</tr>
<tr>
<td>HBS-CHD</td>
<td>Health Behaviour Scale-Congenital Heart Disease</td>
</tr>
<tr>
<td>IPQ</td>
<td>Illness Perception Questionnaire</td>
</tr>
<tr>
<td>IPQ-R</td>
<td>Revised Illness Perception Questionnaire</td>
</tr>
<tr>
<td>M</td>
<td>Mean</td>
</tr>
<tr>
<td>MI</td>
<td>Myocardial Infarction</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>RS</td>
<td>The Resilience Scale</td>
</tr>
<tr>
<td>SD</td>
<td>Standard deviation</td>
</tr>
<tr>
<td>SOC</td>
<td>Sense of coherence</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>SRM</td>
<td>Self-Regulatory Model</td>
</tr>
<tr>
<td>TPB</td>
<td>Theory of Planned Behaviour</td>
</tr>
<tr>
<td>VIF</td>
<td>Variance inflation factors</td>
</tr>
</tbody>
</table>
Appendix A: Search strategy


1. Health risk behaviours and chronic illness:

A: Keyword search: “health risk behavio*” OR “risky behavio*” OR "risk behavio*" (n = 55,094)

B: Keyword search: “chronic illness*” OR “chronic condition*” OR “chronic disease*” OR "congenital heart disease" (n = 438,035)

C: Keyword search: “Pediatric*” OR “Paediatric*” OR “Adolescen*” OR “young people” OR "young person” OR “youth” OR “teenager*” OR "young adult*" (n = 5,415,879)

D: Combine selections A AND B AND C (n=380).

Reference results = 380

Filtered down to 14 papers.

2. Illness perceptions, chronic illness and health behaviours:

A: Keyword search: “illness perception*” OR “illness representation*” OR "illness belief*” OR "self regulat* model" OR "common sense model" (n = 5,351)

B: Keyword search: "health behavio*" OR "adherence" OR "self management" (n = 388,157)

C: Keyword search: (i) “chronic illness*” OR “chronic condition*” OR “chronic disease*” OR "congenital heart disease" (n = 438,035)

(ii) OR "diabet*" OR "asthma*" OR "epilep*" OR "hypertensive" OR “renal” OR “cystic fibrosis” OR "cardiovascular" OR "cancer" OR "sickle cell anaemia" (n =15,076,919)

Above C (i) and (ii) combined (n = 16, 477, 481)

D: Keyword search: “Pediatric*” OR “Paediatric*” OR “Adolescen*” OR “young people” OR "young person” OR “youth” OR “teenager*” OR "young adult*" (n = 5,415,879)

E: Combine selections A AND B AND C(i) AND D (n = 28)

F: Combine selections A AND B AND C(i and ii) AND D (n = 130)
Reference results = 130
Filtered down to 13 papers.

3. Resilience, chronic illness and health behaviours:

A: Keyword search: “resilience” OR “resilient” OR "resiliency" (n = 94,572)

B: Keyword search: "health behavio*" OR "adherence" OR "self management" OR "health risk behavio*" OR "risky behavio*" (n = 397,676)

C: Keyword search: (i) “chronic illness*” OR “chronic condition*” OR “chronic disease*” OR "congenital heart disease" (n = 438,035)

(ii) OR "diabet*" OR "asthma*" OR "epilep*" OR "hypertensive" OR “renal” OR “cystic fibrosis” OR "cardiovascular" OR "cancer" OR "sickle cell anaemia" (n =15,076,919)

Above C (i) and (ii) combined (n = 16, 477, 481)

D: Combine selections A AND B AND C (i) (n = 57)

E: Combine selections A AND B AND C (i and ii) (n = 166)

Reference results = 166
Filtered down to 11 papers.


1. Health risk behaviours and chronic illness:

A: Keyword search: “health risk behavio*” OR “risky behavio*” OR "risk behavio*" (n = 14,961)

B: Keyword search: “chronic illness*” OR “chronic condition*” OR “chronic disease*” OR "congenital heart disease" (n = 21,512)

C: Keyword search: “Pediatric*” OR “Paediatric*” OR “Adolescen*” OR “young people” OR "young person” OR “youth” OR “teenager*” OR "young adult*” (n = 282,474)

D: Combine selections A AND B AND C (n = 73)
Reference results = 73

Filtered down to 12 papers.

2. Illness perceptions, chronic illness and health behaviours:

A: Keyword search: “illness perception*” OR “illness representation*” OR "illness belief*" OR "self regulat* model" OR "common sense model" (n = 2,025)

B: Keyword search: "health behavio*" OR "adherence" OR "self management" (n = 49,180)

C: Keyword search: (i) “chronic illness*” OR “chronic condition*” OR “chronic disease*” OR "congenital heart disease" (n = 21,512)

(ii) OR "diabet*" OR "asthma*" OR "epilep*" OR "hypertensive" OR “renal” OR “cystic fibrosis” OR "cardiovascular" OR "cancer" OR "sickle cell anaemia" (n = 125,712)

Above C (i) and (ii) combined (n = 396,587)

D: Keyword search: “Pediatric*” OR “Paediatric*” OR “Adolescen*” OR “young people” OR "young person” OR “youth” OR “teenager*” OR "young adult*" (n = 282,474)

E: Combine selections A AND B AND C(i) AND D (n = 7)

F: Combine selections A AND B AND C(i and ii) AND D (n = 39)

Reference results = 39

Filtered down to 4 papers.

3. Resilience, chronic illness and health behaviours:

A: Keyword search: “resilience” OR “resilient” OR "resiliency" (n = 19,226)

B: Keyword search: "health behavio*" OR "adherence" OR "self management" OR "health risk behavio*" OR "risky behavio*" (n = 52,154)

C: Keyword search: (i) “chronic illness*” OR “chronic condition*” OR “chronic disease*” OR "congenital heart disease" (n = 21,512)

(ii) OR "diabet*" OR "asthma*" OR "epilep*" OR "hypertensive" OR “renal” OR “cystic fibrosis” OR "cardiovascular" OR "cancer" OR "sickle cell anaemia" (n = 125,712)

Above C (i) and (ii) combined (n = 396,587)
$D$: Combine selections A AND B AND C(i) (n = 19)

$E$: Combine selections A AND B AND C(i and ii) (n = 173)

Reference results = 173

Filtered down to 11 papers.
Appendix B:
Invitation Letter

Understanding health behaviours in young adults with Congenital Heart Disease

Invitation Letter

Hello,

(Insert name of NHS CHD centre) are taking part in a research project which is part of a study being carried out by Louise Johnson, Psychologist in Clinical Training from the University of Leeds. This study is interested in understanding health behaviours in young adults with congenital heart disease.

You have been identified by our service as being a potential participant for this study. Please find enclosed an information sheet which tells you more about the project and how to get involved. It is entirely up to you as to whether you choose to take part in this study.

If you would like to take part in the study, please go to the following website to complete the questionnaires: https://www.survey.leeds.ac.uk/chd

Thank you for your time.

(Insert signature and job title)
Appendix C:
Participant information sheet

Understanding health behaviours in young adults with Congenital Heart Disease

Information sheet

You are being invited to take part in a research project. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read this leaflet carefully and talk to others if you wish. If you have any questions or would like further information then feel free to contact me. My contact details can be found at the bottom of this information sheet.

What is the purpose of the project?
We would like to find out more about the health behaviours of young adults with Congenital Heart Disease and understand what factors may affect such behaviours.

Why have I been chosen?
You have been chosen because you attend one of the services in England which support young adults with congenital heart conditions.

Do I have to take part?
It is up to you to decide whether or not to take part in the study. We ask that you only complete the online questionnaire if you are sure you want to take part. All questionnaires are anonymous and therefore we will be unable to remove your responses once you have completed them.

What do I have to do?
If you agree to participate, we ask that you go to the following website to complete four questionnaires online: [https://www.survey.leeds.ac.uk/chd](https://www.survey.leeds.ac.uk/chd)

The kind of questions you will be asked are about your beliefs about your heart condition, how strong you feel as a person and your participation in certain health behaviours. These questionnaires should take no more than 20 minutes to complete.

What are the possible disadvantages of taking part?
Some of the questions ask you to think about your heart condition and what is like to live with your condition. It is possible that you may find some of the questions upsetting. If you do find it upsetting, there will be links to resources at the end of the questionnaire that you may find helpful.
What are the possible benefits of taking part?
Your responses will help us to better understand factors associated with health behaviours in young adults with congenital heart disease. It is hoped that this will be used to inform services about how best to help young people with congenital heart disease. All participants who complete the questionnaires will be given the opportunity to enter a prize draw to win £50 worth of Amazon vouchers.

Will my taking part in this project be kept confidential?
All the questionnaire responses will be kept strictly confidential. Questionnaires will be completed anonymously and your responses will not be identifiable in any reports or publications. If you wish to participate in the prize draw then you will need to provide an email address or telephone number so we can contact you. This will be kept separate from your questionnaire responses and will only be used for your participation in the prize draw.

Who is organising the research?
This research is being undertaken as part of a Doctorate in Clinical Psychology project at the University of Leeds.

Contact for further information:
Louise Johnson
Psychologist in Clinical Training
University of Leeds

Address: Clinical Psychology Training Programme
Leeds Institute of Health Sciences
University of Leeds
Charles Thackrah Building
101 Clarendon Road
Leeds
LS2 9LJ

Email: umlj@leeds.ac.uk

Contact in case of formal complaint:
Clare Skinner,
Faculty Head of Research Support,
Faculty of Medicine and Health Research Office,
Room 10.110,
Level 10, Worsley Building,
University of Leeds, Clarendon Road,
Leeds,
LS2 9NL.

Email: C.E.Skinner@leeds.ac.uk
Telephone: 0113 343 4897
Appendix D:
About You questionnaire

1. Gender:  Male ☐  Female ☐

2. How old are you: ____

3. Which part of the country do you live:
North East ☐  North West ☐  Yorkshire and the Humber ☐  South East ☐
East Midlands ☐  West Midlands ☐  South West ☐  Wales ☐  Scotland ☐
Northern Ireland ☐

4. What is your highest level of education:
GCSE/NVQ ☐  A-level ☐  University ☐  Post-graduate ☐

5. Employment status:
Full-time paid work ☐  Part-time paid work ☐  Student ☐  Voluntary work ☐
Homemaker ☐  Self-employed ☐  Unable to work due to ill health ☐
Unemployed ☐

6. What is your diagnosis:
Tetralogy of Fallot ☐  Transposition of the great arteries ☐
Tricuspid atresia ☐  Total anomalous pulmonary venous connection ☐
Truncus arteriosus ☐

7. How many operations you had on your heart since birth:
0 ☐  1-2 ☐  3-4 ☐  5+ ☐

8. How often do you attend clinic appointments at you congenital heart service:
At least every 3 months ☐  At least every 6 months ☐  At least every year ☐
At least every 5 years ☐  When needed ☐
# Appendix E: HBS-CHD

## Health Behaviour Scale – Congenital Heart Disease

**UK English**

### Health behaviour

This questionnaire is about your health behaviour. *Colour* the correct answer black. Only *1 answer per question* please.

1. Do you consume alcohol from time to time? (by alcohol is meant: beer, wine, spirits, alcopops...)

   □ No  
   (Proceed to question 4)

   □ Yes

   **If yes, how often?**
   - once a month or less
   - 2 to 4 times a month
   - 2 to 3 times a week
   - 4 or more times a week

2. When consuming alcohol, how many glasses do you have on average?

   - 1 to 2
   - 3 to 4
   - 5 to 6
   - 7 to 9
   - 10 or more

3. How often do you drink 6 glasses or more on one occasion?

   - Never
   - Less than once a month
   - Monthly
   - Weekly
   - Daily or almost every day
4. Do you smoke cigarettes occasionally or regularly?

☐ No  (Proceed to question 7)

☐ Yes

5. During the last 30 days, on how many days did you smoke cigarettes?

☐ 1 to 2 days
☐ 3 to 5 days
☐ 6 to 9 days
☐ 10 to 19 days
☐ 20 to 29 days
☐ on all 30 days

6. During the last 30 days, on the days you smoked, how many cigarettes did you smoke a day?

☐ 1 cigarette or less a day
☐ 2 to 5 cigarettes a day
☐ 6 to 10 cigarettes a day
☐ 11 to 20 cigarettes a day
☐ More than 20 cigarettes a day

7. How often, in the last 12 months, did you take the following drugs?

<table>
<thead>
<tr>
<th>Drug Type</th>
<th>Never</th>
<th>once a month or less</th>
<th>2 to 4 times a month</th>
<th>2 times or more a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cannabis (marijuana, weed)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>b. Ecstasy (E, MDMA, XTC)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>c. Cocaine</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>d. Hallucinogenic mushrooms</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>(magic mushrooms)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e. Speed</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>f. Sleeping pills, sedatives or</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>tranquillisers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g. Other drugs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
8. Have you been to the dentist in the past year?

☐ No

☐ Yes

(Proceed to questions 10 and 11)

9. If not, when did you last go to the dentist?

☐ I never go to the dentist
☐ 1-2 years ago
☐ 2-3 years ago
☐ More than 3 years ago

10. How often do you brush your teeth?

☐ I don’t brush my teeth
☐ I brush my teeth every now and then
☐ Once a day
☐ Twice a day
☐ 3 times a day
☐ More than 3 times a day

11. How often do you floss your teeth?

☐ I don’t floss my teeth
☐ I floss my teeth every now and then
☐ Once a day
☐ Twice a day
☐ 3 times a day
☐ More than 3 times a day
12. Do you regularly walk or cycle to school or to your place of work? 

☐ No  
(Proceed to question 14)  

☐ Yes

13. If yes, how long does it take by bike or on foot (there and back)?

☐ < 15 min  
☐ 15-30 min  
☐ 30-45 min  
☐ > 45 min

14. Do you regularly practice a sport? (this includes school sports but NOT the bike ride or walk to school or to your workplace)

☐ No  
(the questionnaire stops here)  

☐ Yes

15. During a 7-day week, how many hours of the following physical activities do you do?

a. Sport at school, during P.E. lessons or other sports periods

__________________________ hours/week

b. Sports or activities that are very physically demanding, which increase your heart rate (e.g. football, a long run, basketball, squash, rowing, rugby, hockey, spinning, Thai boxing, kickboxing, cycle racing, mountain biking, tennis...)

__________________________ hours/week

c. Sports or activities that are moderately physically demanding and where, afterwards, you don’t feel exhausted or worn out (e.g. jogging, volleyball, swimming up and down, ballet, dancing, judo, karate, athletics, badminton, fitness classes, horse riding, wall climbing...)

__________________________ hours/week

d. Sports or activities with minimal physical effort or gentle exertions (e.g. snooker, ten-pin bowling, darts, golf, playing cards, yoga, fishing,...)

__________________________ hours/week
Appendix F:
IPQ-R

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name............................................. Date.............................................

YOUR VIEWS ABOUT YOUR ILLNESS
Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling Yes or No whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

<table>
<thead>
<tr>
<th></th>
<th>Have experienced this symptom since my illness</th>
<th>This symptom is related to my illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Sore Throat</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Nausea</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Stiff Joints</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Sore Eyes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Wheeziness</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Headaches</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Upset Stomach</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Sleep Difficulties</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Dizziness</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Loss of Strength</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

<table>
<thead>
<tr>
<th>VIEWS ABOUT YOUR ILLNESS</th>
<th>STRONGLY DISAGREE</th>
<th>DISAGREE</th>
<th>NEITHER AGREE NOR DISAGREE</th>
<th>AGREE</th>
<th>STRONGLY AGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>971 My illness will last a short time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>972 My illness is likely to be permanent rather than temporary</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>973 My illness will last for a long time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>974 This illness will pass quickly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>975 I expect to have this illness for the rest of my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>976 My illness is a serious condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>VIEWS ABOUT YOUR ILLNESS</td>
<td>STRONGLY DISAGREE</td>
<td>NEITHER AGREE NOR DISAGREE</td>
<td>AGREE</td>
<td>STRONGLY AGREE</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>---------------------------</td>
<td>-------</td>
<td>----------------</td>
<td></td>
</tr>
<tr>
<td>My illness has major consequences on my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness does not have much effect on my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness strongly affects the way others see me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness has serious financial consequences</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness causes difficulties for those who are close to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is a lot which I can do to control my symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What I do can determine whether my illness gets better or worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The course of my illness depends on me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing I do will affect my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have the power to influence my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My actions will have no affect on the outcome of my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness will improve in time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is very little that can be done to improve my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My treatment will be effective in curing my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The negative effects of my illness can be prevented (avoided) by my treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My treatment can control my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is nothing which can help my condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The symptoms of my condition are puzzling to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness is a mystery to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t understand my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness doesn’t make any sense to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a clear picture or understanding of my condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The symptoms of my illness change a great deal from day to day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My symptoms come and go in cycles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness is very unpredictable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I go through cycles in which my illness gets better and worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get depressed when I think about my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When I think about my illness, I get upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness makes me feel angry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness does not worry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having this illness makes me feel anxious</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness makes me feel afraid</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

<table>
<thead>
<tr>
<th>POSSIBLE CAUSES</th>
<th>STRONGLY DISAGREE</th>
<th>DISAGREE</th>
<th>NEITHER AGREE NOR DISAGREE</th>
<th>AGREE</th>
<th>STRONGLY AGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress or worry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hereditary - it runs in my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A Germ or virus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet or eating habits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chance or bad luck</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor medical care in my past</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pollution in the environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C8</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My own behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mental attitude e.g. thinking about life negatively</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family problems or worries caused my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overwork</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My emotional state e.g. feeling down, lonely, anxious, empty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ageing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C14</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C15</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accident or injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My personality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C18</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Altered immunity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the table below, please list in rank order the three most important factors that you now believe caused YOUR ILLNESS. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. ____________________________________________
2. ____________________________________________
3. ____________________________________________
Appendix G:
Resilience Scale

The Resilience Scale™ (RS™)

Please read the following statements. To the right of each you will find seven numbers, ranging from "1" (Strongly Disagree) on the left to "7" (Strongly Agree) on the right. Click the circle below the number which best indicates your feelings about that statement. For example, if you strongly disagree with a statement, click the circle below "1". If you are neutral, click "4", and if you strongly agree, click "7", etc. You must answer every question to submit the test for scoring.

<p>| | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When I make plans, I follow through with them.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>2. I usually manage one way or another.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>3. I am able to depend on myself more than anyone else.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>4. Keeping interested in things is important to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>5. I can be on my own if I have to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>6. I feel proud that I have accomplished things in life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7. I usually take things in stride.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>8. I am friends with myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>9. I feel that I can handle many things at a time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>10. I am determined.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>11. I seldom wonder what the point of it all is.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>12. I take things one day at a time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>13. I can get through difficult times because I've experienced difficulty before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>14. I have self-discipline.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>15. I keep interested in things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>16. I can usually find something to laugh about.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>17. My belief in myself gets me through hard times.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>18. In an emergency, I'm someone people can generally rely on.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>19. I can usually look at a situation in a number of ways.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>20. Sometimes I make myself do things whether I want to or not.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>21. My life has meaning.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>22. I do not dwell on things that I can't do anything about.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>23. When I'm in a difficult situation, I can usually find my way out of it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>24. I have enough energy to do what I have to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>25. It's okay if there are people who don't like me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix H:
Ethical approval letter

Health Research Authority
National Research Ethics Service

NRES Committee North West - Preston
At NHS Centre, Manchester
Edale House
2nd Floor
4 Minshall Street
Manchester
M1 3DZ

Telephone: 0161 608 7810
Fax: 0161 608 8260

23 December 2013

Miss Louise Johnson
Meadow View
The Avenue
Collingham
LS22 5BU

Dear Miss Johnson

Study title: The association between illness perceptions, resilience, and health risk behaviours in young adults with Congenital Heart Disease (CHD).

REC reference: 13/NW/0688
Protocol number: n/a
IRAS project ID: 141574

The Proportional Review Sub-committee of the NRES Committee North West - Preston reviewed the above application in correspondence.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mrs Carol Ebereszer, nrescommittee.northwest-preston@nhs.net.

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.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).
Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved were:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td></td>
<td>16 December 2013</td>
</tr>
</tbody>
</table>
Membership of the Proportional Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Information is available at National Research Ethics Service website > After Review

13/NW/0083 Please quote this number on all correspondence
We are pleased to welcome researchers and R & D staff at our NRES committee members’ training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

[Signature]

Dr Patricia Wilkinson
Chair

Email: nrescommittee.northwest-preston@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 ResearchEthicsandGovernanceAdministrator

Ms Anne Gowing, Leeds teachingHospitalsNHS Trust
Appendix I:
Consent form

Understanding health behaviours in young adults with Congenital Heart Disease

Consent form

The purpose of this form is to ensure that you are willing to take part in this study. Before you complete the questionnaires, please read and complete the following:

I have read and understood the participant information sheet

I understand that all my responses will remain anonymous

I understand that once I have completed the questionnaires it will not be possible for my responses to be removed

I agree to take part in this study
## Correlations of Illness Perceptions (IPQ-R) and Resilience (RS)

<table>
<thead>
<tr>
<th></th>
<th>Identity</th>
<th>Timeline acute/chronic</th>
<th>Consequences</th>
<th>Personal control</th>
<th>Treatment control</th>
<th>Illness coherence</th>
<th>Timeline cyclical</th>
<th>Emotional perceptions</th>
<th>Resilience</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IPQ-R</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeline acute/chronic</td>
<td>0.32 **</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consequences</td>
<td>0.48 **</td>
<td>0.32 **</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal control</td>
<td>0.01 †</td>
<td>0.01 †</td>
<td>-0.11 †</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment control</td>
<td>-0.12 †</td>
<td>-0.34 ***</td>
<td>-0.27 *</td>
<td>0.24 *</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness coherence</td>
<td>0.05 †</td>
<td>-0.05 †</td>
<td>-0.08 †</td>
<td>0.02 †</td>
<td>0.21 *</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeline cyclical</td>
<td>0.28 **</td>
<td>0.07 †</td>
<td>0.43 **</td>
<td>0.08 †</td>
<td>-0.11 †</td>
<td>-0.12 †</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional perceptions</td>
<td>0.22 *</td>
<td>0.10 †</td>
<td>0.48 **</td>
<td>-0.04 †</td>
<td>-0.03 †</td>
<td>-0.18 †</td>
<td>0.35 **</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>RS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resilience</td>
<td>-0.12 †</td>
<td>0.08 †</td>
<td>-0.27 †</td>
<td>0.07 †</td>
<td>-0.02 †</td>
<td>0.08 †</td>
<td>-0.04 †</td>
<td>-0.17 †</td>
<td>1.00</td>
</tr>
</tbody>
</table>

*τ = Kendall’s Tau
*ξ = Pearson’s Correlation

* = Correlation is significance at 0.05 level
** = Correlation is significance at 0.01 level