# The Development of the Youth Empowerment Scale

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy in the Faculty of Medical and Human Sciences

2013

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#### **Abstract**

#### THE UNIVERSITY OF MANCHESTER

**ABSTRACT OF THESIS** submitted by Annmarie Grealish for the Degree of PhD in Psychology and entitled The Development of the Youth Empowerment Scale, 20<sup>th</sup> December 2013.

This study developed and validated the Youth Empowerment Scale (YES) for young people with psychosis. This PhD thesis consisted of four phases. Phase 1 conceptualised empowerment from the perspective of young people with psychosis. Phase 1 qualitative findings informed the development of the measurement of empowerment; the Youth empowerment Scale (YES). Phase 2 developed and validated the YES in a non-clinical population. Phase 3 explored the relationship between psychological processes (self-efficacy, control, coping, thinking style, and social support), empowerment, mental health wellbeing and recovery. The YES was then validated again in phase 4 on a clinical population, young people within Child and Adolescents Mental Health Services (CAMHS). This study confirmed that the YES is a valid and reliable measure of empowerment which can be used in future work identifying and supporting empowerment for young people with psychosis.

#### **Declaration and Copyright Statement**

#### **DECLARATION**

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning

#### **Published work**

This thesis is submitted in alternative format (with four papers). Phase 1 paper was published in *Clinical Psychology and Psychotherapy* in 2011. Phase 2 and 4 papers are currently submitted and under review. The phase 3 paper has been reviewed by *Psychology and Psychotherapy: Theory, Research and Practice* and revisions are currently being revised.

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#### **Acknowledgements**

I would like to thank my supervisors, Dr Sara Tai and Professor Tony Morrison for their invaluable guidance, support and advice.

I extend warm thanks to Dr Richard Emsley at the Centre for Biostatistics at the University of Manchester knowledge and patience.

Thanks also to Steven Holtzman at the Centre for Data Analysis Research, Princeton, NJ for answering my factor analysis questions.

Special thanks go to all the CAMHS staff and young people who kindly agreed to take part in my study and to Dr Gemma Trainor, Nurse Consultant, Greater Manchester West Mental Health Foundation Trust for helping me access the data.

I am grateful to the University of Salford for supporting this PhD.

I would also like to thank my family and friends for their support. In particular Clare and Ian Baguley for keeping me warm and inspired.

Finally, I'd like to thank Andrew, Fraser and Duncan for their patience, support and encouragement.

#### **Chapter 1: Introduction and Literature Review**

This chapter will provide a definition of empowerment and a general overview of research and theoretical development of the concept. Specifically, the importance of empowerment in relation to the mental health of young people will be explored, and evidence demonstrating how empowerment impacts outcomes for young people with psychosis. In addition, justification of the need for a quantitative measure of empowerment is provided, as a key aim of this thesis. The research presented in the thesis consists of four phases. Phase 1 conceptualises empowerment from the perspective of young people with psychosis. The findings from this qualitative study informed the development of a measurement of empowerment; the Youth empowerment Scale (YES). This current chapter describes how this is the first study to examine empowerment from the perspective of young people with psychosis, and highlights the need and utility of a young person specific empowerment scale. Phase 2 develops and validates the YES in a non-clinical population and this measure was then validated again in phase 4 on a clinical population, young people within Child and Adolescents Mental Health Services (CAMHS). Finally, phase 3 explores the relationship between psychological processes (self-efficacy, control, coping, thinking style and social support) empowerment, and mental health, wellbeing, and recovery. The psychological variables explored in this phase 3 derive from findings from phase 1 which are related to empowerment and are well documented in the adult literature, however very little is written from young people's perspective.

#### 1.1.1 Defining empowerment

Over the last two decades, there has been an increased focus on the concept of empowerment. Consequently the term empowerment is in widespread use by researchers, practitioners and people concerned about mental health issues. The word empowerment is cited frequently in mental health research, scholarly articles and government policies, but the definition of empowerment has remained varied. Edelman (1977) cautions us on the unclear use of language in relation to politics of human services and noted that new language can be used to describe existing unchanged practices. The term empowerment has been used so often and so

widely that it's meaning and its application has become ill defined. The concept of empowerment is derived from the Latin word 'potere' which means "to be able". Empowerment is a concept which has been examined from the perspective of multiple disciplines, such as sociology (Morrall, 1996), social work (Freire, 1970; Stevenson & Parsloe, 1993), psychology (Fox et al., 2009; Rappaport, 1984; Zimmerman et al., 1988), health promotion (Tones & Tilford, 2001) and nursing (Rodwell, 1996; Gibson, 1991). However, the specific definition of empowerment has varied depending on the context in which it has been used. Cattaneo and Chapman (2010) provided a critique of a wide range of the commonly cited definitions of empowerment and categorised them as 'mastery', 'participation', 'the social good', 'goal achievement' and 'the nomological network of empowerment'.

Empowerment embraces the idea that individuals have the right to make their own choices about their health care. The popularity of empowerment models was stimulated by the World Health Organisation's approach to health promotion in the eighties which was based on helping people to bring about changes and control over their own lives. WHO (1986, 2010) defines empowerment through the definition of health promotion as a process which enables people to increase control over and to improve their own personal health. It is highlighted in their Ottawa Charters (1986, 2010) that people cannot achieve the fullest health potential unless they are able take control of those things which determine their health. In its most general sense, empowerment encompasses a sense of personal control, and is central to the work of improving human lives and achieving better health and wellbeing. The writings of Paulo Freire have also influenced empowerment and can be encapsulated in Freires' term 'critical consciousness raising' (CCR). Freire (1972) describes the concept of 'consientizacao', involving a change in consciousness where people gain the knowledge to make an accurate and realistic judgement of their place in their world in relation to others. From this position of awareness they are able to act to change their world or alternatively change themselves relative to that world. This philosophy of Freire (1972) means that not only will the individual have control over the decision making process that affects them but they will also have choices over how to respond to problems. In the context of mental health users, it involves users

identifying problems as they see them, not as those in positions of power see them, which means users, mental health services and clinicians meeting as equals. Freire (1972) argues that empowerment requires a dialogue between those who have been disempowered and those who have been traditionally oppressive. This exchange forms a mutual understanding of past problems and future opportunities.

There are many interpretations of empowerment that describe it as either a process or as an outcome (Bernstein et al., 1994; Rissel, 1994; Laverack & Wallerstein, 2001). Theorists (e.g. Israel et al., 1994; Kieffer, 1984; Rappaport et al., 1987; Zimmerman, 1995, 2000) argue that empowerment can be seen as both a process and an outcome, whereby individuals gain and strengthen the skills and resources they need to have greater control over their lives, and the actual attainment of important goals. Within the context of mental health, empowerment might involve a person with mental health problems being able to heal, recover and resume their previous social role; thus offering the individual a sense of hope. Although several authors have attempted to conceptualised empowerment (see section 2.2 below), there is no clear definition that relates to empowerment and mental health. In attempting to apply the concept to mental health settings specifically psychology and long term rehabilitation; Rappaport (1987), Zimmerman (1995, 2000) and Kieffer (1984) have contributed considerably to conceptualising empowerment. The applicability of their understanding of empowerment will now be considered.

Rappaport (1987) defined empowerment as a process through which people, organisations, and communities gain mastery over their lives. Rappaport (1987) explores the idea that individuals are experts in their own expression through thoughts, feelings, actions, and beliefs; and individuals should be encouraged to focus on enhancing the possibilities to control their own lives. He also notes that empowerment is easier to define by its absence, but difficult to operationalise as it takes on different forms in different people and contexts. Zimmerman (1995) defines empowerment as the act of enabling people to gain skills and abilities to act on their own in order to reach their self-defined goals. Zimmerman (1995) proposed a conceptual model of psychological empowerment consisting of three domains: intrapersonal, interactional, and behavioural. The intrapersonal component refers to the manner in which individuals think about themselves with

respect to their ability to achieve a particular outcome in a particular area of their life. It includes concepts of perceived control, competence, self-efficacy, and motivations to control. The interactional component assesses how individuals understand and relate to their social environment. This component addresses one's ability to develop "critical awareness" of the resources and options that are available to them and how to manage them in order to achieve social change. Interactional characteristics include individuals having possession of relevant skills such as decision making, problem solving, critical awareness and leadership. The behavioural component of psychological empowerment refers to an action taken in the environment. Zimmerman (1995) argued that all three domains must be measured in order to fully capture psychological empowerment. Zimmerman (1995) also cautions against simple universal measurement for empowerment arguing this may confuse our understanding of empowerment as it may not mean the same thing for every person, organisation, or community. Therefore the aim of the current thesis was to understand empowerment from the perspective of young people with psychosis by construing a measure that was based on their dynamic experiences instead of static outcomes. Outcomes may also fluctuate and depend on circumstances, where people may experience empowerment in one setting but not another, and at one time but not another.

Zimmerman (2000) also refers to 3 basic aspects of empowerment which include participation, control and critical awareness. Participation refers to the individual's actions that contribute to community contexts and processes. Control refers to the perception of ability to influence decisions and critical awareness is referred to the ability to analyse and understand the social and political environment. The literature shows how these three aspects are crucial to understanding empowerment theory and application in practice. The literature suggests when adults participate in decision making and meaningful activities they are likely to be empowered (Chavis & Wandersman, 1990; Rappaport, 1987; Riger, 1993; Wandersman & Florin, 2000; Zimmerman & Rappaport, 1988). These examples do not examine the concept from the perspective of young people with psychosis. Zimmerman (2000) argues that it is through participation and control that critical awareness is developed allowing a person to understand power structures, decision-making processes, how to influence decisions and mobilise

resources. Eklund (1999) defined participation as "marginal" (when people have none or little influence in the process), "substantial" (when people are involved in defining priorities and activities execution) or structural (when it is a comprehensive component of the project and an ideological basis for all activities). Control comes with participation which is the perception of the ability to influence decisions, solve problems and build on effective participation (Riger, 1993). Control enables the participation process to be gradual and coherent to people's critical awareness which implies a redistribution of power so the process can be meaningful and real, and participation can boost an empowerment process (Riger, 1993).

Another example of seminal research into empowerment that can only be hypothesised as relevant to young people with psychosis is Kieffer (1984). This work on personal empowerment is one of the most prominent studies to examine individual empowerment as a process. He argued that empowerment is a gradual process, which includes four stages: entry, advancement, incorporation, and commitment. The entry stage is the initial exploration of authority and social norms characterised by powerlessness, support within a caring community of peers, sense of integrity and attachment. The advancement stage possesses three important characteristics that are necessary to the progress of continuing the empowerment process, which include peers and mentor support that are important to develop critical awareness. The main focus of the third incorporation stage is where organisational and political competencies and confrontation with activity takes place and where proactivity is developed. In the final stage commitment is where social actions are brought to the individual's daily life structure. In Kieffer's (1984) theory, empowerment means a gradual process that goes from marginal, to substantial and structural participation. These four stages are essential allowing active participation to lead to continual community involvement and build a future for individuals and their social environment.

In these definitions the important aspects of the concept of empowerment, such as understanding the empowerment process and the positive outcomes, are examined from adult perspective; meaning they still remain untested in young people with psychosis. Therefore we can only hypothesise that similar positive outcomes are

likely for young people with psychosis but given that there are no means of measuring outcomes of empowerment this study aims to address this gap. The current thesis focuses on young people with psychosis and thus empowerment will be examined from the individual level rather than collective or organisational level. Individual empowerment will be understood by drawing upon two theoretical perspectives; firstly the concept espoused by Rappaport (1987) whereby individuals are empowered when they gain control over their lives. Secondly, Zimmerman's validation model of psychological empowerment (Zimmerman, 1995) is incorporated, with reference to the concept of process, which helps the individual gain control over their lives by equipping them with skills and abilities to act on issues that they define as important.

#### 1.1.2 Defining empowerment in terms of mental health

Most existing definitions of empowerment in the mental health literature relate to the function of self-help programs, how mental health services and clinicians can promote empowerment and how people suffering with severe mental illness can become integrated into the community (Carpinello et al., 2000; Castelein et al., 2008; Rogers et al., 1997; Rush, et al. 2006; Segal et al., 1995; Wallerstein, 2006). Most of the definitions within the mental health literature view empowerment as increased control over the illness, treatment and that individuals receiving treatment are accepted as individuals instead of as an object of medical intervention (Chamberlin, 1997; Fisher, 1994). The notion of empowerment from the perspective of mental health was referred to by Chamberlin (1997) as a process that has a number of qualities such as having decision making power, access to information and resources, and options from which to make choices. There are no consensual definitions of the concept of empowerment within the mental health literature but there are some common dimensions shared which include self-esteem, self-efficacy, power, involvement, choice and control over their own life situation, and care and support (Baguley et al., 2007; Barker & Buchanan-Barker, 2005; Calnan & Gabe, 2001; Hansson & Bjorkman 2005; Small et al., 2013; Spencer, 2013; Stevenson et al., 2003).

It is well noted in the literature that the concept of empowerment can be associated with other aspects of mental health care such as deinstitutionalisation,

listening, explanation, information, support, choice, meeting basic needs, involvement, self-determination and the power to make decisions (Rogers et al., 1997; Wallerstein, 2006). Wallerstein (2006) defines empowerment as the level of choice, influence and control that users of mental health services can exercise over events in their lives. Empowerment is also defined as a process of gaining control over one's life and having the ability to influence organisational and societal structure in which one lives (Segal & Silverman, 1995). Although many variations of the definition of empowerment exist within mental health, they are rooted in the common idea of subordinated people gaining or attaining the capacity to control their own lives and to influence the community and social structures that affects them (Clark & Krupa, 2002; Finfgeld, 2004; Rogers et al., 1997; Segal & Silverman, 1995; Wallerstein, 2006). It is clear from the mental health literature that empowerment is about the power to make decisions, free choice and about the transfer of control back to individuals. This relates back to Freire's philosophy (Freire, 1970) that in order to empower individuals and improve their quality of life equal partnerships between service users and providers must be established. This would allow service users to self-manage their needs rather than focus remaining on the needs of the service providers. Self-management is a good example of empowerment as this helps the individual to control their own treatment and lives.

#### 1.2 Why empowerment is essential within mental health

There is consensus within the literature that empowerment is central to better mental health, wellbeing and recovery. Empowerment has frequently been linked to improving the effectiveness and quality of care by enabling the individual to take greater control, expand their capabilities, make informed choices and decisions about their lives (Cattaneo & Chapman, 2010; Fisher & Gosselink, 2008; Joseph Rowntree Foundation, 2006; Woodall et al., 2010; Zimmermann and Rappaport, 1988). This literature demonstrates the positive impact of empowerment on one's self-efficacy, confidence, self-esteem, motivation, personal control, critical awareness, ability to problem solve and skills development. Therefore, this process of empowerment can enable young people with psychosis to take action to achieve influence over themselves and to work with others leading to behaviour change.

Other notions of empowerment have stemmed from work within the field of adult mental health rehabilitation. Chamberlin (1997) referred empowerment in this context as a process that has a number of qualities, such as having decision making power, having access to information and resources, and having a range of options from which to make choices. Wallerstein (2006) maintains that people understand their own needs far better than anyone else, and therefore, should have the power to define and act upon them. Increasingly, the literature indicates that recovery from mental illness and positive wellbeing is dependent on empowered participation in one's own care (Brosnan, 2012; Harper & Speed 2012). Successful delivery of mental health services is more likely when a sense of empowerment can be facilitated in individuals who access those services.

Empowerment has been recognised as a core element of health promotion in the Ottawa Charter on Health Promotion (WHO, 1986). This charter states that people should be empowered to promote their own health, interact effectively with health services and be active partners in managing their own illnesses. Wallerstein (2006) found evidence of empowerment improving health outcomes and quality of life among individuals with chronic illnesses. They assert how empowering characteristics such as patient decision-making, effective dialogue between clinicians and patients, coping skills, showed effective illness management, improved health behaviours and mental health outcomes. These findings were also apparent in studies which focused on empowerment and health outcomes for individuals with chronic mental illness (Frame, 2003; Lorig et al., 2001a, 2001b; Melnyk et al., 2004; Roberts, 1999; Rosenfield, 1992). In addition Wallerstein (2006) also showed how these empowering strategies were also evident in family/carers and how empowerment increased caregiver efficacy, coping skills, access and effective use of health services. These findings were also mirrored in other studies on how empowerment helped to reduce depression and anxiety in caring for chronically ill children (McCallion et al., 2004; Sherman, 2003; Taub, 2001). Wallerstein (2006) concluded that patient empowerment produced improvement in self-regulated disease management, use of health services and health disparity outcomes. They argued that empowering initiatives can lead to health outcomes and that empowerment is a viable public health strategy.

### 1.3 The importance of empowerment for young people with psychosis

Despite numerous conceptual definitions for empowerment, few can be applied specifically to young people experiencing mental health problems. Existing studies that relate to empowerment in young people are derived from youth empowerment models such as the Adolescent Empowerment Cycle (AEC) (Chinman & Linney 1998); the Transactional Partnering Model (TP) (Cargo et al., 2003); the Youth Development and Empowerment (YD & E) (Kim et al., 1998); and the Empowerment Education model (EE) (Freire, 1970). These youth models incorporate many of the key features of empowerment theory described by Rappaport (1987) and Zimmerman (1995, 2000), and focus on a meaningful engagement through genuine participation between adults, youth and organisations. These youth empowerment models (Cargo et al., 2003, Chinman & Linney 1998; Kim et al., 1998; Freire, 1970) demonstrate the importance of empowerment for young people. For instance they provide the young person with opportunities for skill development to enable them to act upon their own knowledge, gain critical awareness, set goals for themselves and to attain the capacity to influence the community and social structures that affect their lives.

Although these models have common themes they also acknowledge that they do not qualitatively conceptualise empowerment from the young person's perspective (Cargo et al., 2003, Chinman & Linney 1998; Kim et al., 1998; Freire, 1970). For instance the AEC, YD & E and EE models were based on existing theories of youth development, psychology and theories of critical social praxis rather than through research. The TP Model was developed as part of a qualitative research however it offered limited conceptualisation of empowerment from the perspective of young people. Instead it mainly focused on the role of adults in creating an empowering environment and the various ways in which they enabled youth. Although these studies demonstrate how the concept of empowerment may apply to young people they are dependent on adult studies. In order to understand young people's experiences of their psychotic illness and make user empowerment a reality, it is necessary to developing an empirically based young person focused concept of empowerment within the context of mental health

#### 1.4 Empowerment in young people, including psychosis

Young people with psychosis can face many obstacles to obtaining treatment and entry into the mental health system often occurs in the context of crisis (Gerson et al., 2009). It is also the case that the longer psychosis goes untreated the worse the outcomes for the young person (Harrigan et al., 2003; Noramn Lewis & Marshall, 2005). Walker & Child (2008) demonstrated how young people with serious mental health conditions who had higher levels of empowerment, selfdetermination, and self-efficacy were more likely to have successful transition outcome. Other studies (Catalano et al., 2002; Durlak & Wells, 1997; Elias et al., 1991; Flay, 2002; Kellam & Anthony, 1998; Weissberg et al., 2003) showed how preventive adolescent programmes lead to positive changes in psychological and behavioural adjustment, academic performance and cognitive skills in young people, whilst also supporting the prevention of mental health problems. These studies demonstrate how young people with psychosis and their families need to have a sense of feeling empowered in order to be able to engage with services and reduce the risk of relapse and rehospitalisation. Therefore empowering young people with psychosis can increase their understanding about their symptoms, aetiology and treatment of psychosis as this empowerment process can help them to gain knowledge that helps them to understand their experiences. Knowledge can be empowering as it can help individuals to take an active role in the management of their illness (Rosenberg, 1965). This emphasises the need to better understand how empowerment can enhance current practices allowing young people with psychosis to access services, gain control over their lives and develop skills that equip them to take action on issues of concern to them.

#### 1.5.1 What is psychosis and the continuum understanding

The term "psychosis" is a symptom or feature of mental illness rather than a diagnosis. Psychosis is a term used to describe serious of mental disorders, including mood disorders, personality disorders, substance-induced psychotic disorder and it is also the defining feature of schizophrenia (Benning, 2007; Kendall et., 2013; Read et al., 2004; Tengan & Maia, 2004). Schizophrenia is the most common form of psychosis characterised by hallucinations and/or delusions that alters thoughts, perception, affect, and behaviour. Schizophrenia is one of the

leading causes of long term disability which can have catastrophic effects on the individual's capacity to lead a rich and meaningful life (Kendall et al., 2013; Mueser & McGurk, 2004; Stafford et al., 2013).

Adolescence is a critical period for the development of mental health. Three quarters of serious lifelong mental illness typically develop before the age of 25 and young people aged 12 to 25 have the highest incidence and prevalence of mental illness across their lives, (Brown, 2010; McGorry et al., 2013; Royal College of Psychiatrist, 2010; Saha et al., 2007; Stafford et al., 2013). Prospective studies have also suggested that by the age of 21, more than half of young people will have experienced a mental health problem of some kind (Royal College of Psychiatrist, 2010). Schizophrenia affects approximately 1.6 to 1.9 per 100 000 in the child population with prevalence increasing rapidly from age 14 (Kelleher et al., 2012; Kendall et., 2013). Population-based studies show how the prevalence of psychotic symptoms are commonly found in a non-clinical population and how psychosis exists in the general population as a continuous phenotype rather than as an all-or-none phenomenon (Kelleher et al., 2009; Moffitt et al., 2010; van Os et al., 2000, 2008; van Os, 2003). These studies report a prevalence rate of 5-8% in the general population, which is approximately ten times higher than the prevalence of diagnosed psychotic disorders. A systematic review by (Kelleher et al., 2012) reported the median prevalence of psychotic symptoms was 17% among children aged 9 to 12 and 7.5% among adolescents aged 13 to 18. This study also reported how common psychotic symptoms are in young people and how prevalence is higher in younger children (9 to 12 years) compared to older children (13 to 18 years). As a result, psychosis can have serious consequences on the future wellbeing of the child or young person as it can impair a person's developmental milestones, relationships, physical health, and education. Therefore it is important that services, prevention strategies and treatments are developed to address these problems in a way that will maximise their effectiveness in supporting future mental wellbeing (Birchwood, 2003; Bloom et al., 2011; Hollis, 2000; McGorry et al., 2013).

Psychotic illness in young people is generally similar to psychosis in adults, but in practice the clinical picture is more complicated because of factors such as

maturity level and personality development (Kendall et al., 2013; Morrison et al., 2011; Tengan & Maia, 2004). The nature of the presenting symptoms for adultonset psychosis differs from those of adolescent-onset psychosis and this makes it more difficult to diagnose and leads to diagnostic confusion (Chuma & Mahadun, 2011; Fusar-Poli et al., 2012). Symptoms frequently seen in young people are: thought disturbances, speech disturbances, visual and auditory hallucinations, (Volkmar et al., 1995; Tolbert, 1996; Hollis, 2000). The two most widely recognised classification systems for diagnosing mental health conditions are the ICD-10 (WHO, 1992) which is commonly used in European countries, and the DSM-IV (American Psychiatric Association, 1994) which is commonly used in the United States. Diagnostic criteria in adolescence are somewhat different from those used in adulthood as they incorporate an understanding of the youth's developmental, social, educational, and psychological needs (AACAP, 2001; Clark, 2001). However, the diagnostic concept of schizophrenia has been criticised for being scientifically questionable on the grounds that it groups a whole range of different problems under one label assuming that everyone within the group have the same disorder (Bentall, 2003). An alternative focus would be to concentrate on improving outcomes, partnership working, recovery and ensuring individuals are treated on the basis of their unique symptoms rather than according to overarching diagnostic criteria (NICE, 2013; Royal College of Psychiatrist, 2010).

#### 1.5.2 Psychosis and youth

The onset of psychosis is usually preceded by a period of non-psychotic symptoms, known as prodromal symptoms lasting one to three years (Chuma & Mahadun, 2011; Ruhrmann et al., 2010). This period is characterised as the "critical period as the greatest deterioration in cognitive and social functioning occurs early in the course of the illness (Birchwood et al., 1998, 2013; McGorry et al., 2013; Singh, 2010). Therefore the delay in untreated psychosis or prevent transition to psychosis from this prodromal syndrome is undesirable and should be reduced to an absolute minimum (Birchwood et al., 2013). Young people with psychosis face a shorter life expectancy by about 15 to 20 years than the general population, largely because of cardiovascular disease, type two diabetes, suicide, obesity partly from antipsychotic medication (Mykletun et al., 2009; Royal

College of Psychiatrist, 2010; Saha et al., 2007). For many young people psychosis is a challenging and debilitating condition which is indicated in the high rates of suicide (Bertelsen, et al., 2008; Jablensky, 1995; Palmer et al., 2005; Tarrier et al., 2004), depression and anxiety (Buckley et al., 2009; Mulholland & Cooper, 2000; Tarrier, 2005), poor social and cognitive functioning (Bentall & Morrison, 2002; Birchwood, 2003; Green et al., 2004; McGorry et al., 2001), substance misuse (Dixon & Lehman, 1995). These factors can delay recovery, lead to stigma and discrimination, and disrupt home and family life thus imposing a heavy burden on carers (Harrop et al., 2001; Jackson & McGorry, 2009).

Over the past two decades there has been considerable improvements in the outcomes for young people with psychosis. This has been largely attributed to the improvements in research methodologies and the changes in diagnostic and therapeutic practice (Menezes et al., 2006; Malla & Payne, 2005; Roth & Fonagy, 2006). Several studies have resulted in greater understanding of the psychological processes underpinning psychosis which lead to advances in psychological interventions, most commonly notably cognitive behavioural therapy (Addington et al., 2011; Morrison et al., 1995, 2007; Morrison, 2001; Tai & Turkington, 2009). These studies demonstrated how inclusive language and engagement helps to increase understanding of the person's perspective of their psychotic experiences and ways they might best enhance their coping abilities. Other studies demonstrated that individuals with psychosis often have developmental histories characterised by disrupted attachment histories, loss, and trauma and therefore such experiences can compromise their ability to cope and manage distress in later life (Bebbington et al., 2004; Liotti & Gumley, 2008; Read & Gumley, 2008). These studies demonstrated by monitoring symptoms such as level of distress and functioning, factors such as engagement, social relationships and empowerment can lead to better mental wellbeing and recovery. Therefore outcome studies which focus on recovery, empowerment and resiliency can help to introduce measures aimed at preventing poor outcomes for young people with psychosis thus improving their mental wellbeing.

# 1.5.3 Early Intervention Services (EIS) for young people with psychosis

The need to provide early intervention, prevention strategies along with the manner in which services are delivered to young people with psychosis are crucial for future wellbeing (Birchwood et al., 2013; Birchwood & Singh, 2013; Jackson & McGorry, 2009; McGorry et al., 2013). The UK government have prioritised developing services that address the needs of young adults with a first episode of psychosis (DoH 2001, 2004, 2006; NICE, 2002, 2009, 2013). There is a common agreement that an early episode of psychosis has a major influence on the longterm outcome of the disorder and implications for the secondary prevention of the impairments and disabilities which accompany psychosis (Birchwood et al., 1998, 2013; NICE, 2013). Findings of studies into Early Intervention Services (EIS) (Bertlolte & McGorry, 2005; Bird et al., 2011; Dodgson et al., 2008; Mihalopoulos et al., 2009; NICE, 2009) highlight the importance of early treatment, protective factors and empowerment in order to prevent mental health problems in adulthood. The EIS research demonstrated a decrease in relapse and rehospitalisation, and better long-term prognosis along with improved empowerment and recovery (Allot et al., 2002; Birchwood et al., 1998; Marshall et al., 2005; Pitt et al., 2006). EIS for young people with psychosis have been shown to be superior to generic community mental health teams on every outcome. These include improved relapse rates by more than 50%, decreased rehospitalisation, greater levels of user satisfaction and are more cost-effective (Bertlolte & McGorry, 2005; Bird et al., 2011; Dodgson et al., 2008; Mental Health Policy Implementation Guide, 2011; Mihalopoulos et al., 2009). NICE guidelines (NICE, 2009) also acknowledged the success of EIS compared to CMHT care for people with psychosis and the evidence also suggest that well implemented EIS can achieve significantly more benefits than costs (Bagley & Pritchard, 1998; Foster et al., 2007; Zechmeister et al., 2008).

Empowerment is a key component of recovery within the EIS approach which shows that if the families are actively engaged and empowered the outcomes improve significantly for both the individual and family (Addington et al., 2005; Norman, et al., 2008; Royal College of Psychiatrists, 2010). This literature

highlights how the family experiences less stress and disruption when they are more empowered and consequently are better able to cope with their relative's illness. A user led study by Pitt et al. (2007) showed how the rebuilding of the self is a key element to the recovery process, which involves the process of empowerment. Young people with psychosis and their families need to have a sense of feeling empowered in relation to the treatments they receive in order to be able to engage with services and reduce the risk of relapse and rehospitalisation. In spite of these improved outcomes there is a need to better understand how EIS can develop and how empowerment can enhance their current practices allowing young people to access services, gain control over their lives and develop the skills that equips them to take action on issues of concern to them.

# 1.5.4 Child and Adolescent Mental Health Services (CAMHS) for young people with psychosis

Special considerations are needed for patient populations such as, children and young people, as the developmental stage may greatly influence the clinical presentation and outcome (Birchwood et al., 2013; Jackson & McGorry, 2009). The variations in the presentation of young people versus adult psychosis may have important implications for designing and delivering treatment to young people (McGorry et al., 2013). Because of the relative rarity of early psychosis in young people below the age of 16, many professionals are frequently unfamiliar with some aspects of presentation or management and appropriate service provision (admission directly into an inpatient bed in an age-appropriate environment) is not readily available. A lack of age appropriate provision may also mean that adult psychiatrists are called on to manage and treat a child or young person presenting with a psychotic disorder (Bailey, 2013; McGorry, 2002). Treatment planning should address biological, psychological and social factors within a framework that takes note of a young person's developmental stage (Bailey, 2013; Birchwood et al., 2013; Jackson & McGorry, 2009; McGorry et al., 2013). This approach also necessitates a multi-modal approach to treatment that includes pharmacotherapy, individual psychotherapy, family therapy and educational or vocational strategies.

From CAMHS and government policy perspective empowerment is often noted to be important when delivering services for young people with mental health problems (Ahern & Fisher, 2001; CAMHS Review, 2008; Cargo et al., 2003; Chinman & Linney, 1998; DoH, 2006; Kim et al., 1998; Mental Capital & Wellbeing, 2008; New Horizons, 2009; The Children's Plan, 2008; Walker & Gowen, 2011). These services and policies for young people all have common themes which include building resilience, wellbeing, early intervention, partnership working and empowering the individual at improving their mental health. However, studies by Booth et al. (2004), Hoagwood et al. (2001), Muir et al. (2012) show how young people often disengage from services before completing treatment. They argue that services should adopt a youth-friendly approach in order to reduce the low uptake and deterrents to service access. WHO (2002) developed an international framework on how health services can adopt a youth friendly approach, which ensures that they are accessible, acceptable and appropriate (AAA). Empowerment is a key aspect of the WHO AAA framework, whereby clinicians have the capacity to support young people to engage with services and ensuring they have autonomy over their own treatment.

The Carnegie UK Trust (2008) reported that young people accessing mental health services are more likely to feel empowered if they are given the opportunity to ask questions and are supported in the decision making regarding their own treatment. Given the potential for empowerment to improve engagement with services and increase participation in one's own care, this thesis aims to examine this knowledge gap from the perspective of young people with psychosis. For most young people the first experience of psychosis is the most frightening and they often describe a range of psychological distress (Jackson & McGorry, 2009). Young people often underestimate the need for outside help and instead attempt to deal with their problems on their own (Rickwood et al., 2005). Therefore it is important that young people with psychosis are empowered through the provision of information on mental health problems, opportunities for support and treatment that can lead to positive changes in psychological and behavioural adjustment.

#### 1.6.1 Empowerment measures for adults

Despite the growing emphasis on empowerment as the goal of mental health services the literature reviewed shows that there are still very few measures by which levels of empowerment can be assessed. Castelein et al. (2008) compared three frequently used empowerment instruments used for adults with severe mental illness on fifty people with psychotic disorders in the Netherlands. This study evaluated internal consistency, discriminant and convergent validity, sensitivity to symptom levels, and clinical usefulness of the Empowerment Scale (Rogers et al., 1997), the Personal Empowerment Scale (Segal et al., 1995), and the Mental Health Confidence Scale (Carpinello et al., 2000). All three scales were found to measure some aspect of empowerment but concluded that these scales for individuals with psychosis were too broadly defined (Castelein et al., 2008). These measures are mainly developed from adult with severe mental illness perspective. Although these studies have shed light on the construct of empowerment the concept is still evolving and the number of empirical studies on empowerment is limited.

#### 1.6.2 Empowerment measures for young people

There is a clear need for the development of a scale that can measure the empowerment of young people. The few studies that currently exist within in the literature that examined empowerment from young people have utilised the Youth Empowerment Scale-Mental Health (YES-MH) (Walker et al., 2010) and the Developmental Asset Framework (Benson et al., 1998, Leffert et al., 1998). Walker et al. (2010) developed the Youth Empowerment Scale-Mental Health (YES-MH) to be used in people (ages 9 to 21) but did not provide a conceptualisation of empowerment from the perspective of young people. They adapted the Family Empowerment Scale (FES; Koren et al., 1992) by consulting with groups of young people to alter the wording of items on the FES. The specific relevance of the scale may also be limited due to its original use as a carer scale. It is possible that young people are more likely to experience a negative power differential with services compared to an adult, resulting in high levels of dependence. Therefore, the dependent and disempowering nature of their relationships with carers would be essential to consider. The DAF was designed to

have practical significance for the mobilisation of communities and to develop the positive experiences of relationships and opportunities that adults provide for young people (Benson et al., 1998, 2007; Leffert et al., 1998; Scales, 2011). Empowerment was referred to as one of four external assets in the DAF. Empowerment was seen as an important ingredient for young people in becoming bonded to community and dependent on consistent adult presence and voice (Benson et al., 1998, 2007; Leffert et al., 1998; Scales, 2011). The authors of this study identified that not qualitatively conceptualising what the participants might feel in terms of their enhanced sense of empowerment was a significant limitation (Benson et al., 2007).

### 1.6.3 The need to measure empowerment in young people with psychosis

Empowerment is viewed as a priority by policy makers, CAMHS, youth programmes and professionals, there is consequent interest in addressing the needs of young people and in improving levels of empowerment (CAMHS Review, 2008; DoH, 2006, 2010; Mental Capital & Wellbeing, 2008; New Horizons, 2009). Given the potential for empowerment to improve engagement, clinical practice, health outcomes and recovery; there is a lack of evidence related to empowerment and recovery and wellbeing outcomes for young people with psychosis. Wallerstein (2006) and Woodall et al. (2010) reviewed the available evidence using a modified review approach on empowerment and health outcomes and highlighted that the lack of evidence considering the link between empowerment, health and wellbeing may be because of the measurement challenges. Therefore given the need for early intervention, treatment and engagement with young people with psychosis this thesis conceptualises how empowerment applies in practice so that an effective systematic measure of empowerment can be measured. This process gives understanding of how empowerment as an outcome can reduce the severity of illness, improve wellbeing and aid recovery for young people with psychosis.

Review of the literature shows that the lack of a precise definition has made it difficult to measure and to employ the concept of empowerment in mental health

services such as CAMHS for young people. An in-depth review of the empowerment literature presented in this thesis concludes that empowerment has been defined primarily from an adult perspective rather than from the perspective of young people, in particular young people with psychosis. The lack of a definition of empowerment from young people's perspective and in particular young people with psychosis is an obstacle to its consistent application in practice. Therefore services cannot attain the aims of government policies lacking meaningful measures of empowerment as an outcome. When we consider how the government (DoH 2004, 2001; NICE, 2002) have prioritised developing services that address the needs of young people with psychosis a clear conceptualisation of empowerment from their perspective has not yet been established. Whilst policy shows positive aspiration for young people with psychosis the use of an adult focused concept of empowerment for young people is potentially problematic. Many young people still experience interventions being done 'to' or 'for' them instead of being focused on giving young people the knowledge, skills and resources to do things for themselves. The Children and Young People's Mental Health Coalition (2010) note the need to help young people to foster knowledge, self-awareness and personal, social, and emotional skills. This can empower them to take increasing responsibility for their emotional health as they become adults and is likely to have the most significant and long-term impact on the mental health and emotional wellbeing of the next generation and generations to come. The literature shows that if empowerment is going to be supported as a positive outcome for young people with psychosis, we need to develop an understanding of where positive empowerment occurs. For this, we need to develop an outcome measure that identifies and rates empowerment for young people with psychosis.

#### 1.7.1 Summary and rationale for studies

The literature review demonstrates the importance of empowerment as a goal and outcome for young people in general but it is apparent that this construct is not well defined from a young person perspective particularly within the field of mental health (CAMHS Review, 2008; DoH, 2006, 2010; Mental Capital & Wellbeing, 2008; New Horizons, 2009). Given the gap within the literature, and the need to develop a tool that can measure and evaluate empowerment, the starting point for this thesis was to conceptualise empowerment from the

perspective young people with psychosis. This need for an empowerment measure for young people with psychosis is particularly important given how services for young people such CAMHS often claim that they are promoting government policies such as independence, engagement and partnership working (CAMHS Review, 2006; DoH 2001, 2004, 2006). It would be therefore be useful to assess whether clinician working with young people believe their interventions and treatments are promoting empowerment in young people with psychosis and also whether young people with psychosis agree with them.

In an attempt to measure empowerment for the purpose of research and to employ the concept in CAMHS, an in-depth review of the empowerment literature concluded that empowerment has been defined in many different ways. This allows researchers and clinicians to pick from a menu of related, and at times vague concepts rather than rely on a cohesive picture. This thesis will develop and capture this cohesive picture by including key concepts from prior literature, refining them where necessary and linking them together with young people's perspective. The aim of this thesis is to develop a valid outcome measure of empowerment for young people with psychosis that is meaningful, practical to implement and offer a scale for benchmarking and improvement within CAMHS. Having an empowerment measure for young people with psychosis serves several purposes. This measure could be used to highlight good and bad practices, for discussion and negotiation, and to promote and measure concrete and sustainable actions that result in empowerment. For instance, an increase in empowerment scores following participation in treatment and intervention would be a positive indicator about that service for young people with psychosis. If scores did not increase, clinicians should try to identify the elements that interfere with young people becoming empowered. Such understanding could help to inform services promoting recovery, independence, and facilitating the uptake of social, educational and employment opportunities for those young people.

#### 1.7.2 Aims and Hypothesis

In response to the identified need to conceptualise empowerment from the perspective of young people with psychosis and develop a specific empowerment

measure this research will be undertaken across four phases which are detailed within this thesis.

#### **Phase 1 Aims:**

This study aims to qualitatively conceptualise empowerment from the
perspective of young people with psychosis aged 14-18 years using
Interpretative Phenomenological Analysis (IPA). No other studies have
conceptualised empowerment from the perspective of young people with
psychosis.

#### Phase 2 Aims:

- This study aims to utilise the themes derived from the in depth interviews in phase 1 to develop the new measure; the Youth Empowerment Scale (YES).
- Explorative factor analysis will be used to analyse the data from all the completed questionnaires.
- This study hypothesises that the YES will be a valid and reliable measure of empowerment in young people within a non-clinical population and will demonstrate convergent validity with other related constructs such as quality of life and wellbeing.

#### **Phase 3 Aims:**

- This study aims to explore the relationship between psychological processes (self-efficacy, control, coping, thinking style and social support) empowerment, and mental health, wellbeing, and recovery.
- Mediation analysis will be used to analyse the data from all the completed questionnaires. This study hypothesises that the mediation model will demonstrate that the psychological processes derived from phase 1 interviews are mediated by empowerment and, in turn, by improving mental health, wellbeing and recovery.

#### **Phase 4 Aims:**

 This study aims to validate the Youth Empowerment Scale (YES) within a clinical population of young people

- Confirmatory factor analysis will be used to analyse the data from all the completed questionnaires.
- This study hypothesise that the YES will be a valid and reliable measure of empowerment in young people within a clinical population and will demonstrate convergent validity with other related constructs such as mental wellbeing.

#### **Chapter 2: Research Methodology**

This chapter examines the research strategy and the data collection methods used in order to provide a rationale for the chosen research framework. In addition, issues related to validity and reliability will be addressed. Creswell and Plano Clarke (2007) highlighted the growing trend for using a range of approaches which strengthens rather than divides inquiry, and proposed that research strategies can include qualitative, quantitative and mixed methods strategies. The following section will provide an overview of the research strategies used in the four studies which includes a review of qualitative, quantitative, and mixed methods strategies.

### 2.1 Introduction and rationale for qualitative approach used in Phase 1

Qualitative research is concerned with describing, interpreting and understanding the meanings which focuses on the person's lived experiences (Polit & Beck, 2013). A review of the qualitative approaches highlighted the most commonly used four main approaches: ethnography, grounded theory, case studies and phenomenology (Denzin & Lincoln, 2011; Silverman, 2006; Polit & Beck, 2010, 2013). A qualitative approach was chosen in phase 1 which aimed to qualitatively conceptualise the concept of empowerment from the perspective of young people with psychosis with a focus on using these results to inform the development of the new Youth Empowerment Measurement (YES) in phase 2 study. In order to meet the study aims, a philosophical or epistemological position (Bryman, 2004) had to be adopted which fits into a qualitative interpretative paradigm and is phenomenological in nature; therefore, Interpretative Phenomenological Analysis (IPA) was the selected choice of method for this study. IPA was deemed the best method for capturing the lived experience of the participants by focusing on their experiences and perceptions of empowerment and to understand how they make sense of these experiences.

Phenomenology aims to explore human experiences through detailed descriptions of the phenomenon being studied while seeking to understand how people experience and interpret their world (Creswell, 2003). Phenomenology also acknowledges the complexities of human experience, recognising the multiple realities constructed separately by each individual (Denzin & Lincoln, 2011). IPA is an approach for addressing research questions concerning how people make sense of a particular phenomenon that they are experiencing. IPA was developed by Jonathan Smith in the mid 1990s as an approach to qualitative research in psychology, and was developed to allow rigorous exploration of idiographic subjective experiences and, more specifically, social cognitions (Smith, 1996). Shifting from the simple biomedical model of disease and illness (Yuill et al., 2010), health psychologists recognise the importance of understanding patients' personal perceptions and interpretation of their bodily experiences, and the meanings they assign to these experiences (Brocki & Wearden, 2006; Engel, 1977). IPA is now regarded as useful in healthcare research because it helps to uncover meaning in a descriptive manner and is useful for making sense of research participants' experiences and perceptions (Pringle et al., 2011).

Other qualitative approaches were considered such as ethnography, grounded theory and case study; however, these were not deemed appropriate for addressing the study aims. Ethnography is concerned with the study of culture and subculture which focuses on the description and interpretation of cultural patterns of thought and behaviour (Morse et al., 2002; Reeves et al., 2008). The aim of ethnography is to provide rich, holistic insight into people's views, actions and the nature of the location they inhabit, through the collection of detailed observations and interviews (Reeves et al., 2008). Hammersley and Atkinson (1995) stated that the task of ethnographers is to 'get inside' how the participant sees the world by observing and documenting the culture, the perspectives and practices of the people in these settings which was not our aim.

Grounded theory is another qualitative approach which was developed in the 1960s by Glaser and Strauss (1967). Grounded theory focuses on the structures and processes within social settings. Grounded theorists search for social process present in human interaction and the aim is to discover patterns and processes and to understand how a group of people define their reality (Hutchinson, 1993). In grounded theory the method of constant comparative analysis is the main feature,

as data collection and analysis occur simultaneously and each item of the data is compared with every other item of the data (Glaser & Strauss, 1967). Theory is constructed through a systematic process of data comparison, clustering codes and developing categories. Grounded theory both describes and explains the system or behaviour under study and therefore is a method for developing theory that is grounded in data systematically gathered and analysed (Strauss & Corbin, 1994), which was not our aim.

Case study research is another qualitative approach which is a form of descriptive research that explores a detailed picture of the phenomenon being researched as a distinct entity or case. Case study research does not attempt to test or build theoretical models but instead the researcher strives for an in-depth understanding of a livid experience by person or a group (Clarke & Reid, 2006) the purpose of descriptive case studies is to achieve a better understanding of a situation in a particular area with a specific person or group. IPA in comparison to the above qualitative approaches is idiopathic which favours the service user's voice allowing understanding of the individual's relationship with their condition, distress and, recovery (Reid et al., 2005). Pringle et al. (2011) argues that IPA offers detailed insights into patients' beliefs and experiences which is why it was deemed the best qualitative approach for research aims.

IPA requires the researcher to interpret each story looking for similarities and differences across a group of participants (Brocki & Wearden, 2006). Using IPA enables the researcher to gain insight and understanding of young people with psychosis and their parents' experiences of empowerment. It also enables participants to tell their story of what empowerment and disempowerment means and what would be helpful when their mental health is compromised. IPA was therefore used to analyse the data in phase 1 as it was felt that this approach best allowed for retaining the young people's language in the analytic process. This study is helpful in understanding the potential of IPA as a research methodology because it provides a valuable insight into participants' experiences, perceptions and understanding of empowerment.

IPA is a research method that is particularly useful when working with children and young people as it not only provide opportunities express their views freely but it is also a potential source to participate in decision-making matters because of their position in adult dominated society. It is difficult to argue that research with young people is different from research with adult when you consider how the developmental arguments (Woodhead, 1998) may account for some of the distinctions between younger and older children and with adults. The challenge in researching young people is how best to enable them to express their views to an adult researcher. The challenge according to Chistensen and James (2000) is how to maximise their ability to express themselves at the point of data gathering so that researcher can enhance their willingness to communicate and the richness of the findings. Previously this approach has been successfully used by the National Child and Adolescent Mental Health Support Service to explore children's' experiences of stigma and mental health. The process involving dual reflexivity with young people as participants actively shaping the research process and the researcher helping to mitigate against the power differentials that often occur in studies with young people as subject (Chistensen & James, 2000).

The term 'interpretative phenomenological analysis' is used to signal the dual facets of the approach i.e. phenomenology and symbolic interactionism (Brocki & Weardon, 2006). IPA is phenomenological in its orientation and is strongly connected to the interpretative or hermeneutic tradition (Palmer, 1969). Similar to symbolic interactionism approaches, IPA acknowledges the significance of the interactions between the researcher and participant (Osborn & Smith, 1998; Smith et al., 1997, 1999). IPA recognises that the researcher is central to the research study and that the joint reflections of both the participant and researcher forms the analytic account produced. Therefore IPA's aim is achieved through interpretative activity on the part of the researcher who aims to assume an insider perspective (Conrad, 1987), or, in other words, to stand in the shoes of the participant. This is referred to the 'double hermeneutic' where the researcher "is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2008, p. 53). IPA acknowledges that the key to this approach is how the researcher interprets the participant's responses in analysing and making sense of these

experiences and can make claims about the participant's emotional state and thought through a process of interpretative activity (Smith et al., 1999).

IPA is also idiographic in its approach in that it attempts to understand how a particular experiential phenomenon is understood from the individual's perspective in a particular context (Smith et al., 2009). This attention to the idiographic approach requires that the researcher engages deeply with each participant's transcript during analysis and integration only occurs later in the analysis (Willig, 2008). Ultimately the analysis is a synthesis of participants' capacity to describe and discuss their experiences and the researcher's interpretation, reflection and ability to theorise (Baillie et al., 2000). With IPA, it is not only what is common to the participants' accounts that is considered, but also differences (Smith et al., 2009), referred to as convergence and divergence of the analysis (Smith, 2011).

# 2.2.1 Doing IPA: Sampling

There is a consensus towards a homogeneous small sample size in IPA which can be gained by purposive sampling in order to facilitate in depth analysis that produces detailed understanding, and identifies common themes and issues effectively (Reid et al., 2005; Smith & Osborn, 2008). This sampling approach acknowledges that if the sample is too homogeneous, transferability of the study findings may be more difficult (Smith et al., 2009). In accordance with the recommendations for IPA, all efforts were made to ensure that the sample was homogeneous (Quinn & Clare, 2008). For example, all participants who had ongoing contact with CAMHS following admission (minimum 6 months when recruited) and were considered to be in recovery. The participants suffered from a range of mental health and social difficulties ranging from persistent persecutory delusions, active hallucinations, social isolation, exclusion and absence from school.

'Less is more' when considering the number of participants with IPA (Reid et al., 2005), because this fits with the 'idiographic commitment' of IPA (Hefferon & Gil-Rodriguez, 2011, p.757). Smith et al. (2009) recommends between five and ten participants when using IPA as they argue that reduced number of participants

allows for a richer depth of analysis that might be inhibited with a larger sample. However, Reynolds and Prior (2003) argue that IPA can also be used effectively with larger sample sizes providing that appropriate time and resources are given. There is a concern that small numbers of participants may not be representative of the wider population and equally that large sample sizes might prove to be too time-consuming and lengthy analysis. However, Smith et al. (2009) suggest a more pragmatic approach when considering the transferability and practicality of an IPA study, suggesting that a clearly rendered rich account of participants' experiences that is related to the up to date literature, will allow the reader to apply to the general population.

# 2.2.2 Doing IPA: Collecting data

Semi-structured interviews are the most common form of data collection in IPA, with some studies also employing focus groups (Brocki & Weardon, 2006). Semi-structured interviewing will be used in this study as this allows flexibility, enables the researcher to follow up emerging themes or topics and develop a rapport with the participants which in the case of young people with psychosis and their parents is crucial to the data collection (Reid et al., 2005; Smith et al., 2009).

# 2.2.3 Doing IPA: Data analysis

There has been considerable critique of the rigour of qualitative research studies (Barbour, 2007; Horsburgh, 2003), and a major challenge of qualitative research is evaluating the truthfulness of the findings. IPA's strength is that it is both a methodology and method with strong theoretical connections combined with a systematic approach to analysis (Brocki & Weardon, 2006; Smith et al., 2009). Smith et al. (2009) and Smith and Osborn (2008) detail a systematic step-by-step process of analysing data and how to look for themes which fulfils the rigour criteria in IPA. These will be applied to this study as follows:

#### 2.2.3.1 Reading the transcript

The first stage of the analysis the researcher reads and re-reads the interview transcript a number of times. This enables the researcher to become familiar with

the text and to become attuned to the participants' experiences. During the reading process, initial ideas can be noted on the left margins of each transcript.

#### 2.2.3.2 Making or noting the themes

Once familiar with the transcript, the second stage of the analysis is to note the themes on the opposite margin of the transcript from the initial notes. Significant key points on what the participant actually says can be identified.

#### **2.2.3.3 Summary List**

Once the whole interview transcript is analysed, common themes can be further defined and noted on the right hand margins. The themes can be compiled into a list. This process helps the researcher to ensure that all aspects of the interview are covered.

# 2.2.3.4 Master list or Grouping of Main Themes

Master lists of the main themes are then compiled for each interview. This process involves close examination of the margin notes and clustering together similar items. This process can be repeated several times as themes can be added or changed and often entails several revisions (Campbell & Morrison, 2007; Smith et al., 2009). Clustering together the similar themes can be seen as the initial themes which encompass similar items. Each theme can be given a heading which encapsulates the tone of the theme whilst ensuring that the participant's own words are used in the headings. This can be done to ensure that the analysis remains close to the text and the participant's experiences. Themes can be assembled into groups by clustering those that seem related to each other together with associated sub-themes. These sub-themes can be organised under a thematic heading. Smith and Osborn (2008) emphasise that at this point, the researcher must be able to establish and justify higher order themes to allow theoretical connections to be made. Also, Biggerstaff and Thompson (2008) warn that just because a theme may be the most frequent, does not also mean it should be superordinate above other themes. Therefore their advice on the richness of the selected text and how the theme might inform other parts of an individual's account were considered (Biggerstaff & Thompson, 2008).

#### 2.2.3.5 Coding the Themes

Once the themes are identified and organised, the themes can be coded on the left hand side of the transcript. This process ensures that all the occurring themes are identified in the transcript and allows the researcher to examine 'fit' of the theme. A 'master' list of the main themes can be compiled for each interview.

# 2.2.3.6 Initial Analysis and The Final list of Themes Extracted

The initial analysis can be based upon the findings of each interview and all the themes and sub-themes compiled into a single list. In this stage the themes can be listed from each group and then grouped together with similar themes from the other interviews. This process forms new clusters of themes and sub themes which involves separating the sub themes from the main themes. The final process in this stage is to ensure that the overall theme accounts and reflects the experiences of the participants. This process verifies the themes drawn from the transcripts and connects the theme with the quotes from the transcript.

# 2.3 Verification of Findings

While validity in IPA is not prescriptively defined, Smith et al. (2009) do refer to Yardley (2000, 2008) citing her four areas approach; sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance. Smith et al. (2009) also highlight that rigour with IPA is enhanced by auditing and being open to external audit as this can enhance credibility of findings and rigour. Therefore, an independent audit as recommended by (Smith et al., 2009) will be used in this study to examine the research question, the research proposal, the interview schedule, audio tapes, initial descriptive and later interpretative analysis of the transcripts and the final report.

The final themes following analysis will be presented to the co-researchers for verification of findings and shared agreement. This approach is taken in many IPA studies (e.g. Perry et al., 2007; Tebbet & Kennedy, 2012; Walsh-Gallagher et al., 2012). The main researcher undertaking the data analysis will present the initial findings to the study's co-researchers (researcher's supervisors) who will check, modify and confirm the themes to confirm the reliability of the analysis. The rationale here is that the more people that independently agree with the

emerging findings, the more it enhances the believability and creditability thus reducing the risk of researcher bias.

Smith et al. (2009) do not discuss returning to participants for verification of findings. This stance on not returning to participants for verification in this study follows the argument of Morse et al. (2002) who warn that 'while it is an attractive idea to return the results to the original participants for verification, it is actually not a verification strategy'. Morse et al. (2002) also highlight that 'it is actually more often a threat to validity' (p.16), and warns that researchers 'may be forced to restrain their results to a more descriptive level in order to address participants' individual concerns' (p.16). In addition, because analysis involves interpretation across a number of participants, it is questionable if participants could identify their experiences if asked to (Morse et al., 2002). Instead of going back to the participants the researcher will post a summary of the study findings and give brief feedback. The participants will also be invited to comment on the draft Youth Empowerment Scale (YES) which will be structured following the analysis.

#### 2.4 Conclusion

IPA offers researchers a structured and rigorous approach to qualitative data collection and analysis. With strong roots in phenomenology and symbolic interactionism, IPA provides researchers the opportunity to adopt an insider view to data analysis which is in keeping with the patient centred aspirations of research in particular.

# 2.5 Introduction and rationale for quantitative approaches used in Phase 2, 3 and 4

This section aims to describe the methodology of phase 2, 3 and 4, which are all quantitative studies. Quantitative research is a formal, objective, systematic process which is generally undertaken to establish facts, demonstrate relationships, determine effects or test theory (Polit & Beck, 2013). Quantitative researchers are particularly interested in discovering cause and effect relationships, generating data that can allow outcomes to be predicted, and generalising sample findings to more broadly defined populations (Burns & Grove, 2005). Phase 2 aims to develop the new measure the Youth Empowerment Scale (YES) and provide a preliminary testing and validation of the new measure.

The YES will be based on phase 1 findings which captures the meaning of empowerment for young people with psychosis. The dimensionality of the YES will be investigated through explorative factor analysis which seeks to reduce a large set of items to more manageable set of factors. Factor analysis is widely used for theory and instrument development and to assess the construct validity of an instrument which is why it is deemed the most appropriate statistical technique in this study. Phase 3 aims to use mediation analysis to explore the psychological factors that determine empowerment in young people using the YES, which in turn will mediate mental wellbeing and recovery. This study is a cross sectional internet based questionnaire study and the data will be analysed using the SPSS macros developed by Preacher and Hayes (2008). Confirmatory factor analyses will then be conducted on phase 4 clinical sample to rigorously test the hypotheses about scale structure, the validity of the factor solution and the scale length.

# 2.6 Introduction and rationale for factor analysis used in Phase 2

The term factor analysis was firstly introduced by Thurstone (1931). Factor analysis is a statistical procedure for use with multivariate data. The main purpose of factor analyses is to firstly reduce the number of variables and secondly to detect the structure in the relationships between variables, which means to classify the variables. The main goal of factor analysis is data reduction which begins by

assessing commonality within a set of variables and then goes on to determine how subset of variables within that set differ from one another. Factor analysis helps us to identify which variables seem to be strongly linked together, and produces an associated set of variables which are known as a factor (Pett et al., 2003). Factor analysis also reduces a large set of variables into a smaller number of factors with common characteristics or underlying dimensions and can be used to describe many of the variables under study (Pett et al., 2003). Tabachnick and Fidell (2001) defined factor as a cluster of related observed variables that represents a specific underlying dimension of a construct which is as distinct as possible from the other factors included in the solution.

Factor analysis is not only useful in describing and reducing data, but also in instrument development. It can be used to test the validity of ideas about the grouping of items into sub-scales (Tabachnick & Fidell, 2001). Rempusheski (1990) highlighted that there is a limited interest in and knowledge about the process of instrument development which unfortunately has led to a proliferation of unreliable and invalid instruments in the health care arena. Pett et al. (2003) maintain that factor analysis is particularly useful when examining complex concepts made up of a number of variables as it can be used to determine the extent to which variables are related to the same dimension. The researcher then interprets and names the factors following an examination of the variables within a factor (Pett et al., 2003). Therefore the method of factor analysis will be used in this study to examine the interrelationships among the items that measures the construct of empowerment in the YES and then to identify its subdimensions. Our goal in using this method is to arrive at a reduced set of factors that summarises and describes the structural interrelationships among the items in a concise and understandable manner.

### 2.7 Sample Size

The sample size is crucial determinant of reliable estimation in factor analysis (Field, 2009). The reliability of factor analysis is dependent on sample size therefore the literature recommends having between 5-10 subjects per variable and up to a total of 300 subjects, which test parameters are reasonably stable (Comrey & Lee, 1992; Field, 2009; Tabachnick & Fidell, 2001). Therefore our

power calculation indicates a minimum of 235 participants is required on the basis of 5 participants per variable for the 47 items on the YES.

# 2.8 Doing Factor Analysis

There are two types of factor analysis, exploratory and confirmatory (Pett et al., 2003). Confirmatory factor analysis (CFA) will be employed in phase 4 to test the relationships postulated in advance. CFA tests whether a specified set of constructs is influencing responses in a predicted way (Pett et al., 2003). Exploratory factor analysis (EFA) attempts to discover the nature of the constructs influencing a set of responses and will be employed to assess the construct validity of the YES. Initially, EFA will be used to reduce the set of variables in the YES and to examine how underlying constructs influences the responses on a number of measured variables. For remaining items, internal consistency will be assessed using Cronbach's alpha. Construct (concurrent) current validity will be analysed using correlations, comparing the subscale scores of the YES and the other validated measures. When using EFA a number of decisions will be required, including factor extraction method to be used, the rotation strategy, and the number of factors to be extracted. The following three sequential steps on EFA will be used (Field, 2009; Hatcher, 1994; Williams et al., 2012) which primarily focuses on:

- (a) the factor extraction method,
- (b) the number of factors to retain, and
- (c) the method use to rotate factors.

#### 2.8.1 Factor Extraction Method

The first step in this study is to determine the factor extraction model. There are a variety of factor extraction models available such as a common factor model or a components model. Principal component analysis (PCA) is by far the most popular but both theory and empirical evidence favour common factor analysis as the more appropriate (Browne & Cudeck, 1992; Fabrigar et al., 1999; Gorsuch, 1990). PCA will be initially conducted to reduce the number of variables by creating linear combinations that retain as much of the original measures' variance as possible. However, a common factor model and maximum likelihood will also

be used when the analysis is repeated in order to understand the latent (unobserved) variables that account for relationships among measured variables

#### 2.8.2 Factors to Retain

The second step in this study is to determine the number of meaningful factors to retain. Options available include Kaiser's eigenvalues greater than one rule (Kaiser, 1960), the scree test and retaining the number of factors that gives a high percentage of variance accounted for by a given factor. Using the scree test, all factors with eigenvalues over Kaiser's criterion of greater than 1 will be examined. The scree test will be used to identify the number of meaningful factors to retain based on and the scree plot. The initial analysis will run to obtain eigenvalues of each component and SPSS will extract all factors with eigenvalues >than 1.

#### 2.8.3 Rotation and Extraction Method

The third step is to determine the type of rotation and extraction method, which helps to simplify and clarify the data structure. Two basic types of analytical rotations can be used to help with interpretation of the factors: orthogonal rotations which forces uncorrelated factors, and oblique rotations which allows correlated factors. Oblique rotation is mostly preferred as it is better at representing reality, it produces better simple structure and helps with the interpretation of the factors. An oblique rotation will be applied because it was hypothesised that there will be a correlation between the factors. This will be followed by interpreting and conceptualising the rotated solution. This will be done by identifying which items loads on to each retained factor, followed by conceptualising meaning of items that loads on the same factor, and conceptualising the differences in items that loads on different factors. Items loading near the 0.40 or greater (in absolute value) will be used to interpret the results (Field 2009).

#### 2.9 Scale Structure

Following the procedure recommended by Field (2009) an initial principal components analysis (PCA) will be conducted on the YES which will also screen

for sampling adequacy. The KMO statistic value and Bartlett's Test of Sphericity will be used to support the suitability of PCA. The entire sample will be analysed via principal components analysis (PCA) and maximum likelihood (ML) extraction methods, followed by oblique (direct oblimin) rotations.

# 2.10 Internal Consistency

Internal consistency will be assessed by calculating Cronbach's coefficient alpha for the total scale and the factors identified by the EFA. Internal consistency will show the extent to which all the items in a test are measuring the same concept or construct (Tavakol & Dennick, 2011). There are different reports about the acceptable values of alpha and there is a consensus with the range value from 0.70 to 0.95 but a maximum value of 0.90 has been recommended (Field, 2009; Streiner, 2003; Tavakol & Dennick, 2011). A low value of alpha could be due to a low number of questions or poor inter-relatedness between items or heterogeneous constructs and too high value may suggest that some items are redundant as they are testing the same question but in a different guise (Tavakol & Dennick, 2011).

# 2.11 Construct validity

Construct validity is defined as the ability of a measure to assess the hypothesised construct which is empowerment in this study. Construct validity will be assessed through existing validated scales i.e. GHQ-12, EQ-5D and the MDES where we could hypothesise relationships with overall empowerment based on existing theory and the main themes found in our qualitative study. Pearson correlation coefficients will be conducted to examine concurrent validity of the YES in relation to these validated scales (GHQ-12, EQ-5D, MDES).

#### 2.12 Conclusion

The aim of this study is to develop and preliminary validate the new measure of empowerment for young people with psychosis using data from our phase 1 qualitative study using the quantitative methods outlined above.

# 2.13 Introduction and rationale for mediation analysis used in Phase 3

The aim of this study is to use mediation analysis to explore the psychological factors that determine empowerment in young people which in turn will mediate mental wellbeing and recovery. This study is a cross sectional internet based questionnaire study. The data will be analysed using Statistical Packages for Social Sciences (SPSS version 20) and the SPSS macros developed by Preacher and Hayes (2008). Mediation analysis is the standard procedure for analysing causal mechanisms, where a set of linear regression models are fitted and then the estimates of mediation effects are computed from the fitted models (Baron & Kenny, 1986; Mackinnon, 2008; Shadish et al., 2001). Traditionally, causal mediation analysis was understood and implemented within the linear structural equation modelling (LSEM) framework (Baron & Kenny, 1986; MacKinnon, 2008) but the limitation for this framework is well argued in the literature (Imai et al., 2010). Imai et al. (2010) highlights the limitation of LSEM framework as it does not offer a general definition of causal mediation effects independent of a particular statistical model, its inability to specify the key identification assumption, and its difficulty of extending the framework to nonlinear models.

Baron and Kenny's causal steps are commonly used in establishing mediation (Baron & Kenny, 1986). These four causal steps test are specific sequence of tests of relationships among variables, all of which generally must be significant to declare that the meditational model holds. Using the casual steps approach, in order for M to be considered a mediator of the effect of X on Y, one must first establish that there is an effect to be mediated, meaning evidence that X and Y are associated. This method test tests whether X is related to M by predicting M from X in a regression analysis, and whether M is related to Y by predicting Y from M in a regression analysis that also includes X as a predictor. If the two paths are jointly significant, mediation exists.

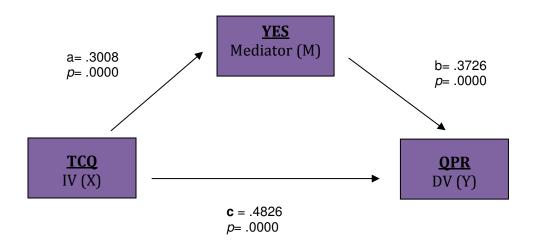
Baron and Kenny (1986) proposed criteria for the claim that a variable (M) is responsible for mediating the effect of an independent variable (X) on a particular dependent variable (Y). Meeting these steps does not, however, conclusively

establish that mediation has occurred because there are other (perhaps less plausible) models that are consistent with the data. More statisticians (MacKinnon et al., 2004; Preacher & Hayes, 2004, 2007; Shrout & Bolger, 2002) are now advocating a move away from statistical procedures that rely on assumptions, particularly when they are unrealistic. These statistical methodologists are advocating for computationally intensive methods such as bootstrapping as one of the better methods for estimating and testing hypotheses about mediation. They argue that these methods make fewer unwarranted assumptions and, as a result, can produce more accurate inference. Therefore SPSS macro described by Preacher and Hayes (2008) will be used in this study to classify the type of mediation and to test whether empowerment (using the YES) mediates wellbeing, better general health and recovery.

#### 2.14 Direct and Total Effect

Bootstrap methods using SPSS macro (Preacher and Hayes, 2008) will be used to test the direct and total effects and the indirect effects. *Figure 1*, represents a single mediation model that shows a coefficient for X in a model predicting M from X, and b and c' are the coefficients in a model predicting Y from both M and X, respectively. Paths a and b quantifies the *indirect effect* of X on Y through M, whereas path c' quantifies the *direct effect* of X. All of these paths are quantified with regression coefficients. The coefficient a reflects the relation of the intervention X to the mediator M, the b coefficient reflects relation of M to Y adjusted for the X variable. A c' coefficient represents the relation of X on the outcome Y that is not through the mediator M. The simple relationship between X and Y is referred to as the Total Effect of X on Y.

**Figure 1.0:** Illustration of the path coefficients of a mediation design. X affects Y indirectly through M.



SPSS macro described by Preacher & Hayes (2008) and Hayes (2013) will be used to classify the type of mediation by estimating the coefficients and significance (p value) of all paths a, b, c, c' under "Direct and Total Effects". The total and direct effects outputs will provide the significance tests of all the paths (a, b, c, c') and tells you what type of mediation or nonmediation you have:

- The direct effect *a* path (X to M) is significant if all the p-values are less than 0.05 (*p* < .05). The direct effect *b* path (M to Y, controlling X) is significant if the p-values are less than 0.05 (*p* < .05).
- The total effect c path (X to Y without the M) is significant if the p-values are less than 0.05 (p < .05).
- The direct effect c' path (X to Y controlling for the M) is significant if all the p-values are less than 0.05 (p < .05).

#### 2.15 Indirect Effects

Preacher and Hayes (2008) argue that the bootstrap methods are the most powerful tests of the indirect effect which is why it was used in this study to compute confidence limits of the mediated effect. Statistical methodologists (Bollen & Stine, 1990; MacKinnon et al., 2004, Shrout & Bolger, 2002) highlight two important reasons for conducting bootstrap resampling for the mediated effect. Firstly they argue that these methods provide a general way to test significance and construct confidence intervals in a wide variety of situations where analytical formulas for quantities may not be available. Secondly, the

methods do not require as many assumptions as other tests, which is likely to make them more accurate than traditional mediation analysis. Therefore mediation will be tested by determining whether or not the confidence interval contains zero. The null hypothesis of no indirect effect will be tested by determining whether zero is inside of the confidence interval. If not, it will be claimed that the indirect effect is different from zero. Although still a relatively new approach to testing mediation hypotheses, research to date has shown that bootstrapping the indirect effect is superior to the causal steps, both in terms of power and Type I error rates (MacKinnon et al., 2004).

Using parameter from these models, the estimated mediated effect of (ab) will be calculated for each sample. Rather than relying on normal distribution theory assumed by the Sobel test bootstrap tests implemented by Preacher and Hayes (2008) will be used to generate an empirical sampling distribution of a\*b. Using the SPSS script for the indirect procedure (Preacher & Hayes, 2008) bootstrapping will be performed which is a type of robust technique to control for nonnormality, and it gives you output in the form of "confidence intervals" instead of "p values".

#### 2.16 Conclusion

This study will examine the relationship between psychological processes (based on key findings from phase 1) empowerment, and mental health wellbeing, and recovery using the quantitative methods outlined above.

# 2.17 Introduction and rationale for confirmatory factor analyses used in Phase 4

This study aims to validate the YES using a clinical sample by using confirmatory factor analyses (CFA) to determine whether the hypothesised structure of the YES provides adequate fit to the data and to verify that the all items on the YES were properly aligned with the correct facets. This study also aims to demonstrate convergent of the YES with the existing validated measures administered to all young people with mental health problems in CAMHS; The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997); The Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) (Gowers et al., 1999); and The Beck Youth Inventories, Second Edition (BYI-II) (Beck et al., 2005). These measures were used because of their emphasis on the concept of strengths and difficulties, recovery, functional capacity and wellbeing which are all key factors in empowerment.

Explorative factor analyses (EFA) is a theory generating method which will be used in phase 2 to generate a theory about the constructs underlying the YES. This study is following this up with confirmatory factor analyses (CFA) which is a theory testing model. CFA must be performed using a completely different dataset by putting the results of the EFA directly into a CFA on the same data you are only fitting the data instead of testing theoretical constructs (Holtzman & Vezzu, 2011). If the results show a significant lack of fit when CFA is performed it is acceptable to follow this up with an EFA in order to locate inconsistencies between the data and the model. However it is advisable to test any modification you decide to make to your model on new data (Holtzman & Vezzu, 2011). Therefore CFA will be performed on phase 4 clinical data to test theoretical constructs of the YES and to confirm the fracture structure of the YES.

When undertaking CFA a comprehensive analysis of covariance structures is required and the common measurement model for this is structural equation modelling (SEM). The measurement model for CFA and SEM is a multivariate regression model that examines the relationships between a set of observed dependent variables (factor indicators) and a set of continuous latent variables

(factors) (Brown, 2006). The relationships are described by a set of linear regression equations for both the observed dependent and the continuous latent variables. EFA in phase 2 will determine the factors on the YES and the loading of items on each factor. CFA tests whether a specified set of constructs is influencing responses in a predicted way and has the ability to test constraints on the parameters of the factor model to the methodology of EFA. CFA provides explicit framework for confirming prior notions about the structure of a domain of content and is strongly recommended for assessing the extent to which the hypothesised organisation of a set of identified factors fits the data (Pett et al., 2003). CFA was deemed the most appropriate method for establishing the validity of the factor model on the YES, the relationship between factor loadings, whether a set of factors are correlated or uncorrelated, and the convergent and discriminant validity of the measures.

#### 2.18 Sample Size

The lack of agreement on sample size in CFA/SEM research is well noted in the literature including the several guiding rules of thumb (Hogarty et al., 2005; MacCallum et al., 1999). Some of the general rules of thumb for CFA/SEM research suggests having a ratio of sample size to the number of free parameters such as 20:1 (Tanaka, 1987), 10:1 (Everitt, 1975; Pett et al., 2003), 5:1 (Bentler & Chou, 1987) or having a sample size of 200 (Kenny, 2012). The sample size in this study will be based on the rule of thumb that suggests having 10 people for every variable in the model (Everitt, 1975; Kenny, 2012; Pett et al., 2003).

# 2.19 Doing Confirmatory Factor Analysis

The statistical software packages STATA version 12 and Mplus version 7.1 will be used to undertake the CFA. CFA will be performed using the following steps:

# 2.19.1 Specifying the factor model and the pattern of loadings on the factors

This involves selecting the factors and the specified pattern of items which loads onto a particular factor, all of which will be informed by the results of the EFA in phase 2. These loadings will be fixed at zero instead of non-zero for indicators not

supposed to load on a certain factor. It is common to impose a model constraint to yield a meaningful scale in CFA. Kline (2010) states that one factor loading per factor needs to be fixed at a certain value in CFA to determine the scale of the respective factor thus identifying it (Kline, 2005). For instance, the parameters to be estimated will be the loadings of the items on the first factor, all the other variables loading onto the other factors will be constrained to having zero loadings. This will be repeated when estimating the parameters on the other factors. Kline (2010) highlights the importance of specifying the factor loading as by specifying which items should load onto a particular latent factor helps in terms of theoretical weight and meaning. Having made these specifications the next step will be to conduct and examine the syntax for CFA in Mplus output.

# 2.19.2 Examining the analysis output.

This involved examination of the covariance matrix, then the fit of the overall model to the data and then the direction, magnitude, and statistical significance of parameter estimates. The initial step in this model evaluation procedure is to obtain the covariance matrix. The covariances between each of the variables will be calculated which also involves assessing whether the variables are the same (or matches) as the variables identified in the EFA in phase 2. The covariance matrix is often seen as the better basis for the application of SEM than the correlation matrix as the adequacy of the model is judged by how well it reproduces the observed covariance matrix (Everitt & Palmer, 2011; Field, 2009). The use of correlation matrix can also result in many problems such as incorrect parameter estimates, standard errors and test statistics (Everitt & Palmer, 2011).

# 2.19.3 Evaluating model fit

The next step in this model evaluation is to examine if the hypothesised model fits the observed data. Fit is referred to the ability of a model to reproduce the data which is usually the variance-covariance matrix (Kenny, 2012). In CFA, several statistical tests are used to determine how well the model fits the data but there are varying opinions and several number of fit indices and evaluation criteria cited in the literature (Holtzman & Vezzu, 2011; Hu & Bentler, 1998; Kline, 2010). Having a good-fitting model does not necessarily mean that the model is correct,

valid and it also does not explain the large proportion of the covariance, instead it only indicates that the model is plausible (Kenny, 2012; Schermelleh-Engel, et al., 2003). The absolute fit indices proposed by (Kline, 2010) is the most commonly used test which determines how well the model fits the data (Hooper et al., 2008; McDonald & Ho, 2002). The absolute fit indices recommends reporting the chi-squared test to degree of freedom ratio ( $\chi^2$  to df) closer to zero, the RMSEA (<.06 to .08), the CFI ( $\geq$ .95), and the SRMR ( $\leq$ .08) which will be used for interpreting and evaluating the model in this study (Bryant & Yarnold, 1995; Hooper et al., 2008; Hu & Bentler, 1999)

#### Chi-squared Test

The chi-square likelihood ratio is generally used in SEM and CFA to evaluate the "exact fit index" which quantifies how well a model fits the data (Matsunaga, 2010; Maxwell, 2008). The chi-squared test will be used in this study which indicates the difference between expected and observed covariance matrices. Values closer to zero and a chi-square p-value greater than 0.05 indicate a smaller difference between the expected and observed covariance matrices, which is one indicator of good fit (Holtzman & Vezzu, 2011, Kenny, 2012; Matsunaga, 2010). However, one difficulty with the chi-square test is that it is very sensitive to sample size (Joreskog, 1969, Kenny, 2012). Although it is simple and easy to interpret it is widely recognised to be problematic and criticised because of its susceptible to the impact of sample size. For larger sample sizes such as 400 or more, the chi-square is almost always statistically significant and one my fail to find a model that fits (Type II errors) whilst for smaller size about 75 to 200 the chi-square test can a reasonable measure of fit but one may fail to reject the hypothesis due to lack of statistical power (type I error) (Kenny, 2012; Russell, 2002; Schermelleh-Engel et al., 2003). As a result, other measures of fit have been developed which suggest that researchers using a CFA/SEM should employ the "two criteria" strategy to evaluate model fit (Hu & Bentler, 1999). Therefore given the argument for researchers examine at least two different types of it indices (Holtzman & Vezzu, 2011, Kenny, 2012; Matsunaga, 2010), this study will employ other fit statistics such as "clusters" (RMSEA, GFI, AGFI, RMR, and SRMR) to evaluate the fit of the model.

# Root mean square error of approximation (RMSEA)

The root mean square error of approximation (RMSEA) represents the cluster called approximate fit index which is an estimate of discrepancy per degree of freedom in the model (Kline, 2010). RMSEA is currently the most popular measure of model fit which is virtually reported in all papers that uses CFA/SEM (Kenny, 2012). The RMSEA (Steiger, 1990) was used in this study as it avoids issues of sample size by estimating the amount of error of approximation and the degrees of freedom per model. RMSEA values range from 0 to 1 with a smaller value indicating better model fit. A value of .06 or lower is typically indicative of good model fit (Hu & Bentler, 1999), but a value of 0.08 or less is also considered acceptable (Browne & Cudeck, 1993; Marsh et al., 2004). MacCallum et al. (1996) suggest that 0.01, 0.05, and 0.08 indicate excellent, good, and mediocre fit respectively whilst Kenny (2012) suggested 0.10 as the cutoff for poor fitting models.

#### Comparative Fit Index (CFI) and Tucker-Lewis index (TLI)

The next cluster of fit index is called incremental fit index which assesses the overall improvement of a proposed model as opposed to an independence model where the observed variables are uncorrelated (Bentler, 1990; Byrne, 2006). The comparative fit index (CFI; Bentler, 1990) and the Tucker-Lewis index (TLI; Tucker & Lewis, 1973) are two incremental fit index that are commonly used to measure model fit and were used in this study. CFI values range from 1 to 0 with larger value considered as a good model fit. For a model to be considered adequate fit, it should have CFI value of .95 or higher (Hu & Bentler, 1999) although a cutoff of .90 is argued in the literature (Russell, 2002). The TLI and CFI are highly correlated but only one should be reported and CFI is reported more often than the TLI (Kenny, 2012).

#### Standardized Root Mean Square Residual (SRMR)

The final cluster of model fit index used in this study is called the residual-based index which focuses on covariance residuals or discrepancy between the observed covariance and the predicted covariance (Schermelleh-Engel et al., 2003). The standardized root mean square residual (SRMR) is the most widely residual-based index used and was used in this study. The SRMR is an absolute measure of fit, it

tends to be smaller as sample size increases and as the number of parameters in the model increases (Kenny, 2012). SRMR value ranges from 0 to 1 but should be less than .10 (Bentler, 1995; Kline, 2010). A value of .08 or less is indicative of good fit model (Hu & Bentler, 1999; Kenny, 2012).

#### 2.20 Conclusion

The aim of this study is to examine the psychometric properties of the YES in a clinical population and the factor model which will be based on our previous EFA study with young people in a non-clinical population. CFA of the clinical sample responses to the YES will examine the factor model obtained from the non-clinical sample and determine whether it fits the clinical data. Our aim is produce a valid and reliable measure of empowerment for young people with psychosis using the quantitative methods outlined above.

# Chapter 3: Phase One - Qualitative Exploration of Empowerment from the Perspective of Young People with Psychosis

#### 3.1 Abstract

Evidence suggests that empowerment is central to improving the effectiveness and quality of mental health care. Empowerment includes increased involvement, choice and access to health information for service users. Within the process of empowerment, individuals may better understand their health needs and accordingly improve their prognoses. Despite the widespread use of the term 'empowerment' within mental health, there have been no studies examining how young people with psychosis understand and conceptualise the term empowerment or which factors are conductive to them developing a sense of empowerment. This study aims to qualitatively conceptualise empowerment from the perspective of young people aged 14-18 experiencing psychosis.

Individual interviews were conducted with nine young people with a diagnosis of a psychotic disorder regarding their understanding and experience of empowerment. The interviews were audiotaped, transcribed verbatim and analysed using Interpretative Phenomenological Analysis. Results indicated that young people who have experienced psychosis conceptualised empowerment as being listened to, being understood, taking control and making decisions for themselves. Young people place high importance on experiencing personal empowerment in relation to being users of mental health services and regard being empowered as the most important factor for determining their own recovery. Results also revealed that young people view mental health workers as very variable in their ability and willingness to address and help facilitate empowerment. They also identified daily routine, structure and avoidance of inactivity as additional means of increasing empowerment. The implications for research and practice are discussed.

# 3.2 Background

Empowerment has been defined from numerous perspectives including sociology (Morrall, 1996), social work (Stevenson & Parsloe, 1993), psychology (Zimmerman & Rappaport, 1988), health promotion (Tones, 1992) and nursing (Rodwell, 1996). Empowerment is viewed within this literature as a positive and helping process that enables a person to take charge of their lives, make informed choices and make decisions about their lives. The importance of empowerment is emphasised in the literature on adult recovery from psychosis (e.g. Andresen et al., 2003; Neil et al., 2009; Pitt et al., 2007). Pitt et al. (2007) found clear links between this notion of personal expertise and the theme of empowerment for people recovering from psychosis. They proposed that clinicians can help reduce the sense of disempowerment often experienced by adult service users by simply providing information on how they might manage their problems for themselves. It is currently unknown whether the benefits of empowerment experienced in adult mental health care are the same for younger service users with psychosis. There is a clear need to explore the knowledge gap of what empowerment means to young people with psychosis; understanding how they view the concept of empowerment would provide a valuable insight into their needs and help to inform service development.

There is an increased policy commitment to addressing the needs of young people with a first episode of psychosis in the UK (DoH, 2004; NICE, 2009). Empowerment has become a commonly used term within Child and Adolescent Mental Health Services (CAMHS) where it is espoused as a major element of successful service delivery (DfES, 2006, 2003; DoH, 2004). There are a number of documents that stresses the need for increased partnership and the importance of listening to young people (Garcia et al., 2007; Young Minds, 2003). Although the concept and benefits of empowerment from an adult perspective are well documented (Clearly & Dowling, 2009; Powers, 2003), there is a relative lack of understanding of the construct from a young person perspective. The current study aims to examine how the concept of empowerment applies to young people with psychosis.

Qualitative approaches were employed specifically to examine the understanding and experience of the concept of empowerment from the perspective of young people and their parents. Qualitative methods permit broader understanding and insight into complex human behaviours in comparison to what might be obtained from surveys or other quantitative measures of personal understanding and experience (Denzin & Lincoln, 2000). Zimmerman and Rappaport (1988) offered general theoretical guidelines for studying empowerment that were employed in the current study. Interpretative phenomenological analysis (IPA) was employed to examine the participant's experience of empowerment. IPA forms part of the social cognition paradigm in social psychology and is primarily concerned with an individual's account of an event, or an 'insider's perspective' (Smith et al., 2009).

#### 3.3 Methods

# 3.3.1 Participants

There is a consensus towards the use of smaller sample sizes in IPA as this allows in depth analysis that produces detailed understanding (Reid et al., 2005). The current study included nine young people aged between 14-18 years (mean age was 24.6); five males (mean age was 16.8) and four females (mean age was 16). Eight of the participants identified themselves as white British ethnic origin and one participant described themselves as being of Asian origin. All nine participants were recruited from CAMHS and had received a psychiatric diagnosis of a schizophrenia spectrum disorder. The mean duration of their psychotic symptoms was 5 years with a range of 3-8 years.

Participants were identified by a consultant psychiatrist as having capacity to provide informed consent to participate in the study and nobody invited to take part in the study declined. All participants were considered to be in recovery at the time they were invited to take part. In practice recovery was defined as a state where the participants were coping with their symptoms and the time in recovery varied from person to person (Neil et al., 2009).

All participants were receiving anti-psychotic medication for their symptoms and had experienced at least one previous admission to an inpatient unit. However, at the time of the interview all were in receipt of outpatient treatment from a multidisciplinary mental health team along with intensive support from their parents. None of the young people were in employment or full-time education at the time of interview. It is important to consider the way in which the involvement of the young people's parents within the current study might have impacted the results. Not only did the parents facilitate the interviews, supporting and encouraging the young people, the parents added to the perceptions and responses that were used in generating themes from this data. The meaning ascribed to incidents by parents, who often were initially more forthcoming than the young people, was re-iterated to the young people; not asking for their confirmation of this incident but inquiring if the young people wished to add detail or additional examples triggered by the parent's data. The manner in which parents and young people construct meaning is in keeping with the symbolic interactionist roots of IPA. Blumer (1969) describes symbolic interactionism as the process in which:

"Humans act toward things on the basis of the meanings they ascribe to those things."

"The meaning of such things is derived from, or arises out of, the social interaction that one has with others and the society."

"These meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he/she encounters."

Within the current research, symbolic interactionism provides a framework in which to understand the way in which the young people, in conjunction with their families, experience empowerment or disempowerment when interacting with CAMHS. This is significant both in understanding the interrelatedness of young people and their families when attempting to describe their experiences and in when considering the subsequent YES scale as a means of gauging empowerment for young people in the context of their family lives as well as their interaction with CAMHS.

#### 3.3.1.1 Reflexivity

Malterud (2001) emphasised the importance of ensuring researcher reflexivity when undertaking qualitative research. Malterud (2001) referred to reflexivity as the ongoing process by which the researcher considers how their own knowledge, values, behaviours and presence might have had an effect on data collection and

analysis. Parahoo (2006) also indicated that a researcher must endeavour to inform the reader how these factors might influence their research. The following section will provide a reflexive account of the researcher's background, understandings, perspectives, and initial hypotheses.

#### 3.3.1.2 Pre-research pre-conceptions and beliefs

The impetus to undertake research concerning empowerment in young people with psychosis stemmed from the researcher's awareness of and concern over the lack of empowerment generally experienced by young people with psychosis; and the negative impact this is known to have on their wellbeing.

Having worked as a Mental Health Nurse and Cognitive Behavioural Therapist, I had observed and read around the concept of empowerment for young people with psychosis. Whilst working with young people I became aware of the potential for power imbalances to exist within the therapeutic relationship. There was, to some degree, expectation on my part that young people would follow my direction (meeting times, CBT homework etc,); and I was mindful that they might subsequently behave cautiously with me, responding to perceived power attributed to me. I was also exposed to and influenced by other professionals; who ranged from highly formal, directive and 'professional', to friendly and inclusive. There was also a perceived wisdom within the setting I worked in that staff who were close in age to young service users lacked authority. Indeed, the culture of the clinical setting was one whereby staff felt they had to maintain a position of authority, ensuring young peoples' compliance with institutional rules and treatment. This view no doubt affected the general attitude of staff within the setting and created an authority seeking culture amongst staff; distancing them from young service users and thus reducing empowerment. My exposure to this work environment alerted me to issues of power and empowerment. I developed a view that individual empowerment is highly variable, and whilst affected by issues around illness and self-esteem, are also very much affected by self-efficacy, power, involvement, choice, control, quality of interactions with staff, and quality of support (Baguley et al., 2007; Barker & Buchanan-Barker, 2005; Calnan & Gabe, 2001; Hansson & Bjorkman 2005; Small et al., 2013; Spencer, 2013; Stevenson et al., 2003).

My clinical experience of empowerment was further sensitised when working as a researcher on the Telehealth Project (Grealish et al., 2005). This research project was funded in response to the increased pressure faced by CAMHS and the need for specialist services to be accessible with mainstream health services. Therefore, this project aimed to evaluate the experience of young people who were given access to CAMHS consultations via video conferencing equipment. Undertaking this research with young people with psychosis heightened my view that experiences of feeling disempowered are a common occurrence amongst this patient group. At this stage I became more mindful of the dominance adults occupied and a clear tendency for clinicians to disregard the wishes of young people with psychosis due to the nature of their illness. This experience did not necessarily alter my earlier assumptions about empowerment, but did add to my understanding that empowerment can be viewed in terms of choice, or its absence (Wallerstein, 2006). Also the view that empowerment relates to the level of influence and control that mental health service users have over their services and their lives (Segal & Silverman, 1993).

Whilst conducting the research for my thesis, I was also struck by the relative paucity of empowerment literature from the perspective of young people with psychosis. Thinking reflexively, my experience of the relative disempowerment of young people with psychosis, and the complicity of staff in this, will have affected the way I undertook the original interviews. This experience made me alert to the experiences related by the young people themselves. Listening to their experiences and valuing them as well as the accounts given by parents. My experience was overwhelmingly of young people with psychosis not being empowered through their interactions with staff. I perceived a hierarchical relationship whereby senior staff (usually medical psychology professionals) were culturally permitted to be empowering, so those instances where they gave young people control or permitted positive risk taking were seen as good practice. More junior staff (nursing staff) who did the same were often viewed as 'weak' or 'colluding', and therefore their attempts to empower of facilitate were often discouraged. Therefore within the interviews my experience will have contributed to me endeavouring to be as empowering as possible in an effort to have them tell their stories.

#### 3.3.2 Ethical Issues and Approval

Ethical approval for the study was obtained from a local NHS research ethics committee (LREC, Reference number: 06/Q1409/46), see Appendix 1. Each participant was provided with written information about the study. Written ascent and consent was obtained from each young person and their parents to participate, including permission for interviews to be audio taped and transcribed. As a result of the consent stipulations all the participants' parents were aware of and attended the interviews. In all cases participants and parents were interviewed jointly. The young people were all given the option to be interviewed alone. They all requested their parent's presence indicating that the parents were able to confirm their experiences and remind them of their journey of care. Parents also guided the interviews as they contributed to all aspects of the questions. Parents also made significant contributions to the processes of engagement and information gathering in the current study. Parents were often able to recall detail, especially regarding timing and process that the young person could not.

#### 3.3.3 Procedure

Semi-structured interviews are commonly used in IPA studies (Smith & Osborn, 2003). In the current study, a semi-structured interview schedule was developed to obtain young peoples' descriptive accounts of their experiences of empowerment. The interview schedule was designed to facilitate the participants' ability to formulate a personal narrative using their own words (See appendix 2). Open ended, neutral questions were employed so participants could talk with a minimum amount of interruption or constraint from the interviewer. An example of one of these is, 'Can you tell me a bit about the mental health professionals you have been involved with?' Further questions were asked to allow clarification of issues raised by the young person and parents that were not covered by the schedule. An example of a clarifying question would be, 'You indicated that your key worker was a big help, what did exactly did they do that you found helpful?' These questions elicited information about access to and transition from CAMHS to adult services.

#### 3.3.4 Data Analysis

Data from the interviews was analysed using the principles of IPA outlined by Smith et al. (1999). Interviews were transcribed verbatim followed by a systematic step-by-step process where transcripts were analysed individually, in sequence by the first author. Initially, each transcript was read and re-read a minimum of 5 times, enabling a process of familiarisation with each account. The aim of the first reading was to become attuned to the young peoples' experiences and perceptions of empowerment. The second and third readings were dedicated to identifying common and repetitive themes related to the participant's experience of empowerment. The fourth and fifth readings aimed to identify themes and note connections. Relevant items were then marked, emerging themes noted and then ordered into preliminary lists.

During the reading process, initial ideas were noted on the left margins of each transcript. Following this, common themes were further defined and noted on the right hand margins. The themes were then grouped and compared. Master lists of main themes were then compiled for each interview. These were compared for all interviews and assembled together along with associated sub-themes that flowed from the higher order categories. The initial analysis was based upon the findings of the first author. The second and third author checked, modified and confirmed these themes. These findings were then presented to the fourth author who confirmed the reliability of the analysis. This process verified the themes drawn from the transcripts and the connection with the quotes. These themes with the corresponding quotes were organised using a table to illustrate areas of commonality.

#### 3.4 Results

Analysis of the transcripts revealed six main themes. These were:

- 1) Individual control and choice versus inflexibility
- 2) Being listened to, respected and validated
- 3) Communication
- 4) Response of services
- 5) Coping and structure
- 6) Quality of relationship and support

From these main themes a number of sub-themes were identified; all of which are presented in Table 1.1. The 6 main themes and representative quotes describing their experiences are described below. Participants' names have been changed in order to protect confidentiality.

#### 3.4.1. Individual Control and Choices versus Inflexibility

Individual control over life choices was regarded as important to all participants, even if control related to what they perceived to be a less significant life choice that others might regard trivial. Being permitted choice was highly valued, even if this potentially increased attempts at coercion from others. Young people feel strongly about being validated in their personal view about how they should live their lives, particularly during times of mental distress. Maintaining control and choice were regarded as protective factors against their detrimental consequences of clinicians' inflexibility.

#### 3.4.1.1 Treatment

Both young people and their parents reported that perceived control and choice of treatment increased empowerment, as did having a sense of personal involvement in all aspects of treatment process. They also reported that by being able to express their positive and negative personal opinions about their treatment was in itself empowering. Young people endorsed clinicians who were more flexible in terms of treatment delivery, providing a range of options, helped increase perceived empowerment. Young people emphasised that even when considered to be "unwell" having "choice" was essential.

B - they would just shove you on a medication and that were it, take it

Table 1.1 Phase 1: Structure of IPA - Main Themes

Theme 1:  Individual control  and choices versus  inflexibility	Theme 2: Being Listened to, Respected and Validated	Theme 3: Communication	Theme 4: Response of Services	Theme 5: Coping and Structure	Theme 6: Quality of Relationships and Support
3.4.1.1 Treatment 3.4.1.2 Managing personal wellbeing 3.4.1.3 Lifestyle within institutions 3.4.1.4 Symptoms	3.4.2.1 Being listened to and understood 3.4.2.2 Validation from services and professionals involved in care	3.4.3.1 The quality of information 3.4.3.2 Information about treatment 3.4.3.2 Talking about symptoms	3.4.4.1 Recognition of need 3.4.4.2 Services failing to recognise, engage and respond when help is sought.	3.4.5.1 Coping mechanisms 3.4.5.2 Structuring time and planning for the future	3.4.6.1 Clinicians 3.4.6.2 Emotional support from clinicians 3.4.6.3 Practical support from parents 3.4.6.4 Practical support from clinicians to parents

#### 3.4.1.2 Managing personal wellbeing

Having the freedom to take charge of their own personal care, such as utilising their own coping mechanisms for distress was considered empowering. Both young people and parents found that having the flexibility and freedom to employ their own coping strategies was very important as coping styles are personal and might not be generalisable to others.

C - Because I had the freedom to go anywhere like when I was hearing the voices and stuff I had the freedom to use my ways of coping (pointing to the chart) I didn't have to ask anyone could I go to my room things like that (5sec pause) and I was able to chill out as well whenever I wanted and this relaxed me

# 3.4.1.3 Lifestyle within institutions

Both young people and parents reported that the degree of control they perceived themselves to have over their own lifestyle choices when living within institutions affected their feelings of empowerment. Staff enforced rule structures were often experienced as patronising and inflexible, something which participants identified as a block to their ability to access their own coping mechanisms and a detriment to their own recovery.

E - when I was at (Y) they wouldn't let me out for walks that annoyed me and me worse no freedom it was terrible ... you need to free to do your own things and not treated like a little kid ... you need power and if you don't have that you can't do anything

#### **3.4.1.4** Symptoms

Perceived control in relation to symptoms was identified as an important aspect of empowerment by both young people and their parents. Both equated a sense of feeling in control of one's own symptoms with being empowered. Participants opined that perceived control subsequently leads to increased confidence in managing symptoms. Young people specified that feeling in control of their symptoms meant that they felt less confused, more able to ignore auditory hallucinations, less anxious and more able to utilise other coping mechanisms.

H - it (empowerment) helps to stay in control and just not do it not to do what the voices say

# 3.4.2. Being Listened to, Respected and Validated

All participants stated that the experience of feeling heard by others aids empowerment as it is validating, enables them to feel as though problems are being addressed directly, reduces confusion, and helps them to cope better. Participants associated not feeling listened to with interpersonal disputes with clinicians. The experience of not having their personal viewpoints heard or respected was identified as a trigger for potential incidents involving their own disruptive behaviours.

#### 3.4.2.1 Being listened to and understood

Young people and their parents identified that being listened to facilitates empowerment through a process of being made to feel understood. Participants specified that if clinicians can communicate in a jargon free and non-patronising manner, this has the effect of making them feel respected, heard and understood. Participants also noted that if they perceived clinicians not to be listening, they had less confidence that the clinician would know how to help.

C - yes that's it they were always reassuring me and talked in a nice manner. That helps a lot when you are feeling ill. I think when someone listens to you you get better and more better they understand me more and what I'm trying to say.

# 3.4.2.2 Validation from services and professionals involved in care

Participants said that another critical element to feeling empowered was being able to speak about their experiences and feel as though others' believed them. Many people recalled experiences in which they felt their points of view had been ignored and not taken seriously and described having their conversations cut short by clinicians and being patronised. They described these experiences as upsetting and distressing, especially if they felt people did not believe their accounts of what they were perceiving and the symptoms they were experiencing. Clinicians who validated personal distress and experiences were regarded as facilitators of empowerment. Participants made a direct link between the experience of being listened to with a sense of being believed, respected, helped and understood

G - when they didn't believe me and it was like I was nothing cause no one was listening to me and they didn't believe me so I felt like I'm worthless

#### 3.4.3. Communication

Young people and their parents highlighted the value of clear communication between clinicians and young people, both directly with the young person and as processed through their parents. People expect treatment options to be discussed and explained. Young people need to be able to talk about symptoms when they feel able to and with reference to terms they can understand as opposed to those used by clinicians.

#### 3.4.3.1 The quality of information

Participants spoke of the importance of receiving information about their treatment and how to access and make best use of services. Getting consistent, clear and accurate information about their treatment, symptoms and services was seen to facilitate feeling empowered. However, where information was not forthcoming or clear, participants experienced frustration, isolation and a perception of not being helped. Participants also reported that the quality of communications was very much dependent on individual clinicians, where those who appeared to show interest and took their time in giving information were perceived as being more skilled, which subsequently created an alliance that was empowering.

A - They were so good at explaining things, they'd keep explaining things until I understood them and they didn't use big words.

#### 3.4.3.2 Information about treatment

Participants reported that decisions regarding treatment options were rarely collaborative and no explanation or justification of decision outcomes was provided to young people or parents. They found this lack of information and discussion disempowering and a common cause for young people not engaging in treatment. Participants found that the more information and explanation they received about treatment, the more empowered they felt. This resulted in young people feeling they were part of the decision making process and that treatment was more acceptable.

F - they just told me I was going on Olanzapine and that was it (did they explain to you how this medication works and it side effects) no they didn't they just told me that I can get sleepy

#### 3.4.3.3 Talking about symptoms

Opportunity to talk and discuss symptoms with clinicians was seen as empowering as this process enabled participants to increase their understanding of symptoms and facilitated their ability to seek help. They found this empowering because discussion of symptoms reduced anxiety and fear. Clinicians who discussed symptoms were valued not simply for their knowledge, but for their willingness to engage with young people when they needed and wanted to.

A - cause you know what is going on and you know how to get help eh (5sec pause) like Dr XX helped me to understand what was going on in me head so I was able to recognise when it would start and get help with

# 3.4.4. Response of Services

Families both value and fear the knowledge and expertise of clinicians, often perceiving power over access to services and the nature of interventions to rest with health care providers.

#### 3.4.4.1 Recognition of need

Both young people and their parents reported past experiences whereby lack of knowledge possessed by some clinicians regarding mental health problems was alarming. They also noted a common reluctance to accept or engage with their needs with some participants reporting incidents when General Practitioners (GPs) and CAMHS clinicians refused to engage with them at all. Parents reported having experiences where they felt they had to plead with some services to obtain a response and help for their child, which they found distressing and isolating. Parents expressed anxieties regarding the process involved in transferring from CAMHS to adult services. The process of disengaging with one service and accessing another was described as disempowering. They also reported that the accessing support was dependant upon the parents' ability to advocate for the child and access services.

D – the GP just did nothing, meself and mum pleaded with him begged him to help us, he just didn't understand my illness.

#### 3.4.4.2 Services failing to recognise, engage and respond when help is sought.

Some participants reported that clinicians failed to listen, minimised their needs and flatly refused to believe in their symptoms. These experiences resulted in participants losing confidence in services. They would then try to deal with the symptoms themselves at considerable risk and cost. Ultimately the services failure to engage with the need presented disempowered the individuals, removing them from service contact for long periods and often precipitating crisis.

I - he (the doctor) said I was just doing it (acting on my voices) he just said that I could control what I was doing and that I should get on with my work and stuff

# 3.4.5. Coping and Structure

Participants described a difference between individually acquired methods of coping and learned coping and identified the usefulness of clinicians both supporting individual coping styles and also teaching alternative techniques. Participants reported that boredom was a common cause of symptom exacerbation in which clinicians' creativity and flexibility was helpful in helping to overcome this and plan for the future.

#### 3.4.5.1 Coping mechanisms

Developing coping mechanisms for symptoms and an understanding of when and how to utilise them was considered crucial to achieving empowerment. Participants reported that in instances where clinicians were prepared to support young people to develop existing personal coping mechanisms as well as teaching new coping techniques, symptom reduction was more likely. Techniques that were introduced to young people and parents with patience and clarity resulted in them being able to make use of these during periods of relapse and increased participants' confidence in being able to utilise them in a variety of situations and environments. Young people particularly valued having strategies they developed themselves recognised by clinicians. They described this as empowering as the fostering of new ways of coping allowed them to be less dependent on the health service and to recover.

B - they thought me different methods to use like m listening to my discs put the earphones into your ears so that it's right. And like getting a elastic band to pulling at it and stuff

# 3.4.5.2 Structuring time and planning for the future

Young people identified boredom as a cause of stress, leading to deterioration in mental health. They believed that daily structure and having available activities to engage in prevented boredom and increased empowerment; and is especially valued during periods of feeling unwell. They also reported an ability to form more effective therapeutic relationships with those clinicians who helped to engage them in structured activity. Boredom was equated with increased stress,

and anger, which participants associated with symptom exacerbation, and delayed recovery. Participants viewed time in hospital as an opportunity to engage and work with clinicians and had expectations that clinicians would play a role in facilitating this process. When this did not happen, young people and their families reported feeling disempowered and trapped.

The young people interviewed in the current study were aware that they had spent relatively lengthy periods of time in hospital and subsequently missed out on educational opportunities, employment and experience of structured activity. Their parents all expressed concern regarding their children's future and wondered what would happen to their child when they are no longer able to look after them. There was a view that mental health services had failed to address the educational and employment needs of their children. While accepting that periods of hospitalisation were required, parents and young people felt that this incurred missed opportunities. There was a view that hospital could be used to educate young people to better deal with future illness and to address the educational and social gap that occurred as a result of mental health problems. Parents saw a clear need to plan for their children's' future and did not feel that health services were addressing this.

# D - Keeping me busy and having a structured day. I hate it when I get bored that's when I get stressed

#### 3.4.6. Quality of Relationships and Support

Clinicians were regarded polemically as either the best source of help or the main problem. Participants identified a need for clinicians need to plan ahead and make themselves available to their patients, providing direct face to face contact and also involving parents as a key resource.

#### 3.4.6.1 Clinicians

Participants felt it was important and empowering for them to be able to approach clinicians and have face to face contact when required. Some participants reported that when clinicians did not permit this, their perception of the clinician's role became less positive; they perceived the role as policing rather than engaging or therapeutic.

E - he (the doctor) said look for me to be able to keep you out of hospital I need you to tell me everything if you tell me everything we can try and stop you being unwell and going into hospital. He said if you then I might not be able to stop you and he actually said and sometimes even if you tell me we might not be able to keep you out of hospital

#### 3.4.6.2 Emotional support from clinicians

Participants reported how important it was to receive emotional support from staff in order to achieve empowerment. Participants who received emotional support perceived clinicians to be approachable, friendly, fun and with a sense of humour. They perceived these clinicians to be listening, engaging and helping them to understand their problems. These clinicians were also able to give reassurance. Participants valued the basic communication and engagement skills delivered suggesting that this set the scene and allowed empowerment.

F - they had a laugh with me... and that helped me to relax and I felt I could open up to them they were so caring friendly and always listened to me talk me and stuff and they tried to understand me as well and I had fun with them as well

## 3.4.6.3 Practical support from parents

Young people reported that they can achieve empowerment even when extremely unwell, particularly if their parents are involved. Young people felt uncomfortable or felt less able to make decisions when unwell, but implicitly trusted their parents to make the best decisions on their behalf. This suggests that clinicians can still ensure young people can be empowered by supporting their parents in the decision making process and ensuring that they are involved at all levels.

H - I can't make decisions at that time and sometimes I can't remember what happened so I rely on my parents to look out for me when I am ill and make the best decision for me. But it (empowerment) can also be important at that stage as well because I need help with what to do and how to cope when I'm feeling bad.

#### 3.4.6.4 Practical support from clinicians to parents

Participants reported their concern over the lack of support given to parents when young people were unwell, particularly when discharged. Some parents tried contacting the services when their child was having difficulties and received little or no support from services. They described this experience as very disempowering as they felt unsupported and isolated. Parents reported that small

things such as a contact person with telephone numbers, teaching them how to recognise early warning signs, coping skills and helping them to understand their child's illness would help to overcome these anxieties and they would feel more empowered if they had these access to these reassurances and resources.

F - they can advice my mum with stuff and say if you need help here's the card with the phone number so you can get in touch with such and such a person

#### 3.5 Discussion

This study provides a qualitative analysis of the conceptualisation of empowerment from the perspective of young people with psychosis and their parents. Results provide evidence that young people and their parents share a similar understanding of the term empowerment. They also have similar ideas regarding the necessary processes to feeling empowered. Participants regard empowerment as an ongoing experiential process that continues to develop as opposed to a definitive end-state. An individual's experience of empowerment can be positively or negatively affected at every new contact with mental health services and mental health professionals. Personal empowerment can be defined at any one time by an array of factors, with previous negative or positive experiences supplying context and perspective.

The six themes obtained from the data in this study and presented in this paper illustrate the ways in which young people with psychosis experience empowerment. The implications of these findings will now be discussed.

The importance of developing individual control and choice over treatment and experience of symptoms is a key principle of health and personal empowerment. Young people and their parents are generally critical of mental health services in which clinicians' application of rule structures are experienced as patronising and inflexible. They considered this to impede their ability to utilise personal coping mechanisms and slow down the recovery process. This is consistent with Rogers et al. (1997) and Stevenson (2000) who suggest that processes through which clinicians create powerlessness as opposed to empowerment mirror illness processes and symptoms. Our findings indicate a need for clinicians to develop greater awareness and flexibility about the experiences of distress and

powerlessness that young people encounter during contact with services. As reported by Hunter et al. (2010) these findings show that clinicians must also routinely give service users the opportunity to employ a variety of strategies and knowledge that would enable them to exercise more control and choices over their symptoms. Having choices, participating in decision making and taking control born out of a shared process between clinicians and young people /parents are all factors that adult participants have recognised to be empowering in previous research (e.g. Barker et al., 2004). Consistent with previous findings, young people in this study also felt that being allowed to exert control over major decisions was beneficial in both the short and long term.

Young people and their parents also identified a need for clinicians to listen more and to believe and validate the symptoms and difficulties they reported. Participants emphasised that being listened to aided empowerment by making them feel respected, heard and understood. Garcia et al. (2007) and Claveirole (2004) also emphasised the importance of listening and the negative impact of not being understood. In the current study, several young people and their parents expressed associated increased distress and worsening of symptoms as a consequence of not being listened to. Clinicians need to be aware of the serious consequences for adolescents and their parents when they are not listened to or believed.

Quality of communication was another significant theme to emerge from this study. Participants identified the sharing of information about their treatment, symptoms and services as crucial to feeling empowered. The importance of good quality communication is well recognised within the literature (Byrne et al., 2010; Lloyd, 2005; Rethink, 2003). In the current study, participants' experiences of poor communication were comparable to examples within the literature (e.g. Ahmad et al., 2003; Kirby et al., 2003; Street et al., 2003). Participants identified that discussion of symptoms with clinicians could be empowering in itself, as the discussion allowed them to build a therapeutic relationship and better understand their difficulties and find help. This idea of open and safe communication echoes the findings of Barker et al. (2005) who suggested that being listened to and

feeling that your own experience is being transmitted to the clinician is fundamental to building an honest therapeutic relationship.

The way in which services respond to users and whether individual clinicians demonstrate a willingness to accept or engage with the needs expressed by participants is significant. Parents reported great difficulties, disclosing instances when they felt they had needed to plead with services in order to get a response and help for their child. They perceived that access to support was dependant on prior knowledge of services. This is in contravention to current government policy (DoH, 2004), which emphasises easy access to services in order to maximise the prevention of problems becoming more serious and difficult to treat. Parents reported feeling left alone to deal with problems and only receiving further support when in crisis. Where young people reported experiences of not being able to engage with services, they associated this with their mental health deteriorating. This pattern is well recognised in the literature (Birchwood, 2003; McGorry et al., 2002). Research emphasises the importance of early intervention for adolescents with psychosis to future prognosis and recovery. The lack of early intervention was seen as a disempowering factor for most of the participants in this study.

All of the participants in the current study believed that coping mechanisms, structuring their time and planning for the future contributed to their experience of empowerment. This is consistent with recent research which holds that meaningful activity enhances the quality of life of young people and increases their ability to cope with symptoms (Rethink, 2003; Sin et al., 2005). By adopting new ways of coping, often under the guidance of clinicians, young people in this study reported experiencing improvement in functioning and becoming less dependent on services. Where activity was lacking or discouraged by clinicians boredom became a factor. Young people associated boredom with feelings of disempowerment; time spent alone without purpose contributed to increased psychotic symptoms, and delayed recovery. This finding is particularly consistent with Sin et al. (2005) who argue that young people need to be engaged in a meaningful way in order to help them address their symptoms. Young people and parents recognised the social and educational damage caused by psychosis. They

felt that service providers had an opportunity to engage young people regarding social, educational and employment opportunities.

Finally, our findings emphasise the importance of the quality of the relationship and support delivered by individual mental health professionals. This was regarded by all participants as fundamental to empowerment. Spending time with clinicians was seen as invaluable as this helped to build a therapeutic relationship and by doing so clinicians helped young people to understand and cope with their symptoms. Participants who did not experience this quality of contact with clinicians found this disempowering as they felt the nature of the relationship was distant or containing. Qualities such as being approachable, friendly, having a sense of humour and being fun were highly regarded by young people and were associated with those clinicians who could help them to understand their problems. Young people felt that clinicians could also ensure that they were empowered when very unwell by supporting their parents in the decision making process. These findings are similar to those of Taub et al. (2001) who found that when family groups were engaged in care levels of empowerment increased.

# 3.6 Methodological Limitations

Participants for this study were recruited through one NHS locality. This has implications for the extent to which findings from this sample (n=9) can be generalised to all young people with psychosis across the UK. Despite this, participants provided a rich and varied account of their experiences with empowerment. The age range of the participants (14-18 years) was somewhat broad and the findings may be representative of this. It would be beneficial for future studies to focus on specific age groups e.g. 14-15 year olds or 18-19 year olds to establish whether age related differences are significant. The method used (IPA) while allowing access to fuller and richer accounts of the participant's experiences and their understanding of empowerment does require that the researcher take care to minimise the risk of bias during analysis. This is achieved by the researcher being aware of their own experience, potential bias and the influence these may have on the analysis. Quinn and Clare (2008) caution that IPA analysis must be grounded in the text and suggest that other researchers should have access to the analysis to help note potential bias. In this research the

researcher used the participants own words to develop the themes and worked closely with three other researchers to complete the analysis. Moreover the participants themselves were given access to the initial findings and the opportunity to challenge the findings, this process resulted in the themes which are presented in the participants own words.

# 3.7 Implications for future research and clinical practice

This study has highlighted a number of potential directions for future research. The findings clearly illustrate some of the less acceptable aspects of clinical care as experienced by young people with psychosis, and their relatives. For example, this includes experiences of clinicians not listening and not validating their personal experiences. Results also suggest that actions taken by staff to facilitate empowerment, such as provision of clear communication and coaching on coping strategies, are highly valued by young people. Participants emphasised the importance of visibility of staff efforts to facilitate empowerment. This illustrates a need to raise awareness of mental health workers to service users' empowerment related experiences and the provision of skills training in promoting empowerment in young people. The evidence of a relationship between empowerment, recovery and functional outcome also makes the case for investment in clinician's ability to facilitate empowerment (Hunter et al., 2010; Pitt et al., 2007; Watkins, 2007). These findings indicate that an empowerment tool for use with young people with psychosis is necessary. Clinicians have a clear influence on young people's experience of empowerment but currently lack an objective means of measuring empowerment. Future research aimed at understanding the psychological processes underlying empowerment might also be beneficial.

# Chapter 4: Phase Two - The Development and Psychometric Validation of the Youth Empowerment Scale (YES)

#### 4.1 Abstract

The concept of empowerment is viewed as a positive and adaptive state that is inextricably linked with wellbeing, particularly within the context of mental health. This paper presents the psychometric properties, validity and reliability of a new measure of empowerment for young people, the Youth Empowerment scale (YES), developed in collaboration with young people. 264 participants aged 11 to 19 years completed the YES as well as measures of quality of life and wellbeing. The YES items represented themes derived from extensive interviews with young people with psychosis regarding what empowerment meant to them (Grealish et al., 2011. Exploratory factor analysis suggested a three-factor solution relating to empowerment; factor one receiving help and validation, factor two choice and control and factor three effective help-seeking. The 21-item scale had very high internal consistency ( $\alpha = 0.89$ ) and correlated significantly with related measures, demonstrating concurrent validity. The YES is a valid and reliable tool for measuring empowerment in young people for research and clinical purposes.

#### 4.2 Introduction

There is substantial evidence that positive mental health and wellbeing is inextricably linked to a sense of empowerment. Similarly, recovery from mental health problems is found to be dependent on empowered participation in one's own care (Brosnan, 2012; Harper & Speed, 2012). Therefore, successful delivery of mental health services is more likely where a sense of empowerment can be facilitated in individuals who access those services. Empowerment relates to issues such as engagement, recovery, involvement, partnership and collaborative working, choice, access to health information, improving quality of care, and health outcomes (Carnegie UK Trust, 2008; Day, 2008; Garcia et al., 2007; HASCAS, 2008; Koelen & Lindstorm, 2005; Pitt et al., 2007; Starkey, 2003).

An array of definitions of empowerment exist (see Cattaneo & Chapman, 2010), but the work of theorists such as Rappaport (1987), Kieffer (1984), and

Zimmerman (1995, 2000) are most frequently cited in the literature. Rappaport (1987) defined empowerment as a process whereby people, organisations, and communities gain mastery over their lives. Rappaport (1987) purported that individuals are experts in their own expression through thoughts, feelings, actions, and beliefs; and individual should be encouraged to focus on enhancing the possibilities to control their own lives. Kieffer's (1984) emphasised individual empowerment as a gradual process involving four stages: entry, advancement, incorporation, and commitment. Empowerment develops from marginal, to substantial and eventually, structural participation. Thus the four stages are essential so that active participation can lead to continual community involvement. Zimmerman (1995) defined empowerment as the act of enabling people to gain skills and abilities to act on their own in order to reach their selfdefined goals. Much of the existing research defining and measuring empowerment is based on work with adults, but it is unclear how this translates into understanding the needs of and best ways of delivering services for young people with mental health problems.

The few studies that currently exist within the literature on empowerment in young people are derived from youth empowerment models (Benson et al., 1998; Cargo et al., 2003; Chinman & Linney, 1998; Freire, 1970; Kim et al., 1998; Leffert et al., 1998; Walker et al., 2010). These youth models incorporate many of the key features of empowerment theory described by Rappaport (1987) and Zimmerman (1995, 2000) by facilitating the youth adult partnership model. These models demonstrate a meaningful engagement through genuine participation between adults, youth and organisations. They are grounded in providing the youth opportunities for skill development to enable them to act upon their own knowledge, gain critical awareness, set goals for themselves and to attain the capacity to influence the community and social structures that affect their lives. There is clearly consistency between models of empowerment developed from work with adults and those developed about young people. However, youth models (Benson, 2007; Cargo et al., 2003; Chinman & Linney, 1998; Freire, 1970; Kim et al., 1998) are largely theoretically based and thus the conceptualisation of empowerment has not been developed directly from the perspective of young people.

Our earlier work (Grealish et al., 2011) aimed to address this gap by examining the concept of empowerment directly from the perspective of young people with psychosis. Findings demonstrated that young people with psychosis regard empowerment as an on-going experiential process that develops over time, rather than a single state. From this perspective, an individual can be positively and negatively affected by every new contact with mental health services and the mental health professionals working with them. Empowerment was also regarded as crucial to recovery, quality of life, and being in control of their mental health and personal destiny. Young people reported frequent experiences of feeling disempowered by clinicians; usually due to ineffective communication, not having their needs understood, and lack of help to control and manage their problems themselves. These findings were consistent with previous studies, which highlighted the lack of choice, information and partnership experienced by young people (Carnegie UK, Trust, 2008; Day, 2008; Fraser & Blishen, 2007; Muir et al., 2012; Worrall-Davies & Marino-Francis, 2008).

The term empowerment is commonly encouraged for young people in programmes, service and government polices (Ahern & Fisher 2001; CAMHS Review, 2008; Cargo et al., 2003; DoH 2006; Foresight Mental Capital and Wellbeing Project, 2008; New Horizons, 2009; The Children's Plan, 2008; Walker & Gowen, 2011), but many young people still experience interventions being done 'to' or 'for' them instead of being focused on giving young people the knowledge, skills and resources to do things for themselves. The Children and Young People's Mental Health Coalition (2010) highlighted that if we help young people to foster knowledge, self-awareness and personal, social and emotional skills this can empower them to take increasing responsibility for their emotional health as they become adults and is likely to have the most significant and longterm impact on the mental health and emotional wellbeing of the next generation. As the interest in mental health prevention, health promotion and early intervention services is expanding for young people, availability of reliable and valid tools to measure empowerment becomes ever more necessary. The lack of means for assessing empowerment in young people is an obstacle to meaningful measurement for the purpose of understanding outcomes and consistent application in practice. In the current study, individual empowerment is defined as a process in which individuals gain control over their lives, develop the skills and abilities that equips them to decide on and take action regarding the issues of concern to them.

There are only two validated measures that focus on empowerment within young people - The Family Empowerment Scale (FES; Koren et al., 1992); and the Youth Empowerment Scale-Mental Health (YES-MH; Walker et al., 2010). The FES assesses empowerment in families/carers whose children have emotional or behaviour disorders, thus the focus is on parents of children with emotional or behaviour disorders as opposed to the young person directly. Walker et al. (2010) adapted the FES and designed a 20-itemed measure of empowerment for young people with mental health problems (the YES-MH). Their measure provides empowerment scores in three domains: self, services and system. Walker et al. (2010) adapted the FES in consultation with groups of young people to alter the wording of items. Factor analysis on sample of 185 young people revealed the scale to have good to excellent internal reliability. The three subscales are "plan and planning process reflect my perspective" (8 items, Cronbach's a=.898); preparation to participate (4 items, a=.750); and accountability (4 items, a=.784). However, as the FES was developed as family specific scale, there are concerns that conceptually, empowerment is still representative of an adult perspective. The specific relevance of the YES-MH for young people with mental health problems may be limited due to its original use as a carer scale. While changes were made these were decided upon by the researchers rather than developed from young people themselves. Given the contention that young people are even more likely to have a power differential with services, the dependent and disempowering nature of their relationships with carers must be considered. The YES-MH items do not arise from young people's experience.

A clear conceptualisation of empowerment from an adult perspective has been established in the literature; however, there is a need to develop similar understanding from the perspective of young people, along with suitable means for measuring empowerment. Such understanding could help to inform services promoting recovery, independence, and facilitating the uptake of social, educational and employment opportunities for those young people.

In the current study we utilised a continuum approach to understanding mental health, in which such problems are based on normal processes that are on a continuum with 'good' mental health at one end and severe mental illness at the other (Dogra et al., 2002). Approximately one-fifth of children and adolescents worldwide suffer from serious mental health problems (Belfer, 2008; Kessler et al., 2007) with approximately 1 in 10 children in England and Wales identified as having a treatable mental health disorder (Meltzer et al., 2000). A systematic review by (Kelleher et al., 2012) reported the median prevalence of psychotic symptoms was 17% among children aged 9 to 12 and 7.5% among adolescents aged 13 to 18. This study also reported how common psychotic symptoms are in young people and how prevalence is higher in younger children (9 to 12 years) compared to older children (13 to 18 years). On this basis, there is evidence for developing a measure of empowerment which is applicable for use with all young people. Therefore, the current study developed and validated the YES in a nonclinical sample (N=264). The next phase of the thesis aims to examine whether the measure maintains its psychometric properties in a clinical population.

The current study aimed to develop the new measure the Youth Empowerment Scale (YES) and provide a preliminary testing and validation of the new measure. The findings from our earlier qualitative study (Grealish et al., 2011) directly informed the development of the YES which suggested 6 main themes that captured the meaning of empowerment for young people with psychosis. We hypothesised that the YES would be a valid and reliable measure of empowerment in young people within a non-clinical population and that we could demonstrate convergent validity with other related constructs such as quality of life and wellbeing.

#### 4.3 Methods

#### 4.3.1 Participants

Two hundred and sixty four (n=264) participants completed the measures, 133 Males and 131 Females. Participants were aged 11-19 years of age, the mean age was 13.87 years (SD 1.833). All of the participants were attending secondary school; two schools in England and one school in Ireland. The ethnic groups

within the non-clinical sample were as follows: White British 40.5% (n=107), White Irish 32.2% (n=85), Black British 15.5% (n=41), Black Other 3.8% (n=10), Indian 3% (n=8), Pakistani 3% (n=8), and Asian Other 1.9% (n=5). Table 2.1 displays the descriptive statistics for this sample.

Our sample size was in accordance with recommendations for reliable estimation in factor analysis of between 5-10 subjects per variable or up to a total of 300 subjects, (Comrey & Lee, 1992; Field, 2009; Tabachnick & Fidell, 2001). Our power calculation indicated a minimum of 235 participants, on the basis of 5 participants per variable for the 47 items on the YES were required. 264 were recruited, which is considered a 'good' sample size for this particular analysis (Field, 2009; Pett et al., 2003).

## 4.3.2 Measures

All participants (n=264) completed the four scales outlined below:

#### 4.3.2.1 Item generation and development of the YES

Item generation and development of the YES

Items for the YES were developed from in depth interviews with young people with psychosis (Grealish et al., 2011). Qualitative analysis based on the Interpretative Phenomenological Approach (IPA) revealed six main themes, including: i) individual control and choices versus inflexibility; ii) being listened to, respected and validated; iii) communication; iv) response of services; v) coping and structure; vi) quality of relationship and support. Specifically, 47 items for the YES were initially generated from direct quotations related to each theme. Supporting quotations from the interviews conducted in phase 1 were identified for each of the six main themes, including the seventeen subthemes. Each quotation was then reworded to form a statement. For example both of these quotations below contributed to a final question (item 10) on the YES; "Generally, things to help you take control, having the freedom to do things in hospitals..." and "Helps you to stay in control and you get better quicker" contributed to item 10 'I feel I have control over my difficulties'. See Appendix 5 for the initial 47 items of the YES. All items generated were then refined in collaboration with participants who took part in the phase 1 study (young people with psychosis),

until a final consensus was reached between the research team and the young people. The penultimate version of the YES was a 47 item self-report measure that asked participants to respond to each item on a four-point Likert scale. Items were scored from 1-4, "not at all" (1), "somewhat" (2), "moderately so" (3), "very much so" (4), with higher scores indicative of someone with greater senses of empowerment. Reverse coding was used in order to reduce the tendency toward acquiescence and negative response biases and to encourage respondents to read each question carefully. Positively and negatively worded items were balanced throughout the scale, 11 of the items were scored negatively (highlighted in yellow in Appendix 5) and the remaining 36 items were scored positively. Participants completing the scale in the current study were instructed that "the experience of not being empowered is a common one. It is particularly common when under stress. Listed below are a number of attitudes and thoughts that people have expressed about not being empowered".

# 4.3.2.2 The General Health Questionnaire (GHQ-12)

The GHQ-12 (Goldberg, 1972; Goldberg & Williams, 1988) has been found to be reliable and well-validated tool for determining the severity of psychological problems as well as general wellbeing in both adults and adolescents (Gao et al., 2004; Goldberg et al., 1997; Tait et al., 2002). The GHQ-12 is a 12 item self-report questionnaire that asks whether the participant has experienced a particular symptom or behaviour recently. Responses are scored on a four-point likert type scale of 0 (less than usual) to 3 (much more than usual). The total score for each scale is found by adding the items together with a score of 15 or higher indicating psychological problems and lower general wellbeing. The GHQ-12 is a reliable instrument and has good content validity (Goldberg et al., 1997).

#### 4.3.2.3 The Making Decisions and Empowerment Questionnaire

The MDES (Rogers et al., 1997) is a 28-item self-report questionnaire that measures empowerment on a four-point Likert scale ranging from 1 (strongly agree) to 4 (strongly disagree). All the items are summed and averaged to arrive at an overall empowerment score. The MDES has five factors, which include 1) self-efficacy - self-esteem; 2) Power – powerlessness; 3) community activism; 4) righteous anger; and 5) optimism – control over the future. Responses were scored

on a four-point likert type scale of 1 (strongly agree) to 4 (strongly disagree). The lower the scores on the MDES the higher the levels of empowerment are perceived. Rogers et al. (1997) reported that the scale showed a satisfactory reliability in terms of internal consistency ( $\alpha = .86$ ) and good construct validity; being positively associated with quality of life, social support, and self-esteem and negatively associated with the use of traditional mental health services. Reliability coefficients for this scale are in the range of 0.73 to 0.85 (Strack et al., 2007).

#### 4.3.2.4 The EQ-5D

The EQ-5D (EuroQol Group, 1990) is a validated two-part measure consisting of a self-reported description and a self-rated valuation of health-related quality of life. The self-reported description is for health in the five domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Respondents were asked to rate their health in each domain on a three ordinal levels coded 1 (no problems), 2 (moderate problems), 3(severe/extreme problems, where lower scores indicating better health. The self-rated valuation uses a visual analogue scale (VAS) in the form of a 20-cm "thermometer" with a graduated 0-100 scale; with 100 representing "best imaginable health state" and 0 representing "worst imaginable health state". Respondents rate their health as they perceive it to be 'today' on the vertical scale at 0 ("worst imaginable health state") and at 100 ("best imaginable health state") indicating where they perceive their present state of health to lie, relative to these anchors. The EuroQol EQ-5D is both a validated and internationally acknowledged measure to describe and value health (Badia et al., 1996; Slevin et al., 1988). It is often used as an outcome measure in both clinical and health care service outcomes (Brooks et al., 2003; Rasanen et al., 2006).

#### 4.3.2.5 Demographic information

The demographic information (in Appendix 3) was collected for age, gender, city/town of residence, who do they live with and ethnicity. The 47 item YES was self-completed with the other measures. The teachers administered the measures with participants from the schools.

# 4.3.3 Ethical Approval

The current study was granted ethical approval (reference number: 01/07P) from the University of Manchester Research Ethics Committee, see Appendix 4. Written consent was obtained from all participants prior to participation. Agreement was obtained from the schools through which recruitment took place and parental ascent was also sought prior to obtaining consent from the young people participating in the study.

#### 4.3.4 Data Analysis

The data were analysed using Statistical Packages for Social Sciences (SPSS version 20). Frequency and descriptive statistics were presented for the demographic variables and to identify missing data, characteristics of the study variables and make comparisons of interest. Factor analysis is widely used for theory and instrument development and of an instrument within the health care arena. Exploratory factor analysis (EFA) was employed to assess the construct validity of the YES (Pett et al., 2003; Tabachnick & Fidell, 2001). Initially, EFA was used to reduce the set of variables in the YES and to examine how underlying constructs influenced the responses on a number of measured variables. For remaining items, internal consistency was assessed using Cronbach's alpha. Construct (concurrent) current validity was analysed using Pearson correlations, comparing the subscale scores between the YES and the scores on the other validated measures GHQ, EQ-5D and the MDES.

We followed three sequential steps for the EFA (Field, 2009; Hatcher, 1994; Kim & Mueller, 1978). The first step was to determine the factor extraction model. Principal component analysis (PCA) was conducted to reduce the number of variables by creating linear combinations that retain as much of the original measures' variance as possible. The second step was to determine the number of meaningful factors to retain. Using the scree test, all factors with eigenvalues over Kaiser's criterion of greater than 1 would be retained (Kaiser, 1960). The third step was to apply oblique rotation to aid interpretation of the factors. This identified which items loaded on to each retained factor, followed by conceptualising meaning of items that loaded on the same factor, and

conceptualising the differences in items that loaded on different factors. The criteria for retaining items were: (i) items with loadings of .40 or higher and (ii) a crossloading item that loaded at .40 or higher on two or more factors was eliminated from the analysis. Tabachnick and Fidell (2001) state that .32 is a good rule of thumb for the minimum loading of an item. A factor with fewer than three items is viewed as generally weak and unstable whilst 5 or more strongly loading items are desirable and indicate a solid factor. An oblique rotation was used because it was hypothesised that there would be a correlation between the emerging factors.

#### 4.4. Results

# 4.4.1 Frequency Distribution

Prior to conducting EFA on the YES, the data was screened using frequency analysis and item non-responses were noted. Table 2.1 describes the sample and range of scores for the participants were evenly distributed. The distribution of scores for this sample are displayed in Figure 2.1 which showed near-normal distribution. Examination of the missing data shows that there was more missing from males compared to females but this was not significant (p=.49), see Table 2.2.

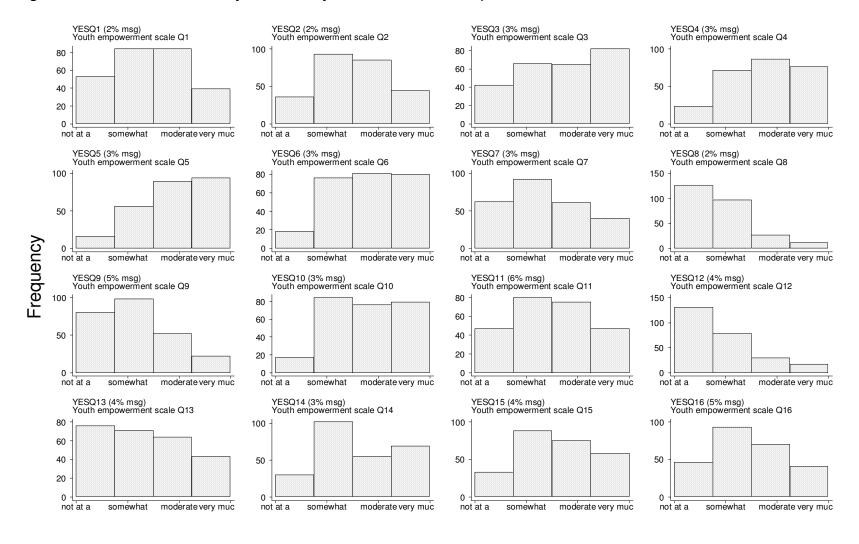
Table 2.1 Phase 2: Descriptive Statistics

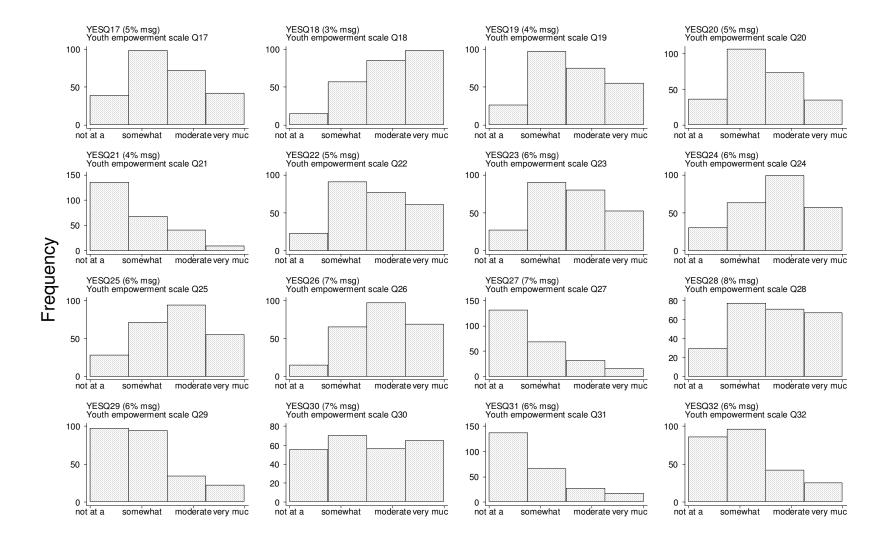
Variable	Summary Statistics			
<b>Age</b> (n=264)	Mean 13.87 Std. Deviation 1.833 Range 11-19			
Gender (n=264)	N %			
Male	133	50.4		
Female	131	49.6		
Ethnicity (n=264)	N	%		
White British	107	40.5		
White Irish	85	33.2		
Black British	41	15.5		
Black (other)	10	3.8		
Indian	8	3.0		
Pakistani	8	3.0		
Asian Other	5	1.9		

## 4.4.2 Gender differences

An independent samples t-test was conducted to understand whether empowerment, mental health and quality of life differed by gender. As can be seen in Table 2.2 males scored slightly higher on the empowerment scale (YES) and they also scored better on the mental health outcomes (GHQ-12). There was no significance differences found in the YES (p=0.49), EG5D (p=0.25), EQ5D-VAS (p=0.22) and MDES (p=0.88) scores between genders. There was a significant difference in the GHQ-12 for males (m=20.48, SD=4.97) and for females (m=22.27, SD=5.632); t(245)=-2.640, p=0.009.

Figure 2.1 Phase 2 Distribution of Item Scores for the Non-Clinical Sample





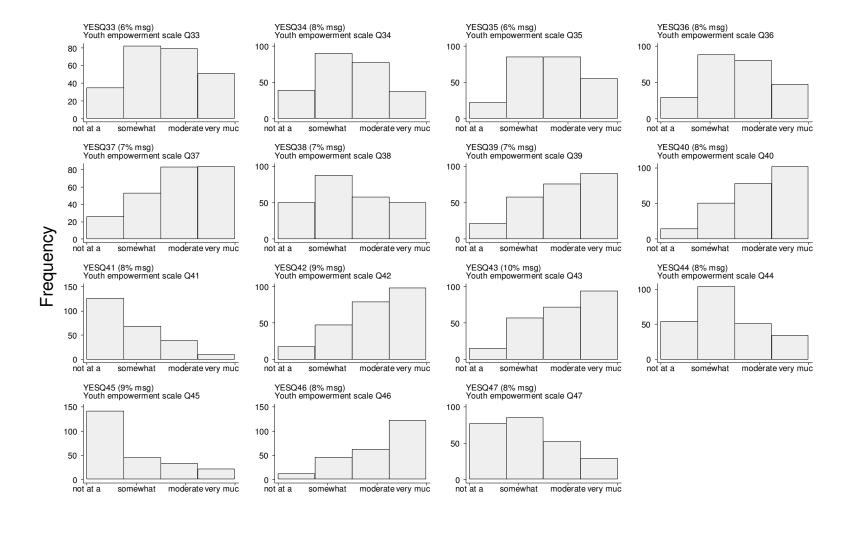


Table 2.2 Phase 2: Group Statistics and Independent Samples Test

	Group Statistics				Independent Samples Test t-test for Equality of Means				
	Gender	N	Mean	Std. Deviation	t	Df	Sig. (2-tailed)	95% Confidence Interval of the Difference	
							,	Lower	Upper
YES		189	58.08	11.007	.680	187	.497	-2.084	4.275
	Male	85	58.68	9.969					
	Female	104	57.59	11.813					
GHQ		247	21.37	5.374	-2.640	245	.009	-3.116	453
	Male	124	20.48	4.971					
	Female	123	22.27	5.632					
EQ5D		245	5.67	1.208	1.134	243	.258	129	.480
	Male	114	5.76	1.459					
	Female	131	5.59	.935					
EQ5D VAS		242	78.55	21.671	-1.227	240	.221	-8.923	2.073
	Male	112	76.71	25.256					
	Female	130	80.13	17.974					
MDES		191	60.73	9.888	145	189	.885	-3.090	2.667
	Male	78	60.60	12.434					
	Female	113	60.81	7.718					

# 4.4.3 Explorative Factor Analysis

The KMO statistic value was 0.84, exceeding the recommended value of 0.6 (Kaiser, 1970), Bartlett's Test of Sphericity was significant (p < 0.0001), and the determinant of the correlation matrix (=4.39, E=011) supporting the suitability of PCA with this data set.

The next step was determining the number of factors to retain. The first solution identified thirteen factors with an eigenvalue greater than 1 and explained 63.62% of the total variance. The criteria for deleting items within a factor were: (i) items with loadings of less than 0.35 and (ii) a crossloading item that loaded at .35 or higher on two or more factors. Tabachnick and Fidell (2001) state that .32 is a good rule of thumb for the minimum loading of an item. A factor with fewer than three items is viewed as generally weak and unstable whilst 5 or more strongly loading items (>.35 or higher) are desirable and indicate a solid factor. All factors with eigenvalues greater than 0.35 were extracted which produced three clear factor solution. The total variance for first factor accounted for 32.4%, the second factor accounted for 9.2% and the third factor accounted for 7.6%. This suggests that the items on the YES are unidimensional.

The next step was the rotation and extraction of factors, to simplify and clarify the data structure. The entire n=264 was analysed via principal components analysis (PCA) and maximum likelihood (ML) extraction methods, followed by oblique (direct oblimin) rotations. Twenty six items in total were eliminated on the basis of the item selection criteria described above (PCA, eigenvalues greater than 0.35 and oblique rotation) which retained and supported a three factor solution in Table 2.3. Factor loadings for the YES are clearly defined, with high factor loadings ranging from .367 to .762 on factor one, .492 to .674 on factor two, and .423 to 636 on factor three. The three factors retained in the EFA reduced the YES from 47 items to 21 items (see Table 2.4). All items were theoretically checked followed by conceptualising the meaning of items that loaded on the three factors. These were compared to the findings in our earlier study (Grealish et al., 2011) and used to interpret the results.

The final step of the EFA was interpreting the factors, presented in Table 2.3. Factor one consisted of 9 items and was labelled as *'receiving help and validation'*. Factor two consisted of 5 items and was labelled *'choice and control'*. Factor three consisted of 7 items and was labelled *'effective help-seeking'*. The descriptive statistics for each subscale were as follows: factor 1 (mean=22.71, SD=6.01), factor 2 (mean 14.37, SD 3.54), and factor 3 (mean=20.86, SD=4.08).

# **4.4.4 Internal Consistency**

Cronbach's alpha was used as a measure of internal reliability and the YES displayed excellent internal reliability on the Total Score ( $\alpha = 0.89$ ). Cronbach's alpha coefficients were also computed for internal consistency of items on the three factors (factor 1  $\alpha$ =0.86; factor 2  $\alpha$ =0.78; factor 3  $\alpha$ =0.76) indicating good internal consistency. Item-total correlations were therefore reasonably strong in demonstrating reliability and supporting the items on the three factors.

Table 2.3 Phase 2: Factor structure and item loadings for 3 factor solution of the YES. Factor loadings <.35 not shown

	Receiving Help	Choice and	Factor 3 Effective
	and Validation	control	Help-Seeking
Q17 I feel understood by adults (apart from family & friends)	.762		
Q14 I feel that adults (apart from family & friends)	.749		
listen to me when I have a problem			
Q15 When I tell adults (apart from family &	.749		
friends) about a problem I feel they support me			
Q16 I feel that adults (apart from family & friends)	.724		
take my point of view seriously			
Q20 If I talk to adults (apart from family & friends)	.687		
about a problem, I feel believed			
Q19 If I ask an adult (apart from family & friends)	.646		
for help, they hear what I say and use this to help			
me			
Q30 I have other adults (apart from family &	.518		
friends) that I feel I could go to if things are			
difficult for me			
Q34 Other people (apart from family & friends)	.468		
have been useful in helping me to find ways to			
cope with my problems			
Q22 Other people take the time to explain things	.367		
to me			
Q6 When things go wrong I still feel able to make		.674	
choices what I want to do			
Q10 I feel I have control over my difficulties		.664	
Q5 I feel I can make my own decisions about		.647	
what I do to help me feel better about my			
difficulties		504	
Q4 I feel my ways of coping are respected by		.581	
Q3 When I need help from others to deal with my		.492	
problems, I feel I have a say in how they treat me		.492	
Q26 When I have been unwell other people have			.636
been willing to listen to my problems			.000
Q25 When I have been unwell other people have			.609
told me how to deal with things			.000
Q24 When I have been unwell I needed			.559
treatment, other people have explained this to			
me			

Q18 I feel that being listened to helps me cope with my problems	.498
Q43 It is easier to talk to the adults I spend time	.455
with about my problems	
Q40 If I feel comfortable with an adult I find it	.429
easier to go and ask that person for help	
Q46 My parents helps me to sort things when I	.423
am unwell	

Table 2.4 Phase 2: Youth Empowerment Scale (YES)

		Not at all	Somewhat	Moderately so	Very much so
	feel understood by adults (apart from amily & friends)	1	2	3	4
f	feel that adults (apart from family & riends) listen to me when I have a problem	1	2	3	4
f	When I tell adults (apart from family & riends) about a problem I feel they support me	1	2	3	4
	feel that adults (apart from family & riends) take my point of view seriously	1	2	3	4
	f I talk to adults (apart from family & riends) about a problem, I feel believed	1	2	3	4
f	f I ask an adult (apart from family & riends) for help, they hear what I say and use this to help me	1	2	3	4
f	have other adults (apart from family & riends) that I feel I could go to if things are difficult for me	1	2	3	4
f	Other people (apart from family & riends) have been useful in helping me to find ways to cope with my problems	1	2	3	4
	Other people take the time to explain hings to me	1	2	3	4
	When things go wrong I still feel able to make choices what I want to do	1	2	3	4
11. I	feel I have control over my difficulties	1	2	3	4
a	feel I can make my own decisions about what I do to help me feel better about my difficulties	1	2	3	4
	feel my ways of coping are respected by others	1	2	3	4
V	When I need help from others to deal with my problems, I feel I have a say in now they treat me	1	2	3	4
15. \	When I have been unwell other people nave been willing to listen to my problems	1	2	3	4
	When I have been unwell other people nave told me how to deal with things	1	2	3	4

17. When I have been unwell I needed treatment, other people have explained this to me	1	2	3	4
18. I feel that being listened to helps me cope with my problems	1	2	3	4
19. It is easier to talk to the adults I spend time with about my problems	1	2	3	4
20. If I feel comfortable with an adult I find it easier to go and ask that person for help	1	2	3	4
21. My parents helps me to sort things when I am unwell	1	2	3	4

# 4.4.5 Construct validity

Pearson correlation coefficients were conducted to examine concurrent validity of the YES in relation to GHQ, EQ-5D and the MDES (see Table 2.5).

Table 2.5 Phase 2: Construct Validity / Correlations

		YES21Total	GHQtotal	EQ5Dtotal	EQ5DVAS	
GHQtotal	Pearson Correlation	-0.433 <sup>**</sup>				
	N	178				
EQ5Dtotal	Pearson Correlation	-0.386**	0.384**			
	N	187	230			
EQ5DVAS	Pearson Correlation	0.353**	-0.390 <sup>**</sup>	-0.405**		
	N	184	228	239		
MDESTotal	Pearson Correlation	-0.336**	0.151 <sup>*</sup>	0.261**	-0.407**	
	N	155	179	191	188	
**. Correlation is significant at the 0.01 level (2-tailed).						
*. Correlation is significant at the 0.05 level (2-tailed).						

Statistically significant correlations (P <0.05) were found between the YES and the GHQ-12 (r = -0.433, p <0.001) and the self-reported description of the EQ-5D (r = -0.386, p <0.001). Positive correlation was found between the YES and the self-rated valuation of the EQ-5D (VAS) (r = 0.353, p <0.001), and an inverse correlation with the MDES (r = -0.336 p <0.001). These provide support for the hypothesis that experiences of empowerment are associated with a better quality of life and mental wellbeing. Several studies in young people and adults have

linked empowerment to better mental health, wellbeing and recovery (Benson, 2007; Carnegie UK Trust, 2008; Marshall et al., 2005; Pitt et al 2007; Walker et al., 2010). These studies suggest that empowerment is linked with better prognosis, decease in relapse and rehospitalisation, and better quality of life. Given that the psychological wellbeing in children and young people has become a priority and increasingly important outcome of healthcare (DCSF, 2010; DoH, 2006; NAC, 2011; NCSS, 2011), we hypothesised that the YES would correlate with established questionnaires that measures these construct. This study shows how these established scales correlated with the YES which further supports the hypothesis that experiences of empowerment are associated with a better quality of life and mental wellbeing.

#### 4.5 Discussion

The aim of this study was to develop a reliable and valid scale for measuring empowerment in a non-clinical population as part of a larger study to validate the scale with a clinical population. This study examined the properties of the YES and the results demonstrated that the YES performs well as a general measure of empowerment, with good internal consistency and concurrent validity. The measure has face-validity with items chosen to reflect the six main themes of empowerment identified in our earlier study: Individual control and choices versus inflexibility; Being Listened to; Respected and Validated; Communication; Response of Services; Coping and Structure; and Quality of Relationship and Support which reflected the concept of empowerment for young people with psychosis (Grealish et al., 2011). On the new scale the scores were welldistributed and showed near-normal distribution. Accordingly, this suggests that floor and ceiling effects are minimised for practical applications. This is important for a tool designed as a generic measure of assessing empowerment in young people who faces significant mental health challenges and a growing commitment to ensure young people's voice are heard when receiving care from CAMHS. The psychometric properties of the scale proved to be good and show well-distributed scores robust to demographic variation.

In line with much previous research, this study confirmed a strong link between empowerment and better mental health and quality of life (e.g. Benson, 2007; Carnegie UK Trust, 2008; Marshall et al., 2005; Walker et al., 2010). While there is evidence about the role of empowerment in improving health and wellbeing particularly in adults, there is no research we know of that has directly evaluated the effect of empowerment on young people with psychosis. Although there is evidence to suggest that empowerment is strongly linked with recovery in adults with psychosis (Pitt et al., 2007), this relationship needs to be further explored in young people with psychosis. The data presented here confirm that experiences of empowerment, mental health and quality of life are common in the non-clinical population of young people as correlations between empowerment, mental health and quality of life were found in this sample. Participants with lower scores of empowerment had higher levels of psychological problems and lower general wellbeing as measured on the GHQ-12. This result is considered to be consistent with Resnick et al., (2004); Pitt et al., (2007); and Salmon & Hall (2003). These scales examined the positive relationship between empowerment, recovery and general wellbeing for people living with mental illness. Participants with higher scores of empowerment had better health as measured by low score on the first part of the EQ-5D and high score on the second part VAS of the EQ5-D. This hypothesis tested convergent validity. There was a significant inverse correlation between participants' scores on the YES and those on MDES (Rogers et al., 1997). Participants with high scores of empowerment had also greater general empowerment as demonstrated by lower scores on the MDES. This hypothesis tested convergent validity.

#### 4.6 Methodological Limitations

Our findings were entirely based on non-clinical data from young people attending secondary schools. This has implications for the extent to which findings from this sample (n=264) can be generalised to young people with mental health problems such as psychosis. Despite this, the findings confirmed reliability and validity of the scale as it correlated with other validated measures such as MDES, GHQ-12 and EQ5D. We plan to validate the YES in a clinical sample using confirmatory factor analysis (CFA).

#### 4.7 Conclusion

This study sought to develop and validate a scale to measure empowerment for young people using EFA. Three factors consisting of 21 items were established. Cronbach's alpha for the total scale was .89. The items were considered to be both conceptually and theoretically congruent with the functions of empowerment as proposed by young people in our earlier study (Grealish et al., 2011). The study tested content and convergent validity associated with the scale, and significant relationships were found to exist between this new measure and validated measures of wellbeing, quality of life and the making decisions and empowerment questionnaire. This study showed that there is a correlation between the sense of empowerment and increase in wellbeing and quality of life. Few quantitative studies on how empowerment correlates to general wellbeing and quality of life have been conducted and we know of no previous studies that directly tested this relationship in young people. This study has demonstrated how the new measure correlates well with general wellbeing and quality of life and concludes that the YES has performed well with this population.

# Chapter 5: Phase Three - Does Empowerment Mediate the Effects of Psychological Factors on Mental Health, Wellbeing, and Recovery in Young People?

#### 5.1 Abstract

**Purpose and Aim:** There is clear consensus that empowerment is key to recovery from mental health problems, enabling a person to take charge of their life, and make informed choices and decisions about their life. However is, little known about the mechanisms through which empowerment effects mental health in young people. The current study involved young people aged 16-29 years, and examined empowerment as a potential mediator of the relationship between psychological factors (social support, cognition, coping, and control) and mental health, wellbeing and recovery from personal problems.

**Methods:** A cross sectional, internet-based questionnaire study recruited 436 young people aged between 16-29 attending three universities in England (n= 363) and Ireland (n= 56). Psychological factors, mental wellbeing, empowerment, and recovery from personal problems were measured through participants completing the following self-report measures of; the General Self-Efficacy Scale, Rotter's Internal and External locus of control scale, the Brief COPE, the Significant Others Scale, the Thought Control Questionnaire, Dysfunctional Attitude Scale, the Brief Core Schema Scale, the 12-Item General Health Questionnaire, the BBC Well-being Scale, the Youth Empowerment Scale, and the Process of Recovery Questionnaire.

**Results:** Mediation analysis revealed that empowerment does mediate the relationship between psychological factors and mental health, wellbeing, and recovery from general life problems. This mediation model proposed that social support, thinking style, coping, and control are important psychological factors related to mental health, wellbeing and recovery, with empowerment as the mediator.

Conclusions: The results of this study contribute to understanding the importance of empowerment by demonstrating it mediates the relationship between psychological processes and mental health, wellbeing and recovery in young people. Clinical implications for clinicians working within CAMHS, and facilitating empowerment within young people experiencing mental health problems, are discussed.

#### **5.2 Introduction**

There is clear evidence that empowerment is key to achieving positive mental health, recovery, and wellbeing (Brosnan, 2012; Harper & Speed, 2012; Pitt et al., 2007; WHO, 2009; Woodall et al., 2010). Subsequently, there is increasing recognition of empowerment being important from the perspective of young people with mental health difficulties and the need for services to be empowerment orientated (DH & DCSF, 2009; DfES, 2006, 2003; DoH, 2004). The current study examined empowerment as defined from a young person's perspective (Grealish et al., 2011). This definition relates to the work of Rappaport (1987) with adults, who defined individuals as being empowered when they gain control over their lives; with emphasis on individuals being experts in their own expression through thoughts, feelings, actions, and beliefs. It is also consistent with Zimmerman's validation model of psychological empowerment (Zimmerman, 1995) which regards empowerment as a process which helps the individual gain control over their lives by equipping them with skills and abilities to act on issues that they define as important.

The importance of empowerment in relation to mental health from an adult perspective is well documented (Brosnan, 2012; Frame, 2003; Garcia et al., 2007; Harper & Speed 2012; Pitt et al., 2007; Starkey, 2003; WHO, 2010; Woodall et al., 2010), but far less understood from the perspective of young people. Although there is no single definition of wellbeing it is perhaps best defined by Beddington et al. (2008) as a state "in which the individual is able to develop their potential, work productively and creatively, build strong and positive relationships with others, and contribute to their community". We hypothesised that empowerment would mediate good psychological wellbeing. Grealish et al. (2011) demonstrated that young people experiencing psychosis perceive empowerment to be

fundamental in their recovery, and for increasing quality of life, a sense of agency, and wellbeing. Young people believe that empowerment cannot be 'given' but is, instead, developed through a collaborative endeavour between clinicians and service users. Young people assert that such a collaboration can facilitate their feeling empowered by clinicians demonstrating respect and empathy, providing information and psycho education relevant to their difficulties, teaching them coping strategies, spending time with them, listening to them, and offering emotional support (Grealish et al., 2011; Mitcheson & Cowley, 2003; Starkey, 2003; Walker & Donaldson, 2011).

This is the first study within the literature exploring the relationship between psychological processes, empowerment and mental health in young people. The psychological processes measured in this study were derived from the six main themes captured in our qualitative study, which were instrumental in feeling empowered in young people (Grealish et al., 2011). These findings are consistent with evidence from studies with adults which also demonstrate that empowerment is related to self-efficacy (Moattari et al., 2012; Small et al., 2013; Walker & Gowen, 2011), a sense of coping strategies (Ben-Zur & Yagil, 2005; Gutierrez & Nurius, 1994; Wallerstein, 1993), perceived control (Anderson, 1996; Koelen & Lindstorm, 2005; Conger & Kanungo, 1988; WHO, 2010), thinking style (Thomas & Velthouse, 1990), and social support (Logan & Ganster, 2007). Furthermore, these psychological factors, within adults, have also been associated with better mental health, wellbeing and recovery from mental health difficulties (Bonney & Stickley, 2008; Kinderman et al., 2011; Neil et al., 2009; WHO, 2009). Despite increasing recognition of empowerment being important from the perspective of young people with mental health difficulties and the need for services to be empowerment orientated (DH & DCSF, 2009; DoH, 2004, 2006), there is almost no research exploring the psychological mechanisms through which an individual experiences feeling empowered amongst young people. A brief rationale for the psychological processes targeted in the current study will now be provided.

Young people define self-efficacy as a belief that one has the capabilities to accomplish goals and overcome obstacles, resulting in effective problem solving

(Grealish et al., 2011). Self-efficacy is a thinking style that influences a person's behaviours, judgments, and belief ability to succeed in a particular situation (Bandura, 1994). Bandura (1994) found that higher levels of self-efficacy enhanced human accomplishment and personal wellbeing, while those with lower levels of self-efficacy found challenges threatening, and often gave up when faced with challenges. This suggests that self-efficacy in young people with mental health problems is related to increased confidence in their own abilities to exercise greater control over difficult situations.

'Control' was described by young people as a process of gaining a sense of having perceived personal control over difficulties or situations that arise, in relation to mental health problems (Grealish et al., 2001). This sense of personal control is embedded within Rotter's social learning theory (Rotter, 1966, 1982) of locus of control, which reflects an individual's belief that they are able to control the outcomes of events. This association between control and empowerment is also evidenced within the literature from an adult perspective (Hansson & Bjoorkman, 2005; Leksell et al., 2007; Rappaport, 1987; Rogers et al., 1997; WHO, 2010; Woodall et al., 2010) and demonstrates people cannot achieve their fullest health potential unless they are able take control of the things that determine their health. Marmot et al. (2008) and Syme's (2004) work on social determinants of health provides good evidence for this. Their work is important in relation to empowerment and control in the general population as it demonstrated that the amount of control people tended to have over their circumstances was greater as their job status increased, and that health status was related to where on the employment hierarchy ladder they were. They argued that the more control one has over things that are important to them the better their mental and physical health is.

The development of coping skills in adolescence is an important factor in helping young people to maintain positive adaptation to stressors as psychosocial stress can occur as a result of significant adversity (Compas et al., 2001). Coping utilises personal resources to deal with difficult situations, and empowerment is the positive outcome of doing so. Coping is the key foundation to empowerment, as it helps to foster personal resilience through the utilisation of resources. The positive

effects of having coping strategies, such as dealing with the symptoms of psychosis, is well evidenced in the literature (Goldberg et al., 2007; Tarrier, 2000; Zeidner & Endler, 1996; WHO, 2010).

Reduced thought control and negative beliefs are characteristics of people with psychosis (Hutton et al., 2013; Morrison & Wells, 2007; Morrison, 2001; Varese et al., 2012). Addressing thinking style is a key factor in empowerment as the majority of people diagnosed with schizophrenia and psychoses experience social and vocational disability which diminishes their quality of life and can limit their recovery (Grant & Beck, 2009; Neumann et al., 1998; Warner, 2004). This understanding is consistent with how young people with psychosis in our earlier study (Grealish et al., 2011) reported being able to control their thoughts made them feel empowered.

People suffering from mental health disorders have been shown to have poor levels of social adjustment and difficulty with interpersonal relationships and have difficulty in forming an adequate supportive social network (Brenner et al., 1994; Roder et al., 2006, 2011; Royal College of Psychiatrist, 2010; Weissman et al., 2007). Social support can help with the interpersonal difficulties and reduction in social contacts associated with psychosis (Roder et al., 2006; Royal College of Psychiatrist, 2010). Young people who feel more connected to their families, friends, clinicians, society (education/training) and CAMHS felt more empowered, less troubled by their symptoms and were less likely to have suicidal thoughts or behaviour (Grealish et al., 2011). Supporting young people to access education and employment can be empowering as these activities can reduce social isolation and exclusion from social relationships and the wider community (Royal College of Psychiatrist, 2010; Wallertstien, 2006).

Empowerment clearly has an impact on psychological processes as it has the potential to improve mental health, wellbeing and recovery in young people. What is unclear is how empowerment and psychological processes are linked. For the purpose of this study we consider that mental health problems are based on normal processes that are on a continuum with 'good' mental health at one end and severe mental illness at the other (Dogra et al., 2002). Population-based

studies have demonstrated how psychotic symptoms are common, with a prevalence rate of 5–8% in the general population, which is approximately ten times higher than the prevalence of diagnosed psychotic disorders (Kelleher et al., 2009; Moffitt et al., 2010; van Os et al., 2000, 2008; van Os, 2003). A systematic review by Kelleher et al. (2012) showed how common psychotic symptoms are in young people and how prevalence is higher in younger children (9 to 12 years) compared to older children (13 to 18 years). This review reported the median prevalence of psychotic symptoms as 17% among children aged 9 to 12 and 7.5% among adolescents aged 13 to 18. Therefore there is clear justification for exploring the role of empowerment in a non-clinical population. The relationship between psychological variables, empowerment and wellbeing is common to all young people so can be understood by looking at a non-clinical population. These findings might then be applied to people with mental health difficulties.

The current study aimed to explore the relationship between psychological processes (self-efficacy, control, coping, thinking style and social support) empowerment, and mental health, wellbeing, and recovery. We hypothesised that empowerment will mediate the impact of psychological processes on mental health, wellbeing, and recovery.

#### 5.3 Methods

#### **5.3.1 Participants**

A cross sectional, Internet based self-report questionnaire study was conducted. Four hundred and thirty six (n=436) participants completed the measures, 254 Females and 182 Males. Participants were aged 16-29 years (mean age was 23.50 years (SD 3.667)). All participants were attending universities; three universities in England (n=343) and one university in Ireland (n=93). The ethnic groups within the sample were as follows: White British 49.8% (n=217), White Irish 22.5% (n=98), Black British 12.2% (n=53), Black Other 5.7% (n=25), Pakistani 3.7% (n=16), Indian 3.4% (n=15), and White Other 2.8% (n=12). Participants were asked to provide details of their current educational or organisation status and city they live in. Table 3.1 displays the characteristics and the descriptive statistics for this sample.

Table 3.1 Phase 3: Descriptive Statistics

Variable	Summary Statistics		
<b>Age</b> (n=436)	Mean 23.50 Std. Deviation 3.667 Range 13		
Gender (n=436)	N	%	
Male	182	41.7	
Female	254	58.3	
Ethnicity (n=436)	N	%	
White British	217	49.8	
White Irish	98	22.5	
Black British	53	12.2	
Black (other)	25	5.7	
Pakistani	16	3.7	
Indian	15	3.4	
White (other)	12	2.8	

#### 5.3.2 Measures

Participants were required to provide demographic information (in Appendix 6), including sex, age, living circumstances, name of their current School / Organisation / University / Place of Work /Other, and ethnicity. Eleven further self-report measures were administered through an Internet based webpage using SelectSurvey, taking approximately 40 minutes to complete. Due to logistical constraints of the web SelectSurvey, measures were presented in a fixed order.

## 5.3.2.1 Measures of Psychological Processes:

## 1. Self-efficacy:

The General Self-Efficacy Scale (GSE; Sherer et al., 1982) is a 30-item self-report questionnaire that measures the participants' general self-efficacy expectations in relation to educational, vocational, and social domains. Responses to statements are scored on a five-point Likert scale of 1 (disagree strongly), 2 (disagree somewhat), 3 (neither agree or disagree), 4 (agree somewhat), 5 (agree strongly). Higher scores indicate greater self-efficacy. Internal consistency reliability findings for the general self-efficacy and social self-efficacy subscales were .86 and .71 respectively (Sherer et al., 1982). This measure has been found to be a

well-validated tool for assessing general and social efficacy and is widely used in clinical, educational, and organisational settings (Chen et al., 2001). It has proven valid in terms of convergent and discriminant validity with self-esteem, anxiety and depression (Hays & Buckle, 1992; Saltzman & Holahan, 2002).

#### 2. Control:

Rotter's Internal and External (I-E) locus of control scale (Rotter, 1966) consists of 23 forced choice (internal versus external statements) and 6 self-report inventory for a total of 29 paired statements which high scores reflect external locus of control and low scores reflect internal locus of control (Rotter, 1966). Responses to statements in items 2a, 3b, 4b, 5b, 6a, 7a, 9a, 10b, 11b, 12b, 13b, 15b, 16a, 17a, 18a, 20a, 21a, 22b, 23a, 25a, 26b, 28b, 29a, were given each a one point score; whilst the remaining six items were scored as zero. A score of 0 to 7 is considered as high internal locus of control, a score of 8 to 18 is considered mixed meaning both internal and external locus of control, and a score of 19 to 23 is considered as high external locus of control (Rotter, 1966, 1975). The scale has good internal consistency, Cronbach's alpha of 0.74 to 0.88 (Anastasi, 1982; Spector, 1988). Rotter's scale has been widely used in school age children, adolescences, and adults and its validity has been documented in numerous studies during the past three decades (Judge & Bono, 2001; Phillips & Gully, 1997; Rotter, 1975; 1992).

#### 3. Coping:

The Brief COPE is a self-administered scale developed to identify coping response to stressful situations either generally or on specific occasions, (Carver, 1997). The Brief-COPE Inventory is consistent with the factor structure of the longer full inventory of the COPE (Carver et al., 1989). The Brief COPE is composed of 28 items, and yields 14 subscales with two items for which psychometric properties measure emotion-focused, problem-focused, and dysfunctional coping. Responses are scored on a four-point Likert-type scale of 1 (I haven't been doing this at all), 2 (I've been doing this a little bit), 3 (I've been doing this a medium amount), 4 (I've been doing this a lot); querying a variety of different coping methods (e.g., receiving emotional support from others, criticising oneself). The total score for each scale is found by adding the items

together with higher scores indicating greater intensity of use of the coping strategy. The measure has been validated under a number of investigations. Despite the fact that the scale had two items their reliabilities ranged from .50 to .90 (Carver, 1997).

## 4. Social Support

The Significant Others Scale (SOS) (Power et al., 1988) measures emotional and practical social support. Scores for actual and ideal levels of social support for a range of key relationships in a person's life are obtained. The current study utilised the short flexible SOS which asked the respondent to rate three potentially important relationships. Respondents were asked to rate that relationship to the actual levels of support they receive and their ideal levels of support on a 7-point Likert scale of 1 (never), 2 (very rarely), 3 (rarely), 4 (sometimes), 5 (somewhat frequently), 6 (frequently), 7 (always). A total score was obtained by summing the items to achieve a total score at an individual level; the higher the score the greater the frequency of actual or ideal support. The number of support figures gives a measure of structural aspects of support, whereas scores on emotional and practical functions give a measure of the quality of support. The SOS has good test re-test reliability (Johnston et al., 1995; Power et al., 1988) and found that the four functions i.e. actual emotional, ideal emotional, actual practical and ideal practical were significant ranging between .73-.83 for the constant role relationships.

## 5. Thinking Style

Three self-reported measures were employed: the Thought Control Questionnaire (TCQ; Wells & Davies, 1994), Dysfunctional Attitude Scale (DAS; Weissman & Beck, 1978) and the Brief Core Schema Scale (BCSS; Fowler et al., 2006).

## 5a) Thought Control Questionnaire (TCQ)

The TCQ is a 30 item self-report measure that assesses the frequency with which individuals use distraction, worry, punishment, reappraisal, and social control strategies to cope with unpleasant and unwanted thoughts. Items are scored on a four-point Likert-type scale of 1 (never), 2 (sometimes), 3 (often), 4 (almost always). The TCQ measures five factors (each based on six questionnaire items)

that represent different strategies for controlling unwanted thoughts: Distraction (item 1,9,16,19,21 and 30); Social Control (items 5, 8, 12, 17, 25 and 29); Worry (items 4, 7, 18, 22, 24 and 26); Punishment (items 2, 6, 11, 13, 15 and 28); and Re-appraisal (items 3, 10, 14, 20, 23 and 27). The Social Control sub-scale contains three reverse scored items (5, 8 and 12). After reverse scoring items 5, 8 and 12, the total TCQ score was obtained by summing up the six items for each of the five sub-scales, with higher scores indicating greater use of strategy. Wells and Davies (1994) reported moderately high internal consistency of the subscales, they found a Cronbach's Alpha scores ranging from .64 and .83, indicating that it is a stable measure.

## 5b) Dysfunctional Attitude Scale (DAS)

The DAS is a 40-item self-report measure for assessing attitudes associated with depressive symptoms. The DAS contains items that identify specific patterns of maladaptive thinking which are presented in seven major value systems: Approval, Love, Achievement, Perfectionism, Entitlement, Omnipotence, and Autonomy. Ten items represent functional beliefs and the other thirty items represent dysfunctional attitudes. Items are scored on a 7-point Likert scale of 1 (disagree totally), 2 (disagree very much), 3 (disagree slightly), 4 (neutral), 5 (agree slightly), 6 (agree very much), 7 (agree totally), and a total score can be obtained by summing the forty items. Scores ranges from 40 to 280, with higher scores indicating more dysfunctional attitudes and lower scores indicates more adaptive beliefs and fewer thinking styles. It has a very good internal consistency and stability. Weissman and Beck (1978) found a Cronbach's alpha internal consistency value of .89 and test—retest reliability of .81.

# 5c) The Brief Core Schema Scale (BCSS)

The BCSS is a 24-item self-report measure of core beliefs about self and others. It was specifically designed for clinical and non-clinical populations experiencing symptoms of psychosis. Participants were asked to indicate whether they held each belief using a dichotomous 'No' or 'Yes' format. If they answered yes to holding that belief they were then required to indicate how strongly they held the belief on a four-point Likert-type scale of 1 (believe it slightly), 2 (believe it moderately), 3 (believe it very much), 4 (believe it totally). Four sub-scales scores

are calculated: negative beliefs about self (six items), positive beliefs about self (six items), negative beliefs about others (six items) and positive beliefs about others (six items). Total scores for each of the four subscales can range from zero to 24 with higher scores indicating higher belief conviction or greater endorsement of items. The BCSS has adequate internal reliability and demonstrated concurrent and discriminant validity with Cronbach's  $\alpha$  coefficients >.78 (Fowler et al., 2006).

## 5.3.2.2. Measures of Empowerment:

The Youth Empowerment Scale (YES)

The YES (Grealish et al., submitted) is a 21-item self-report measure, developed on the basis of statements derived from interviews with service users' about their understanding and experience of empowerment (Grealish et al., 2011). Each item is rated on a 4-point Likert scale of 1 (not at all) to 4 (very much so) with higher scores indicative of empowerment. A total score can be obtained by summing the 21 items to achieve a total test score. The YES has excellent internal consistency and stability. Grealish (Submitted) found a Cronbach's alpha internal consistency value of  $\alpha$ = 0.89. The YES has also very good concurrent validity as it significantly correlated with other measures of empowerment and quality of life.

## 5.3.2.3. Measures of Mental Health, Wellbeing and Recovery

Three self-reported outcome measures were also obtained: The 12-Item General Health Questionnaire (GHQ-12; Goldberg & Williams, 1988), The BBC Wellbeing Scale (Kinderman et al., 2011), and the Process of Recovery Questionnaire (QPR; Neil et al., 2009).

## 7a) General Health Questionnaire (GHQ-12)

The GHQ-12 (Goldberg & Williams, 1988) consists of 12 items, which assess the severity of a mental problem over the past few weeks. Each item is rated on a four-point Likert-type scale of 0 (more so than usual), 1 (same as usual), 2 (less so than usual), 3 (much less than usual). The scale generates a total score ranging from 0 to 36 with higher scores indicate greater levels of general psychiatric distress (worse health) and lower general wellbeing. The internal consistency of

the GHQ-12 is in the range of 0.80 to 0.90 depending on the study, (Holi et al., 2003; Russ et al., 2012).

## 7b) BBC Wellbeing Scale

The BBC Wellbeing Scale (Kinderman et al., 2011) is a 24-item self-report assessment of general wellbeing, which contains three subscales: subscale 1 relates to psychological wellbeing which is represented by 12 items (5 to 16); subscale 2 relates to physical health and wellbeing and these are represented by 7 items (1-4, and 22-24); subscale 3 relates to relationships which are represented by items 5 items (17-21). Each item is rated on a 5-point Likert scale ranging from 0 (not at all), 1 (a little), 2 (moderately), 3 (very much), 4 (extremely) with higher scores indicative of wellbeing. The BBC well-being scale has excellent internal consistency, Cronbach's alpha coefficients for the total 24-item scale  $\alpha$ =0.93; subscale 1  $\alpha$ =92; subscale 2  $\alpha$ =88; subscale 3  $\alpha$ =78, (Kinderman et al., 2011).

# 7c) Questionnaire about the Process of Recovery (QPR)

The QPR (Neil et al., 2009) is a 22-item self-report measure assessment of personal recovery from psychosis. Since personal recovery is something experienced rather than assessed by an expert, this self-report measure was deemed appropriate for this study as it reflects the wider aims of recovery including quality of life and social relationships. It measures two domains of recovery, intrapersonal and interpersonal factors. Each item is rated on a 5-point Likert scale ranging from 0 (disagree strongly), 1 (disagree), 2 (neither agree nor disagree), 3(agree), 4 (agree strongly) with higher scores indicative of recovery. The QPR has good internal reliability and demonstrated concurrent and discriminant validity with Cronbach's alpha coefficients of subscale 1  $\alpha$ =0.94; subscale 2  $\alpha$ =0.77 (Neil et al., 2009).

## **5.3.3 Ethical Approval**

The current study was granted ethical approval (reference number: 653/07P) from the University of Manchester Research Ethics Committee, see Appendix 7. Consent was obtained from all institutions through which recruitment took place. Once consent was received from the establishment, young people were invited to take part through email advertising a web-based study investigating whether

empowerment mediate the effects of psychosocial factors on wellbeing in young people. Online consent was obtained from all participants prior to participation.

## **5.3.4 Statistical Analysis**

The data were analysed using Statistical Packages for Social Sciences (SPSS version 20) and the INDIRECT SPSS macro developed by Preacher and Hayes (2008). Frequency and descriptive statistics were presented for the demographic variables and to identify missing data, characteristics of the study variables and make comparisons of interest.

To test whether empowerment mediates the relationship between psychological processes, mental health, wellbeing, and recovery we used statistical mediation analysis, based on the causal steps process (Baron & Kenny, 1986). This involves:

- 1. estimating the effect of an independent variable (X) on an outcome (Y);
- 2. estimating the effect of *X* on the mediating variable (*M*)
- 3. estimating the effect of *X* and *M* on *Y* simultaneously.

The INDIRECT SPSS macro (Preacher & Hayes, 2008) were used to estimate the total effects and decompose these into direct and indirect effects. The total effect of X on Y can be expressed as the sum of the direct and indirect effects. The indirect effect is computed as a\*b. Preacher and Hayes (2008) argue that bootstrapping is the most powerful test of the indirect effect, and we used a bootstrap procedure with 1000 replications to compute 95% confidence limits of the mediated effect. Mediation was assessed by determining whether or not the confidence interval contains zero. All models adjusted for age and gender as possible confounders.

Several authors (Emsley et al., 2010; MacKinnon et al., 2004, 2004, 2007; Shrout & Bolger, 2002) highlight that this procedure can rely on untestable assumptions. Prominent amongst these is the assumption that there are no unmeasured confounders which could account for any observed associations. Due to the nature of the study design, we were unable to collect and adjust for all possible confounders in this analysis besides age and gender, and so results are considered to be association rather than causal effects.

#### **5.4 Results**

#### 5.4.1 Correlations:

Pearson correlation coefficients were calculated between total scores on all measures to test whether empowerment was significantly associated with self-efficacy, control, coping, thinking style, social support, mental health, wellbeing and recovery. It was predicted that empowerment would be positively associated with all the scales except the DAS, GHQ-12 and BCSS which would be negatively correlated. The results in Table 3.2 indicate that the strength of association between the measures and the YES is high and are statistically significant (P < 0.001). The correlation coefficients indicated that higher levels of empowerment equate to higher levels of recovery, mental health and wellbeing. The results in Table 3.2 indicate that there was a particularly strong positive correlations between the YES and the GES (r = 0.95, p < 0.001), SOS (r = 0.87, p < 0.001), RLC (r = 0.955, p < 0.001) and a high inverse correlation between the YES and the BCSS (r = -0.87, p < 0.001).

A correlation coefficient of 0.8 or 0.9 is regarded as a high correlation and indicates that there is a very close relationship between the variables (Cohen, 1988, 1992). However, Field (2009) cautions us when interpreting correlation coefficients as they give no indication of the direction of causality. Therefore we cannot assume that a cause-effect relationship exists between the variables for two reasons. Firstly, there may be other measured or unmeasured variables affecting the results and secondly, the correlation coefficient does not indicate which direction causality operates. For mediation analysis, it is useful to assess whether the independent X (psychological factors) and mediator M (empowerment) variables are correlated to be sure that M is actually offering some sort of mediation (Preacher & Hayes, 2008). In the current study, mediation analysis was undertaken using bootstrapping methods to test the size and significance of the indirect effect by determining whether or not the confidence intervals contained zero. However, the mediation analysis results below for these particular variables did show that empowerment contributed a significant effect over and above the independent variable alone.

Table 3.2 Phase 3: Correlations

		YES	SES	TCQ	DAS	ввс	QPR	ВСОРЕ	GHQ	BCSS	sos
GSE	Pearson Correlation	.955**									
GSE	N	436									
TCQ	Pearson Correlation	.639**	.679**								
ICQ	N	435	435								
DAS	Pearson Correlation	441 <sup>**</sup>	466 <sup>**</sup>	642**							
DAS	N	436	436	435							
ввс	Pearson Correlation	.646**	.686**	.811**	698**						
ВВС	N	436	436	435	436						
QPR	Pearson Correlation	.560**	.594**	.698**	788**	.878**					
QPR	N	435	435	434	435	435					
ВСОРЕ	Pearson Correlation	.747**	.794**	.829**	591 <sup>**</sup>	.864**	.750 <sup>**</sup>				
BCOPE	N	436	436	435	436	436	435				
GHQ	Pearson Correlation	587**	623**	735 <sup>**</sup>	.753**	921 <sup>**</sup>	953 <sup>**</sup>	786**			
GIIQ	N	434	434	433	434	434	433	434			
BCSS	Pearson Correlation	875**	838**	557**	.391**	566 <sup>**</sup>	497 <sup>**</sup>	655**	.514**		
ВСЗЗ	N	436	435	434	435	435	434	435	433		
sos	Pearson Correlation	.879**	.839**	.540**	357**	.547**	.470**	.641**	.494**	.962**	
303	N	435	435	434	435	435	434	435	433	434	
DI C	Pearson Correlation	.972**	.930**	.622**	430 <sup>**</sup>	.629**	.546 <sup>**</sup>	.728**	.572**	.853**	.880**
RLC	N	436	436	435	436	436	435	436	434	435	435

<sup>\*\*.</sup> Correlation is significant at the 0.01 level (2-tailed)

# 5.4.2 Mediation Analysis:

The total direct and indirect effects outputs are presented in Table 3.3.

- The total effect is significant for all relationships (p < 0.001). There was an association between social support, self-efficacy, thinking style, coping, and locus of control on wellbeing, mental health and recovery.
- The direct effect c path (X to Y controlling for the M) is significant for all relationships (p < 0.001). The estimated direct effect of social support, self-

efficacy, thinking style, coping, and locus of control on wellbeing, mental health and recovery, controlling for empowerment, were all significant.

Table 3.3 provides the indirect effects (path a\*b) for each combination of independent and dependent variables.

The results revealed a significant indirect effect for the SOS, TCQ, DAS, COPE, BCSS and RLC on all outcomes; where the confidence interval did not include 0, indicating that there is a statistically significant indirect effect. These values are shown in Table 3.3. There was no significant indirect effect for self-efficacy (GSE). The indirect effect of social support, thinking style, and locus of control on wellbeing, mental health and recovery through empowerment was statistically significant. These results indicate that individuals with mental health problems who experience empowerment are more likely to experience better mental health, wellbeing and recovery.

Table 3.3 Phase 3: Mediation Analysis of Independent Variable (IV) on Dependent Variable (DV) by YES

IV	DV	Total effect	Direct effect	Indirect Effect		Indirect effe	
				= a*b	Boot SE	Lower	Upper
sos	GHQ	0.2938	-0.0228	0.3232	0.4275	0.1943	0.4505*
sos	QPR	0.5351	-0.0467	0.6758	1.5265	0.3148	0.7689*
sos	Wellbeing	0.5944	-0.0343	0.7226	1.6022	0.3406	0.8870*
GSE	GHQ	0.3886	0.4415	-0.1681	0.3717	-1.0738	0.3934
GSE	QPR	0.7094	0.8030	-0.3120	0.6922	-1.9239	0.6965
GSE	Wellbeing	0.7821	0.8936	-0.3650	0.7121	-2.0436	0.6656
TCQ	GHQ	0.3149	0.2674	0.0470	0.0196	0.0194	0.1066*
TCQ	QPR	0.5711	0.4826	0.0868	0.0372	0.0368	0.2013*
TCQ	Wellbeing	0.6378	0.5442	0.0938	0.0416	0.0363	0.2150*
DAS	GHQ	-43.8132	-37.4786	-6.3151	2.1000	-11.7548	-3.0795*
DAS	QPR	-88.5205	-78.3146	-10.2706	3.4218	-18.1153	-4.8709*
DAS	Wellbeing	-72.7434	-57.6084	-14.9851	4.6654	-26.8605	-7.3640*
BCOPE	GHQ	0.4195	0.4170	0.0025	0.0015	0.0004	0.0070*
BCOPE	QPR	0.7651	0.7595	0.0056	0.0033	0.0011	0.0154*
BCOPE	Wellbeing	0.8457	0.8425	0.0032	0.0021	0.0006	0.0099*
BCSS	GHQ	0.1690	0.0011	0.1626	0.0310	0.1162	0.2428*
BCSS	QPR	0.3139	0.0194	0.2759	0.0548	0.2158	0.4179*
BCSS	Wellbeing	0.3396	0.0019	0.3280	0.0603	0.2280	0.4685*
RLC	GHQ	0.3037	0.2773	0.0270	0.0176	0.0059	0.0897*
RLC	QPR	0.5475	0.4989	0.0502	0.0328	0.0093	0.1458*
RLC	Wellbeing	0.6194	0.5669	0.0531	0.0332	0.0111	0.1632*

All total and direct effects are statistically significant (p<0.001)

<sup>\* 95%</sup> confidence interval does not contain 0, indicating that the indirect effect is statistically significant

#### 5.5 Discussion

The current study aimed to identify whether empowerment mediates the relationship between psychological processes (self-efficacy, social support, thinking style, coping, and locus of control) and mental health, wellbeing, and recovery from personal problems in a general population of young people. Young people with mental health difficulties previously identified the psychological variables examined in the current study as being associated with feeling empowered (Grealish et al., 2011), but these have never been explored in young people without mental health difficulties. As hypothesised, social support (SOS), thinking styles (TCQ, BCSS and DAS), coping mechanisms (COPE), and locus of control (RLC) directly predicted mental health, wellbeing, and recovery; but the relationship was stronger when mediated by empowerment. This has important implications for our understanding of the mechanisms through which empowerment is likely to be facilitated in young people. This is the first study to apply a formal statistical test of mediation on empowerment.

Participants who reported greater perceived control over unwanted thoughts (TCQ) and fewer cognitive distortions (DAS) scored higher on indicators of better mental health, wellbeing and recovery from personal problems. These associations were stronger when mediated by empowerment. This suggests that distress can be managed by targeting beliefs and attitudes. These findings are consistent with other studies, which show how poor quality of life and recovery is often found in people with mental health difficulties. However, empowering individuals to engage with services and the care they receive can help increase wellbeing and improve the chances of recovery (Birchwood et al., 2001; Fowler et al., 2009; Grant & Beck, 2009; Kinderman et al., 2011; Morrison et al., 2003; Warner, 2004). This study also highlights the importance for clinicians to inquire about the different ways in which individuals manage their thinking styles and provide some intervention for individuals who might perceive they have less control over their thinking and thus feel disempowered by perceived cognitive impairment and function. Studies by Abramowitz et al. (2003), Morrison and Wells (2007), and Morrison et al. (2003) demonstrated that punishment and worry-based strategies are associated with psychological dysfunction, whilst distraction and reappraisal may be helpful. Grant and Beck (2009) also found that defeatist beliefs regarding performance correlates with cognitive impairment, negative symptoms, and poor functioning in schizophrenia. They argued that by eliciting and modifying defeatist performance beliefs it is possible to increase engagement in constructive activity, which is consistent with our earlier study (Grealish et al., 2011). Results from the current study demonstrate that greater use of thought control and beliefs strategies is more likely to occur when an individual feels empowered.

The current study also found that empowerment partially mediates social support, whereby participants reporting better social support on the SOS were more likely to have better mental health and recovery from personal problems. Again, empowerment mediated the relationship between social support and mental health, wellbeing and recovery. These findings are consistent with other studies which emphasise on the negative impact of social impairment and isolation on people with mental health problems on the their ability to engage in employment, education, family and social relations (Brenner et al., 1994; Logan & Ganster 2007; NICE, 2003; Roder et al., 2006, 2011; Weissman et al., 2007). The emphasis on social support and meaningful connections between young people and clinicians was strongly associated with empowerment in our earlier study (Grealish et al., 2011). Young people reported how the lack of supportive and interpersonal relationships was seen as disempowering as it hindered their access to education, employment and social relationships thus increasing their social isolation. The current study also highlights how the mechanism of empowerment has a positive influence on social support. This is consistent with what young people reported in our earlier study in that social support and the quality of relationship delivered within services were fundamental to empowerment.

Positive mental and emotional wellbeing is dependent on good quality of relationships with family and friends which can help the person's ability to access employment, education and appropriate mental health services when needed. Studies by Addington et al. (2008), Pitt et al. (2007), and Wood et al. (2010) show how social support can help with the interpersonal difficulties and reduction in social isolation and exclusion which is often associated with psychosis. Our results show that obtaining social support is more likely for individuals who feel

empowered, thus increasing their chances of recovery and better mental health. These findings suggest that empowerment promotes and maintains good social support, therefore clinicians should facilitate young people establishing social networks, as this can empower them to engage in employment, education, family and social relations.

The current study also found that empowerment mediates the effects of locus of control and coping on mental health, recovery and wellbeing. In accordance with previous findings, there is an important association between empowerment and control (Hansson & Bjoorkman, 2005; Leksell et al., 2007; Marmot & Wilkinson, 2006; Marmot, 2007; Rogers et al., 1997; Rappaport, 1987; WHO, 2010; Woodall et al., 2010). Previous research has demonstrated that individuals cannot achieve their greatest health potential unless they perceive they have control of the things that determine their health. The current study further validates this finding and also corroborates what young people with mental health problems reported in our previous study (Grealish et al., 2011) in that control was crucial to being able to experience feelings of empowerment, enabling them to exert influence over their care, decision making and other difficulties. Through asking young people about perceived control, the current study highlighted the importance of control relative to empowerment for all young people. Individuals who have the capacity to act in response to distress appear to be able to exert more control over their experiences compared to those individuals with what Rotter (1966) describes as external locus of control. Individuals who have the capacity to take control are likely to experience empowerment while those unable to do so will not experience empowerment resulting in reduced motivation and productivity.

Our findings are also consistent with literature suggesting that empowerment and coping are interconnected and interdependent which leads to better outcomes (Compas et al., 2001; Goldberg et al., 2007; Nuechterlein, 1987; Walker & Gowen, 2011; Woodall et al., 2010; WHO, 2010). As young people reported in our earlier study (Grealish et al., 2011) coping is a key precursor to feeling empowered and in turn, this further enables the development of coping strategies required for dealing with stressful events and personal problems. The WHO (2009, 2010) also identified coping as the foundation of empowerment. Active

coping requires the ability to identify a specific problem, or stressor, and concurrently act to alleviate the effects of that stressor. The current study has implications for clinicians who might aim to facilitate young people being empowered to take charge of their own health by encouraging their confidence in and ability to play an assertive role in their own care.

Finally, the current study also examined the role of self-efficacy on mental health, wellbeing and recovery from personal problems. However, this was not partially mediated by empowerment. Although self-efficacy was significantly (p < 0.001) in the total effects it was not significant in the indirect effect. However the current study has demonstrated that empowerment can influence whether young people experience self-efficacy. Greater self-efficacy was positively correlated with better mental health, wellbeing and recovery from personal difficulties. This further supports Bandura's theory of self-efficacy, which purports that higher levels of self-efficacy improve individuals' sense of accomplishment and personal wellbeing (Bandura, 1994). Walker and Child (2008) also demonstrated that young people with serious mental health conditions who had higher levels of empowerment, self-determination, and self-efficacy were more likely to have improved health outcomes. Clinicians working with young people are encouraged to ensure individuals have confidence in their own abilities to exercise greater control over difficult to control situations.

# 5.6 Strengths and Limitations

This is the first known study that has examined whether empowerment mediates the relationship between psychological processes (self-efficacy, social support, thinking style, coping, and locus of control) and mental health, wellbeing, and recovery from personal problems in a general population of young people. This section will highlight some of the methodological constraints that need to be acknowledged when interpreting the results and consider possible future research directions.

Our findings were entirely based on a non-clinical data from young people attending university and therefore were not epidemiologically representative. This has implications for the extent to which findings from this sample (n=436) can be

generalised to young people with mental health problems, particularly psychosis across the clinical population. Despite this, participant's scores were normally distributed on all the measures used in this study. Although this study used measures specifically for people with mental health problems, all the measures positively and inversely correlated from the non-clinical sample. Berry et al. (2006) and van Os et al. (2000) highlight the use of non-clinical samples in psychosis research and how this is increasingly popular due to the recognition that psychotic symptoms are on a continuum with normal experiences and can contribute to the understanding of psychosis. So, despite the benefits of using a non-clinical population, it is possible that the results might not be replicated in a clinical population. The conclusion from our findings is that empowerment mediates the impact of psychological processes such as: social support, thinking style, coping, and control. Further research using the same measures in a clinical population would help to confirm or refute these findings.

The methodological constraints to a cross sectional Internet-based design also needs to be considered in the current study. The sample was self-selected students from four different universities, recruited by email. The gender ratio consisted of a higher number of female participants (58%). Freeman et al. (2005) highlighted that people who often self-select for questionnaires type studies may be more prone to psychological problems. This raises issues concerning whether the measures were sufficient to capture the individual's mental health experience, and whether any of the participants had received treatment for a previous psychiatric disorder. Additionally, there is the possibility of self-reporting biases, although Freeman et al. (2005) highlighted that the anonymity of Internet research can reduce the influence, but it is not possible to completely rule it out. There is also concern about multiple entries from the same participant which is another challenge for Internet recruitment. The current study employed a number of strategies to minimise the chances of this; we recruited participants from legitimate organisations such as universities, and entry to the survey site was referred from a link in the email advertisement. This meant that the participant would not be able to participate a second time unless they were sent an email advertisement a second time. Eysenbach (2004) highlighted how Internet recruitment can be viable if studies are conducted on a larger scale, if the right newsgroups are targeted, the right incentives chosen, and the right wording is used and therefore success in recruiting participants online are similar to those for getting responses in traditional mail and telephone surveys (Edwards et al., 2002).

Another methodological constraint to consider is that our results were based on a cross-sectional design. This can limit the conclusions over the causal directions of the relationships between associated variables and how these relationships can be most likely be bi-directional. Longitudinal data can provide richer information for the investigation of mediation, using methods such as latent growth curve and latent difference score models, because of the ability to investigate the effect of prior change in the mediator on later change in the outcome. The results of the correlation analysis indicates that there were high correlations between the YES and several of the variables considered as outcome variables (GSE, BCSS, SOS and RLC). This cautions our conclusions regarding mediation, not only because of the cross-sectional structure, but also because it could mean that these constructs were overlapping, and so the mediator and outcome were too similar. However the bootstrapping suggested that the YES did seem to add something extra but further research is required to examine whether the psychological variables that were highly correlated are actually core components of empowerment.

The cross-sectional design was also limited by not having randomised experimental manipulation. Mediation analysis in the randomised design is ideal for testing theories such as empowerment as it can provide stronger evidence of causality. MacKinnon (2008) suggests that if a mediation analysis suggests partial or complete mediation, additional research is needed to establish whether this is replicable and real and if possible to manipulate the effect of the proposed mediating variable experimentally. The usefulness of causal inference models, experimental designs, and different alternatives to learning more about mediation are an important topic for further developments and would advance our ability to answer mediation questions in psychology.

# **5.7 Conclusion**

In summary, this study examined the relationship between psychological processes (social support, thinking style, coping, and control), empowerment, and mental health, wellbeing, and recovery. Our tentative conclusion from our findings is that empowerment mediates the impact of psychological process such as: social support, thinking style, coping, and control. Further research using the same measures in a clinical population would help to confirm or refute these findings.

# Chapter 6: Phase Four - Development and Validation of the Youth Empowerment Scale (YES) for a Clinical Population

#### 6.1 Abstract

#### **Purpose and Aim:**

Empowerment is central to the work on improving human lives as it is inextricably linked to greater health and wellbeing, particularly within the context of mental health. Although there are validated measures of empowerment from an adult perspective they are lacking for young people with mental health problems. Validated measures to quantify empowerment can help clinicians address related issues in practice, such as facilitating engagement and partnership working with young people with mental health problems. Given the importance of empowerment within mental health, development a valid and reliable measure of empowerment for young people in Child and Adolescent Mental Health Service (CAMHS) is required. The aims of the current study were to test the goodness of fit of the hypothesised structure of the Youth Empowerment Scale (YES) within a clinical sample using confirmatory factor analysis, and demonstrate convergent validity with existing validated measures, which are routinely administered in CAMHS services. This is the first study to develop and examine the factor structure of the YES through confirmatory factor analysis in a clinical population.

**Methods:** A total of 278 young people (ages 13 to 18 years old) undergoing treatment in CAMHS completed the YES as well as self-report measures of; The Strengths and Difficulties Questionnaire (SDQ), The Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA); and The Beck Youth Inventories, Second Edition (BYI-II). These measures were used because of their emphasis on the concept of strengths and difficulties, recovery, functional capacity and wellbeing which are considered to be important factors associated with empowerment.

**Results:** Confirmatory factor analysis demonstrated that all standardised factor loadings for the three factor models were statistically significant (ps < .05) but the overall model did not provide adequate fit for the clinical sample. The 18-item

scale had very high internal consistency ( $\alpha = 0.90$ ) and correlated significantly with related measures, demonstrating concurrent validity.

**Conclusions:** The YES is a valid and reliable tool for measuring empowerment in young people for research and clinical purposes but needs further development to continue to improve model fit and factor structure. This instrument is of particular value to CAMHS clinicians in determining empowerment and mental wellbeing in young people in a clinical setting.

#### **6.2 Introduction**

Population-based studies demonstrate how psychotic symptoms are common in the general population, with a prevalence rate of 5–8%, which is approximately ten times higher than the prevalence of diagnosed psychotic disorders (Kelleher et al., 2009; Moffitt et al., 2010; van Os et al., 2000, 2008; Yung et al., 2009). There is considerable prevalence of psychosis amongst young people. A systematic review by Kelleher et al. (2012) showed this and noted that prevalence is higher in younger children (9 to 12 years) compared to older children (13 to 18 years). This review reported the median prevalence of psychotic symptoms as 17% among children aged 9 to 12 and 7.5% among adolescents aged 13 to 18. The WHO (2001) ranked schizophrenia and other forms of psychoses which affect young people as the third most disabling condition and maintain that it poses an enormous burden both in terms of economic cost and of human suffering.

Psychosis is particularly damaging for young people as it impacts at a critical time when they are developing key life skills, relationships and vocations. The greatest deterioration in cognitive and social functioning occurs earlier in the course of psychotic illness and therefore the duration of untreated psychosis is undesirable and needs to be reduced in order to reduce the severity of symptoms, prognosis and outcomes, (Bentall & Morrison, 2002; Birchwood, 2003; Birchwood et al., 1998, McGorry, 2002; Morrison et al., 2012). Therefore the earlier treatment is obtained the better the long term prognosis, recovery and outcome will be for the individual with the illness (Bertlolte & McGorry, 2005; Birchwood et al., 1998; Bird et al., 2011; Marshall et al., 2005; Norman et al., 2005). The evidence from Early Intervention Services (EIS) has demonstrated how empowerment is a key

component in reducing the deterioration of psychotic illness in young people. Empowerment has been particularly relevant for young people within EIS where recovery-based approaches involving early appropriate treatment have demonstrated decreased relapse and rehospitalisation, and better long-term prognosis (Allot et al., 2002; Birchwood et al., 1998; Bird et al., 2011; Marshall et al., 2005). Therefore the EIS experience demonstrates that empowerment is of particular relevance to young people.

There is evidence within the literature of the positive effects of empowerment on individuals' self-efficacy, self-esteem, control, critical awareness, and knowledge. It increases partnership-working and engagement, thus enabling the individual to take charge of their lives (Cattaneo & Chapman, 2010; Day, 2008; Fisher & Gosselink, 2008; Pitt et al., 2007; Woodall et al., 2010). Across disciplines, empowerment has been linked to recovery, greater health and wellbeing. Empowerment also remains a key principle to the World Health Organisation (WHO, 2002) as it is central to increasing control over one's health thus achieving greater health and wellbeing. WHO describes how being empowered can enable an individual to take action to achieve influence over themselves, and work with others which can lead to behaviour change. Literature indicates that recovery from mental illness and positive wellbeing is also dependent on empowered participation in one's own care (Brosnan, 2012; Harper & Speed, 2012). Successful delivery of mental health services is more likely where a sense of empowerment can be facilitated in individuals who access those services.

Empowerment is critical to recovery based service provision, however studies continue to show how young people often disengage from services before completing treatment. This failure to engage with services indicates a lack of control and the commensurate empowerment on the part of the young people (Booth et al., 2004; Hoagwood et al., 2001; Muir et al., 2012). Given how essential early treatment and engagement with services is for young people with psychosis empowerment is an important means of improving health outcomes for your young people with psychosis. Wallerstein (2006) cites evidence of empowerment improving health outcomes and quality of life among individuals with chronic illnesses as these individuals were more effective in managing their

illness and willing to modify their health behaviours. These findings were also apparent in studies which focused on empowerment and health outcomes for individuals with chronic mental illness (Frame, 2003; Lorig et al., 2001a, 2001b; Melnyk et al., 2004; Pitt et al., 2007). These studies demonstrate how people with mental health problems can heal, recover, and resume their previous social role; thus gaining a sense of hope. Although empowerment of mental health service users is key to improving health outcomes at the individual and societal level, there is a lack of understanding of the construct from a young person's perspective; and in particular young people with psychosis.

Over the last two decades, the importance of empowerment for young people with mental health problems has been recognised, although the term has been used so often and so widely that its meaning and its application has become ill defined. Edelman (1977) cautions us on the unclear use of language in relation to politics of human services and noted that new language can be used to describe the same old practices. Cattaneo and Chapman (2010) reviewed the wide range of commonly cited definitions of empowerment and categorised them as 'mastery', 'participation', 'the social good', 'goal achievement' and 'the nomological network of empowerment'. Although several authors have attempted to conceptualised empowerment, Rappaport (1987) and Zimmerman (1995, 2000) are the most cited in the literature. Rappaport (1987) defined empowerment as a process whereby people, organisations, and communities gain mastery over their lives. His definition explores the idea that individuals are experts in their expression through thoughts, feelings, actions, and beliefs and individual should be encouraged to focus on enhancing the possibilities to control their own lives. Zimmerman (1995) defined empowerment as the act of enabling people to gain skills and abilities to act on their own in order to reach their self-defined goals. Our qualitative study (Grealish et al., 2011) examined how young people with psychosis experienced empowerment which supported the two theoretical perspectives of (Rappaport, 1987, Zimmerman, 1995); whereby individuals gain control over their lives, develop the skills and abilities that equips them to decide on and take action regarding the issues of concern to them.

The UK government (DoH, 2004, 2001; NICE, 2002) has made a commitment to addressing the needs of young people with psychosis, an endeavour in which the concept of empowerment is critical. Given the positive policy aspiration for young people with mental health problems (CAMHS Review, 2008; DoH, 2006; Mental Capital & Wellbeing, 2008; New Horizons, 2009; The Children's Plan, 2008) demonstrating its importance for recovery and wellbeing there is a need for suitable means for measuring empowerment for this group. Such outcome measure could support services in attaining the policy goals of promoting recovery, independence and wellbeing. As well as facilitating the uptake of social, educational and employment opportunities that young people require.

There are currently no formal methods for measuring empowerment specifically with young people with mental health difficulties or in services such as CAMHS. Currently there are only two validated measures of empowerment that bear relevance to young people; The Family Empowerment Scale (FES; Koren et al., 1992); and the Youth Empowerment Scale-Mental Health (YES-MH; Walker et al., 2010). The FES focuses on parents of children with emotional or behavioural disorders, as opposed to the young person directly acting as the informant. Walker et al. (2010) adapted the FES in consultation with groups of young people to alter the wording of items and then produced the 20-itemed measure of empowerment for young people with mental health problems (the YES-MH). Given that the FES was developed specifically for families and carers, it is still more representative of an adult perspective on empowerment. The Youth Empowerment Scale (Grealish et al., submitted) utilised in the current study was developed from extensive qualitative interviews with young people who experienced psychosis (Grealish et al., 2011). Six main themes were developed in relation to what being empowered means to young people with psychosis, which were then used to develop items of the YES. Exploratory Factor Analysis (EFA) of the measures in a non-clinical population identified a three-factor solution.

Empowerment models and measures that are conceptualised from adult perspectives and applied to young people (Benson et al., 1998; Cargo et al., 2003; Chinman & Linney, 1998; Freire, 1970; Kim et al., 1998; Leffert et al., 1998; Walker et al., 2010) might be problematic. None of the models or measures of

empowerment currently used for young people have been developed directly from the perspective of young people. Although there is need to understand and measure empowerment from the perspective of young people, current research, understanding of the concept and measurement is from an adult point of view. This could potentially encourage an ethos whereby young people continue to experience interventions being done 'to' or 'for' them instead of being facilitated to acquire the knowledge, skills and resources to do things for themselves. The Children and Young People's Mental Health Coalition (2010) highlighted the need to change the current status quo and argued that if we help young people to foster knowledge, self-awareness and personal, social and emotional skills this can empower them to take increasing responsibility for their emotional health as they become adults. Additionally, they argue that this could have the most significant and long-term impact on the mental health and emotional wellbeing of the next generation, and generations to come. As clinicians working with young people with psychosis increasingly move into mental health prevention, health promotion and early intervention oriented roles, the need for reliable and valid measure of empowerment that can be used to support clinical working, conduct further research to develop understanding of empowerment and to develop interventions which specifically aim to address empowerment issues becomes more apparent. The paucity of methods for measuring empowerment in young people with psychosis is an obstacle to meaningful measurement for the purpose of understanding outcomes and consistent application of empowerment in practice.

The current study aims to validate the YES (Grealish et al., submitted) in a clinical population by using confirmatory factor analyses (CFA) to determine whether the hypothesised structure of the YES provides adequate fit to the data and to verify that the all items on the YES were properly aligned with the correct facets. This study also aimed to demonstrate convergent of the YES with the existing validated measures administered to all young people with mental health problems in CAMHS; The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997); The Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA) (Gowers et al., 1999); and The Beck Youth Inventories, Second Edition (BYI-II) (Beck et al., 2005). These measures were used because

of their emphasis on the concept of strengths and difficulties, recovery, functional capacity and wellbeing which are all key factors in empowerment.

#### 6.3 Methods

## 6.3.1 Participants

Two hundred and seventy eight (n=278) participants completed measures, 80 Males (28.8%) and 198 Females (71.2%). Participants were aged 13-18 years, with a mean age of 15.96 years (SD 1.141). All participants were attending CAMHS in England (n=170) and Ireland (n=108). Ethnic groupings for the sample were as follows: White British 45.7% (n=127), White Irish 38.8% (n=108), Black British 5.4% (n=15), Indian 4.3% (n=12), Pakistani 3.6% (n=10), Black Other 1.1% (n=3), and White Other 1.1% (n=3). Table 4.1 displays the descriptive statistics for this sample. Examination of the missing data showed that there was no missing data from the demographic information.

The lack of agreement on sample size in CFA is well noted in the literature including the several guiding rules of thumb (Hogarty et al., 2005; MacCallum et al., 1999). Our sample size was based on the rule of thumb that suggests having 10 people for every variable in the model (Everitt, 1975; Pett et al., 2003; Schreiber et al., 2006). Our power calculation indicated a minimum of 210 participants, on the basis of 10 participants per variable for the 21 items on the YES were required. 278 were recruited, which is considered a 'good' sample size for this particular analysis (Everitt, 1975; Kenny, 2012; Pett et al., 2003).

Table 4.1 Phases 4: Descriptive Statistics

Variable	Summary Stati	Summary Statistics				
Age (n=278)	Mean 15.96 Std. Deviation 1.141 Minimum 13 Maximum 18 Range 5 Skewness686 Kurtosis260					
<b>Gender</b> (n=278)	N	%				
Male	80	28.8				
Female	198	71.2				
Ethnicity (n=278)	N	%				
White British	127	45.7				
White Irish	108	38.8				
Black British	15	5.4				
Indian	12	4.3				
Pakistani	10	3.6				
Black Other	3	1.1				
White Other	3	1.1				
Diagnosis (Yes, n=258)	N	%				
Depression	67	24.2				
Depression & self Harm	19	6.9				
Depression and Psychosis	24	8.7				
Depression and PTSD	9	3.2				
Psychosis	41	14.8				
Anorexia Nervosa	14	5.1				
Bipolar Disorder	7	2.5				
Depression & Anxiety	36	12.5				
Depression & Eating Disorder	25	9.0				
OCD and Phobia	16	<i>5.8</i>				
No formal diagnosis (n=20) Main problems: Self Harm & Eating Difficulties						
Anxiety & Self Harm	3	1.1				
Hearing Voices	6	2.2				
Low Mood	5	1.8				
LOW MOOU	6	2.2				

## **6.3.2 Measures**

All the participants (n-278) were required to provide demographic information (in Appendix 8), including sex, age, problem severity and diagnosis (if applicable). The YES was completed by all young people attending both in-patient and outpatient CAMHS. Participants also gave consent to provide data through a clinician

rated HoNOSCA, BYI-II, and SDQ, outlined below. The participants also agreed for any results of existing self-report measures already completed as part of the routine CAMHS practice to be included in the current study.

## 6.3.2.1 The Youth Empowerment Scale (YES)

The YES was based on an item pool developed from qualitative interviews with young people with psychosis (Grealish et al., 2011), which revealed 6 main themes that captured the meaning of empowerment from a young person's perspective. Explorative factor analyses (EFA) was used in a second study with a non-clinical sample of young people (Grealish et al., submitted), which identified a 3-factor solution of the YES. The YES is a 21-item self-report questionnaire that measures empowerment on a four-point Likert scale. Responses are scored from 1-4, "not at all" (1), "somewhat" (2), "moderately so" (3), "very much so" (4), with higher scores indicative of someone with a greater sense of empowerment. The YES measures three domains of empowerment, adults/others helping and validating; 'having a say, choice, coping strategies, decisions and control; and unwell factors. Factor one consists of 11 items ( $\alpha$ =0.86), factor 2 consists of 5 items ( $\alpha$ =0.78) and factor 3 consists of 7 items ( $\alpha$ =0.76). The YES is a reliable instrument which yielded an overall Cronbach alpha coefficient of  $\alpha = 0.89$  and good construct validity; being positively associated with a better quality of life and general health.

## 6.3.2.2. The Strengths and Difficulties Questionnaire (SDQ)

The SDQ (Goodman, 1997) is a well-validated screening questionnaire that asks about children and adolescents' behaviours, emotions, and relationships. It can be administered to parents and teachers, as well as children and adolescents aged 4-17 years-old. The extended version for 11-17 year old adolescents was employed in the current study. The initial 25 items examines positive and negative behavioural attributes on a three point scale options, 0 (not true), 1 (somewhat true), or 2 (certainly true). Responses for each item were grouped into one of the five subscales, hyperactivity/inattention, emotional symptoms, conduct problems, peer relationship problems, and prosocial behaviour (Goodman, 1997). The extended version of the SDQ includes an impact supplement which enquires

further about the participants perceived severity of their difficulties, chronicity, overall distress, social impairment, and burden to others (Goodman, 1999).

Responses are scored on a three point scale for each item, 0 (not at all/ only a little), 1 (quite a lot), and 2 (great deal). Responses to items from the first four subscales are added to give a total difficulties score, and ratings of participant distress and the impact of difficulties on home life, friendships, classroom learning and leisure activities are combined to form the impact score. An impairment score was calculated by aggregating the scores for distress and social impairment. The SDQ is a validated and internationally acknowledged measure to screen for psychiatric disorders and is often used as an outcome measure of treatment in mental health care and as a research instrument (Bourdon et al., 2005; Goodman, 2001, Goodman et al., 2000; Mellor, 2004). The subscales on the SDQ also correlate with related diagnostic groupings and complements the HoNOSCA clinical evaluation by providing measures of change from the clinician, parent and child perspectives (Goodman & Goodman, 2009; Hawes & Dadds, 2004; Mathai et al., 2003).

# 6.3.2.3. The Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA)

The HoNOSCA (Gowers et al., 1999) was developed to measure mental health and outcomes amongst children and adolescents attending CAMHS. Since the Department of Health (DoH, 1998) and the Audit Commission's review of CAMHS (Audit Commission, 1999) launched the approval of HoNOSCA as an outcome measure this has led to its routine use in many mental health services. This measure assesses the behaviours, impairments, symptoms and social functioning of children and adolescents with mental health problems. The HoNOSCA is a 15-item questionnaire to be completed by clinician, where the first 13 items relate to the young person's mental health symptoms and functioning (Gowers et al., 1999). These 13 items are categorised into four subsections: behaviour (1-4), impairment (5-6), symptoms (7-9), and social (10-13) (Burgess et al., 2009). The two remaining items relate to parental knowledge about the young person's condition as well as access to services. All 15 items are rated on a five-point severity scale, ranging from 0 (no problem) to 4 (severe

problems), (Bilenberg, 2003). In this study only the clinical features (item 1 to 13) were included. The scoring of HoNOSCA does not require diagnostic sophistication as it is based on descriptions of behaviour. Although there are no norms on the items scores, Burgess and colleagues (2009) suggest that a score of 2 or above can be considered as evidence of clinically significant difficulties that call for further follow-up. Therefore items scored 2 or above were considered potential clinical significance in this study. Several studies have shown good results on the validity, interrater reliability and levels of acceptability in multi-disciplinary practice of the HoNOSCA (Bilenberg, 2003; Brann et al., 2001; Garralda et al., 2000; Gowers et al., 1999; Yates et al, 1999). Studies have also confirmed the usefulness of assessing clinical change and outcome in CAMHS (Garralda et al., 2000).

## 6.3.2.4. The Beck Youth Inventories, Second Edition (BYI-II)

The BYI-II (Beck et al., 2005) was used in this study to examine the psychological symptoms in young people in order to gain a comprehensive picture of the individual's mental health and wellbeing. The BYI-II consists of five selfreport inventories which can be used separately or in combination to assess thoughts, feelings, and behaviours associated with emotional and social impairment in youth aged 7 to 18 (Beck et al., 2001, 2005). The five inventories each contain 20 items that assess symptoms in depression, anxiety, anger, disruptive behaviour and self-concept. The Beck Depression Inventory (BDI) is designed to identify early symptoms of depression including negative thoughts about one's self and future, sadness, and physiological indications of depression. The Beck Anxiety Inventory (BAI) measures fearfulness, worrying, and physiological symptoms associated with anxiety. The Beck Anger Inventory (BANI) measures hostilities, perceptions of mistreatment, feelings of anger and hatred. The Beck Disruptive Behavior Inventory (BDBI) measures delinquent and aggressive behaviours associated with conduct disorder and oppositional defiant behaviour. The Beck Self-Concept Inventory (BSCI) measures self-perceptions such as competence, potency, and positive self-worth. Participants describe how frequently the statements has been true for them and all items are answered on a four-point frequency scale 0 (never), 1 (sometimes), 2 (often), 3 (always). Each inventory is scored by adding the 20 ratings and these scores can range from 0 to 60 (Beck et al., 2001). Total scores can also be converted into T scores with a mean of 50 and a standard deviation of 10. Higher scores on depression, anxiety, anger and destructive behaviour inventories indicate higher levels of that construct/disorder or distress. Scoring for the self-concept inventory is in the opposite direction which means higher scores reflect better self-esteem. The BYI-II has shown excellent psychometric properties along with good reliability (Cronbach's alpha = 0.88 - 0.94) and robust validity in a variety of clinical and non-clinical settings (Beck et al., 2001, 2005).

# **6.3.3 Ethical Approval**

The current study was granted ethical approval (see Appendix 9) from the National NHS Research Ethics Committee (REC, reference number: 11/NW/0869) in the UK and the HSE Research Ethics Committees (REC) in Ireland. Research governance approval was also obtained from local NHS Research and Development Committees (R&D). Once consent was received from the CAMHS, young people were invited to take part through their responsible clinician. Written consent was obtained from all participants prior to participation. Agreement was obtained from CAMHS through which recruitment took place and parental ascent was also sought prior to obtaining consent from the young people under 16 years old participating in the study.

## **6.3.4 Statistical Analysis**

The statistical software packages STATA version 12 and Mplus version 7.1 were used to undertake confirmatory factor analysis (CFA). The Statistical Packages for Social Sciences (SPSS version 20) was used to present the frequency and descriptive statistics for the demographic variables and to identify missing data, characteristics of the study variables and make comparisons of interest. CFA was performed in this study to establish the validity of the three factor structure on the YES, the relationship between two or more factor loadings, and test the statistical fit of the model. CFA tests the hypothesis that a relationship between the observed variables and their underlying latent construct(s) exists (Brown, 2006; Pett et al., 2003). CFA is used when some knowledge is known about the underlying dimensions of the construct under investigation and assesses the extent to which

the hypothesised organisation of a set of identified factors fits the data (Levine, 2005; Pett et al., 2003). The purpose of our analyses was to determine whether young people in a clinical population experience of empowerment reflect the same three factor model found for young people in a non-clinical population. We hypothesised the 21 item scale to represent the three empowerment factors and each item was hypothesised to load on only one of the three factors, which is reported in Table 4.2. CFA was performed using the following steps:

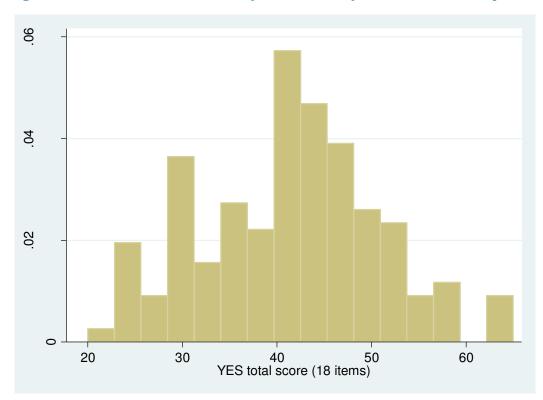


Figure 4.2: Phase 4 Distribution of Total Scores for the Clinical Sample

Table 4.2 Phase 4: Hypothesised Three Factor Model According To Our Previous Study With Young people in Secondary Schools (non-clinical population)

	Factor 1	Factor 2	Factor 3
Q10 I feel understood by adults (apart from family & friends)	.762		
Q7 I feel that adults (apart from family & friends) listen to me when I have a problem	.749		
Q8 When I tell adults (apart from family & friends) about a problem I feel they support me	.749		
Q9 I feel that adults (apart from family & friends) take my point of view seriously	.724		
Q13 If I talk to adults (apart from family & friends) about a problem, I feel believed	.687		
Q12 If I ask an adult (apart from family & friends) for help, they hear what I say and use this to help me	.646		
Q19 I have other adults (apart from family & friends) that I feel I could go to if things are difficult for me	.518		
Q21 Other people (apart from family & friends) have been useful in helping me to find ways to cope with my problems	.468		
Q14 Other people take the time to explain things to me	.367		
Q4 When things go wrong I still feel able to make choices what I want to do		.674	
Q6 I feel I have control over my difficulties		.664	
Q3 I feel I can make my own decisions about what I do to help me feel better about my difficulties		.647	
Q2 I feel my ways of coping are respected by others		.581	
Q1 When I need help from others to deal with my problems, I feel I have a say in how they treat me		.492	
Q18 When I have been unwell other people have been willing to listen to my problems			.636
Q17 When I have been unwell other people have told me how to deal with things			.609
Q16 When I have been unwell I needed treatment, other people have explained this to me			.559
Q11 I feel that being listened to helps me cope with my problems			.498
Q24 It is easier to talk to the adults I spend time with about my problems			.455
Q22 If I feel comfortable with an adult I find it easier to go and ask that person for help			.429
Q25 My parents helps me to sort things when I am unwell			.423

# 6.3.4.1 Specifying the factor model and the pattern of loadings on the factors:

This involved selecting the 3 factors and the specified pattern of items which loaded onto a particular factor, which was based on the results of our previous research with young people attending secondary schools (Grealish et al., submitted). These loadings were fixed at zero instead of non-zero for indicators not supposed to load on a certain factor. It is common to impose a model constraint to yield a meaningful scale in CFA. Kline (2010) states that one factor loading per factors needs to be fixed at a certain value in CFA to determine the scale of the respective factor thus identifying it. Kline (2010) also highlights the importance of specifying the factor loading by specifying which items should load onto a particular latent factor helps in terms of theoretical weight and meaning.

# 6.3.4.2 Evaluating model fit:

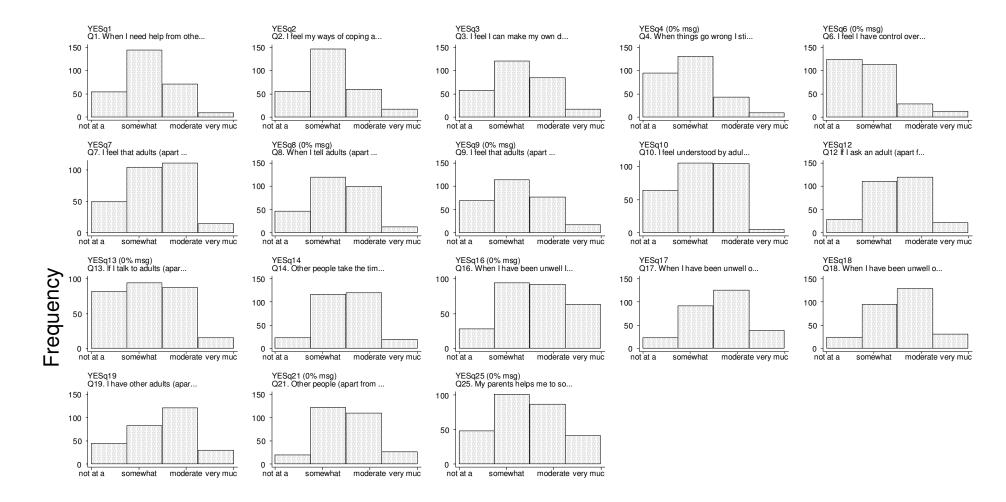
The next step was to examine if the hypothesised model fits the observed data. In CFA, several statistical tests are used to determine how well the model fits the data but there are varying opinions and several fit indices and evaluation criteria cited in the literature (Holtzman & Vezzu, 2011; Hu & Bentler, 1998; Kline, 2010). A "good model fit" does not mean that the model is correct: instead it indicates that the model is plausible (Schermelleh-Engel et al., 2003). A ratio of chi-square to degree of freedom ratio ( $\chi^2$  to  $df \le 2$  or 3) suggests reasonable fit (Hatcher, 1994) but the chi-square statistic is sensitive to sample size. Therefore, the fit indices proposed by (Kline, 2010) and the cut-off levels for determining model fit (Hu & Bentler, 1999) were used for interpreting and evaluating the model in this study on the basis of their overall consensus in regard to recommended fit index cut-off in the literature. Hu & Bentler (1999) recommend reporting the root mean square error of approximation (RMSEA; <.06 to .08), the comparative fit index (CFI;  $\ge$ .95), and the standardized root mean square residual (SRMR;  $\le$ .08).

## **6.4 Results**

# **6.4.1 Frequency Distribution**

Prior to conducting CFA on the YES, the data was screened using frequency analysis and item non-responses were noted. Table 4.1 describes the frequency distribution and range of scores for the participants were evenly distributed. The distribution of scores for this sample are displayed in *figure 4.1* which showed near-normal distribution. There was no missing data for the demographic information.

Figure 4.1 Phase 4 Distribution of Item Scores for the Clinical Sample



### **6.4.2 Confirmatory Factor Analysis**

Using Mplus version 7.1 we performed CFA on this sample (n=273) using the 3 factor model and the factor loading patterns. 1.8% (n=5) of the data were missing from the YES, but using maximum likelihood estimation allows for all observed data to be included in the analysis. To execute the analysis, three latent factors and the specified pattern of items which loaded onto a particular factor were selected, including the fixed zero loadings for indicators not supposed to load on a certain factor. All the items loaded significantly onto their respective factors. Standardised loadings ranged from 0.564 to 0.880 on factor 1, between 0.450 and 0.785 on factor 2 and between 0.513 and 0.764 on factor 3.

This model was then examined to evaluate whether the hypothesised model fitted the observed data. Kline's fit indices were used to assess if the model under the test fitted the data adequately by interpreting the chi-squared test, the RMSEA, the CFI, and the SRMR (Kline, 2010). Table 4.3 displays the model fit statistics results for various 3 factor models. Chi-square value for the original model fit was not significant,  $\chi^2$  (186) 1512.14, p <.001, suggesting a lack of fit between the original hypothesised model and the data. However, due to the sensitivity of chi-square value in large samples, other fit indices were assessed (Kline, 2010). Examination of these indices in Table 4.3 also showed that the original model does not provide a good fit to the data with the RMSEA 0.16, the CFI 0.61, and the SRMR 0.105. Therefore we did conduct post-hoc modifications because of the poor fit of the data to the model.

On examining the results it is clear that item 11 does not significantly load onto the third factor and has a large residual variance unaccounted for by the factor. To improve the fit we removed item 11 from the factor, labelled as model 2, and fit this CFA model as before, with the results shown in Table 4.3. This subsequent model 2 did not fit the data either, and we then examined the regression loadings and residual variance. Items 22 and 24 had smaller standardised loadings onto factor 3 and large residual variances (0.713 and 0.805) respectively, indicating that they might not load onto the third factor either. We removed these items (see model 3) and refit this on the sample, with the results shown in Table 4.3 again.

As before, the model 3 is not a good fit to the data, but is an improvement on previous models, with all the fit indices moving towards recommended thresholds,  $\chi^2$  (132) 1008.58, p <.001, RMSEA = .15, the CFI 0.70, and the SRMR = .087. Examining the standardised loadings and residual variances, it is not clear which other items should be dropped on statistical reasoning, and we are left with the three factor model on the 18 items, see Table 4.4.

Table 4.3 Phase 4: Model Fit Statistics for Various 3 Factor Models

Model number	1	2	3
Items	21	20	18
Log likelihood	-5367.61	-5077.03	-4558.29
# parameters	66	63	57
Chi-square value,	1512.14,	1393.91,	1008.58,
Degrees of freedom,	186,	167	132
p-value	<0.001	<0.001	<0.001
BIC	12618.79	11902.60	10445.93
ABIC	12409.51	11702.83	10265.19
AIC	12379.36	11674.06	10239.15
RMSEA	0.160	0.163	0.155
CFI	0.611	0.629	0.702
TLI	0.560	0.578	0.655
SRMR	0.105	0.102	0.087

# **6.4.3 Construct validity**

Construct (concurrent) validity was analysed using Pearson correlations coefficients, comparing the total scores of the YES, and the SDQ, HoNOSCA, and BYI-II (see Table 4.5). An inverse correlations were found between the YES and the HoNOSCA (r = -0.161, p < 0.001), the SDQ (r = -0.122, p < 0.001) and the BYI-II (r = -0.504, p < 0.001). The YES scale demonstrates good construct

validity by the strong correlations with other scales, all in the hypothesised direction.

The construct validity of the individual subscales on the YES was also assessed using Pearson correlations coefficients (see Table 4.6). High positive correlations were found between the three individual subscales on the YES; factor 1 (r = 0.938, p <0.001), factor 2 (r = 0.811, p <0.001), and factor 3 (r = 0.833, p <0.001), suggesting that each are measuring the general concept of empowerment. The total score on the YES ranged from 20-65 (see figure 4.2) demonstrating that there is a range in the different levels of empowerment across the sample. This supports the idea that the total score is a valid summary measure for the scale; that empowerment in this sample and as measured by this scale, can be measured on one dimension with good reliability. The YES has 18 items each scored on a 4 point Likert scale (1=not at all, 2=somewhat, 3=moderately so, 4=very much so), with higher scores indicative of someone with a greater sense of empowerment. Items on the three factors; choice and control, receiving help and validation and effective help seeking subscales are scored simply by totalling the numbers endorsed by respondents. As the subscales were strongly related and measuring similar construct of empowerment, a total score on the YES can be obtained by summing each subscale to get a total score.

Table 4.4 Phase 4: Items and their Factor Loadings Retained in the Analysis

	Factor 1	Factor 2	Factor 3
Q10 I feel understood by adults (apart from family & friends)	0.655		
Q7 I feel that adults (apart from family & friends) listen to me when I have a problem	0.759		
Q8 When I tell adults (apart from family & friends) about a problem I feel they support me	0.870		
Q9 I feel that adults (apart from family & friends) take my point of view seriously	0.880		
Q13 If I talk to adults (apart from family & friends) about a problem, I feel believed	0.773		
Q12 If I ask an adult (apart from family & friends) for help, they hear what I say and use this to help me	0.722		
Q19 I have other adults (apart from family & friends) that I feel I could go to if things are difficult for me	0.564		
Q21 Other people (apart from family & friends) have been useful in helping me to find ways to cope with my problems	0.650		
Q14 Other people take the time to explain things to me	0.583		
Q4 When things go wrong I still feel able to make choices what I want to do		0.785	
Q6 I feel I have control over my difficulties		0.450	
Q3 I feel I can make my own decisions about what I do to help me feel better about my difficulties		0.499	
Q2 I feel my ways of coping are respected by others		0.568	
Q1 When I need help from others to deal with my problems, I feel I have a say in how they treat me		0.499	
Q18 When I have been unwell other people have been willing to listen to my problems			0.764
Q17 When I have been unwell other people have told me how to deal with things			0.513
Q16 When I have been unwell I needed treatment, other people have explained this to me			0.689
Q25 My parents helps me to sort things when I am unwell			0.605

Table 4.5 Phase 4: Correlations

		YES Total
HoNOSCA	Pearson Correlation	-0.161
	N	129
SDQ	Pearson Correlation	-0.122
	N	71
BYI-II	Pearson Correlation	-0.504**
	N	50

<sup>\*\*.</sup> Correlation is significant at the 0.01 level (2-tailed)

Table 4.6 Phase 4: Intercorrelations among the YES subscales

		Factor 1 Choice and control	Factor 2 Receiving help and validation	Factor 3 Effective help seeking	
YES Factor 2 Receiving help and validation	Pearson Correlation	.661 <sup>™</sup>	•	.614 <sup>**</sup>	
	N	273	-	274	
YES Factor 3 Effective help seeking	Pearson Correlation	.666 <sup>**</sup>	.614 <sup>**</sup>		
	N	275	274	-	
YES Total	Pearson Correlation	.938**	.811 <sup>**</sup>	.833 <sup>**</sup>	
	N	273	273	273	

<sup>\*\*.</sup> Correlation is significant at the 0.01 level (2-tailed)

### 6.4.4 Gender differences

Independent samples t-test was conducted to understand whether empowerment, mental wellbeing and health outcomes for young people differed based on gender. As can be seen on Table 4.7 females scored slightly higher on the empowerment scales than males and they also scored better outcomes on the other outcomes measures (HoNOSCA, SDQ and BYI-II). There was no significance difference found in the YES (p=0.80), SDQ (p=0.06) and BYI-II (p=0.09) scores between gender except for the HoNOSCA (p=0.008). There was significance in the HoNOSCA for males (m=19.95, SD=5.282) and for females (m=17.51, SD=4.620) conditions; t(129)=-2.700, p=.008. Although males and females scored significantly differently on the HoNOSCA the outcomes remains the same in that when a person feels empowered their mental wellbeing and health also increases.

Table 4.7 Phases 4: Group Statistics and Independent Samples Test

		Group Statistics			Independent Samples Test t-test for Equality of Means				
	Gender	N	Mean	Std. Deviation	t	df	Sig. (2-tailed)		
				Deviation			(2-tailed)	Lower	Upper
YES		273	41.5385	9.51235	252	271	.801	-2.814	2.175
	Male	80	41.31	8.949					
	Female	193	41.63	9.757					
HoNOSCA		131	18.29	4.956	2.700	129	.008	.654	4.240
	Male	42	19.95	5.282					
	Female	89	17.51	4.620					
BYI-II		51	124.06	33.422	1.683	49	.099	-6.383	72.133
	Male	3	155.00	13.000					
	Female	48	122.13	33.410					
SDQ		71	41.03	3.738	1.865	69	.066	116	3.443
	Male	28	42.04	4.376					
	Female	43	40.37	3.140					

### **6.4.5 Internal Consistency**

Cronbach's alpha was used as a measure of internal reliability of the overall 18 items on the YES which displayed excellent internal reliability YES Total Score ( $\alpha=0.90$ ). Cronbach's alpha coefficients were also computed for internal consistency of items on the three factors (factor 1  $\alpha$ =0.89; factor 2  $\alpha$ =0.63; factor 3  $\alpha$ =0.72) indicating good internal consistency. Item-total correlations were therefore reasonably strong in demonstrating reliability and supporting the items on the three factors. Test-retest reliability has not yet been assessed in the YES as the same individuals have not completed the YES at repeated time points; this will be important in future developments.

#### 6.5 Discussion

This current study examined the psychometric properties of the YES in a clinical population and tested the three factor model developed from a previous exploratory factor analysis with young people from a non-clinical population. Confirmatory Factor Analysis of the clinical sample demonstrated that all standardised factor loadings for the three factor model were statistically significant (ps < .05). This demonstrates that each item on the scale adequately harmonises with its corresponding factor. Model fit was improved following the respecification phase (Kenny, 2012) which generated two alternative models in Table 4.4. The respecification of model 3 was significantly better than the alternative two models when three items were deleted from factor 3 which differed to the remaining 4 items. These four remaining items on factor 3 focuses on being 'unwell' and therefore were theoretically deemed appropriate to delete from the scale. There is a lot of controversy concerning fit indices in the literature (Holtzman & Vezzu, 2011; Hu & Bentler, 1998; Kenny, 2012; Kline, 2010; Schermelleh-Engel, et al., 2003). Some researchers argue that fit indices do not add anything to the analysis and argue that cutoff for a fit index can be misleading and subject to misuse (Barrett, 2007; Hayduk et al., 2007). Although most researchers believe in the value of fit analysis they do caution on that 'good fitting model' does not mean that the model is correct or valid instead it indicates that the model is plausible (Kenny, 2012; Schermelleh-Engel, et al., 2003). In this study

all the items load onto their factors in spite of there being a sample difference between the clinical and non-clinical populations.

This study provides evidence of convergent and discriminant validity of the YES. Convergent validity demonstrated that the three factors were related to empowerment and had stronger convergent validity than discriminant validity, which suggest that the YES provides valid measures of each construct. An examination of correlations among scales reveals that the clinical sample of young people ratings of total difficulties score on the SDQ, and the psychological symptoms and functioning on the BYI-II and HoNOSCA were each strongly and inversely associated with their ratings of empowerment (YES). These findings mirror other studies that suggest how the experience of empowerment is associated with better mental wellbeing, better prognosis, and decrease in relapse and rehospitalisation (Benson, 2007; Carnegie UK Trust, 2008; Marshall et al., 2005; Pitt et al., 2007; Walker et al., 2010). Our results suggest that when a young person feels empowered their mental health and wellbeing also increases. These findings supports the hypothesis that is already noted in the literature that the experiences of empowerment are associated with better mental health and wellbeing (Benson, 2007; Carnegie UK Trust, 2008; Marshall et al., 2005; Pitt et al 2007; Walker et al., 2010). Therefore this scale can help with the priorities of current healthcare which focuses on better psychological wellbeing for young people (DCSF, 2010; DoH, 2006; NAC, 2011; NCSS, 2011).

### 6.6 Future Research

Future research will further develop this measure on a larger more homogenous clinical population of young people with psychosis. This study recruited young people with mental health problems but not psychotic population specifically. Therefore future research can identify how the three factors in YES are specifically applicable to young people with psychosis and allow further examination of the predictors of empowerment in psychotic populations that emerged from out qualitative and quantitative studies. Use of the YES might benefit in longitudinal studies or randomised trials of clinical interventions for young people with psychosis. This would also inform us whether any change in

empowerment scores are associated with changes in mental wellbeing, recovery and quality of life.

## 6.7 Methodological Limitations

Participants were entirely based on clinical data from young people attending CAMHS suffering from different types of mental disorders (e.g. depression, anxiety, eating disorder) and did not permit testing fit of model for young people with psychosis separately. This has implications for the extent to which findings from this sample (n=278) can be generalised to all young people with psychosis across the clinical population. However, our purposes were to determine the three factor model of the YES in a clinical population and to test its convergent and discriminant validity. Despite the clinically diverse sample participants scores were normally distributed and the findings confirmed reliability and validity of the scale as it correlated with other validated measures such as SDQ, BYI-II and HoNOSCA. Given that the original hypothesised model poorly fitted the clinical data, our next MC-CFA will examine how three factor structure in model 3 will statistically test its fit in both clinical and non-clinical population and population. However, the fact that the YES has been confirmed as a valid and reliable measure of empowerment in our EFA and this current CFA study, we hope that this will put the scale on a good foundation for future work for young people with psychosis.

#### 6.8 Conclusion

In summary, the YES is a valid measure of empowerment in young people with psychosis. This instrument would be of particular value to CAMHS clinicians involved in working on interventions and service delivery in improving mental health wellbeing and deceasing symptoms of psychosis. The YES is a reliable and valid scale in determining empowerment in young people in a clinical setting.

# **Chapter 7: Discussion and Conclusion**

This chapter presents a discussion of the research findings for each of the four phases in the context of the current literature. Issues identified by the four research studies are discussed, with conclusions and recommendations outlined. Limitations of the research, contribution to knowledge and the future research directions are also identified. CAMHS is the setting in which a high proportion of young people with psychosis are managed (The National CAMHS Review, 2008). Creating a valid and reliable measure of empowerment for use in this particular setting was the key aim of this thesis. An empowerment scale validated for Young people in CAMHS will allow the empowerment effect of interventions to be measured.

### 7.1 Summary of the overall study aim and across the 4 phases

This thesis reports the finding of four empirical phases of a study aimed at developing an understanding and method for measuring empowerment in young people with psychosis. Phase 1 of this study qualitatively conceptualised the concept of empowerment from the perspective of young people aged 14 to 18 years experiencing psychosis. The six main themes found in this qualitative study informed the development of a self-report measure of empowerment; the Youth empowerment Scale (YES). This is the first study to examine empowerment from the perspective of young people with psychosis, which highlights the need for and utility of a specific empowerment scale from the perspective of young people. Phase 2 of this thesis developed and validated the YES in a non-clinical population aged 11 to 19 years. Explorative factor analysis suggested a three factor model with 21 items relating to empowerment. Phase 3 of this study employed the new validated measure the YES to examine whether empowerment mediates the relationship between psychological factors and mental health, wellbeing, and recovery from general life problems in young people aged 16-29 years. Identification of the psychological factors explored in phase 3 (selfefficacy, control, coping, thinking style and social support) was based on reports obtained directly from young people with mental health difficulties conducted in phase 1. These psychological factors were also well documented in the adult literature although very little has been written on the applicability of these findings from the perspective of young people. In the final study, the YES was then validated on a clinical population, young people aged 13 to 18 years currently receiving services from Child and Adolescent Mental Health Services (CAMHS) for mental health difficulties. Confirmatory factor analysis was used to determine whether the hypothesised structure of the YES developed in phase 2 provided adequate fit to the clinical data and to verify that the all items on the YES were properly aligned with the correct facets.

# 7.2 Summary of findings

### 7.2.1 Phase 1: Qualitative Study

Phase 1 involved qualitatively conceptualising empowerment from the perspective of young people aged 14 to 18 years who were experiencing psychosis. Individual interviews were conducted with nine young people with a diagnosis of a psychotic disorder and their parents. In depth exploration of their understanding and experience of empowerment was conducted. Data was analysed using Interpretative Phenomenological Analysis (IPA), which was deemed the best method for examining the participant's experience of empowerment. IPA in comparison to other qualitative approaches is idiopathic which favours the participant's responses in making sense of these experiences (Smith et al., 1999). Results indicated that young people and their parents shared similar understandings of the concept of empowerment. Their ideas were also similar regarding the necessary processes to feeling empowered. The data analysis revealed six main themes which illustrated the ways in which young people with psychosis experience empowerment, these were: Individual control and choice versus inflexibility; Being listened to, respected and validated; Communication; Response of services; Coping and structure; and Quality of relationship and support

Our findings indicate a need for clinicians to develop greater awareness and flexibility about the experiences of distress and powerlessness that young people with psychosis often experience within mental health services. Participants reported that they wish to be heard and understood. In contrast they reported

experiencing rigid rule structures, inflexible practices, and were unable to exert control over decisions about their care reporting how these disempowering practices slowed down their recovery. There is evidence that clinicians create powerlessness worsening symptoms and delay recovery (Carnegie UK Trust, 2008; CAMHS Review, 2008; Claveirole, 2004; DoH, 2006, 2010; Mental Capital & Wellbeing, 2008; New Horizons, 2009). These sources indicate that young people's experiences are often not listened to, their own coping strategies are overlooked, family networks underutilised and distress ignored or minimised.

Quality of communication was also significant whereby young people identified the value of sharing of information about their treatment, symptoms and services as crucial to feeling empowered. Young people with psychosis found this empowering as this helped them to understand their difficulties and how to access for help. The link between early intervention and improved recovery is well documented within the literature (Birchwood, 2013; McGorry et al., 2013). However this study found that participants and their parents were often faced with clinicians unwilling to engage with them. These experiences of poor communication were also comparable to examples within the literature (e.g. Ahmad et al., 2003; Byrne et al., 2010; Kirby et al., 2003; Lloyd, 2005; Rethink, 2003; Street et al., 2003). Some parents described pleading with services in order to get a response and help for their child which is a contravention to current government policy (DoH, 2004), which emphasises easy access to services in order to maximise the prevention of problems becoming more serious and difficult to treat.

Although Wallerstein (2006) and WHO (2010) recognise empowerment as a process which enables people to increase control over and to improve their own personal health, the current study shows that young people cannot achieve the fullest health potential unless they are empowered in taking control of the things that determine their health. There is evidence that clinicians create powerlessness worsening symptoms and delaying recovery (Carnegie UK Trust, 2008; CAMHS Review, 2008; Claveirole, 2004; DoH, 2006, 2010; Mental Capital & Wellbeing, 2008; New Horizons, 2009). These sources indicate that young people's experiences are often not listened to, their own coping strategies are overlooked,

family networks underutilised and distress ignored or minimised. Given how services such as CAMHS often claim that they are promoting government policies (CAMHS Review, 2006; Carnegie UK Trust, 2008; DoH 2001, 2004, 2006) such as exercising control and choices over young people's illness, engagement and partnership working these results show that there is still a need for further improvements. From a policy perspective (DoH 2004, 2001; NICE 2002) the concept of empowerment remains critical and given the interest in improving levels of empowerment for young people with psychosis such as EIS this study contributes by filling the knowledge gap in conceptualising empowerment and developing the actual measure which reflects their concept. Therefore having a measure that will assist in exploring the effects of interventions which aims to increase empowerment will be useful for both clinicians and young people with psychosis to address these disempowering practices

Young people with psychosis identified certain psychological processes as being instrumental in empowerment which were also consistent with the adult literature on empowerment (Ben-Zur & Yagil, 2005; Koelen & Lindstorm, 2005; Logan & Ganster, 2007; Moattari et al., 2012; Thomas & Velthouse, 1990; WHO, 2010). Empowerment was identified as having a positive impact on psychological processes such as; self-efficacy, social support, thinking style, coping, and control and these psychological processes were found to be associated with better mental health, wellbeing and recovery in young people with psychosis. These findings were also mirrored in the adult literature on empowerment (Bonney & Stickley 2008; Brosnan, 2012; Harper & Speed, 2012; Kinderman et al., 2011; Neil et al., 2009; Pitt et al., 2007).

# 7.2.2 Phase 2: Explorative Factor Analysis Study

Phase 2 involved developing and providing preliminary testing and validation of the new measure, the Youth Empowerment Scale (YES) in a non-clinical population of young people aged 11 to 19 years attending secondary school. An item pool of 47 was developed as the YES, derived from the six main themes captured in the phase 1 qualitative study. The results demonstrated that the YES performed exceptionally well as a valid and reliable measure of empowerment with young people in a non-clinical population. EFA was used to test the structure

of the YES which produced a three factor model solution consisting of 21 items. The three factor model was found to represent the construct of empowerment as three domains; 'Receiving Help and Validation', 'Choice and Control', and 'Effective Help-Seeking' respectively. The items were considered to be both conceptually and theoretically congruent with the functions of empowerment as proposed by young people in phase 1 study. A more comprehensive assessment of the psychometric quality of the scale was used in phase 4 to assess its utility as an outcome measure and as a possible research tool to assess the relationship between young people with psychosis, delivery of care within CAMHS, empowerment and important outcomes such as recovery, mental wellbeing and quality of life. Psychological wellbeing in children and young people has become a policy priority and an increasingly important outcome of healthcare (DCSF, 2010; DoH, 2006; NAC, 2011; NCSS, 2011). This study meets these priorities by providing a valid and reliable outcome measurement of empowerment which captures all aspects of health from the young person with psychosis.

This study demonstrated how scores on the new YES were well-distributed and showed near-normal distribution which suggests that floor and ceiling effects are minimised for practical applications. This is important for a tool designed as a generic measure of assessing empowerment in young people who faces significant mental health challenges and a growing commitment to ensure young people's voice are heard when receiving care from CAMHS. The Cronbach's alpha was used to measure for internal reliability and the YES total score displayed very good internal reliability ( $\alpha = 0.89$ ). Cronbach's alpha coefficients were also computed for internal consistency of items on the three factors (factor 1  $\alpha$ =0.86; factor 2  $\alpha$ =0.78  $\alpha$ =0.76) which were also considered internally consistent.

This study also demonstrated good convergent validity with other related constructs such as quality of life, mental wellbeing, and the making decisions and empowerment questionnaire. This study mirrors other findings in the literature that shows the strong link between empowerment, better prognosis, decease in relapse and rehospitalisation, better mental health and quality of life (e.g. Benson, 2007; Carnegie UK Trust, 2008; Marshall et al., 2005; Walker et al., 2010). This study demonstrated how the experiences of empowerment, mental health and

quality of life are common in the non-clinical population of young people as correlations between empowerment, mental health and quality of life were found in this sample. Participants with lower scores of empowerment had higher levels of psychological problems and lower general wellbeing as measured on the GHQ-12. This result is considered to be consistent with Resnick et al. (2004), Pitt et al. (2007), and Salmon and Hall (2003) which examined the positive relationship between empowerment, recovery and general wellbeing in adults with mental illness. This is the first study that quantitatively examined how empowerment correlates to mental wellbeing and quality of life in young people. Whilst studies such as Pitt et al. (2007) show evidence of the role of empowerment in improving health, wellbeing and recovery in adults with psychosis, this relationship has not being examined in young people other than in phase 3 of this study.

# 7.2.3 Phase 3: Mediation Analysis Study

Phase 3 is the only known example of a study that explores the relationship between psychological processes (self-efficacy, control, coping, thinking styles and social support) empowerment, and mental health, wellbeing, and recovery in a general population of young people. As mentioned above the psychological processes targeted in this study were derived from the six main themes captured in phase 1, in which young people identified psychological factors they considered to be relevant in their own experiences of feeling empowered. The psychological processes they identified were consistent with studies with adults which have also demonstrated that empowerment is related to self-efficacy (Moattari et al., 2012; Small et al., 2013), coping (Ben-Zur & Yagil, 2005), control (Koelen & Lindstorm, 2005), thinking styles (Thomas & Velthouse, 1990), and social support (Logan & Ganster, 2007). These psychological factors, within adults, were associated with better mental health, wellbeing and recovery from mental health difficulties (Bonney & Stickley, 2008; Brosnan, 2012; Harper & Speed, 2012; Kinderman et al., 2011; Neil et al., 2009; Pitt et al., 2007). Although there is increasing recognition of empowerment being important from the perspective of young people with mental health difficulties and the need for services to be empowerment orientated (DH & DCSF, 2009; DfES, 2006, 2003; DoH, 2004), there is almost no research exploring the psychological mechanisms through which an individual experiences feeling empowered amongst young people.

Mediation analysis was used to analyse the data from all of the completed questionnaires. This mediation model revealed that social support, thinking styles, coping mechanisms, and control directly predicted mental health, wellbeing, and recovery; but the relationship was stronger when mediated by empowerment.

The concept of controlling one's thinking style effectively is implicit in several treatment approaches (Wells & Davies, 1994) and can be an integral part of the empowerment experience. This concept is particularly important in young people with psychosis as the intention is to prevent problems becoming more serious. This study showed that participants who reported better thinking styles (TCQ, BCSS and DAS), scored higher on indicators of better mental health, wellbeing and recovery from personal problems. These associations were stronger when mediated by empowerment which were also consistent with other studies which showed the importance of empowering individuals to engage with services and their care as this can help with better mental wellbeing and recovery (Birchwood et al., 2001; Fowler et al., 2009; Grant & Beck, 2009; Kinderman et al., 2011; Morrison et al., 2003; Warner, 2004). Therefore if clinicians examine the different ways in which individuals use their thought control strategies to control their unwanted intrusive thoughts this can be an integral part of the empowerment experience.

Control was found to be an important element in the empowerment process for young people with psychosis in phase 1, which referred to the individual's perception of his or her ability to control the outcomes of events. Results from this study showed that empowerment partially mediates control whereby participants with control over their experiences (RLC) were more likely to have better mental health and recovery from personal problems. This association between control and empowerment is also evidenced within the adult literature (Hansson & Bjoorkman, 2005; Johnson Roberts, 1999; Leksell et al., 2007; Woodall et al., 2010). This demonstrates that people cannot achieve their fullest health potential unless they are able take control of the things that determine their health. The current study has implications for clinicians who aim to empower young people to take charge of their own health by encouraging their confidence in and ability to play an assertive role in their own care.

The emphasis on social support and the quality of the relationship delivered by clinicians within services was universally held to be fundamental to empowerment in phase 1. Supportive relationships, such as family connections, long-term friendships, and meaningful connections between the young person with psychosis and clinician were associated with empowerment. Mental health disorders can impair a person's ability to socialise normally and can have a negative impact on their ability to form an adequate supportive social network (Brenner et al., 1994; NICE, 2003; Roder et al., 2006, 2011; Weissman et al., 2007). The results from this study found that empowerment partially mediates social support whereby participants with better social support (SOS) were more likely to have better mental health and recovery from personal problems. These findings were also consistent with other studies which emphasise the negative impact of social impairment and isolation on young people with mental health problems on the their ability to engage in employment, education, family and social relations (Logan & Ganster, 2007; Roder et al., 2006, 2011; Royal College of Psychiatrist, 2010, Wallertstien, 2006; Weissman et al., 2007). This suggests that there is a clear overlap between empowerment and social support which increases wellbeing and recovery in young people. If young people are empowered to access social support and to engage in meaningful social activities along with supportive relationships this can reduce the social isolation and exclusion which is often experienced by young people with psychosis.

Empowerment and coping are interconnected and interdependent in that coping is a way to set into motion personal resources to deal with the problem and empowerment is the positive outcome of successfully coping or dealing with the problem. The use of coping strategies in stressful events such as dealing with the symptoms of psychosis is well recognised in the literature (Goldberg et al., 2007; Tarrier, 2000; Zeidner & Endler, 1996). Young people in our phase 1 study also identified coping as essential aspect of empowerment in the combat against exacerbation or relapse of psychotic symptoms. Results from this study showed that empowerment partially mediates coping; participants who demonstrated greater coping ability were more likely to have better mental health and recovery from personal problems. These findings are supported by other studies that indicate that empowerment and coping are interconnected and interdependent,

leading to better outcomes (Compas et al., 2001; Goldberg et al., 2007; Woodall et al., 2010. WHO (2009, 2010) identified coping as the foundation of empowerment and reported that active coping required the ability to identify a specific problem, or stressor, and concurrently act to alleviate the effects of that stressor. The current study has implications for clinicians who aim to empower young people to take charge of their own health by encouraging their confidence in and ability to play an assertive role in their own care.

This study has important implications for our understanding of the mechanisms through which empowerment is likely to be facilitated in young people. The study has demonstrated how empowerment mediates the relationship between psychological processes and mental health, wellbeing and recovery in young people. The results of this study contribute to the understanding of empowerment by demonstrating the importance of clinicians understanding and being able to assess the different ways in which individuals manage their thinking styles. This study also highlights the importance of the manner in which clinicians facilitate young people to establish social networks in order to empower them to engage in employment, education, family/social relations and encourage young people to play an assertive role in their own care. These findings demonstrate how clinicians can promote positive mental and emotional wellbeing in young people by promoting the mechanisms through which empowerment is likely to be facilitated.

### 7.2.4 Phase 4: Confirmatory Factor Analysis (CFA) Study

This final phase examined the psychometric properties of the YES in a clinical population of young people aged 13 to 18 years of age and the three factor model which was based on phase 2 EFA study in a non-clinical population. CFA was used to determine whether the hypothesised structure of the YES provided adequate fit to the data and whether all the items on the YES were properly aligned with the correct facets.

CFA of the clinical sample demonstrated that all standardised factor loadings for the three factor model were statistically significant which meant that each item on the YES adequately harmonises with its corresponding factor. In this study CFA showed how all the items on the YES loaded onto the same factors in spite of there being a sample difference between the clinical population in this study and the non-clinical population in phase 2. This study confirmed how the concept of empowerment is measured in three factors; receiving help and validation, choice and control; and effective help-seeking. These findings were also similar to the findings in the adult literature on empowerment measures (Castelein et al., 2008; Carpinello et al., 2000; Rogers et al., 1997; Segal et al., 1995). However the factors on the YES and in particular factor one 'receiving help and validation' is different in young people which may be attributed to how mental illness such as schizophrenia and psychosis is diagnosed in adults. The introduction chapter demonstrated how the clinical presentation of mental illness in young person is more complicated because of factors such as maturity level and personality development (Chuma & Mahadun, 2011; Kendall et al., 2013; Morrison et al., 2011; Tengan & Maia, 2004). The nature of the presenting symptoms for young people makes it more difficult to diagnose which often leads to misdiagnoses or diagnostic confusion which is why empowerment plays important role in ensuring they are being heard and validated. Given the emphasis on early detection and interventions for young people with psychosis this empowerment scale demonstrates the need for such measure derived from young peoples' perspective rather than from the adult perspective

This study has shed light on the construct of empowerment from young people's perspective and shows how the three factors on the YES are supported by the theory of empowerment in the literature e.g. (Kieffer, 1984; Rappaport, 1987; WHO, 1986, Wallerstein, 2006; Zimmerman, 1995, 2000). Within the context of mental health, empowerment might involve a young person with mental health problems being able to heal, recover and resume their previous social role; thus offering the individual a sense of hope.

This study utilised a respecification phase as described by Kenny (2012) which generated two alternative models and improved the fit. The respecification of model 3 was significantly better than the alternative two models when three items were deleted from factor 3. There is controversy concerning fit indices in the literature which argues that fit indices do not add anything to the analysis and that

cut off for a fit index can be misleading and subject to misuse (Barrett, 2007; Hayduk et al., 2007). However, there is a consensus that 'good fitting model' does not mean that the model is correct or valid instead it indicates that the model is plausible (Holtzman & Vezzu, 2011; Hu & Bentler, 1998; Kenny, 2012; Kline, 2010; Schermelleh-Engel, et al., 2003). Given that model 3 fit improved following the respecification we decided not to delete any further items as we did not want to deviate further from the initial theoretical model. Future research will attempt to validate the YES on a larger more homogenous clinical population of young people with psychosis. Although this study recruited young people from a clinical population it did not permit testing fit of model for young people with psychosis separately. Therefore future research can inform us how these three factors in YES are specifically applicable to young people with psychosis and how the construct of empowerment measured in the YES fit that specific population.

The YES demonstrated good convergent and discriminant validity which it also did on our two previous studies (phase 2 and 3). This study showed evidence of convergent and discriminant validity through the use of CFA and Pearson correlation methods in the clinical population. Convergent validity showed that the three factors were related to empowerment and had stronger convergent validity than discriminant validity. These findings suggest that the YES provides valid measures of each construct. An examination of correlations among scales reveals that the clinical sample of young people ratings of total difficulties score on the SDQ, and the psychological symptoms and functioning on the BYI-II and HoNOSCA were also strongly and inversely associated with their ratings of empowerment (YES). These findings are consistent with other studies which demonstrated that empowerment was related to better mental wellbeing, better prognosis, and a decrease in relapse and rehospitalisation (Benson, 2007; Carnegie UK Trust, 2008; Marshall et al., 2005; Pitt et al., 2007; Walker et al., 2010). Therefore this scale can capture the various aspects of empowerment when assessing the psychological wellbeing and recovery for young people which is critical in current healthcare policies for young people (DCSF, 2010; DoH, 2006; NAC, 2011; NCSS, 2011).

This study has demonstrated that the YES is a valid measure for empowerment as a construct for young people with psychosis but needs further development to continue to improve model fit and factor structure. This measure may be useful to ensure that empowerment as a measurable outcome for young people with psychosis receives attention alongside other more clinically focused outcome measures such as recovery, mental wellbeing and quality of life. The YES will also be particularly valuable to CAMHS clinicians involved in working on interventions and service delivery in improving mental health wellbeing and deceasing symptoms of psychosis. Overall, the YES is a reliable and valid scale in determining empowerment in young people in a clinical setting.

### 7.3 Importance and relevance of research

Review of the literature demonstrated how the lack of a precise definition has made it difficult to measure and to employ the concept of empowerment for young people with psychosis. This lack of a definition of empowerment from young people with psychosis is an obstacle to its consistent application in practice. This is the first study that has conceptualised the concept of empowerment in conjunction with developing a meaningful outcome measure of empowerment for young people with psychosis. Services for young people such as CAMHS, youth programmes and professionals cannot attain the aims of government policies in improving levels of empowerment unless a clear conceptualisation of empowerment from their perspective has been established (CAMHS Review, 2008; DoH, 2006, 2010; Mental Capital & Wellbeing, 2008; New Horizons, 2009). The empowerment literature presented in this thesis concludes that empowerment has been defined primarily from an adult perspective. Although policies (DoH 2004, 2001; NICE 2002) report positive aspiration for young people with psychosis the use of an adult focused concept of empowerment for young people is potentially problematic. Many young people continue to experience interventions being done 'to' or 'for' them instead clinicians should focus on ensuring that young people have the knowledge, skills and resources to do things for themselves. Studies show that if clinicians help young people to foster these skills and support them in decision making regarding their own treatment this can empower them to take more responsibility for their health as they become adults thus improving their mental wellbeing and recovery

(Carnegie UK Trust, 2008; The Children and Young People's Mental Health Coalition, 2010). Empowerment was also shown to decrease relapse and rehospitalisation, and better long-term prognosis in EIS (Allot et al., 2002; Birchwood et al., 1998; Booth et al., 2004; Craig et al., 2004; Marshall et al., 2005; Pitt et al., 2007).

Given the need for early intervention, treatment and engagement with young people with psychosis this thesis demonstrated the need for an outcome measure that gives understanding of how empowerment as an outcome can reduce the severity of illness, improve wellbeing and aid recovery for young people with This need for an empowerment measure for young people with psychosis is particularly important given how services for young people such CAMHS often claim that they are promoting government policies such as independence, engagement and partnership working (CAMHS Review, 2008; DoH 2001, 2004, 2006). Therefore having an empowerment measure for young people with psychosis serves several purposes. Firstly, an outcome measurement of empowerment offers a means of benchmarking and improvement within CAMHS. Clinicians can measure whether their understanding of practice being empowering is the same as the understanding of young people with psychosis. Secondly this outcome measure could be used to highlight good and bad practices, for discussion and negotiation, and to promote and measure concrete and sustainable actions that result in empowerment. For instance, an increase in empowerment scores following participation in treatment and intervention would be a positive indicator for both the service providers and for young people with psychosis. If scores did not increase, clinicians should try to identify the elements that interfere with young people becoming empowered. Such understanding could help to inform services promoting recovery, independence, and facilitating the uptake of social, educational and employment opportunities for those young people.

### 7.4 Limitations

This section identifies the limitations of this research and suggests possible future research directions. A critique of the methodological approaches was already

provided in chapter three and a review of the study's rigor was addressed in each of the four phases.

This research focused on developing a valid and reliable outcome measurement of empowerment for young people with psychosis in order to contribute to best practice and current research. Qualitative and quantitative approaches were used to address the research questions, and were chosen for their capacity to examine research problem (Doyle et al., 2009). Greene (2005) highlight that a mixed method approach offers greater possibilities than a single method approach in responding to decision makers agenda as well as to the interests of other interested parties. The research framework used within this study drew on a post-positivist paradigm which supported the use of mixed methods and meticulous attention ensuring that rigour was maintained in all the four phases of the research. Within this study a rationale was given for using a mixed method approach and a clear account was provided of the data analysis that was undertaken on qualitative and quantitative data.

Within this study interviews were conducted and results were used to inform the development of the YES for validation in both clinical and non-clinical population. The target population of the qualitative study in phase 1 included nine participants (n=9) from the one NHS locality and they all had received a psychiatric diagnosis of a schizophrenia spectrum disorder. This has implications for the extent to which findings from this sample (n=9) can be generalised to all young people with psychosis across the UK. However, there is a consensus towards a homogeneous small sample size in IPA (Reid et al., 2005; Smith & Osborn, 2008) and therefore in accordance with the recommendations for IPA, all efforts were made to ensure that the sample was homogenous (Quinn & Clare, 2008). For instance recruited participants had ongoing contact with CAMHS following admission (minimum 6 months when recruited) and were considered to be in recovery. All nine participants suffered from a range of mental health and social difficulties ranging from persistent persecutory delusions, active hallucinations, social isolation, exclusion and absence from school. Reid et al. (2005) argue how 'less is more' when considering the number of participants with IPA. Smith et al. (2009) also advocates for this and recommends between five and 10 participants when using IPA as they argue that reduced number of participants allows for a richer depth of analysis that might be inhibited with a larger sample.

Validity is referred to as study that yields a correct answer whilst reliability is referred to whether repeated study of the same phenomenon by the same method would yield the same answer (Kvale, 1989). Kyale (1989) stated that validation in qualitative research is about checking the credibility of knowledge claims, ascertaining the strength of the study evidence and the plausibility. Despite the small number, participants did provide a rich and varied account of their experiences with empowerment. This study followed the recommendations for IPA (Smith et al., 2009) and found that the small numbers of participants were representative of the wider population. We found that the six main themes found in this study were supported elsewhere in the literature and was further supported in our quantitative studies in phases 2 to 4. Smith et al. (2009) stated that a clearly rendered rich account of participants' experiences that is related to the up to date literature, will allow the reader to apply to the general population. It could also be argued that the age range of the participants (14-18 years) was somewhat broad and the findings may be representative of this. It would be beneficial for future studies to focus on specific age groups e.g. 14-15 year olds or 18-19 year olds to establish whether age related differences are significant.

In phase two and three data was collected from young people in a non-clinical population. This can have implications for the extent to which findings from these samples (phase 2 n=264, phase 3 n=436) can be generalised to all young people with psychosis across the clinical population. Despite this, in phase 2 and 3 participant's scores were normally distributed on the YES and the findings confirmed reliability and validity of the scale as it correlated with other validated measures which are routinely used in CAMHS. Phase 2 focused on validating the YES in a non-clinical population before testing the hypothesised structure in a clinical sample in phase 4. Although both phase 2 and 3 used measures specifically for people with mental health problems it is possible that the results might not be replicated in a clinical population but this limitation is balanced against the numerous benefits to looking at this in a non-clinical population. The aim was to validate the YES in a non-clinical population in phase 2 and to test the

relationship between psychological processes (found in phase 1) and mental wellbeing was one that was common to all young people, not just those with mental health problems. These results from the non-clinical population did not represent the final YES and was further validated in a clinical population in phase 4.

In the final phase 4 findings were entirely based on clinical data from young people attending CAMHS suffering from different types of mental disorders (e.g. depression, anxiety, eating disorder) and did not permit testing fit of model for young people with psychosis separately. This has implications for the extent to which findings from this sample (n=278) can be generalised to all young people with psychosis across the clinical population. However, our purposes were to determine the three factor model of the YES in a clinical population and to test its convergent and discriminant validity. Despite the clinically diverse sample participants scores were normally distributed and the findings confirmed reliability and validity of the scale as it correlated with other validated measures used in CAMHS.

#### 7.5 Future Research

Future research will attempt to validate the YES on a larger more homogenous clinical population of young people with psychosis. Although this study recruited young people from a clinical population it did not permit testing fit of model for young people with psychosis separately. Therefore future research such as qualitative evaluation including focus groups considering the clinical implications and consideration of how services assess, monitor and evaluate recovery can inform us how the three factors in YES are specifically applicable to young people with psychosis. Also how the construct of empowerment measured in the YES fits that specific population. Given that the original hypothesised model did not fit the clinical data in this sample, our next study will validate the YES on a large more homogenous clinical population. Future testing of the measure may also benefit from assessing suitability for using in services for benchmarking, sensitivity to change in clinical trials, development and evaluation of interventions to promote empowerment and autonomy. The YES might benefit in longitudinal studies or randomised trials of clinical interventions for young people with

psychosis, to see whether it is sensitive to the effects of interventions designed to improve empowerment. This would also inform us whether such changes are subsequently associated with changes in mental wellbeing, recovery and quality of life.

#### 7.6 Conclusions

This thesis presented the findings of four phase study carried out to address the research objectives. A mixed method approach was used. Interview data gathered in phase 1 was used to inform the development of the YES. The findings from this phase 2 provided a validated measure of empowerment for young people. The version of the YES developed at this stage was a 47 item self-report measure that asked participants to respond to each item on a four-point Likert scale. The data was analysed using exploratory factor analysis (EFA) which assessed the construct validity of the YES. This measure was used in phase 3 which explored the relationship between psychological processes which were derived from the 6 main themes in phase 1, empowerment, and mental health, wellbeing, and recovery. Mediation analysis demonstrated how the psychological processes such as coping, thought control, and social support were mediated by empowerment and, in turn, improved mental health, wellbeing and recovery. Finally, phase 4 validated the Youth Empowerment Scale (YES) within a clinical population of young people using CFA. This study confirmed the YES as a valid and reliable measure of empowerment which can be used in future work identifying and supporting empowerment for young people with psychosis.

This study has addressed the development and validation of the YES. Results present details of a valid new measurement of outcome of empowerment. Utilisation of these results can contribute to informed decisions in the developmental of a model of best empowerment practice for clinicians in CAMHS.

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## Appendix 1: Ethical Approval (LREC) for Phase One Study

### **Bolton Research Ethics Committee**

Room 181, Gateway House Piccadilly South Manchester M60 7LP

Telephone: 01612372585 Facsimile: 01612372383

4 July 2006

### **Private & Confidential**

Ms Annmarie Grealish, Lecturer in Nursing Allerton Building, Room L826 Frederick Road Campus University of Salford SALFORD M6 6PU

Dear Ms Grealish

Full title of study: Qualitative exploration of empowerment from the

perspective of adolescents with psychosis.

REC reference number: 06/Q1409/46

Thank you for your letter of 8 June 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

### Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully. Please note in particular the requirements relating to the submission of progress and other reports in points 4 and 10.

### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application	5.1	28 March 2006
Investigator CV	1 Sara Tai	
Investigator CV	1 Annmarie Grealish	28 March 2006
Protocol	1	28 March 2006
Interview Schedules/Topic Guides	1	28 March 2006
Interview Schedules/Topic Guides	2	08 June 2006
Participant Information Sheet: Research	2	08 June 2006
participant		
Participant Information Sheet:	2	08 June 2006
Parent/Guardian		
Participant Consent Form: Parental	2	08 June 2006
Participant Consent Form: Participant	2	08 June 2006

### Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q1409/46	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely

### **Dr Frank Bowman**

Chair

Email: elaine.hutchings@gmsha.nhs.uk

Enclosure:	Standard approval conditions
Copy to:	Professor Martin Johnson Director of Salford Centre for Nursing, Midwifery and Collaborative Research Allerton Building, Room L826 Frederick Road Campus University of Salford SALFORD M6 6PU

## **Appendix 2: Qualitative Interview Guide (Phase One Study)**

### **Qualitative Interview Guide:**

### Adolescent's Perspective & Understanding of Empowerment

(Version 2, 8<sup>th</sup> June 2006)

### 1. Background Information

- Can you tell me a bit about yourself?
- Can you tell me how you spend your time?
- What are your hobbies and interest?

### 2. History of Mental Health Problems

- a) When did you first notice things were difficult?
- How did you feel?
- Did anyone else notice things were difficult for you?
- b) Can you tell me about how things have been for you since then?
- Can you tell me about times when things have been okay?
- Can you tell me about times when you have not coped so well?
- Can you tell me who do you turn to when things are not well/can't cope?
- c) Can you tell me a bit about your experiences of symptoms/diagnosis?
- What helped you to understand your symptoms/diagnosis?
- Who helped you to understand these?
- How helpful has your treatment/medication been?

# 3. Can you tell me a bit about the mental health professionals you have been involved with?

- How helpful have they been?
- Did they explain your symptoms/diagnosis?
- Did you understand the information they gave you?
- Did they involve you at all levels of your treatment/care?
- Did they offer you choices and ask for your views on the care they provided?

### 4. Understanding and Experience of Empowerment

- a) What do you understand by empowerment?
- Do you see it as a process?
- Do you see it as important?
- Does it have a start/end point?
- How do you know when you are empowered?
- Does empowerment help you cope/manage your problems and how?
- Does empowerment help you recover better and why

- b) Introduce Zimmerman & Rappaport's definition of empowerment:
- ".....the mechanism by which people, organizations, and communities gain mastery over their lives"
- c) What do you think of this definition of empowerment?
- Do you agree/disagree with it?
- How does it compare to your understanding of empowerment?
- d) What have your own experiences of empowerment been?
- Have there been stages in your care you felt empowered/disempowered?
- What helps empowerment?
- What are the barriers to empowerment?
- What would help you in your difficulties to be empowered?
- When experiencing difficulties with psychosis is empowerment important at this stage?
- Do you see by being fully involved helps you achieve empowerment?
- Do you see choice as important factor?
- Does understanding your difficulties help with empowerment?
- e) What can health care workers do to help with empowerment?
- Do you think they have different attitudes to empowerment to your views?
- What can they do to change or facilitate empowerment?
- What do they do that helps with empowerment?
- f) Has there been other support outside mental health services that has been particularly helpful to achieve empowerment?
- How helpful have family and friends been?
- g) How important is employment to empowerment?
- h) How important is education/training to empowerment?
- i) What changes would you like to see in the mental health services in relation to empowerment?

### 5. Ending

Is there anything I've not raised that you think I need to know about?

Can you tell me a bit about what it has been like being interviewed today and what impact it will have on you?

Has there been anything particularly difficult or distressing that you feel you need additional support for?

## **Appendix 3: Phase Two Demographic Form**

**Title of project:** Development of the Youth Empowerment Scale (YES)

## Please complete all the questions

1. AGE
2. GENDER Male □ Female □
3. WHERE DO YOU LIVE?
4. WHO LIVES AT HOME WITH YOU? (Mum, dad, sister, brother, aunt, uncle etc)
<b>5. ETHNICITY</b> : How would you describe your ethnic background?
a. White $\square$ British $\square$ Irish $\square$ Other
b. Mixed Race
White & Black Caribbean □ White & Black African □ White and Asian □ Other
Wilite and Asian 🗀 Onlei
c. Black or Black British
Black Caribbean □ Black African □ Other
d. Asian or Asian British
Indian □ Pakistani □ Bangladeshi □ Other
e. Chinese or Chinese British
Chinese □ Other

## **Appendix 4: Ethical Approval for Phase Two Study**

### The University of Manchester School of Psychological Sciences Research Ethics Committee

### Tuesday 9th December 2008

#### **Decisions of the Ethics Committee**

When applicants have found their application below, they should note the following instructions on what to do next:

### If the decision is: Final Approval

Correct any minor points mentioned and submit copies of any amended documentation to the SREC in advance of collecting data. The project may commence.

### If the decision is: Conditional approval

Overall, the project is satisfactory but some changes are required. The project may <u>not</u> start until you receive Final Approval.

- 1. Download the Amendments Coversheet from the Intranet. Detail the changes you have made in the space provided. Submit the documents you have been asked to amend or include.
- 2. Leave the documents in the Ethics Amendments/Resubmissions pigeon hole or email them to Jayne Ward, Committee Secretary. Amendments are reviewed between meetings wherever possible.

### If the decision is: Resubmission required

There are several major concerns with the project.

- 1. Re-submit all documents, including the application form and cover sheet, making the changes requested by the SREC. Use the original reference number unless instructed otherwise.
- 2. Leave the documents in the Ethics Amendments/Resubmissions pigeon hole by 5pm on the Monday one week prior to the meeting in which you would like your resubmission reviewed.

The following project has been reviewed:

**Ref:** 01/07P

**Title:** The development of a youth empowerment scale

Type: PG research Level: Level 2

Research Group: Clinical and health psychology

Participants: 250

**Methodology:** questionnaire **Supervisor:** Sara Tai

Author1: Annmarie Grealish Tony Morrison

<b>^</b> -			_		•-	_
Co	m	m	е	n	IS	:

Decision:

1. Amendments received and noted.


**Approved** 

## **Appendix 5: The Penultimate Version of the YES (47 items)**

## **Youth Empowerment Scale (YES)**

The experience of not being empowered is a common one. It is particularly common when under stress. Listed below are a number of attitudes and thoughts that people have expressed about not being empowered. There are no right or wrong answers. Please read each statement and then circle the number that corresponds to how much you believe this. Please give a response to all the statements.

		Not at all	Somewhat	Moderately so	Very much so
1.	When I am unwell I feel able to make my own decisions about which treatments that I receive	1	2	3	4
2.	I feel I have choices about my treatment options when I am unwell	1	2	3	4
3.	When I need help from others to deal with my problems, I feel I have a say in how they treat me	1	2	3	4
4.	I feel my ways of coping are respected by others	1	2	3	4
5.	I feel I can make my own decisions about what I do to help me feel better about my difficulties	1	2	3	4
6.	When things go wrong I still feel able to make choices what I want to do	1	2	3	4
7.	I feel that I get to have a say in what I have to do at school	1	2	3	4
8.	It is other people who tell me what I must do next	1	2	3	4
9.	Other people help me to make decisions about how I live my life	1	2	3	4
10.	I feel I have control over my difficulties	1	2	3	4
11.	When I have problems I feel I am in charge	1	2	3	4
12.	My problems sometimes effect me so much I can no longer make decisions for myself	1	2	3	4
13.	I feel that adults (apart from family & friends) don't listen to my point of view	1	2	3	4
14.	I feel that adults (apart from family & friends) listen to me when I have a problem	1	2	3	4
15.	When I tell adults (apart from family & friends) about a problem I feel they support me	1	2	3	4

	16 111 1 111 (				1
16.	I feel that adults (apart from family & friends) take my point of view seriously	1	2	3	4
17.	I feel understood by adults (apart from family & friends)	1	2	3	4
18.	I feel that being listened to helps me cope with my problems	1	2	3	4
19.	If I ask an adult (apart from family & friends) for help, they hear what I say and use this to help me	1	2	3	4
20.	If I talk to adults (apart from family & friends) about a problem, I feel believed	1	2	3	4
<mark>21.</mark>	Adults (apart from family & friends) do not believe me	1	2	3	4
22.	Other people take the time to explain things to me	1	2	3	4
23.	When I am having difficulties other people take time in giving advice to me	1	2	3	4
24.	When I have been unwell I needed treatment, other people have explained this to me	1	2	3	4
25.	When I have been unwell other people have told me how to deal with things	1	2	3	4
26.	When I have been unwell other people have been willing to listen to my problems	1	2	3	4
<mark>27.</mark>	When I am having a problem other people will not listen to me	1	2	3	4
28.	If I have been troubled by something, someone will notice	1	2	3	4
<mark>29.</mark>	The other adults I know (apart from family & friends) are not interested in my problems	1	2	3	4
30.	I have other adults (apart from family & friends) that I feel I could go to if things are difficult for me	1	2	3	4
31.	If I had to ask other people (apart from family & friends) for help with a problem I think they would tell me to go away	1	2	3	4
32.	When I get things wrong other people say it is my fault	1	2	3	4
33.	When I am having a difficult time, I have a number of things I do to help me cope	1	2	3	4
34.	Other people (apart from family & friends) have been useful in helping me to find ways to cope with my problems	1	2	3	4

35. I can sort out my own difficulties in my own way	1	2	3	4
36. When I have things to do in my life I am less likely to experience problems	1	2	3	4
37. When I am busy I worry less about my problems	1	2	3	4
38. If I am bored, I am more likely to experience problems	1	2	3	4
39. If I have to talk to someone about a problem I prefer to speak to somebody who is cheerful	1	2	3	4
40. If I feel comfortable with an adult I find it easier to go and ask that person for help	1	2	3	4
41. The adults (apart from family & friends) in my life are not interested in my problems	1	2	3	4
42. Having a laugh and having fun with someone makes it easier to trust them	1	2	3	4
43. It is easier to talk to the adults I spend time with about my problems	1	2	3	4
44. Sometimes I feel my parents have to make big decisions for me	1	2	3	4
45. My parents cannot help me with problems	1	<mark>2</mark>	<mark>3</mark>	4
46. My parents helps me to sort things when I am unwell	1	2	3	4
47. Other people help my parents with what to do when I am unwell	1	2	3	4

## Thank you

## **Appendix 6: Phase Three Demographic Form**

**Title of project:** Development and Validation of the Youth Empowerment Scale (YES) for Clinical Population

## Please complete all the questions

1. Age
2. Gender Male □ Female □
3. Where do you live?
4. What is the name of your current School/Organisation/University/Place of Work/Other
<b>5. Ethnicity</b> : How would you describe your ethnic background?
b. White □ British □ Irish □ Other
b. <b>Mixed Race</b> White & Black Caribbean □ White & Black African □ White and Asian □ Other.
c. <b>Black or Black British</b> Black Caribbean □ Black African □ Other
d. <b>Asian or Asian British</b> Indian □ Pakistani □ Bangladeshi □ Other
e. Chinese or Chinese British Chinese  Other.

## Appendix 7: Ethical Approval for Phase Three Study

### The University of Manchester School of Psychological Sciences **Research Ethics Committee**

### Monday 7th June 2010

#### **Decisions of the Ethics Committee**

When applicants have found their application below, they should note the following instructions on what to do next:

### If the decision is: Final Approval

Correct any minor points mentioned and submit copies of any amended documentation to the SREC in advance of collecting data. The project may commence.

### If the decision is: Conditional approval

Overall, the project is satisfactory but some changes are required. The project may not start until you receive Final Approval.

- 1. Download the Amendments Coversheet from the Intranet. Detail the changes you have made in the space provided. Submit the documents you have been asked to amend or include.
- 2. Leave the documents in the Ethics Amendments/Resubmissions pigeon hole or email them to Jayne Ward, Committee Secretary. Amendments are reviewed between meetings wherever possible.

### If the decision is: Resubmission required

There are several major concerns with the project.

- 1. Re-submit all documents, including the application form and cover sheet, making the changes requested by the SREC. Use the original reference number unless instructed otherwise.
- 2. Leave the documents in the Ethics Amendments/Resubmissions pigeon hole by 5pm on the Monday one week prior to the meeting in which you would like your resubmission reviewed.

The following project has been reviewed:

653/07P Ref:

Title: Does empowerment mediate the effects of psychosocial factors on wellbeing

> in young people PG research

Type: Level: Level 2

Research Group: Clinical and Health Psychology

Participants: 300-400approx Methodology: questionnaire Supervisor: Sara Tai

Author1: Annmarie Grealish Author2: Tony Morrison

**Comments:** 

**Decision:** 

1. Amendments received and noted.

**Approved** 

## **Appendix 8: Phase Four Demographic Form**

**Title of project:** Development and Validation of the Youth Empowerment Scale (YES) for Clinical Population

## Please complete all the questions

1. Age
2. Gender Male □ Female □
3. Where do you live?
4. Do you have a Diagnosis? Yes □ No □
If YES, please state
If NO, What do you see as your main problem:
5. Length of illness?
6. Responsible Clinician overlooking your care?
7. Ethnicity: How would you describe your ethnic background?
c. White □ British □ Irish □ Other
b. <b>Mixed Race</b> White & Black Caribbean □ White & Black African □ White and Asian □ Other
c. Black or Black British  Black Caribbean   Black African   Other
d. <b>Asian or Asian British</b> Indian □ Pakistani □ Bangladeshi □ Other
e. Chinese or Chinese British Chinese  Other.

## **Appendix 9: Ethical approval for Phase Four Study**



NRES Committee North West - Lancaster

Barlow House 3rd Floor 4 Minshull Street Manchester M1 3DZ

Telephone: 0161 625 7818 Facsimile: 0161 625 7299

13 December 2011

Ms Annmarie Grealish University of Salford, Mary Seacole Building, Frederick Road Campus, Salford, Greater Manchester M6 6PU

Dear Ms Grealish

Study title:

Development and Validation of the Youth Empowerment

Scale (YES) for Clinical Population

**REC** reference:

11/NW/0869

The Research Ethics Committee reviewed the above application at the meeting held on 08 December 2011.

### Ethical opinion

Ideally the Committee would like 24 hours for consideration of whether to participate, however, given that this is a low risk non interventional study, the Committee accepts the time for this application.

The members of the Committee present 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

**NHS 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 <a href="http://www.rdforum.nhs.uk">http://www.rdforum.nhs.uk</a>.

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

### Other conditions specified by the REC

The Committee would like to see the name removed from the questionnaires

It is 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).

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. Confirmation should also be provided to host organisations together with relevant documentation

#### Approved documents

The documents reviewed and approved at the meeting were:

Version	Date
	25 November 2011
	28 November 2011
Annmarie Grealish	
Professor Anthony Morrison	
Dr Sara-Jane Meiling Tai	
	21 October 2011
2.0	25 November 2011
2.0	25 November 2011
2.0	25 November 2011
2.0	25 November 2011
2.0	25 November 2011
2.0	25 November 2011
-	
1	
2.0	25 November 2011
	Annmarie Grealish Professor Anthony Morrison Dr Sara-Jane Meiling Tai  2.0 2.0 2.0 2.0 2.0 2.0 1

A Research Ethics Committee established by the Health Research Authority

REC application	3.4	28 November 2011

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

### Reporting requirements

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

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

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

### Feedback

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

Further information is available at National Research Ethics Service website > After Review

11/NW/0869

Please quote this number on all correspondence

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

Yours sincerely

Dr Lisa Booth

Chair

Email: carol.ebenezer@northwest.nhs.uk

Enclosures: List of names and professions of members who were present at the

meeting and those who submitted written comments "After ethical review – guidance for researchers"

Copy to:

Ms Lynne Macrae Ms Kathryn Harney

A Research Ethics Committee established by the Health Research Authority

### NRES Committee North West - Lancaster

## Attendance at Committee meeting on 08 December 2011

### **Committee Members:**

Name	Profession	Present	Notes
Dr Brenda Ashcroft	Lecturer	Yes	
Mr David Barber	Pharmacist	Yes	
Dr Lisa Booth	Senior Lecturer	Yes	
Mr James Burns	Retired Lay Member	Yes	Co-opted from Manchester East
Dr Nigel Calvert	Associate Director of Public Health	Yes	
Mrs Andrina Lawrence	Lay Member	Yes	
Dr Brenda Leese	Lay Member	No	
Dr Anas Olabi	Consultant Paediatrician	No	
Susan Page	Dentist	No	
Mrs Gillian Rimington	Lay	Yes	
Dr John Shakespeare	Retired GP	Yes	
Mrs Valerie Skinner	Nurse (Retired)	Yes	
Professor Jois Stansfield	Professor of Speech Pathology	No	
Dr Gary Whittle	Consultant in Dental Public Health (retired)	No	

### Also in attendance:

Name	Position (or reason for attending)		
Laura Brown	Assistant Co-ordinator		
Mrs Carol Ebenezer	Committee Co-ordinator		