Exploring Engagement: A Grounded Theory Study of Young People's Interactions with Healthcare Professionals

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"Adolescence is not just a staging post between childhood and adulthood. It is an exciting, sometimes bewildering time (both for young people and their parents/carers) in which enormous physical and psychosocial changes take place, alongside growing autonomy and responsibility for decision-making. We fail our young people if we do not ensure that everything possible is done to help them travel the sometimes rocky road to adulthood safely."

(World Health Organisation, 2010)

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Thesis Abstract

<u>Background</u>

There is growing recognition in health policies and professional guidance that youth-friendly services must include the values and views of young people in their healthcare. The term "engagement" has become increasingly used in literature to recommend that healthcare professionals should involve young people in participatory methods and include them in their decision-making. Yet, the engagement of young people within health interactions remains a complicated process, often influenced by lived contexts, value systems and lifestyle choices. Successful engagement of young people is often cited to ameliorate health-related behaviours, improve health outcomes and increase awareness of their health needs; yet, a paucity of research exists for healthcare professionals seeking to engage young people effectively in healthcare interactions.

<u>Study Aim</u>

To explore and define young people's engagement within their healthcare interactions.

<u>Methods</u>

A grounded theory study was conducted over a six-month period to gather young people's perceptions of their health interactions.

<u>Results</u>

The grounded theory study identified that young people produce engagement-related behaviour by means of an interpretive process. Three interconnected theoretical categories emerged: (i) prejudgement, the beliefs with which young people enter into health

interactions; (ii) learning to be a patient, the means by which young people learn from their interactions to develop in-context engagement-related behaviour; and (iii) validation, the selective interpretation of information to justify their perception of the interaction. The core category identified that young people demonstrate a reliance on affect heuristics within healthcare interactions, which may influence the extent young people feel able to engage with healthcare professionals. This was elevated into a substantive theory of affect-mediated engagement.

<u>Conclusion</u>

Findings suggest that a dual-process perspective of cognition may be useful to understand how young people engage in their healthcare; this could potentially be used by healthcare professionals to target issues that impact on a young person's engagement. This study's findings form a basis which would benefit nurses, occupational therapists and other healthcare professionals in developing person-centred interactions that empower young people in becoming stakeholders in their own health.

Chapter 1: The Thesis in Context

1.1 Introduction

The thesis focuses on the concept of engagement, a term used by health professionals to describe the process of actions that patients enact to become meaningfully involved in their health decisions and healthcare interactions. The intent of this thesis is to develop this understanding of engagement through the voices and perspectives of young people, rather than as a theoretical concept, developed and implemented by healthcare professionals. The term "engagement" is widely used in healthcare literature, supporting policy and guidelines for healthcare professional practice. Despite the proliferation of this term, the concept of the "engaged" patient relies on theoretical definitions which lack empirical foundations. The concept and process of engagement with young people, therefore, remains unexplored, and there is to date little research to inform practice. The aim of this thesis was to define how engagement is understood within healthcare interactions between young people and healthcare professionals from the young person's perspective in order to develop a substantive theory. This study aimed to explore and define young people's engagement in healthcare interactions from their perspective using a constructivist grounded theory approach (Charmaz, 2006; 2014). The central question for this study was supported by four research aims, all of which are defined below.

Research question:

What does the experience of engagement consist of for young people in healthcare interactions?

<u>Research aims:</u>

- To explore how young people report their interactions of their meetings with healthcare professionals;

- To examine how young people's perceptions of healthcare professionals affect their involvement in their healthcare interactions;

- To investigate how young people navigate healthcare consultations to identify issues and meet their perceptions of need;

- To understand what young people perceive as the barriers and facilitators to engage effectively with healthcare professionals during healthcare interactions.

The thesis provides an account of the social processes that occur when young people interact with health professionals, in so doing determining what facilitates engagement and what detracts from this process. Developing insight into engagement, as an active social process encompassing cognitive, emotional and behavioural factors, will aid healthcare professionals' understanding of young people to meaningfully involve them in their healthcare interactions.

This thesis is presented in seven chapters. This chapter provided background context to this thesis and the impetus for scholarly investigation into the phenomenon. Chapter 2 presents a scoping review identifying the type and range of research that exists on healthcare interactions between young people and health professionals. The focus of the scoping review identified engagement as a poorly defined term requiring further investigation to develop the evidence base. Chapter 3 details the study design of a constructivist grounded theory method, providing detail into the ontological and epistemic underpinnings which shaped the research methods. Chapter 4 gives a detailed account of the analytical methods used within coding and theoretical construction. Chapter 5 presents three theoretical categories that were developed through the analytical processes detailed in Chapter 4, explicating the construction of prejudgement, learning to be a patient and validation in relation to the meaning young people

attached to their care; these concepts are then discussed in greater depth in chapter 6. Chapter 7 details the emergence of the core category and its development into a substantive theory of affect-mediated engagement; findings are then discussed in relation to a dual processes perspective of cognition in relation to young people's experiences of engagement. Finally, the messages from the study are related to their usefulness for the development of policy, practice and further research in chapter 8.

1.2 Young People in Context

Some 11.7 million young people (aged 10-24) are currently living in the United Kingdom (UK), which represent one in five of the population, and, despite being a falling proportion due to our aging population shifting the demographic percentiles, these numbers have a significant implication for healthcare services and service delivery needs (Hagell et al., 2013). In addition, young people are becoming heavier users of healthcare services and, due to their growing numbers, this will drastically increase over the next 10 years (Hagell et al., ibid). As users of healthcare, their needs span across a spectrum of physical and mental health issues and often they will use multiple services (The Royal College of Paediatrics and Child Health, 2003). Yet, despite their increasing use of services, key public health indicators such as obesity, smoking, sexually transmitted infections and teenage pregnancy show little improvement in health and health behaviours (Viner, 2005). Health outcomes such as teenage pregnancy and abortion, substance misuse and risk-taking behaviours, and a range of health inequalities across socio-economic demographics, are much higher in the UK than the European average, and fall behind comparable high-income European countries (Public Health England, 2015). At face value, there appears to be a disparity between what young people need from healthcare services to improve health, behaviour and function, and what outcomes are achieved from the care they receive.

The disparity between young people's health needs and receipt of healthcare services is further problematised by the adolescent life stage, as young people have distinctly different needs that are dissimilar to child or adult populations (Coleman & Hagell, 2007). Traditional healthcare services often fall between child and adult populations, and young people's transitional needs may not be understood or met within these services (McDonagh & Viner, 2006). A key factor in the transitional stage from childhood to adulthood is that behaviours and skills are developing along a continuum of maturation, which has become engrained in how we think about young people as new perspectives have emerged to accommodate developmental approaches in healthcare (Coleman & Hagell, 2015). Viner (2005) asserts that exploration of adult behaviours is a marked feature of this life stage, which has the potential to consolidate into lifelong habits. Such perspectives reflect an ecological approach to health and wellbeing by emphasising the socio-economic and cultural determinants to health and health-related behaviours (World Health Organisation, 2011). The young person's emerging autonomy, social factors, and specific health needs can have a "clustering" effect that can prove problematic for delivering healthcare services that effectively target health needs and health behaviours (Viner, 2005. p902). The notion that early behaviours can become engrained into lifestyle choices may in part explain new approaches in adolescent healthcare that stress the importance of laying foundations for good health early on. For example, The Association for Young People's Health report on Key Data for Adolescence (Hagell et al., 2013) recognises a correlation between health behaviours in early years and the problem behaviours in later life, stressing the importance for early intervention and prevention as a way to positively influence early adulthood. This approach identifies the risks of health issues not being met within adolescent years which may well have negative consequences in later life,

incurring long-term costs for the National Health Service and healthcare delivery systems (Public Health England, 2014). There is a real cause for getting it right with young people when engaging them in their healthcare.

1.3 Engagement in Context

Engaging young people in their health and healthcare has become increasingly important over the last 25 years. The implementation of The United Nations Convention on the Rights of the Child (1989) and The Children Act (1989) have been hugely influential in rethinking how children and young people are worked with; these seminal policies have resulted in a move away from a paternalistic approach in the care of children and young people and towards inclusive practices that empower young people as active stakeholders in their own healthcare. Since these publications, there has been increased focus on young people's rights in decision-making, self-representation within their healthcare choices and empowered autonomy, while healthcare literature largely acknowledge young people have the competence to engage in and exercise degrees of choice within their own healthcare (Redsell and Hastings, 2010). Within the UK, the move towards inclusive practices that seek to engage young patients can be seen in a range of policies and directives (Department of Health, 2000, 2001, 2004, 2006, 2011). These policies acknowledge the young person's right to involvement in their care, to be heard, and to be meaningfully included in health decisions. For example, strategies such as The Healthy Child Programme for 5–19 year olds (Department of Health, 2008) draws on a range of evidence-based research and interventions to recommend ways to work with young people that can improve young people's lives. Such approaches reflect a general ethos for improving the care and wellbeing of young people with the goal to have ameliorated children and young people's services by 2020 (Department of Health, 2009b). This has become increasingly important as young people are less likely than other age groups to engage with

healthcare professionals for their health needs (Chief Medical Officers Report, 2008). The development and dissemination of the You're Welcome quality criteria has contributed to making these changes, aiming to make the services young people use better equipped to meet their needs. Youth policy generally recognises the need to work with young people as a distinct age group, while encouraging young people's autonomy and self-determination is important for young people to make good lifestyle choices for strong foundations in later adult life (World Health Organisation, 2010).

Each of the above policies promote varying degrees of person-centeredness, patient-empowerment and shared decision-making to involve patients in the health interactions to shape care; however, there are large disparities between policy and service receipt. It is recognised that disparities can occur between the delivery of healthcare services and the engagement of patients; for example, in a report on overall trends in patient-centred care between 2002 and 2007, Richards & Coulter (2007) identified that a third of patients were not as involved in decisions about their care as much as they wanted to be. Although the report did not extend into young people's services, these figures may be indicative of a problem that extends into young people's services. Within the culture of the National Health Service, it is recognised that care services can fall short of patient-centred goals. The Kennedy Review (2010) provides support for this notion in its evaluation of cultural barriers within children and young people's services. A range of issues were highlighted in its review of services, specifically that the involvement and engagement of young patients was often inhibited due to paternalistic practices. The report identified a cultural shift is needed in the NHS for holistic and age-appropriate service delivery to occur; hence, a young person's engagement is recognised to be important in their care, yet patient-centred values may not always translate

into practice (Luxford et al., 2011). A key issue within this problem is that there is an ambiguity as to what exactly engagement is, as engagement is often cited yet rarely defined.

The most compelling definition of engagement to date has been provided by Coulter (2011), who describes it as the reciprocal actions that occur between a patient and healthcare professional to facilitate the patient's involvement in healthcare and the decision-making process. Although concisely encapsulating the zeitgeist of person-centred care practices, this definition is largely focussed on the achievement of health goals and joint-working towards shared outcomes; this may not translate into the patient experience of care or reflect their individual perspective. Additionally, this definition is largely based on a healthcare professional's definition of the term, and is it is arguable that it has not been founded within an empirical evidence base. Other perspectives have been derived through qualitative inquiry into the concept of engagement with specific patient groups; for example, Barello et al. (2015) sought to understand the features of patient engagement in heart failure management through a grounded theory design. The findings of the study suggested engagement was a phenomenon that occurred across four distinct phases of meaning making, as the experience of illness became integrated into the processes surrounding care provision. This study provided novel insights into barriers and the facilitators for effectively engaging heart failure patients in their disease management. The approach of Barello et al. (ibid) identified the engagement needs of a specific patient group, charting emotional, cognitive and behavioural factors of engagement from the patient's perspective. This suggests that inquiry into a patient's perspective of engagement can provide new insight into the patient engagement experience.

In relation to young people, there are arguably few direct studies that explore the concept of engagement, or research that explore the young person's perceptions of how *engagement* impacts on their care. The literature tells us young people feel that their views and opinions are not sought by healthcare professionals, are subjected to patriarchal models of practice, are involved in decision-making that remains adult-focused or are expected to use services that are not young person-friendly (Coyne, 2008; Redsell and Hastings, 2010; Hemmingway & Redsell, 2011). This could suggest that the young person's experience of participation differs from an outcome-focused perspective of engagement that healthcare professionals use. Moreover, engagement may not be an in/out binary, as young people often remain in healthcare services despite feeling alienated and disempowered and can be excluded from the decisions that surround their care (Curtis et al., 2004; Sinclair, 2004). In this respect, understanding engagement is important as poor heath within adolescent years can impact on life changes, psychosocial development and life goals (Currie et al., 2008). Furthermore, the everyday experiences young people have within their families, schools, communities and peers, all contribute towards how health is understood, and how they develop their health behaviours (Public Health England, 2013). In these networks and communities, young people form attitudes towards alcohol, drug use and sexual exploration, which can cause immediate and long-term consequences, the implications of which may not be understood by those engaging in such risk-taking behaviours (Sorhaindo, 2007).

It is becoming increasingly important to understand the lived contexts and individual needs of young people in order to understand the barriers young people have in accessing their healthcare; however, these factors may often not be well-understood by services (Scott, 2010). In addition, engagement may be influenced by other factors such as preconceptions of

services, which can be a deterrent from engaging with healthcare services (Moore and Kirk, 2010), for example Beck (2006) suggested that a mistrust of mental health services may be a deterrent for young service and their help-seeking behaviours. Another factor that can inhibit engagement is the perceptions young people form about services (Moore and Kirk, 2010). Such perceptions may contribute feelings of fear, stigma, or mistrust of the healthcare professional gaze. Scott (2010) asserts that, in these situations, it is not the young person who is hard to reach, but rather the services that cause barriers to engagement. This suggests that a greater awareness of service provision is required from the young person's perspective to overcome such barriers, as young people who do not engage with services demonstrate less health-seeking behaviour, have a lower life expectancy, increased morbidity and lower health expectations (Department of Health, 2009). This could suggest that engagement in healthcare is a complicated process, but one that is important to get right.

The literature indicates that poor engagement with healthcare services has long-term repercussions for young people in adult life, and can greatly impact on health-related behaviour, concordance with treatments and care plans, and perceptions of health services. In contrast, getting engagement right may prevent mid to long-term health complications, instil an awareness of the importance of health and tackle negative health-related behaviour (World Health Organisation, 2010). As a primary, secondary and preventative strategy, engagement could potentially have positive effects within young people's transitions to adulthood, in improving physical and emotional health and giving young people a better start through early life chances (World Health Organisation, 2012). In this light, engaging young people in their early years is important to develop better health behaviours, which may potentially carry on in later life (Chief Medical Officer's Report, 2007). It is becoming

increasingly important for health professionals to use young person-friendly approaches in order to get young people more involved in their care (Department of Health, 2007; World Health Organisation, 2010).

This thesis explored the concept of engagement from the young person's perspective in order to provide healthcare professionals with a novel way to understand how young people are engaged in their care, thus providing a foundation for working with young people within the healthcare context.

1.4 Myself in Context
In this final section, I tell you about myself. Concluding this chapter on a personal note is not an intention to draw attention away from the young person's presence, which this thesis is indebted to, but rather to acknowledge that my presence is the final voice that occurred within a collaborative process of co-construction. I align myself within a relativist ontological paradigm which, unlike realist perspectives that assume an objective and universal truth, a relativist perspective assumes that reality is produced through individual interpretation and is dependent on meaning derived from subjective perception (Blaikie, 2007). Additionally, this thesis drew on a constructivist epistemology (this is discussed in more detail in Chapter 3), utilising a grounded theory approach to represent multiple truths in the microcosm of the lived experience (Charmaz, 2004). This philosophical location acknowledges the researchers' role as implicit in the co-production of meaning, and that the participant's narratives are conveyed through the researcher's accounts (Bryant, 2009). Given the relativist ontological underpinnings and social constructivist epistemology, I refer to myself in the first person to recognise my role in such knowledge construction. The first person is traditionally an unconventional mechanism within scholarly texts, as silent authorship is often used in

deference to disciplinary expectations. Such approaches can obscure hidden power relations between research participants as the observed party, and the researcher as an impartial and neutral observer (Charmaz & Mitchell, 1996); these power relations often go unchallenged and can perpetuate oppressive truth regimes through authority of voice (Foucault, 1980). Interpretive approaches seek to explicitly account for the researcher within the research processes, in so doing enhancing methodological credibility by transparently delineating the process of meaning construction (Tobin & Begley, 2004). In recognition of these perspectives, the first person pronoun is used at appropriate points throughout this thesis in order to rebalance power dynamics by utilising reflexive and interpretive strategies (Etherington, 2004); hence, I will draw attention to myself when you need to know my role as an active player within this research through the research memos and within reflexive accounts of theoretical construction. The remainder of this section details my personal location, providing insight into my experience as a healthcare professional that provides occupational therapy to young people, and my beliefs that are guided by my philosophical position.

1.4.1 My Background Context

As an occupational therapist who works with young people, I am very aware of the specific issues that young people face in their receipt of healthcare. Occupational therapy maintains that human occupation, the activities that are initiated within daily life that contribute to a person's self-care, productivity and leisure, have a direct relationship with a person's health and wellbeing. Moreover, occupation is argued to be imbibed with personal meaning (Finlay, 1999), is enacted and shaped within environmental contexts that exert cues and social sanctions (Kielhofner, 2008), and is inextricably entwined with a person's self-expression and self-concept (Christiansen, 2000). Occupational science recognises that there is a meaningful association between *doing* occupations and our potential *becoming* as an occupational being

(Wilcock, 1998). When working with young people, this concept becomes much more pronounced as young people are in a state of transition; as they develop physically, cognitively and emotionally throughout adolescence and into adulthood, skill development and active experimentation occurs alongside an emerging sense of self. However, young people are often not deemed competent to engage in their occupations as would an adult; this is especially relevant within a healthcare context where the child's voice is traditionally subjugated by an adult's authority until the age of 16. Even after the age of 16, marginalisation can occur due to patriarchal approaches that disregard a young person's voice. I acknowledge that my professional perspective is that such barriers to engagement in the healthcare interaction, a meaningful occupation that purposely contributes to a young person's health and wellbeing, can have a detrimental impact on the young person's *doing* and their potential *becoming*.

A defining moment for me was when I was working with a 13-year-old girl to understand her specific needs in order to develop independent living skills. The girl had a mild learning disability and, given the emotional and pubertal changes normal for her age, she would often become tearful. On the day of her therapy, the young girl started crying when she knocked over a cup of juice; her keyworker, a specialist learning disability nurse who was present for the session, informed me she was always crying over nothing and told me to ignore her until she stopped. This statement, indifferent to the girl's frustration in being unable to complete a functional task, was dismissive of her psychological needs as she was learning to come to terms with new emotions. The fact it was said within the girl's earshot, thus dismissing the girl's presence within that therapeutic interaction, brought home to me how young people can be marginalised in the context of a healthcare interaction and side-lined as a lesser person. This experience, amongst many others, stimulated my interest in this thesis and made me

want to understand what it is like for a young person who is expected to engage in a healthcare interaction; to understand what it is like to be involved in something where their views may not actually be sought, and collaboration not necessarily required.

As an occupational therapist who strives to be young person-friendly, whose profession believes itself to be inherently person-centred in its collaborative therapeutic processes (Sumsion, 2006), I wanted to understand what engagement is before I try to achieve it. As such, reflexivity and transparency act as the departure point of this thesis and are maintained throughout my research process. This thesis marks my journey to understand a young person's perspective of engagement, and my understanding of how such engagement occurred for the young people, with whom I had the pleasure of discussing this complex issue.

Chapter 2: A Scoping Review of Studies Evidencing Healthcare Interactions between Young People and Healthcare Professionals

2.1 Introduction

This chapter details the design and findings of a scoping review conducted to explore how engagement between young people and the healthcare professionals is evidenced within healthcare literature. Due to the concept ambiguity of the term engagement, the review identified studies that provide empirical accounts of interactions between health professionals and young people; this approach enabled scrutiny into how reciprocal actions are understood within the literature. First, this chapter provides a rationale for a scoping review as part of a larger grounded theory study, enabling insight into the current state of knowledge within the field without compromising the integrity of the thesis research aims. A detailed account of grounded theory is provided in Chapter 3; however, the methodology is touched on in this section to provide the context in regards to selection of a scoping review. Second, the design and methods are detailed using The York Methodology (Arksey & O'Malley, 2005) as a guiding structure to the review. Finally, findings are presented and suggestions for future research made.

2.2 Rationale

Engagement with extant literature is acknowledged as tension within inductive research designs as formal review and synthesis of literature is normally delayed (Charmaz, 2006). However, as part of the PhD process, it is acknowledged student researchers must conduct a review of the literature as part of their research training; this is traditionally seen to be a requirement by both examining boards and ethical committees. The literature search is often a first step for the student to demonstrate knowledge of their topic, competence in developing

a robust thesis justification and stating thesis originality through identifications of knowledge gaps (McGhee et al., 2007; Dunne, 2011). Additionally, Randolph (2009) highlights conducting a literature review is an important introduction into the wider influences within a field of knowledge. Drawing on Gall (1996) and Heart (1998) to detail pragmatic necessities of developing research practice, Randolph (ibid) suggests that reviewing literature is essential in order to approach the research problem, determine contextual variables, develop awareness of theory and application, and gain methodological insights. Collectively, a literature review is deemed an initial milestone where the student researcher demonstrates competence and awareness. This creates a strain when the ontological and epistemological underpinnings of a research method require a priori knowledge to be restricted to limit influence on theory formation (Dunne, 2011; Elliot & Higgins, 2012).

Within their seminal text on the grounded theory method, Glaser and Strauss (1967) advised that the researcher should not engage with extant literature and should approach a research area in a state of "wonderment". This approach aimed to encourage "fresh eyes", as the literature review was deemed a restrictive device that imposed dominant theoretical constructs on the phenomenon being researched. Bias occurred through "theoretical contamination" and inhibited theory from inductively emerging from data. However, since the original conception of grounded theory, different approaches have addressed engagement with literature, allowing for new, more sympathetic relationship with the literature review to develop. For example, Strauss and Corbin (1998) saw literature as a methodological tool that should be strategically introduced in a grounded theory study at the appropriate time. Rather than maintaining the position of the researcher as tabula rasa, requiring protection from 'theoretical contamination', the researcher's role became understood as complicit within the

act of meaning making. The pragmatism of Strauss and Corbin (1998; 1990) allowed for a moderated perspective of literature that could aid in the formulation of questions and theory development. Engagement with literature became an issue of sensitisation that could stimulate theoretical sensitivity (Strauss & Corbin, 1990).

The introduction of literature has caused great debate between the different methodological schools of thought in grounded theory (Elliott &Higgins, 2012). For example, Glaser (1992a) maintained that theoretical contamination has irresolvable implications on *a posteriori* theory emergence. Glaser maintains that theoretical emergence occurs from an iterative interplay between data collection and analysis and the researcher should not engage with literature within until completion of empirical research. Nonetheless, the result of these debates was that the researcher's relationship with data was called into question, resulting in developments to the original perspective. For example, within a constructivist paradigm, the notion that one can enter into a setting in a state of neutrality is argued to be conceptually positioned within a positivistic paradigm, which would not address the researcher's influence on theory development (Charmaz, 2006). This is because the researcher can never be neutral in their interpretation of a phenomenon, as meaning is constructed through disciplinary emphases and perspectival proclivities. As such, theoretical sensitivity is heightened by reflexivity, and sensitising concepts can explicate how meaning is constructed as the starting point for interpretation and analysis (Charmaz, 2003a; 2006). The researcher enters the field with a wealth of information, and it is the researcher's role to transparently and reflexively make explicit the processes of interpretation within the act of meaning making (Carolan, 2003). As such, introduction to literature prior to commencing a study is not problematic; however, clear justification and positioning is required (Dunne, 2011).

Charmaz (2006) asserts that reviewing literature should be done in such a way as to not influence thinking with pre-existing concepts, but rather to provide a general awareness as a departure point for research. As reviewing the literature was – and still is – acknowledged as essential criteria for research training, the guiding principle became when/how to engage with the literature, rather than if. The format of a scoping review was judged appropriate in order to gain an overview of the size and nature of the evidence to develop awareness of concepts that may relate to the substantive area, but would exempt the need for in-depth critical appraisal; this would allow initial guidance into the field without imposing a pre-set agenda.

Scoping reviews have become an important contribution in research as they can develop an overview of a topic area where there is uncertainty regarding the extent of the knowledge base (Brien et al., 2010). They are recognised as useful in developing a new understanding into areas thought as complex, or areas that are not extensively reviewed (Mays et al., 2001; Levac et al., 2010). In this sense, scoping reviews are useful as a rapid mapping exercise to chart the broad themes that exist within published literature, highlighting what previous research has covered and where knowledge gaps exist (Rumrill et al., 2009; Anderson et al., 2008). As an exploratory research activity, they are also useful to identify the size and nature of an evidence base to determine feasibility for future research activity (Davis et al., 2009; Grant et al., 2009).

Scoping reviews differ from systematic reviews as they do not aim to critique and review the quality of an evidence base, but rather to identify the breadth of evidence (Armstrong et al., 2011). This has led to criticism, as methodological variations across scoping reviews can lack rigour or transparency of their methods of analysis (Brien, 2010: Levac et al., 2010). To reduce

limitations, this scoping review drew on The York Methodology (TYM) (2005) as it is recognised as providing a structured approach for scoping literature. TYM draws on systematic procedures to structure scoping activity across five stages: identification of the research question; identification of relevant studies; study selection and inclusion; charting of study information and data; collating, summarising and reporting results of the review. An optional sixth stage, consultation of research stakeholders, was not used within this study due to its lack of relevance. Systematic processes are used to search, sort and manage studies, while findings are synthesised using an interpretative approach to themes that reoccur across bibliographic citations (Arksey and O'Malley, 2005). Quality is gauged on the transparency of methods such as the thematic analysis used to collate findings (Armstrong et al., 2011).

A recognised strength of a scoping review design is the potential to rapidly map a diverse body of literature (Brien, et al. 2010; Armstrong et al., 2011). This was deemed an effective method to develop an overview of engagement due to the diversity in terminology such as engagement, participation and collaboration. By drawing together disparate evidence, the review aimed to clarify how engagement is understood in the literature in relation to young people interacting with health professionals. The following section details the scoping review design.

2.3 Review Questions
Research questions are the departure point of scoping activity that shape subsequent stages of the review (Levic et al., 2010). Arksey and O'Malley (2005) recommend using a broad approach when developing research questions as these will encourage a comprehensive overview of knowledge within the research area. Research questions were developed in collaboration with thesis supervisions to reflect the practice and research experience of all

parties across various healthcare practices. The scoping review aimed to address the following broad question:

- How is the engagement of young people within healthcare interactions detailed in existing literature?

This broad brush approach was deemed useful as it could encompass a range of interpretations of engagement, hence facilitating an inclusive search strategy. Additional supervisions developed three supplementary questions to refine the focus of enquiry in terms of target populations (young people AND healthcare professionals) and outcome (healthcare interactions between the two target populations). These definitions were developed into three research questions for the scoping review:

- What research has been undertaken to date in relation to health professionals' engagement and collaborating with young people within healthcare interactions?
- What theoretical perspectives, if any, have underpinned studies about health professionals' engagement and collaboration with young people?
- Have studies about health professionals' engagement and collaboration with young people measured engagement?

2.4 Study Identification and Selection

Developing clear inclusion criteria is an important aspect of a review to ensure that the boundaries of the review question are clearly defined (Centre for Reviews & Dissemination, 2009). Such criteria should not be so narrow as to exclude studies which may be of importance to the review, yet not so broad that the review process becomes unmanageable. Arksey and O'Malley (2005) state that a systematic process similar to systematic reviews is necessary to

ensure consistency in decision-making. The following inclusion and exclusion criteria were developed to facilitate the screening process.

Eligible studies

To be included within the review, the research had to fulfil one or more of the following inclusion criteria:

- Studies that explored the perceptions of young people and/or healthcare professionals on engagement within healthcare interactions;
- Studies that investigated the contextual factors of engagement that impact on healthcare interactions with young people;
- Studies that addressed the relational dynamics that exist within healthcare interactions;
- Studies that explored current practices in collaborating with young people in meeting their health-related needs;
- Studies that identified the outcomes of young people who have been engaged in their healthcare.

Studies were excluded for the following reasons:

- Studies not published in the English language;
- Studies concerned with specific biomedical and/or psychological outcome measures that do not relate to engagement in healthcare interactions;
- Studies that explored 'family decision making' - due to the differing dynamics that affect young people when interacting with healthcare professionals compared to interactions as a family unit;
- Studies that did not relate directly to the healthcare interactions within a young person's healthcare.

A screening tool (appendix 1) was developed to provide an efficient means of checking studies for their inclusion eligibility. All the studies were initially screened against titles and abstracts. This provided a general overview of which papers were suitable for in-depth review. After the initial screening took place, physical copies of the most suitable citations were acquired and read in depth to ensure they met the review criteria.

2.5 Search Strategy

Parameters were set identifying literature for inclusion between the period of 2000 to 2012

to reflect the move within policy and practice towards inclusive working (Scott, 2010).

Table 1: List of databases

Source	Database description
ASSIA (Applied Social Sciences Index and Abstracts)	Indexing and abstracting database covering health, social services, psychology, sociology, economics, politics, race relations and education.
Child data	Indexing and abstracting database of books, reports and journal articles within the literature on children and young people.
CINHAL (Cumulative Index to Nursing and Allied Health Literature)	Indexing and abstracting database covering the fields of nursing, biomedicine, health sciences librarianship, alternative/complementary medicine, consumer health and 17 allied health disciplines.
Medline (Medical Literature Analysis and Retrieval System Online)	Indexing and abstracting database for journal articles in life covering medicine, nursing and health care.
Web of knowledge	Citation indexing and search service that uses web linking to fields in the sciences, social sciences, arts and humanities.
SocAbs (Sociological Abstracts)	Indexing and abstracting database for journals, conference papers, books and dissertations in sociology, behavioural sciences, social welfare, health and medicine.

Databases were selected that routinely indexed qualitative and/or quantitative data which

was viewed as relevant to the focus of inquiry (Table 1, above). Synonyms were developed

using combinations of truncations and quotations to best capture the search term. The three

concepts (target populations and outcome) were developed by devising a list of alternate

terms and synonyms developed to ensure breadth of coverage. The Boolean connector OR

was used between the term synonyms, and AND was used between concepts to identify

literature evidencing health interactions between health professionals and young people

(Table 2)

Table 2: Search strategy

("Young people" OR "young person" OR adolescen* OR Teenager* OR "Young adult*" OR Juvenile* OR Youth* OR junior OR "older child")
AND
("healthcare professional*" OR "Health professional*" OR Doctor* OR nurse* OR "Allied health professional*" OR physio* OR "physical therap*" OR "Occupational therap*" OR clinician OR Dietician* OR Dietics OR "Speech and language therapy*" OR podiatr* OR Orthoptic* OR Prosthetic* OR Orthotic* OR psycholog* OR psychotherap* OR radiograph*)
AND
(collaborat* OR engage* OR Partnership OR "Shared decision making" OR Inclusion OR "Patient centred" OR Involvement OR Participation OR "Working together" OR "Joint working")

An initial search of the literature produced expected returns (bibliographic citations n=1038), which were screened using a screening tool with stringent inclusion/exclusion criteria (appendix 1). After screening, a surprisingly low number of studies were suitable for inclusion (n=3) suggesting structural issues within the search strategy. An information scientist based within the school of Nursing, Midwifery and Social work was approached for assistance to test the search strategy and to assess what functions were affecting the search databases. Existing search terms were adapted to include "initial interview" OR Consultation OR "decision making" OR interaction OR appointment OR clinic to capture the processes young people were involved in within healthcare interactions. Child data was substituted for Social Care Online and Social Policy and Practice as the university database subscription had expired. It was felt that combining these two databases would provide enough coverage to compensate for the loss of Child Data. Additionally, PsychInfo was substituted for Web of Knowledge, as it was believed that this switch would yield greater bibliographic citations, and CDSR was added to the database list to check for complementary systematic reviews. A second search returned sizable results (bibliographic citations n=7296), which resulted in 19 studies being determined suitable for inclusion after screening (Figure 1).

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┌─────────────────────────────────────────────┐
│ Papers identified (n=1,038)                 │
│                                             │
│ Assia                        (n=66)         │
│ Child Data                   (n=2)          │
│ CINHAL                       (n=99)         │
│ Medline                      (n=301)        │
│ Web of Knowledge             (n=430)        │
│ Soc Abs                      (n=141)        │
└─────────────────────────────────────────────┘

┌──────────────────────────┐
│ Duplicates removed       │
│                          │
│ Studies reviewed with    │
│ screening tool           │
└──────────────────────────┘

┌─────────────────────────────────────────────┐
│ Papers excluded              (n=1,034)      │
│ Unobtainable                 (n=1)          │
│ Studies identified           (n=3)          │
└─────────────────────────────────────────────┘

┌──────────────────────────┐
│ Search terms revised     │
│                          │
│ Data base list adapted   │
└──────────────────────────┘

┌─────────────────────────────────────────────┐
│ Papers identified (n=7,296)                 │
│                                             │
│ Assia                        (n=407)        │
│ Social Policy and Practice   (n=2)          │
│ CINHAL                       (n=637)        │
│ Medline                      (n=3,040)      │
│ PsychInfo                    (n=423)        │
│ Soc Abs                      (n=557)        │
│ CDSR                         (n=21)         │
│ Social Care Online           (n=557)        │
└─────────────────────────────────────────────┘

┌──────────────────────────┐
│ Duplicates removed       │
│                          │
│ Studies reviewed with    │
│ screening tool           │
└──────────────────────────┘

┌─────────────────────────────────────────────┐
│ Papers excluded              (n=7,273)      │
│ Unobtainable                 (n=4)          │
│ Studies identified           (n=19)         │
└─────────────────────────────────────────────┘
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Figure 1: Citations retrieved from search strategy

In total, two searches were run, refining the search process by using expansion strategies until an appropriate number of results were identified.

2.6 Search Results

Duplicate papers within the database searches were removed from the results. Where data could not be retrieved, a range of strategies were employed to attempt to locate data from an alternate source. The search outcome returned a relatively low number of studies. Of the

eight databases searched, the scoping exercise returned 23 papers for review, of which 19 were suitable after screening (Table 3).

Table 3: Selected studies

Reference	Healthcare interaction	Study aims relating to health interactions	Findings relating to health interactions
Ruenson et al. (2002)	Observations of interactions between HCP, parents and young people. (Decision to include as observations were not of triadic communication, but of inclusive practices).	Identify interactions that illustrate children's participation in decision making. Identify various levels of participation. Draw comparisons between actual and optimal participation. Describe how children, parents and staff interact in the decision making process.	Health care staff can provide information without alternatives or seeking children's views. Health staff can be conflicted between following children's views and the hospital routine.
Shaw et al. (2004)	Young people's perceptions of health staff interactions.	Gain insight into transitional health needs of adolescents with JIA and their parents. Explore how these needs could be met with a programme of transitional care.	Need for age-appropriate communication to make appropriate decisions. Health professionals did not trust young people's narratives. Young person experienced an uncertainty about their right to engage in shared decision making.
Dovey-Pearce et al. (2005)	Interactions with staff in diabetes services.	Improving the quality of care and equity of service provision. **NB.** *Stated aims do not appear to reflect the research aims of the study, but rather the intended use of the research within the service.*	Healthcare consultations would benefit from a holistic approach that explored a young person's life contexts and views that allowed for sensitive interactions that were person focused, not diabetes focussed.

Coyne (2006)	Consultations in hospitals.	Understand participation from the perspective of the child, the parent and nurses.	Most children in the study wanted to be consulted, involved and have their opinions respected regarding their care and treatment.
			Young people reported good experiences when provided with information and consulted about their care.
			Being involved rather than dictated to in consultations made children feel like "adults" in control of their care.
			Young people appreciated health professionals that were approachable and acted with kindness and warmth.
			Children felt excluded when health professionals did not use accessible language, did not include them in discussions whilst they were present and did not demonstrate a genuine interest in things the young person said.
			Talking over children may make them feel less in control.
			Young people felt that health professionals with a 'business like' approach depersonalised them.
Young et al. (2006)	Decision making in community based paediatric physiotherapy.	To explore children's, parents' and practitioners' accounts of shared decision making in the context of community-based physiotherapy services for children with cerebral palsy.	Children believed they did not have any input in the decision making process.

Health professionals cited instances of involvement of decision making which the young person did not account for. |

Kelsey et al. (2007)	Healthcare decision making.	Explore young people's perceptions of their involvement in healthcare decisions relating to management of care.	Young people voiced preference for a level of involvement that was inclusive, supportive and promoted their autonomy.
			Young people felt concern over the limitations of their knowledge in making decisions, and valued effective age-appropriate communication.
			Health professionals can exclude young people from interactions by not respecting the young person in communication and discourse.
			Poor communication with young people can cause anxiety and prevent young people from asking questions about their care.
Savage & Callery (2007)	Healthcare consultations for the dietary management of cystic fibrosis.	None stated.	Children believed they were marginalised when not included, or believed they could not interrupt.
			Children felt a surveillance/interrogative approach to consultations did not allow them to provide answers to express their views.
			Children had a different understanding of health than that of professionals, relating health to energy for physical exertion rather than weight gain as a protective factor against chest infections.
Kirk (2008)	Relationships with health professionals.	Explores relationships with healthcare professionals and young people with complex health needs in relation to transitions to adult services.	Young people found difficulties transitioning from familiar relationships in paediatric healthcare to impersonal and infrequent consultations in the adult clinic.
			Young people struggled with limited time restrictions in interactions.
			Young people identified interactions did not always meet their agendas.
Knopf et al. (2008)	Adolescents' decision making preferences in shared decision making.	Describe decision-making preferences of adolescents with chronic illness and preferences of parents.	The majority of adolescents demonstrated a preference for passive decision making (56%) over shared decision making (37%).
			Discussion of results identified study did not address what 'involvement' meant to the adolescent or preferences of different decision types.

Stegenga & Ward-Smith (2008)	Participation in decision making for cancer treatment.	To explore treatment decision making from the perspective of the adolescent with cancer.	Young cancer patients had a preference for a passive role in decision making. Participants forwarded trust to professionals as experts to make the best judgements. Participants had a strong preference for information to know what to expect. Lack of information, or being kept up to date with hospital procedures that affected the adolescent's care, caused participants frustration and discontent.
Brown & Wissow (2009)	Youth perceptions of interactions with primary care providers.	Explore the association between discussion of sensitive topics within consultations and youth perceptions of care.	Facilitating open discussion of sensitive health topics can improve how young people perceive care receipt.
Britto et al. (2010)	Communication preferences of interactions with specialists.	No aim stated. Identifying gaps between chronically ill adolescents' priorities and physicians' perceptions of adolescents' priorities.	Highlighted where professionals understood and misunderstood adolescents' preferences for communication. Items adolescent patients rated in higher importance than health providers were: feelings of closeness to health professional, knows the family well and will decide what is best for the patient. Health professionals overestimated adolescent's preference when assuming the adolescent is an expert about themselves, does not joke about condition, shows complete respect and tells point of view seriously.
Jedeloo et al. (2010)	Perspectives of health professionals as part of triadic	To integrate findings of a mixed methods research study into the preferences and competencies for	Identified four preferences for healthcare: Conscious and compliant

			Backseat patient
	communications.	hospital consultations of adolescents with chronic conditions.	Self-confident and autonomous
			Worried and insecure
			Each preference sees young people use parents in different ways to navigate their healthcare interactions.
			All young people wanted a say in appointment-related decisions, and the opportunity to talk with doctors alone to discuss sensitive topics.
			10 point rating scale identifying preference
			21.9% of young patients felt they were not independent enough in consultations
			90.4% felt capable of answering doctors' questions independently
			12.8% had gone alone to consultations
			41.3% asked questions to health professional themselves.
Coyne & Gallagher (2011)	Participation in communication and decision making.	To explore children and young people's experiences of participation in communication and decision making.	Children felt less anxious and valued when information was communicated to them in accessible ways.
			Children felt excluded from discourses when information was directed to parents, their preferences were ignored and they were not included in the decision making process.
			Children felt coerced or obligated by decisions made by health professionals that "do things to them."

| | | | Children believe they have the right to be included about discourse that affects their care.

Children felt that health professionals often did not offer true choice between procedures, which limited children's involvement.

Children valued the ability to develop relationships with health professionals, but this was restricted due to lack of time, environment or lack of continuity.

Children can assume a passive role in health communication as they feel intimidated by health professionals as 'the expert' and fear 'causing trouble' by questioning them. |
|---|---|---|---|
| Muir et al. (2011) | Experiences of staff as part of service evaluation. | Questions
How youth-friendly is the "Headspace model" when tested against the WHO's Accessibility, Acceptability, Appropriateness framework? | Young people vocalised a positive regard of staff who had good communication skills and were sensitive to their needs.

Young people valued staff who understood and demonstrated empathy, rather than focusing on treating the illness.

Young people valued staff who provided them with information about their illness and care, and gave them capacity to provide input and ask questions.

Service users who reported poor experiences were those who had not had their expectations managed, or those who did not understand the processes that occurred around their care.

Trust was built with young people when HCP clearly explained confidentiality and how it affected them. |

Price et al (2011)	Healthcare consultation as part of a service transition pathway.	Evaluate the transition pathway through qualitative means. To situate these experiences within the context of psychosocial development theory.	Young people regard HCP who promote a sense of partnership and collaboration. Young people preferred person-centred communication styles.
Sanders et al (2011)	Hospital based sexual health discussions.	To explore young people's expectations and experiences of discussing sexual and relationship health with healthcare professionals whilst attending or having been admitted to an acute children's hospital.	Young people did not want to be directly asked about intimate issues, but wanted to know there was the option/choice to discuss these issues.
Bray (2012)	Consultation with health professionals.	Explore the extent that young people are consulted and involved in planning their care.	Young people view positive experiences of communication when treated as an equal partner in consultation. Young people reported exclusion from medical discussions, lack of choice, being intimidated by health professionals and not being believed by healthcare professionals.
Bray et al. (2012)	Perceptions of decision making for planned continence surgery.	Explore the pre-operative experiences of continent stoma formation.	Young people experienced a loss of trust in health professional where there was a lack of transparent information or expectations were not managed. Young people valued being able to choose their own level of engagement in decision making. Young people may consent to surgery as they feel it is an inevitable choice, rather than through active engagement.

The search outcome identified a wide range of methodologies in the returned studies (Table 4). The largest proportion of studies used qualitative approaches as part of their research, with the majority of papers declaring qualitative methods rather than stating a research methodology.

Table 4: Study research methodologies

Research	Reference
Phenomenology	1
Qualitative methods	8
Grounded theory	4
Mixed methods	1
Quantitative RCT	1
Quantitative – questionnaire	2
Action research	1
Observational analysis	1

Geographical characteristics of the studies are demonstrated in Table 5, with the largest proportion of studies taking place in the UK (n=13). The increased focus in these areas may be reflective of the range of policies that promote engagement in inclusive practices.

Table 5: Study geographical characteristics

Location	Bibliographic citations = (n)
USA	4
UK	10
The Netherlands	1
Sweden	1
Republic of Ireland	3

The term engagement was used intermittently throughout the literature; however, no studies provided a concept definition of the term. When engagement was used, it described young

patients' positive reactions to feeling involved in health interactions, but was not explored in its own right. This identified that, in relation to the research questions of this scoping activity, assumptions were largely made about engagement as a concept but no attempts were made to explain such terms to clarify meaning. A similar issue was found with the term 'young person' as it lacked a consistent definition and age range parameters which affected studies eligible for inclusion. This issue was resolved by including study populations that fell into either side of the inclusion criteria age parameter (13-19). This enabled a wider range of studies than would have otherwise been possible; however, it is acknowledged the populations of the studies also covered child and adult populations (Table 6). This finding confirmed that a lack of population criteria when researching young people may lead to difficulties when sourcing relevant literature.

Table 6: Overview of terms and age ranges

Terms used	Age parameters by study	Range
Youths	11-16 Brown and Wissow (2009)	11-16
Young people	16-25 Dovey-Pearce et al. (2005)	12-25
	16-18 Price et al. (2011)	
	13-16 Bray (2012a)	
	12-16 Kelsey & Abelson-Mitchell (2007)	
	12-25 Muir et al. (2011)	
	14-18 Sanders et al. (2011)	
	8-19 Kirk (2008)	
Children and young people	5 months-18 years Ruenson et al. (2002)	5 months-18 years
	No specified age range Bray et al. (2012b)	
Adolescents	12-18 Shaw et al. (2004)	11-19
	11-19 Knopf et al. (2008)	
	12-15 Jedeloo et al. (2010)	
	11-19 Britto et al. (2010)	
	12-17 Stegenga and Ward-Smith (2008)	
Young adults	19-30 Shaw et al. (2004)	19-30
Children	7-18 Coyne and Gallagher (2011)	7-18
	9-15 Coyne (2006)	
	8-18 Young et al. (2006)	
	6-14 Savage and Callery (2007)	
Older adolescents	16-19 Jedeloo et al. (2010)	16-19

2.7 Charting the Data

A thematic analysis of an interpretive nature was used to develop and synthesise categories within the scoping review. Arksey & O'Malley (2005) draw on the analytical techniques of Ritchie and Spencer (1994) for charting data through thematic analysis. This approach is primarily concerned with identifying patterns that repeat across the data to enable a

description of issues in relation to specific research questions (Braun and Clarke, 2006). This processes is normal for a scoping review as it fosters a 'descriptive analytical' method that summarises information in a meaningful format without the need of in depth critical appraisal (Arksey & O'Malley, 2005). It is recognised that this process resembles qualitative data analysis techniques, and as such description of the thematic analysis performed is necessary to enhance insight into scoping activity findings (Levac et al., 2010). Thematic analysis was performed on all studies in the scoping review and the following section details thematic development.

Studies that met the inclusion criteria were read in depth to gain a working familiarity before any analysis took place. Initial readings were problematic as studies often explored perceptions of health interactions as part of a larger research activity. Braun and Clarke (2006) state a major advantage of thematic analysis is its flexibility and adaptability for determining worth of qualitative data. This proved true when exploring studies, as it enabled only the sections relating to review questions to be analysed and charted, whilst information not relevant to the scoping activity was discounted. Information relating to engagement was extracted and recorded on the screening tool data extraction table. Thematic development occurred over two phases (Figure 2). Coding consisted of developing initial codes through identifying and labelling basic units of data which could be later meaningfully organised into themes (Boyatzis, 1998). Fourteen initial codes were developed as follows: communication, choice, involvement, interaction preference, participatory practices, patient/young person relationship, decision making, information, perceptions of care, taking a role, understanding (minor), time (minor), autonomy (minor), trust (minor).
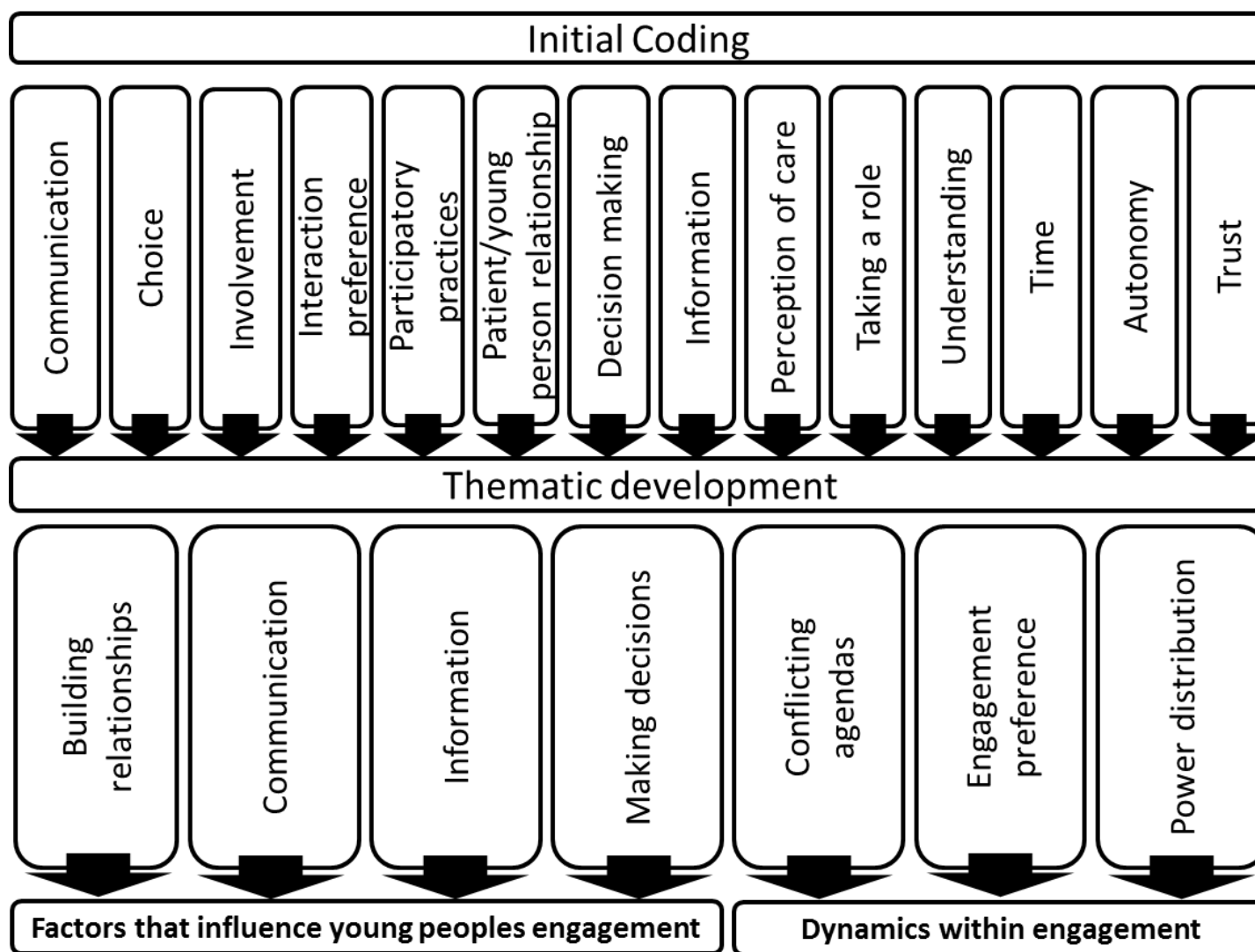
Figure 2: Thematic development

Whilst all codes were considered relevant, those identified as minor codes reoccurred less frequently, but were considered important to the investigation of the phenomenon. Codes were managed and refined using an Excel spreadsheet (Table 7).

Table 7: Thematic management

Category	Source
Communication	• Facilitating open discussion of sensitive health topics can improve how young people perceive the care they receive (Brown and Wissow, 2009) • Young people preferred person-centred communication styles (Price et al., 2011) • How communication occurred is important to help young people manage their own care (Shaw et al., 2004) • Not involving young people in communication can make young people feel excluded and increase their anxiety (Kelsey & Abelson-Mitchell, 2007) • Children were afraid to contradict in health communications (Coyne and Gallagher, 2011) • Young held care staff with good communication skills and who were sensitive to their needs in positive regard (Muir et al., 2011) • Children believed they were marginalised when not included, or believed they could not interrupt (Savage and Callery, 2007) • Children believed they could not express their views in consultations which took a surveillance/interrogative approach (Savage and Callery, 2007) • Parents can facilitate or inhibit children's ability to communicate with health professionals (Coyne and Gallagher, 2011)
Participatory practices	• Young people regard HCP who promote a sense of partnership and collaboration (Price et al., 2011) • Positive experiences were identified when a young person was treated as an equal partner in consultation (Bray, 2012a) • Young people voiced preference for a level of involvement that was inclusive, supportive and promoted their autonomy (Kelsey et & Abelson-Mitchell, 2007) • Positive involvement in continent stoma SDM allowed young patients to choose their own level of engagement and make informed decisions (Bray et al., 2012b) • Young people valued staff who understood and demonstrated empathy for their mental health, rather than focusing on treating the illness (Muir et al., 2011)

Table 7 provides an example as to how qualitative descriptions were allocated to some of the key concepts depicted in Figure 2. By ensuring citations were linked to each concept of interest it was possible to trace emergent themes as analysis progressed. As thematic development

matured concepts were aggregated and refined until robust categories with thick description were formed. The second stage of thematic development subsumed initial categories into themes. This was driven by a largely inductive approach to develop a natural thematic fit that is normal within interpretive analysis (Braun and Clarke, 2006). The scoping review identified two broad themes that provided the best explanation of how engagement was understood within the literature: factors that influence engagement, and dynamic of engagement. The following sections detail the themes that emerged from analysis.

2.7.1 Factors That Influence Young People's Engagement: Building Relationships

The relationships formed between young people and health professionals were addressed in many of the papers. Young people reported positive experiences of engaging with health professionals when they promoted a sense of partnership, were supportive in facilitating decision making and forwarded the young person's autonomy in health interactions (Price et al., 2011; Bray, 2012a; Kelsey & Abelson-Mitchell, 2007; Coyne, 2006). Muir et al. (2011) suggest that trusting relationships with health professionals were formed when the parameters of the relationship and confidentiality had been clearly explained. Young people clearly valued the ability to develop relationships with health professionals; however, the development of the professional/young person relationships was impeded due to lack of time, settings which didn't foster relationship building and lack of constancy with regular staff (Coyne and Gallagher, 2011). Kirk (2008) contextualises some of the difficulties young people experienced when exploring young people's experiences of leaving paediatric services. Previous relationships, formed over many years of consistent care, were lost when discharged at the age of 16 and referred to adult services.

It is acknowledged that professionals may also underestimate how young people value the ability to build trusting relationships (Britto et al., 2010). In a questionnaire, which gathered information from both young patients and healthcare professionals, Britto et al. revealed professionals can significantly underestimate young people's preferences for health professionals who took time to know them and their family well. This indicates that the familiarity of the professional, as a known and trusted person entering the young person's environment, may be a crucial contributing feature in cultivating engagement.

2.7.2 Factors That Influence Young People's Engagement: Communication

Accessible and age-appropriate communication was highlighted as a positive experience for young people by both Price et al. (2011) and Muir et al. (2011). The mode of communication used by professionals, when perceived as accessible and easy to understand, was reported as strong features of good interactions by the young people in these studies. Brown and Wissow (2009) found in a similar vein that, when healthcare professionals facilitated open discussions of sensitive health topics, young people had more positive perceptions of the care they receive. Conversely, the view of Sanders et al. (2011) differs from these reports, who found that young people did not want to be asked direct questions about their sexual health needs, but instead valued communication styles that facilitated interactions which allowed the young people to broach issues they deemed important without being directly asked. Sanders et al. conclude that it was the choice to communicate on own terms that the young people valued. The difference between these two reports of communication style preference may be suggestive of how young people perceive differences in gaining information on issues that affect their health regarding sensitive issues, and the self-disclosure of information of intimate sexual behaviour. However, the commonalities between these reports is that young people

can demonstrate clear preferences on communication styles with health professionals that is influenced by their immediate needs and contexts.

Shaw et al. (2004) identify that it is very important to involve young people in becoming more active in managing their own care and that, when young people felt communication with healthcare professionals was poor, this was perceived to detract from being involved in their own care. Shaw et al. address these findings, stating age-appropriate communication is a means to help the young person develop these skills in health-based communication, and develop their own care as they transition from young people to adults. Kelsey & Abelson-Mitchell (2007) found that, when young people felt excluded from healthcare decision-making, young people reported increased levels of anxiety surrounding their hospitalisation. In addition to anxiety surrounding their care, the study reported young people displayed anxiety in their role as patient, believing they were unable to ask questions of healthcare professionals involved in their care. Savage and Callery (2007) corroborated that young people often felt marginalised in health interactions, and felt that they could not interrupt in professional communications. Savage and Callery (ibid) suggest that this may be due to health interactions taking a surveillance/interrogative approach, in which young people could only offer closed answers that did not allow for their views.

2.7.3 Factors That Influence Young People's Engagement: Information
A number of papers indicated that young people felt information on their health, and care, was an essential feature of good healthcare interactions. These papers indicated that information is a feature that is desirable to make young people feel more involved in their care, and improve their understanding of the impact of the healthcare they experience. Stegenga and Ward-Smith (2008) found that study participants greatly valued information in

order to understand their health needs, and demonstrated a strong preference for information provided in such a way they could access and understand. Coyne (2006) similarly found that information was very important to young people, but that information-seeking behaviour could be a strategy in which young people cope with their health needs experiences. Moreover, the young people in the study reported that, when they believed they were informed and consulted about their care, they felt more content, respected, less anxious and more prepared for their treatment. Interestingly, Muir et al. (2011) found similar results within mental health services. In mixed methods audits of the service, young people reported that they valued staff that provided information about their illness, care and forwarded them capacity to provide input and ask questions. This is suggestive that appropriate and accessible information-giving is a key feature to good healthcare interactions across both physical and mental health services for young people.

The issue of appropriate and accessible information was addressed by the studies of Shaw et al. (2004) and Coyne and Gallagher (2011). Both studies identified that information was only meaningful to young people when in an age-appropriate format which facilitated young people in making appropriate decisions. This suggests that information giving alone is not meaningful unless it is at a similar level of the young person's comprehension. As such, prescriptive information-giving may not automatically improve young people's perceptions of their healthcare interactions. This is also suggestive that information may meet the needs of professionals required to give routine advice, but lacks meaning to the young person on the receipt of the information. Runeson et al. (2002) summarise findings by indicating there may be a bias on the part of health professionals, without the provision of alternatives and without seeking young people's perspectives of the information given. This is suggestive that

information-giving does not automatically improve understanding, and that information that does not facilitate the young person's understanding may be a barrier to involvement. Kelsey & Abelson-Mitchell's (2007) findings suggest that how young people perceive their own knowledge limitations is something that is of concern to them. In health interactions, participants would express concerns about their knowledge limitation regarding their health needs, and expressed preferences of health professional interactions where information was given that facilitated their ability to be involved in decision making. In addition to information on their direct care and health needs, young people are able to state preferences for information regarding the procedural element of healthcare that affects them. Stegenga and Ward-Smith (2008) identified that young people also valued information which kept them up to date with hospital procedures that affected them. Where participants felt they did not know what would happen to them, they expressed frustration and discontent about the processes that surround them.

2.7.4 Factors That Influence Young People's Engagement: Making Decisions

Decision making was identified as a strong theme throughout the literature, suggesting that involvement was perceived as an important feature cutting across a range of health interaction contexts. Coyne and Gallagher (2011) identified that young people expressed strong feelings about having the right to involvement on decisions that affected their body; however, these participants stated they often felt coerced into making decisions by healthcare professionals, or obligated into making a specific decision. Coyne and Gallagher indicated that the young people in the study expressed that health professionals did not offer a true choice between procedures, often reducing decision-making to giving consent. Bray et al. (2012b) reported a similar view from young inpatients awaiting surgery. Participants expressed their decision-making was ultimately an act of resignation, often only consenting to surgery as an

inevitable choice due to the felt expectation of parents and professionals. These studies are suggestive of decision-making becoming a paper exercise on the part of health professionals, with young people identifying the expected role that they feel professionals influence them in playing. In these scenarios, choice in the decision making process is limited to the expected choice of the healthcare professional.

Young people may also be unsure of their role in decision-making and what is expected of them. Shaw et al. (2004) suggested that the young people interviewed feel an uncertainty about their right to engage in the decision-making process. The uncertainty of the young person, as a party in the decision-making, suggests that lack of understanding of how to be involved as an equal party in health interaction may restrict autonomous involvement. The uncertainty felt in these situations is similar to the uncertainty young people feel when asking questions of health professionals, and may be suggestive that young people may not know how to be involved in heath interactions without some form of induction. Without knowing how to interact in appropriate ways with healthcare professionals, young people may be side-lined to passive roles without understanding how to address issues, and how to become meaningfully involved. Young et al. (2006) found that there may be some form of mismatch of belief of what constitutes involvement in decision-making for young people, with professionals and young people stating different perceptions of how decision-making occurred in sessions. Whereas young people felt they had no influence over physiotherapy input, healthcare professionals providing therapy believed young people were actively involved in negotiating session length and times. This suggests that all decisions that a young person engages in throughout their healthcare may not be perceived as a meaningful decision,

and current understandings of decision-making involvement might require young people's perspectives to further inform this area.

The level of decision-making which a young person opts for may be another motivating factor in healthcare interactions. Both Bray et al. (2012b) and Stegenga and Ward-Smith (2008) found that young people in the studies showed preferences to being able to decide their own level of involvement in healthcare interactions and the decision-making process. This was also reflected in the study of Knopf et al. (2008), who found a preference for passive engagement styles in decision-making. Through a survey exploring decision-making preferences with chronically ill young people, Knopf et al. identified 56% demonstrated a preference for passive decision-making, with 37% preferring shared decision-making styles. Knopf et al. notes that these results contradict current beliefs for best practice in engaging young people in decision-making. Yet, Knopf et al. also noted that the ordinal scale tool survey did not address what young people understood as the meaning of 'involvement', or offer alternative methods of engaging in decisions.

2.7.5 Dynamics of Engagement: Conflicting Agendas

The literature clearly demonstrates that young people, when engaged in such a way that nurtures their voice, have strong opinions on how they believe their care should be delivered (Price et al., 2011; Bray, 2012a; Kelsey & Abelson-Mitchell, 2007; Muir et al., 2011). The differing views of how young people believe care should be delivered can be a barrier to effective engagement. Dovey-Pearce et al. (2005) identified that medically focused practices can feel impersonal to young patients, such as consultations that use interrogative methods of questioning. Dovey-Pearce et al. also identified that participants believed that consultations with healthcare professionals, which focused on disease management of diabetes alone, were

not personalised to meet their needs. Dovey-Pearce et al. conclude that healthcare consultations needed to be holistic and age-appropriate to meet the needs of the young person accessing the service in order for it to be effective. Kirk (2098) found similar findings. Young people struggled with changes to clinic structures that felt rushed and impersonal. Both these papers identified that young people could feel that the healthcare consultation was focussed on meeting a set agenda; this did not always meet the young person's expectations regarding what they wanted from that session.

The concept of two agendas in a health interaction was identified by Savage and Callery (2007), who suggested that young patients' perspectives of the dietary management of cystic fibrosis differed from those of the healthcare professional. Whereas the young people related healthy diet to energy for physical exertion, professionals regarded a healthy diet in respect of weight gain as a protective factor against chest infections. Here, the health interactions were designed to measure weight and body measurements as a precaution against growth failure and weight loss, which the young person appeared not to understand.

2.7.6 Dynamics of Engagement: Engagement Preferences
Young people may have very individual preferences to how they engage and, if sought, appropriate ways be expressive of those preferences. Jedeloo et al. (2010) used a mixed methods approach using qualitative interviews, quantitative questionnaires and clinical observations to determine the preference styles young people display for healthcare delivery and self-management. Four behaviours were described that ranged from "fully autonomous" to "backseat patient". Jedeloo et al. (ibid) suggests that young people have preferences to how their interactions occur, and they will manage their behaviour accordingly to fit into the situational dynamics they find themselves in. However, regardless of preference style, all

young people in the study demonstrated a strong desire for individual opportunities to have opportunities alone with professionals to discuss sensitive topics (Jedeloo et al., 2010; Coyne, 2006). This reveals a tension in the literature in how young people shape engagement-related behaviour dependent on context, and is indicative of the current ambiguity in the literature about engagement.

Muir et al. (2011) identified further contradictions between young people's self-assessment of competencies in their engagement-related behaviour and their self-assessed behaviours in their health interactions. Of the 165 young people, 90.4% felt capable of answering questions independently and only 21.9% young patients felt they were not independent enough in consultations. Muir et al. note that only 12.8% of the young people in this study had attended appointments alone, while less than 41.3% of young people reported that they asked health professionals questions themselves. These results suggest that there is an inconsistency as to why young people believed they have self-efficacy to engage in their health dialogues, yet do not participate in the context of their health interactions.

2.7.7 Dynamics of Engagement: Power Distribution

Young people believe they have the right to be included in the discourses that surround their care (Coyne and Gallagher, 2011). Bray (2012a) found that positive experiences of health interactions were reported by young people admitted to hospital for planned surgery when they felt they were treated as an equal partner in their health interactions. Coyne (2006) reports a similar account of young people's perspectives, where young people who felt more involved in and in control of the process of their consultations believed they were treated as an "adult".

Conversely, young people reported that where health professionals did not use accessible language, did not include them in discussions whilst they were present and did not demonstrate genuine interest in their views, they felt excluded and less engaged (Coyne, 2006). Other examples of how young people felt marginalised were where the health professional did not believe their accounts, or checked them against adult voices to seek verification (Bray, 2012a; Shaw et al., 2004).

The literature suggests that young people can be acutely aware of the limitations of their knowledge in making decisions and rely on health professionals to provide age-appropriate and accessible methods for them to gain an understanding of their interactions (Kelsey & Abelson-Mitchell, 2007). Coyne (2006) suggests that these practices on the part of the health professional can be a demonstration of power, indicating those in control of the discourse are also in control of decision-making. Such displays can make young people feel they are 'treated as children', resigning those to passive roles in which they comply with procedures (Muir et al., 2011; Bray, 2012a). As a passive participant, young people can experience anxiety in seeking further knowledge about their care in case it is "causing trouble" for the experts managing their care (Coyne and Gallagher, 2011).

2.8 Scoping Review Findings

As stated above, scoping reviews do not aim to synthesis or appraise studies, but rather map evidence to expound the current state of knowledge and to identify gaps within the literature; this approach is useful to determine directions for future research. Firstly, this scoping review located a small number of studies that suggest there has been relatively little direct research exploring engagement, as a concept, with young people; this is cause for concern given that, as explained in Chapter 1, the engagement of young populations is increasingly acknowledged

as necessary in healthcare compliance and to develop positive lifelong health behaviours. The range of methods used within studies was also a limiting factor; for example, a wide range of methodologies were identified, though these were largely qualitative in nature. In itself, this is not problematic given that engagement is largely associated with the personal meaning of an event and the individual actions a person takes to participate in interactions (Bertoni et al., 2015; Barello et al., 2015). However, engagement is also acknowledged to be an outcome of a healthcare interaction and studies of a quantitative nature, exploring engagement as an outcome measure of care interactions, could be construed as lacking. The concern is that, with little direct research reporting on how to improve outcomes of engagement with young people, practices relating to the engagement of young people in their health interactions may be variable. This is of significance, as the themes of this scoping review suggest that the dynamics of a healthcare interactions are contribute to a young person's perspective of engagement, meaning insight into healthcare interactions dynamics may be important to understand engagement as a process, and as an outcome of the interaction; without a way to understand these aspects of engagement it is arguable that it is difficult to improve practice in this area.

Secondly, it is problematic that the studies in this scoping review used the term engagement intermittently and interchangeably with other terms. No conceptual clarification or theoretical basis was provided for the use of such terms, which appears to contribute to the argument that engagement can be an arbitrary concept within healthcare literature; such ambiguity may propagate conceptual confusion which does little to inform practice or provide guidance. This ambiguity impacted on how the scoping review was conducted, as it was not possible to directly explore engagement; instead the focus of the scoping activity was

defaulted to studies that *evidenced* healthcare interactions *between* young people and healthcare professionals. In a similar fashion, the variation of terms and age ranges used in research about young people creates tensions when determining what studies can relate to this population. For example, it is unreasonable to assume that evidence relating to 'Children and young people' within an age range of 5 months to 18 years (Runeson et al., 2002; Bray et al., 2012b) would also apply to older adolescents aged between 16 and 19 (Jedeloo et al., 2010), or young adults aged between 19 and 30 (Shaw et al., 2004). This seemingly obvious statement reflects tensions when sourcing and procuring relevant literature, as although young people are recognised as high consumers of healthcare services the term 'young person' remains an ambiguous descriptor for this population. Viner and Barker (2005) posits a similar viewpoint, asserting that "the commonly provided age bandings of 5-15 years and 16-44 years in national data statistics provide no information on trends in adolescent health" (p902). This poses problems for consistent data retrieval, comparative analysis, and terminological parity.

Thirdly, engagement appears to be a concept created, used and defined within health culture and practice. The results of this scoping review identified that current research seeks to understand young people's experiences of care, service delivery and care preferences, yet there appears to be little research exploring what young people perceive as important when *engaging* with healthcare professionals; this might suggest that engagement has been explored as a pre-set construct, created through the healthcare professional perspective, and imposed on the young person within research. It may be there is a lack of literature draws on the young person's perspective to explain or understand engagement as a global concept – or, indeed, how such engagement occurs; however a robust systematic search would be

required to confirm this assumption. Despite this, it may be beneficial to address such tensions in future research by drawing a young person-orientated approach to explore the dimensions of engagement within a patient-centred paradigm.

Finally, the findings of this review suggest that engagement is a complicated and individual process occurring with each young person, in each health interaction, and with each health professional. In addition, the needs of engagement may change with health needs, contextualised volition and perceived self-efficacy. The scoping review suggests that various factors influence young people's engagement such as: how relationships are built to facilitate decision-making and autonomy (Price et al., 2011; Bray, 2012a; Kelsey & Abelson-Mitchell, 2007; Coyne, 2006; Muir et al., 2011); how communication occurs and inclusive efforts made to ensure the understanding (Price et al., 2011; Muir et al., 2011; Brown and Wissow, 2009; Shaw et al., 2004); how information is provided in an accessible and age-appropriate format (Stegenga and Ward-Smith, 2008; Coyne, 2006; Muir et al., 2011; Shaw et al., 2004; Coyne and Gallagher, 2011); and that healthcare delivery can include/exclude a young person in decision making (Coyne and Gallagher, 2011; Bray et al., 2012b; Shaw et al., 2004; Young et al., 2006; Stegenga and Ward-Smith, 2008; Knopf et al., 2008). These facets of the healthcare interaction can be facilitated or constrained by dynamics that shape the act of engagement such as: conflicting agendas between the young person and a healthcare professional (Price et al., 2011; Bray, 2012a; Kelsey & Abelson-Mitchell, 2007; Muir et al., 2011; Dovey-Pearce et al., 2005; Savage and Callery, 2007); how a young person's engagement preferences are managed (Jedeloo et al., 2010; Coyne, 2006; Muir et al., 2011); or how power distribution empowers or subjugates the young person's voice (Bray, 2012a; Coyne, 2006; Shaw et al., 2004; Muir et al., 2011). The mapping of the literature suggests engagement is a complex and

multifaceted phenomenon that requires further research in order to develop a better understanding as to how young people experience it and how such knowledge relates to practice.

2.8.1 Limitations of Scoping Review

As identified in section 2.2, scoping reviews have become widely recognised as useful tools to develop preliminary insights into an area prior to conducting larger scale research activity; such investigations enable a greater understanding of the key concepts within an area thought to be complex or underexplored (Mays, Roberts & Popay, 2001). However, as a method for reviewing literature, scoping reviews differ greatly from systematic reviews in many key areas, such as how parameters for research questions are drawn, the level of judgement about quality, methods for data extraction and synthesis and the summative assessment of evidence in the final report (Armstrong et al., 2011). It is important to note that it is for these reasons scoping reviews do not hold the same standard of critical engagement with literature as with systematic reviews, and these differences should be recognised as scoping activity, as a research outcome in its own right, are often used to inform researchers, policy-makers and practitioners in making future decisions within an area of practice (Armstrong et al., ibid). Four limitations to this scoping review are listed below:

I. **Limited strategies were used to procure literature**. This review drew on The York Methodology (Arksey & O'Malley, 2005) to search, sort and manage studies through the processes listed in the above sections; however, it is important to note that a different approach to literature procurement could have potentially yielded a greater number of bibliographic citations. As previously discussed, scoping reviews do not aim to extensively profile a research area, and limiting search strategy criteria is recognised as a useful approach to manage the feasibility of a scoping activity (Levac et al., 2010).

However, such decisions impact on the outcome of the search; in particular, it may have been helpful to profile what literature database are used by the wide range of healthcare professionals listed in the search strategy at the outset of the study. This may have provided a better representation of the wide spread of healthcare literature used across the professions. Additionally, only database results were included in the review; a greater yield of bibliographic citations would most probably have been generated by drawing on additional strategies such as scouring study citations, including book chapters and exploring grey literature. Additionally, it may have been helpful to contact organisations and charities, as engaging with stakeholders in children and young people's health may have stimulated further insights into this area. Finally, the literature was not appraised for quality, as is normal for a scoping review, which may mean that the literature included in this review may not be deemed suitable after critical appraisal.

II. **The search terms used in the scoping review may not be exhaustive**. The scoping review identified that an ambiguity surrounded two of the key search terms used in the search strategy (section 2.6), namely 'engagement' and 'young people'. This implied a conceptual ambiguity and was indicative of a semantic inconsistency in term usage; in itself, this is worrying for healthcare professionals who require a shared vocabulary to engage young people in their care. However, it may mean that, due to this lack of concreteness across key search terms, additional terms may exist that were not identified. Although every effort was made to extensively profile variations of search terms used within this scoping review, the list may not be exhaustive and, therefore, may not provide a full picture of the inter-professional literature. It may have been helpful to pilot search terms used within the scoping to generate a

comprehensive list of potential search terms, as well as to determine an aggregate account of how they are used by healthcare professionals.

III. **The age parameters of the study may not represent young people as a population**. There is a lack of consensus across inter-professional literature as to the age parameters of a young person; this can potentially cause confusion as age ranges appear to differ across terms such as 'children', 'young people' and 'adolescent' which may be due to differing perspectives within education, childhood development and the notion of competence within the eyes of the law. The lack of consensus can be problematic for researchers seeking to represent young people as a demographic. Due to there being no 'one' age classification, various age ranges were included in this review. Although broad search parameters highlighted the level of inconstancy of age bands across terms used in research, it may have been helpful to draw on widely recognised age parameters in health and social care, such as the World Health Organisation (2011) to conduct the review; this approach may have ameliorated the scoping activity and ensured only studies relevant to this age banding were included.

IV. **Other methods of literature review could have been used to initiate the study**. As discussed in section 2.2, the impetus for this scoping review was driven by the tensions that exist when engaging with literature as part of a larger grounded theory study; the ontological and epistemic claims relating to the knower and the known required careful positioning of the researcher role to conduct this scoping review. The format of a scoping review was used to gain an overview of the size and nature of the evidence in relation to young people's engagement with healthcare professionals to develop an awareness of concepts that relate to the substantive area, but would exempt the need for in-depth critical appraisal; by doing so it was possible to glean insight into key

concepts that influence young people within the healthcare setting, without causing undue bias as to how engagement operated as a social processes within the substantive area. However, it is important to recognise there is no consensus as to how one should engage with literature, and competing claims within the grounded theory 'family' mean that different approaches, if well justified, are equally as valid. As such, it may be that a robust systematic literature review could have been equally as beneficial to initiate a grounded theory study, should the tensions be clearly understood, and the issues relating to the literature be carefully navigated prior to study commencement.

Despite the above limitations, the scoping activity identified that empirical evidence relating to how young people engage is lacking; this appears to be exacerbated by ambiguity and semantic confusion about engagement as a term and in its usage. This review has demonstrated that, despite the continued use of the term engagement in health policy strategy, there is no consistent way to understand, assess or evaluate the engagement of young people in their health interactions. This scoping review highlights the need for further research in this area in order to develop and understand what it is for young people to engage in the health interactions that they have with professionals to better inform practice.

2.9 Conclusion

This chapter presented the rationale, design and findings of a scoping review conducted to explore how engagement between young people and the healthcare professionals is evidenced within healthcare literature. This was primarily driven by conceptual confusion that appears to surround the term engagement and an apparent shortage of empirical work in this area. First, a rationale for conducting a scoping review was provided, citing the tensions of

engaging with extant literature within a larger grounded theory study as a key factor. Second, the design and methods of a scoping review that adhered to the principles of The York Methodology (Arksey and O'Malley, 2005) were detailed. Finally, the literature was discussed in relation to a thematic mapping of issues, the range of methodological approaches drawn on within the included studies and the terminological inconsistencies in relation to engagement. The scoping review concluded with an acknowledgment of limitations.

Chapter 3: Research Design: A Grounded Theory Study

3.1 Introduction

This chapter details the methodology and research design used within the study. As demonstrated in the scoping review (Chapter 3), the term 'engagement' remains poorly defined as a way to work with young people. In addition, the paucity of empirical knowledge on the subject provides little insight into how young people become 'engaged' when interacting with healthcare professionals. The following sections provide an account of the study design, drawing on constructivist grounded theory methods advocated by Charmaz (2006) to gather, analyse and synthesise data. The research questions and data collection methods are described, and the process for gaining access to research settings are discussed to elucidate the sampling and recruitment strategies.

3.2 Theoretical Foundations

This section address the ontologies and epistemologies that underpin the study as these influences inform the methodological framework, and channel how research is shaped to gather and analyse data (Lincoln, Lynham & Guba, 2011; Birks and Mills, 2011). As stated in Chapter 1, a relativist ontology that naturally conflated with personal location provided a suitable launch pad by which to explore how young patients experienced engagement with healthcare professionals. The ontological beliefs about existence, and the epistemic relationship between the knower and the known, are essential determinants of how a phenomenon is approached by social researchers (Lincoln, Lynham & Guba, 2011). Questioning the nature of reality is an essential feature of such inquiry, as the theoretical approaches underpinning social research call into question how reality is understood and how

meaning is shared (Ritchie et al., 2013). It is, therefore, important to understand theoretical discourses that surround a methodology in order to justify the research conclusions formed (Strübing, 2007). The prolific dialogues associated with the 'family' of grounded theory methods are well documented (Morse et al., 2008; Urquhart et al., 2010; Bryant & Charmaz, 2007; Corbin & Strauss, 2014; Charmaz, 2007); however, such debates are extensive and protracted. Grounded theory is an area of much contention, with different 'approaches' addressing emergence, theoretical sensitivity, and the concept of researcher objectivity (Glaser, 1978; Strauss & Corbin, 1994; Charmaz, 2008; Boychuk Duchscher & Morgan, 2004). The schism that occurred between the two founding authors (see methodology section below) has seen claims made that methodological deviation 'tortures' data into finding meaning, thus compromising the inductive nature of the grounded theory process (Glaser, 1992b). Exploring the contrasting claims made by authors about different 'types' of grounded theory is outside the scope of this study, yet it is not enough to claim meaning 'emerges' from inductive data analysis alone. Critical engagements with the philosophies that shape grounded theory are essential to understand the implications that arise from a researcher's relationship to data and analysis (Bryant 2009).

The origins of grounded theory are based within pragmatist philosophy and symbolic interactionist sociology of the Chicago School (Charmaz, 2003a; Clarke, 2003; Bryant, 2009). The pragmatist influences of John Dewey and George Herbert Mead on grounded theory can be seen in the premise that knowledge is produced by, and is a product of, action and the interplay of interaction (Corbin & Strauss, 2014). Social action is understood as a product of event experience, and the feelings that arise from said experience, with each aspect of interactions between subjective selves and social others leading into the next (Dewey, 1929).

Furthermore, subjective meaning ascribed to past and present experiences, and the beliefs surrounding future events, influence how the subjective self produces further action and further meaning is generated within social spheres (Meade, 1934). The focus on action, thoughts towards action, and the behaviours that influence interaction, underpins the grounded theorist's perspective of how knowledge is experienced and produced (Corbin & Strauss, 2014).

The epistemic theories of pragmatist philosophy, namely that knowledge occurs from interacting perspectives and as a consequence of action, has had a significant influence on symbolic interactionism and social science research of the time (Strübing, 2007). How meaning is produced, and how action, interaction, and the self, are interpreted in social life, became influential features of the qualitative research methods of the Chicago School of Sociology (Musolf, 2003; Chamberlain-Salaun et al., 2013). Symbolic interactionism assumes reality as a socially produced construct, intrinsically tied to interpretation of action (Charmaz, 1990). The meaning ascribed to social processes arises from individual interpretation and shared social perspectives, requiring discourse to be explored and meaning unpicked when there is dissonance between the two (Blumer, 1969). The influence of symbolic interactionism on grounded theory research is explicit in the explication of social process and the analytical methods, whereby meaning ascribed to human interaction is investigated (Chamberlain-Salaun et al., 2013).

The strength of grounded theory can be said to be its ability to provide insight into how meaning is navigated and coalesced within social settings, and how people situate themselves within their social worlds (Charmaz, 2006). The ontological belief that meaning is both

constructed and shared, thus influencing epistemic theories of knowledge as a social construct of human interaction, became influential in determining the appropriateness of the research methodology selected for the study. The following sections detail methodological underpinnings, resulting in the selection of a constructivist approach for the grounded theory research design.

3.3 Methodology

Grounded theory is a systematic method of qualitative research that seeks to generate new theory to explain phenomenon (Strauss and Corbin, 1990: 1998). It is cited as one of the most used research methods within the social sciences and has been used across disciplines such as psychology, education, and the healthcare sciences (Strauss & Corbin, 1994). Grounded theory is characterised by two main attributes: firstly, the constant comparison method, which aims to iteratively develop codes, categories and themes through data analysis; secondly, theoretical sampling, which involves the identification and selection of rich data sources to explain the social phenomenon (Charmaz, 2006; Hallberg, 2006). These approaches aim to develop a substantive theory that explains an inherent process within a particular social context through the experiences of the people operating within (Creswell, 2007). Martin & Turner (1986) best describe grounded theory as "an inductive, theory discovery methodology that allows the researcher to develop a theoretical account of the general features of a topic while simultaneously grounding the account in empirical observations or data" (p.141). Grounded theory is purported to be inductive research due to the systematic method of analysis it draws on to highlight social process within reoccurring data patterns (Creswell, 1998; Patton, 1990; Crestwell, 2007). This iterative process of data collection, analysis and comparison is known as the constant comparison method, and aims to develop an explanation of how the phenomenon operates through observations grounded in data (Strauss and Corbin,

1990: 1998). This differs from deductive methods of analysis that rely on testing a priori theory and hypothesis (Charmaz, 2006).

The research approach, first developed by Barney Glaser and Anselm Strauss in *Awareness of Dying* (1965), was devised and used to explore dying as a social ritual that permeated the lives, and care, of terminally ill patients. The methods used in this novel study were later refined into a research methodology in *The Discovery of Grounded Theory* (Glaser & Strauss, 1967). The development of grounded theory occurred at a time when qualitative research was dominated by a prevailing positivistic paradigm. Social research in the mid-1960s placed emphasis on verifying extant theories, resulting in an absence of ontological and epistemological positioning and a dearth of inductive theory development (Corbin & Strauss, 2014; Chamberlain-Salaun et al., 2013). Grounded theory was established by Glaser and Strauss as an antithesis to the predominant reliance on positivistic research approaches, and perceived lack of rigour within qualitative methods (Stern, 2009). As such, grounded theory sought to reunite the theories of sociology with the qualitative processes from which they were derived (Martin & Gynnild, 2011). Grounded theory has been cited as pivotal in debunking the positivistic assumptions of the time, highlighting the inherent restrictions of positivistic approaches in developing new interpretations of a phenomenon (Denzin and Lincoln, 1994). Grounded theory provides an alternative research method based in induction, placing emphasis on situating theory within research data (Kenady and Lingard, 2006).

Since its original conception, the founding authors of grounded theory have disagreed as to how the methodology should be applied, resulting in a proliferation of debate which has generated variants to the grounded theory methods (Stern, 2009). Glaser (1992b) contends

that variants to 'classical' grounded theory have veered too far from original methodological processes and, as such, are no longer akin to the grounded theory method. Yet, the assertion of methodological deviation has been equally contested, suggesting the ambiguity arising from the original methodology presentation in *The Discovery of Grounded Theory* (1967) has been the cause of such debate (Dey, 1999). Willig (2013) interprets Dey's rebuttal as disputing the genesis of one 'true' method, as the lack of initial clarity within the original method has since required continual re-interpretation. Melia (1996) provides a different perspective, suggesting that, by understanding the differing ontological assumptions and methodological positions, a researcher can develop better insights as to how to approach research, and how to justify choices. The discourse surrounding methodology has seen grounded theory branch into many directions, each with philosophical implications for research practice (Strauss & Corbin, 1998; Charmaz, 2000; Denzin and Lincoln, 2003; Charmaz 2006). There is a clear epistemological divide between methods, with those purporting objectivity associated with a post-positivist paradigm, whilst interpretive studies, that implicate the researcher within the meaning making process, are aligned with constructivist traditions (Taghipour, 2014). The textual exploration of narrative, and the in-depth deconstruction and reconstruction of meaning associated with a constructivist grounded theory approach, became a decisive factor for using the methodological approaches advocated by Charmaz (2006) within the design of the study.

3.3.1 Constructivist Grounded Theory

Charmaz (2000: 2006) asserts that the positivist assumptions of neutrality and impartiality implicit in methodological predecessors, such as Glaser and Strauss (1967) and Strauss and Corbin (1998), have epistemology objectivist underpinnings that, in essence, disregard the presence of the researcher within the research process. The impetus of a constructivist

grounded theory approach is the epistemological foundation of subjectivism, which redefines the researcher's role as a co-creator of meaning, rather than as an objective reporter of observable facts (Mills & Francis, 2006). This assumes a constructivist paradigm that refutes the existence of an objective reality, instead implying the researcher 'constructs' their findings from the shared meanings that occur between the researcher and research participants (Charmaz, 2003b: 2006). It is the emphasis placed on socially constructed multiple realities that realign constructivist grounded theory with the conceptual underpinnings of symbolic interactionism (Charmaz, 1990). Hence, the researcher is an interpreter of data, representing the phenomenon through the co-creation of meaning (Charmaz, 2006). The final results are inherently collaborative, arrived at through interaction, and bound within temporal, cultural, and structural contexts (Charmaz, 2000). Charmaz (2000: 2004: 2006) asserts that the final representation of the phenomenon occurs through reflexive processes, explicitly identifying how such meanings were arrived at. Ontologically speaking, constructivist grounded theory acknowledges that subjective experiences construct social 'truths', whereas the epistemic roots attempt to reconcile pluralistic perspectives by reciprocally sharing meaning. Constructivism embraces the notion of multiple realities, seeking consensus across multiple individual narratives (Charmaz, 2006).

In relation to the study, such perspectives cut across healthcare experiences and settings to understand the central meaning that 'engagement' with healthcare professionals held for the young person. A constructivist grounded theory approach was identified as appropriate to develop insight into how young people experienced engagement in their interactions with healthcare professionals, and explores the core meanings that were attached to engagement that cut across young people's experiences. By gleaning insight into the meaning attached to

experience, and the beliefs that surround action, insight can be gained into how social structures function (Gardner et al., 2010: 2012). Three intrinsic features of a constructivist methodological design were adhered to throughout to promote reflexivity and fair representation. Firstly, reciprocity between participants and the researcher was facilitated by sharing data interpretations to ensure the co-construction of meaning; secondly, power relations implicit in research were acknowledged from an ethical perspective; and, thirdly, criticism of rigour in grounded theory is often based on its inability to portray transparently how the theory emerged (Cooney, 2011), so researcher reflexivity was addressed by way of memo writing and field notes to maintain transparency (Mills & Francis, 2006). The following sections detail the design and methods that brought about these features.

3.4 Research Question

As demonstrated by the scoping review, the concept of engagement is an ambiguous term lacking clarity or shared consensus. Assumptions of how engagement is enacted by a patient vary and, whilst many definitions exist within texts which guide practice, there is at present no direct research that defines young people's engagement. At present, the few investigations that have been conducted into engagement have focused on engagement as an outcome measure. The Engagement Behaviour Framework (Holmes Rovner et al., 2010) was devised by exploring core patient attitudes and intentions towards care to understand how patients 'behave' as a global concept. The framework expounds behaviours ranging from finding, financing and planning suitable healthcare that meets circumstantial needs. Other measures of engagement focus on detailing how patients navigate healthcare systems, and make choices that contribute to their own health (Gruman et al., 2010). The shifting definition of engagement has seen emphasis placed on the behaviours a patient must independently take in order for positive outcomes to be achieved (Hibbard et al., 2004; Gruman et al., 2010). For

engagement to occur, positive behaviours must be activated and maintained in order to make constructive changes to health and lifestyle (Hibbard & Green, 2013). At present, there appears to be an absence of research developing similar measures for children and young people, or that applies such existing frameworks to young populations. Current approaches to engagement identify the significance of developing practice guidance to facilitate engagement; however, it could be suggested that a limitation with existing measures is focus is placed on behaviour as an outcome. There appears to be great attention on ameliorating patient outcomes, with not enough emphasis placed on the circumstances that bring about engagement, or why such behaviours occur that make patients (dis)engage. The stress placed on engagement as outcome, as opposed to behaviour as an individual process, provides little insight into how engagement occurs, or how such behaviours manifest (Barello et al., 2014).

Given that young people are being increasingly viewed as having the competence to engage and exercise choice in their own healthcare, the need to redefine how professionals involve young people has become an important issue (Redsell and Hastings, 2010). As such, the lack of understanding into what 'creates' engagement and, more specifically, what engagement is within young populations, became the impetus in shaping the research question. Defining the research question is an important feature of qualitative investigation as it guides the focus of enquiry, influences the methods that will be used and provides parameters of what will be studied (Corbin & Strauss, 2008). As opposed to quantitative approaches, which use objectives and hypothesis to narrow focus and limit influencing variables, qualitative research maintains a wide-ranging perspective, promoting exploration of the multiple factors and perspectives that bring about the central phenomenon (Creswell, 2007). A broad approach, therefore, generates multiple perceptions of that which is being explored, allowing for inductive

exploration of the central issues from a multitude of perspectives. Questions with an exploratory emphasis are better placed to produce inductive results, sensitising the researcher to the actions and processes that latently occur, rather than accounting for specific states observed under the study conditions (Willig, 2013). The central question for this study was supported by four research aims, all of which are defined below.

Research Question:
- What does the experience of engagement consist of for young people in healthcare interactions?

Research Aims:

- To explore how young people report their interactions of their meetings with healthcare professionals;
- To examine how young people's perceptions of healthcare professionals affect their involvement in their healthcare interactions;
- To investigate how young people navigate healthcare consultations to identify issues and meet their perceptions of need;
- To understand what young people perceive as the barriers and facilitators to engaging effectively with healthcare professionals during healthcare interactions.

The research question, and supporting research aims, sought to explore the experience of young people's interactions with healthcare professionals in order to arrive at an indicative understanding as to how engagement occurs. The broad approach encouraged adaption and flexibility for exploring and responding to data as it was generated. This supported the constant comparative approach and iterative nature of a grounded theory study (Charmaz, 2006). Moreover, broad research questions provide scope for participants to contribute to the research focus as the phenomenon becomes defined, providing new insights grounded in the

participants' situated world views (Bryant & Charmaz, 2010). The following sections detail the

research methods relating to access, sampling and data collection.

3.5 Ethical Approval

Research practice with children and young people considers consent, confidentiality and

beneficence as core principles that safeguard young people against harm (Powell et al., 2012).

Due consideration and planning, whilst using these core tenants of research ethics, act as

protective factors for reducing the possibility of undue harm and distress which may arise

from involvement. Neuman (2005) notes that ethics are as much about the researcher's

personal standards as their rules of practice, and their utility begins and ends with the

researcher. This implies that those involved in research with human subjects should be aware

of the considerations of ethical issues to ensure nonmaleficence. The following section

provides details of the ethical processes that occurred throughout the study. Formal ethical

approval to conduct this study was granted by the University of Salford, in adherence with

university policy, on 04/02/13 and in respect of departmental standards and governmental

frameworks (Department of Health, 2005; Royal College of Nursing, 2009). Ethical guidance

for occupational therapist researchers was adhered to using the Professional Standards for

Occupational Therapy Practice (College of Occupational Therapists, 2010) and guidance issued

by the UK Research Integrity Office Code of Practice (UKIO, 2006). Due to the nature of one-

to-one interviewing, and the potential risk of allowing un-vetted adults to work alone with

vulnerable young people, a Criminal Records Bureau check was obtained on 10/12/12 via the

University of Salford.

Although many of the key issues in conducting ethical research with young people are the

same as adults, there are many complex factors that require additional consideration (Tinson,

2009). Young people are not always heard, or their voice acknowledged, due to inherent power disparities from paternalistic attitudes that can subjugate young people's views (Davies & Davies, 2011). Moreover, the researcher/participant dynamic of research is recognised as inherently invasive, and consideration into such dynamics is required to minimise these effects (Mayall, 2008). Power imbalances between adults and young people, with adults assuming lack of ability or competence by a young patient, have been argued to have a biological basis of assumed vulnerability (Lansdown, 1994). Assumption about capability made from a developmental perspective may not truly reflect the skills or abilities a young person has, or indeed their competence to make decisions (Lansdown, 2005). Protective assumptions can undermine autonomy, whilst perpetuating unfair dynamics in which the young person cannot be heard. Article 12 of The United Nations Convention on the Rights of the Child (1989) has great historical significance in recognising the civil liberties of the child and, by extension, young persons, asserting the right to have views heard in issues that affect them, and perspectives considered in relation to age and maturity. Alongside The Children Act (1989), emphasis is now placed on inclusive practices that empower young people as active stakeholders in their own healthcare. Since these seminal publications, there has been increased focus on young people's rights in decision-making, self-representation within their healthcare choices, and empowered autonomy, while the right to be heard is now established as a key feature of good practice in communication with young people (Department for Education and Skills, 2001). However, the implementation of these values can be variable (Cave, 2009).

For participation to occur, it is essential that the terms of participation are understood (Alderson & Morrow, 2011). Consent, confidentiality and competence require special attention when working with minors in healthcare (France et al., 2000), with information

required to be appropriate and accessible, and capacity in decision-making accounted for (Coyne, 2010). Similarly, The National Children's Bureau Research Centre (Shaw et al., 2011) asserts that young people's involvement in research requires information to be provided in a format they find accessible and understandable to aid them in making an informed decision in consent. Consideration to competence and issues surrounding consent were given special consideration to rectify implicit power imbalances that might occur from the research process. To ensure an informed decision, printed information sheets were provided in two age-appropriate formats, namely for those aged 13-15 (appendix 3), and those aged 16-18 (Appendix 4), in order to supplement verbal explanations of the purpose of the study and what participation would involve. Particular attention was paid to the risk of subjugation of the young person's voice by seeking assent, as opposed to consent, as an emerging perspective within healthcare research literature argues "it is patronizing to seek parental consent as if this overrides children's own ability to consent to participate in research" (Williams, 2006, p.20). Therefore, consent was also sought from young participants under the age of 16, and every effort was made to empower the young person for informed inclusion within the study. This subtle shift of power, from that of a young person assenting to a parent's decision, and to one of mutuality from all parties involved in the decision-making process, meant that the right to participate remained exclusively with the young person, as the research could not proceed without the young person's expressed agreement.

The young person's right to withdraw from the project without repercussion was explained and recorded at the start of each interview. Young people under the age of 16 who initiated contact with the researcher were asked to discuss their intent to participate with their parents or legal guardian. Each young person had a minimum period of 24 hours in which to make an

informed judgement as whether to proceed, and to gain signed parental consent where appropriate (Appendix 5). In the cases of participants aged 16 years and older, an age-appropriate information sheet was provided, and consent was gained from the young person without the need for parental consultation. The professional consensus for research within healthcare is that young people within this age range are capable of giving their own consent (Medical Research Council, 2004; Royal College of Nursing, 2006).

It is acknowledged that qualitative research that invites people to talk about sensitive issues has the potential to cause emotional distress, which may be upsetting, embarrassing or cause anxiety (McCauley-Elsom et al., 2009). To ensure that sensitive issues raised by the young person could be responded to, an opportunity for debrief was given at the end of each session after the recorder was switched off. A provision to signpost young people to easily accessible services was catered for; however, no concerns were raised and this provision was not required. A risk-analysis approach was taken to all ethical issues that arose within the study (Long & Johnston, 2007). Issues raised were discussed in supervisions with thesis supervisors to gain feedback as to the most appropriate course of action. This ensured that the researcher practised ethically in real world scenarios, whilst keeping the rights of the young person in the highest regard.

3.6 Gaining Entrée

Gaining entrée refers to the process of identifying appropriate research sites, as well as negotiation with site gatekeepers to gain access to participants, which the researcher must undergo as part of the recruitment process (Polit and Beck, 2013). Successful entrée into a research setting involves negotiating many barriers, and ensuring non-malevolence and non-coercive practices are used, if a reciprocal relationship with stakeholders is to be formed (Denzin & Lincoln, 1994). There are many issues identified with gaining entrée that can impede

the research process. The stakeholder's perceptions of research and the researcher may make them wary, and this scepticism is important to address if access to a site is to be gained (Johl & Renganathan, 2009). Moreover, in issues with working with young people, concerns of child protection may require extensive discourse to ensure professional and legal reassurances are made (Shaw, Brady & Davey, 2011). It is, therefore, essential to engage in an open relationship with gatekeepers before participant introductions occur (Feldman et al., 2003). An additional issue that can arise is that, having gained access from gatekeepers, participants do not feel confident in independently approaching the researcher due to a lack of familiarity, perceptions of power relations, or general mistrust (Smith, 2001). This section details the processes used to gain entrée to research sites and the recruitment of young people for interviews.

Secondary and further education sites that provided student support services and pastoral care were identified as suitable research sites for the study. It is known that issues with physical and mental health can impact on a young person's education and educational attendance (Shiu, 2001). Statutory guidance from the Department for Education and Skills asserts that, in order to reduce the impact of ill health on young people's learning, educational services should provide systems of support to ensure that students are not disadvantaged in their education (Department for Education and Skills, 2001). By drawing on these services, it was rationalised that a high incidence of young people who met the study selection, namely of having previous contact with healthcare professionals, would use such services and, therefore, be eligible to participate in the research. Once suitable sites were selected, the key decision-makers within these sites were identified, and the research proposal sent (Appendix 6). Meetings were arranged with managerial gatekeepers to these services, and a full

discussion of the implications of research had. Ethical approval gained by the university was discussed and, in each case, the gatekeepers felt that the researcher's previous experience of working with young people appeased fears of lone working with a vulnerable population. Written organisational consent was gained and prior to commencing research activity on site (Appendix 7).

A phased entry approach can be a gradual method for entering into a research site to minimise service disruption, whilst allowing the researcher to gradually become a known entity to potential participants who attend that site (Shenton & Hayter, 2004). It was agreed that a phased entry to research sites would be the most suitable approach, as this would ensure the students' class timetables were not disrupted, and gradual exposure would allow the young people to build up trust and rapport. Upon initial entry into the sites, a poster display with study information was strategically placed where the young people would see them. Positioning of information was discussed with site gatekeepers, and advice was gained and followed as the best means to achieve these aims. In addition to these strategies, it was agreed that the researcher would be on site on set days in order for participants to approach, of their own volition, for further information. Potential participants were never approached directly, as it has been suggested that researchers can be considered outsiders of an organisation, and perceived as a potential threat (Okumus et al., 2007). Therefore, participants were allowed to approach the researcher on their own terms. The choice of the young person to participate remained paramount throughout the study to ensure there was no perception of coercion by the young person.

3.6.1 The Sites

Sites were targeted that provided specialist services for young people in education, which they could access on a flexible basis. The services identified as appropriate for the study were selected due to their potential for young people in education to contribute to the study within their learning hours, but outside of timetabled education. In addition, both sites had the use of communal spaces which young people could use to interact with their peers, or to seek support from attending staff. The research adhered to the statement of procedures agreed for ethical approval with Salford University. Organisational agreement was obtained from the Additional Learning Support team at Site 1, and student support services at Site 2. Upon gaining organisational agreement, service gatekeepers were identified to liaise with throughout the study. Gummesson (2000) identifies the importance of developing positive relationships with gatekeepers as they play an integral role in introducing potential participants, and can act as a barrier or facilitator to the researcher's progress. Developing a good working relationship with gatekeepers can, therefore, be seen as a crucial aspect of the researcher's role in order to gain access to the right participants for the study (Feldman et al., 2003). Early meetings were held with service managers and staff whilst on site, and hours of attendance were negotiated to minimise disruption, both to the service and to the young people's education.

On entering a research site, participants can be fraught with mistrust and concerns regarding the researcher's intent (Tweed & DeLongis, 2009). A phased entry can be a beneficial method by which to reduce these barriers and to develop familiarity with potential study recruits (Shenton & Hayter, 2004). Upon entering the site, a poster containing study information was strategically placed and age-appropriate information sheets were disseminated through the service gatekeepers. Attendance on site was restricted to agreed set days for 'camp outs' in

order to gradually become integrated into the service culture and allow young people to become accustomed to my on-site presence; young people were not approached to ensure non-coercive research practices, instead allowing young people to initiate contact so that they became involved in the study on their own terms. The following two sections provide information about the sites attended.

3.6.2 Site 1: College in North West England
Young people were recruited from the Additional Learning Support department at Site 1. The Additional Learning Support department provides a specialist service which assesses a student's individual needs and provides student support plans for inclusion into mainstream education. The department works with a range of student needs, ranging from emotional and behavioural difficulties, learning difficulties and disabilities, hearing and sight impairment, dyslexia and general difficulties with literacy, language and numeracy, while students are supported in accessing mainstream curriculum and activities. The department promotes equal access and opportunities and works closely with external agencies to ensure looked-after children, youth offenders, young people who abuse psychoactive substances, young people with targeted education plans and students from disadvantaged backgrounds are supported in their education. The young people from this site who contributed to this study were Mark, Lucky, Sid, Jane, James, Lifey, Paul and Zara.

3.6.3 Site 2: Inner-City High School in North West England
Young people were recruited from student support services at Site 2, a school-based service that provides educational and pastoral support for children and young people who face barriers to their education. The services aim to provide a familiar and non-stigmatising environment where children of secondary school age and young people can seek support,

advice and guidance. The services work closely with families to develop links between the school and home for children and young people affected by mental health problems, substance misuse or domestic abuse, poor attendance due to sickness and long-term health needs, bereavement and loss, carer responsibilities at home affecting their ability to learn, and children and young people with emotional and behavioural difficulties. The young people recruited from this site were Lucy, MarilynM, Rihanna, Beyoncé, Roberta, Tara and Rebecca. Sarah initially consented for interview, but withdrew from the study due to complications in gaining written parental consent.

3.7 Sampling

A recognised strength of a quantitative research is its ability to gather information from large random samples, and determining generalisable findings that are representative of a population (Bowling, 2009). However, quantitative data can be limited by the methods that were used to collect it, lacking the depth and scope of qualitative interviews in favour of results that easily lend themselves to numerical reduction (Frechtling, 2002). In contrast, the qualitative paradigm seeks data that explore the personal feelings and experiences of participants in order to understand their perspective of the phenomenon. The intent of participant recruitment in qualitative research is to collect information-rich data, and sample sizes are often small in comparison to quantitative research. This is not problematic because data collection and preliminary analysis occur simultaneously, guiding the final recruitment and data collection until the study aims are met (Charmaz, 2006). Furthermore, terms such as generalisability and reliability are an alien concept within qualitative research, with these terms detracting from the interpretive nature of the paradigm and the insight that it can shed on phenomena (Robson, 1993). To ensure that this perspective is explored to its fullest, the importance of the chosen sampling strategy becomes more relevant, seeking to identify rich

textual narratives that capture the moment of the phenomenon rather than to discover generalisable truths. The following sections detail the nature of the sampling strategy used within the study.

3.7.1 Inclusion Criteria

The selection criteria for inclusion into the study were as follows:

- Young people who can communicate effectively in the English language;
- Young people (male or female) between the ages of 13 and 19;
- Young people who have been involved in interactions with a healthcare professional in the past 12 months;
- Young people who have the mental capacity to make the decision to consent, and through being able to display that they understand the study sufficiently to give informed consent.

The inclusion criteria were kept purposely broad to allow a wide range of young people, from different backgrounds, and with different healthcare experiences, to be eligible for study inclusion.

3.7.2 Theoretical Sampling

Theoretical sampling is recognised as the appropriate sampling process for grounded theory studies, and refers to the recursive identification and selection of potential data sources that contribute to the exploration of concepts and towards on-going theoretical development (Charmaz, 2006). Theoretical sampling is implicit within the grounded theory research process, guided by theoretical enquiry and the emergence of new data as it arises from the constant comparison method (Charmaz, 2006; Coyne, 1997). Theoretical sampling is a deliberate, non-random method of sampling that does not aim to represent a population, but rather to identify data-rich sources that develop new insights into an area (Breckenridge &

Jones, 2009). Theoretical sampling has often been confused with purposive sampling, which identifies a suitable selection of a population based on known population characteristics that meet the study aims (Pope & Mays, 2008). However, unlike purposive sampling, theoretical sampling does not have a predetermined purpose or necessarily know the population characteristics, instead selecting participants on their ability to contribute to theoretical development and refining the emerging theory (Breckenridge & Jones, 2009). Sampling is, therefore, directed by concurrent analysis with the aim of theoretical saturation, continuing until no new codes are gained from constant comparative analysis (Charmaz, 2006).

A key issue that arose due to the research design was that theoretical sampling of participants was inhibited, as young people were required to self-identify appropriateness for inclusion. However, this was deemed as a minor issue, as targeting specialist services ensured the inclusion criteria in terms of age, prior experience, and capacity were met. Theoretically sampling sites, as opposed to participant selection, enabled data-rich narratives to be identified early on through preliminary screening. As participant interviews progressed, key themes were explored and concepts clarified whilst on site due to increased familiarity with participants. Wherever interactions occurred, note-taking was undertaken immediately after to capture key quotes and develop early memos. Negative cases that did not conform to the current understanding of data were actively sought and explored to ensure range and variance in the final rendering of analysis (Lincoln & Guba, 1985). Theoretical sampling continued throughout the recruitment process until saturation of concepts occurred.

3.7.3 Sample Characteristics

The young people interviewed in this study were aged between 13 and 19 years old. Upon their expression of interest, young people aged between 16 and 19 were provided with age-

appropriate information sheets for their reading age, and given a minimum of 24 hours to identify any issues they wished to raise prior to interview. The professional consensus for research within healthcare is that young people within this age range are capable of giving their own informed consent (Medical Research Council, 2004). Young people under the age of 16 were provided with a guardian or parental information sheet for the young person to take home. Young people in this age range were given one week to take the form home, discuss with their legal guardian and for any queries to be identified prior to the agreed interview date. A telephone number and e-mail address was provided for parents and legal guardians should they wish to raise queries about the study. Young people aged between 13 and 15 were required to bring completed consent forms to their agreed interview slot with the signature of their parent or legal guardians in addition to their own. All the young people taking part in the study were made aware of their rights to withdraw from the study at any time. Table 8 provides information about the young people who participated in the study.

Table 8: Demographics of study participants

Gender	
Male	7
Female	9
Age	
13	4
14	1
15	1
16	4
17	2
18	2
19	2
Participant withdrawal	
Refusal to gain parental consent	1
Stage of education	
High school education (site 1)	8
Further education (site 2)	8
Reported health reasons for health interactions	
Routine check-ups	6
Management of long-term mental health condition	6
Appointment for prescriptions	5
Management of long-term physical health condition	5
Physical rehabilitation	2
Not specified	2
Mental health assessment	1
Contraception and sexual advice	1
Childhood immunisation	1

Seven males and nine females were invited to interview. All the young people met the inclusion criteria; however, one young person under the age of 16 withdrew from the study at the time of the interview. A young person from every age bracket was interviewed, with the highest incidence being the ages 13 (n=4) and 16 (n=4). An equal number of participants from both sites were interviewed, with young people aged 16 being interviewed on both sites. The two highest reported reasons for health interactions were routine check-ups (n=6) and

for the management of a long-term mental health condition (n=6). This was closely followed by young people who had made health appointments for prescriptions (n=5) and for the management of long-term physical health conditions (n=5). Young people identified multiple healthcare professionals' interactions and reasons for healthcare contact.

The sample consisted of a diverse range of young people aged between 13 and 19 years old with various physical and mental health needs. The reasons for health contact, severity of conditions and frequency of contact differed with each young person. Similarly, the interpretations of interactions with healthcare professionals differed on a case-by-case scenario. Due to medical histories, the young people drew on both immediate health interactions (within the previous 12 months), and past interactions with healthcare professionals to discuss their perceptions of engagement. As such, broad snapshots of both recent and retrospective accounts enabled an insight into the participants' perspectives over their transitions from childhood to young adulthood, the meaning young people attached to interactions with healthcare professionals, and how young people developed engagement-related behaviours.

3.7.4 Data Management

Initial interviews were conducted in a private location on each site of the service being accessed. Where interactions occurred on site after the initial interview, privacy was always sought to ensure confidentiality. The University of Salford lone researcher policy was adhered to at all times to ensure safety. Age, sex and type of healthcare interaction were recorded to provide a descriptive analysis of the sample. Interviews were transcribed by a professional service, and data were stored securely on a password-protected computer with access restricted to the researcher. Additional interactions which occurred on site was recorded as

field notes, as written accounts of interactions and memo writing are recognised sources of information when using a grounded theory methodology (Schreiber, 2001). All information obtained was managed according to the Data Protection Act (1989) and the Research Governance Framework for Health & Social Care. The identity of all young persons was protected through the use of a pseudonym, which was selected by the young person at the time of interview. Personal details used for contact and consent purposes were kept separate from computerised data in a locked filing cabinet. Data was used only for the declared purpose of the study and retained in line with the University of Salford data storage policy; all personal details of participants were destroyed on completion of the study and the award of the degree.

3.8 Interview Methods

As identified above, grounded theory studies do not test hypotheses or use pre-formulated research questions that seek to test a theory. Instead, grounded theory seeks to generate un-coerced participant-led data from which a theory can be drawn (Bryant and Charmaz, 2010; Charmaz, 2010). Although a range of data collection methods can be used within grounded theory methodology, face-to-face interview methods are particularly useful because meaning is constructed through participant-researcher interactions in order to generate new knowledge (Charmaz, 2006). Data collection used a semi-structured interview format as this is a well-established method of collecting data within qualitative research methods to enable meaningful interactions with participants, allowing them to share their experiences, thoughts, attitudes and beliefs (Richards and Morse, 2007). This enabled exploration of a range of issues, whilst emphasising aspects of the phenomenon participants perceive as important. Due to the on-site presence maintained on research sites (see above), opportunities to follow-up on key concepts raised within young people's interviews were possible. A purposely-broad approach

to exploring young people's perceptions of engagement was maintained, as this allows participants to define direction and parameters within the interview, and allows the researcher to develop an understanding of the phenomenon grounded in the participants' world-views (Bryant and Charmaz, 2010).

Initial interview questions were developed drawing on themes identified from the scoping review, which were developed into an interview guide (Appendix 2). The interview guide provided early insights into how young people perceived their interactions with healthcare professionals, but also provided flexibility for self-identified topics to be raised as appropriate (Seidman, 2006). As such, questions asked within interviews were not prescriptive, using the interview guide as an aide-memoire to explore aspects of interviews that seemed vital in order to understand the concept of engagement. As the interviews progressed, theoretically relevant data provided meaningful insights outside the pre-set focus of enquiry (Strauss & Corbin, 1990). Insights were explored where appropriate to elucidate theoretical construction (Charmaz, 2006). This process continued in an iterative manner until the social processes emerged from patterns within data analysis, and memo sorting (Bryant and Charmaz, 2010). A full account of this process is provided in the next chapter.

3.9 The Young People
A defining feature that differentiates constructivist grounded theory from other variations of the methodology is the attention it pays to the representation of participants within the study (Charmaz, 2009). The researcher does not aim to neutrally report facts, but rather makes a concerted effort to understand the participants' understanding of the phenomenon and represent the meaning they ascribe to their interpretations of reality (Charmaz, 2006). In representing the participant in this way, it is useful to account for the situation, the

interaction, and perspectives expressed to form a cohesive summary (Charmaz, 1995). The following sections provide a description of the young person's initial interview, providing insight into past experiences with healthcare professionals. Due to the constructive paradigm detailed above, the following reflective account uses the first person to implicate myself as the researcher within the interviews. Ontologically, this can be deemed appropriate due to the relativist nature underpinning constructivist writing (Charmaz, 1990). The young people chose their own pseudonyms to protect their identity and preserve confidentiality.

3.9.1 Mark

Mark was the first young person interviewed; he was very keen to talk about the healthcare professionals he had met whilst managing his diagnosis of pulmonary hypertension. Mark had been diagnosed with his condition as a young child, and explained his diagnosis as "I have these thick arteries which can't expand to get air out and it puts a strain on my heart". Mark explained the impact of his condition while growing up, and how it affected present-day choices at the age of 16. Mark was very frustrated from living with his condition and the limitations it had placed on his day-to-day life. Mark disclosed he was a looked-after child by his extended family; his auntie cared for him because he wasn't allowed to see his father unsupervised. Due to ongoing health needs, Mark had regular contact with a wide spectrum of healthcare professionals, ranging from specialist consultants, nursing staff and allied health professionals. Mark felt that he has had variable experiences from his interactions with healthcare professionals and, throughout our discussions, he would contrast experiences of good practice against bad practice. Mark found the variability of exchanges with healthcare professionals frustrating, saying that it was difficult to know what to expect from them as no two scenarios were alike. Often, Mark said he would feel "left out" in meetings that his auntie attended, and when this happened he would just "switch off". Despite having a high frequency

of contact with healthcare professionals, Mark felt that he doesn't know as much about his condition as he would like to. He explained that healthcare professionals were not very good at explaining his condition to him in a way that he could understand. Mark's general impression of healthcare professionals was that they were just doing their job, and they wanted it done as quickly as possible. He reasoned this was probably why they didn't pay too much attention to him.

3.9.2 Lucky

Lucky was a young person who stated from the outset "I don't like being messed around by these people", preferring his interactions to be quick and to the point to "get things over with". At 17, Lucky had seen health professionals for a range of minor aliments over the years, the most recent being a diagnosis of a chest infection from his general practitioner. Lucky really respected those who "cut to the chase" as he hated getting loads of information that was useless or which he didn't understand. Lucky took time to emphasise his points so that I didn't misunderstand why he wanted quick consultations, making a clear distinction between the "good ones" and those that "weren't bothered". Lucky found health professionals who were unwelcoming or unfriendly difficult to deal with, citing past experiences of healthcare professionals who seemed in a bad mood or wanted to get rid of him as soon as possible. Lucky presented as quite sensitive about healthcare professionals' attitudes towards him, which created a distinction between "those good at their job, and those just doing their job". This influenced his sense of trust and whether he felt that he could forward trust to them in the future. As Lucky and I conversed, he became comfortable in our exchanges and started rephrasing questions into his own words in order to understand them. Lucky used terms like "getting on with" and "getting on board" to explain how he understood engagement. Lucky

said it was always better when he could use his words to understand a problem as, that way, he wasn't confused afterwards.

3.9.3 Sid

Sid had ongoing back problems after falling off a roof at the age of 16. He had seen a range of healthcare professionals for emergency care and rehabilitation and, at the age of 19, experienced chronic back pain which he managed with daily medication. Sid stated he had "started to become addicted" to some of the stronger painkillers, and his doctor often wouldn't give him the painkillers he wanted. As our conversations developed, Sid explained that in his early teens he'd had a range of input from Child and Adolescent Mental Health Services due to suicidal ideation and his tendency to self-harm. Throughout his interview, Sid drew on a range of examples from physical and mental healthcare services to explain his perceptions of how health professional interactions occurred. Sid drew heavily on past experiences and how these experiences impacted on trusting future healthcare professionals. He explained that, when younger, he had difficulties in his home life, and these difficulties affected his mental health. He would often get upset or wound-up and, at these points, he would self-harm. On one occasion, he told a community mental health nurses and she reported this back to his father. He saw that as the worst thing she could have done and affected his trust with the other nurses on the CAMHS team. Sid saw his present-day interactions as complicated due to his past experiences with healthcare professionals. He found it especially difficult when his back pain was very bad and his doctor wouldn't prescribe stronger medication because of his past habit-forming behaviours. He often felt that healthcare professionals weren't listening to his opinion, and that these health professionals had already made their minds up on an outcome independent of his input. Sid struggled with identifying clear boundaries and getting his voice heard.

3.9.4 Jane

Jane was the first girl I interviewed; as such, I had initial apprehensions about being a male healthcare professional seeking to discuss potentially sensitive health needs with a 16-year-old female. I spent time getting to know Jane, allowing her to ask questions about me, which I answered sensitively and directly. As Jane became familiar with my presence, I observed a softening in her tone and an ease developed throughout our interactions. Jane's main contact with healthcare professionals was from primary health services. In her interview, she drew on previous interactions with general practitioners for contraceptive implants, and sexual health nurses for her pregnancy scares. For Jane, forming trust was integral to how comfortable she felt in health interactions, and how she responded was dependent on how much faith she felt she could place in the healthcare professional she was interacting with at that time. Jane negotiated healthcare professional interactions alongside her support networks and current circumstances, and her engagement-related behaviour was often shaped by these factors. As a looked-after child by her extended family, "keeping things secret" from her auntie was a big factor in developing effective relationships with healthcare professionals. Jane explained "why would you go if it got about why you was going?"

3.9.5 James

James was 17 years old and had spent his childhood years in social care settings. At the time of the interview, he lived with foster carers and attended college for an NVQ foundation course. James had a history of anxiety and, within the interview, he drew upon previous health interactions for determining treatment options to manage his condition. Throughout the interview, James reflected on observations of health professionals' behaviour which he found difficult to open up to. James was also sceptical of their apparent rush to place him on medication for his anxiety before exploring other treatment options. James stated at various

points his wariness of healthcare professionals, citing the "serious mistakes" his GP had made when prescribing adult doses of medication at the age of 16. The mistake was identified by his foster carers, and cited their admonishments of the GP's mistake as a main reason of his current distrust. James believed he was "doing a lot better now", but that this was mainly due to his various support networks outside of healthcare which had enabled him to identify better options for managing his anxiety.

3.9.6 Lifey

I first met Lifey between his classes with an A1 art portfolio under his arm. Lifey was 18 and, due to our common interests in art, we found conversation naturally occurred. Lifey shared his art with me and we talked about the influences and motivations for his A-level art project. Lifey was eager to talk about the "rough ride he'd had" from healthcare professionals after he threatened to stab his art teacher in the eye. The college had demanded a mental health assessment and regular contact with the CAMHS team if he wished to continue his studies. Lifey felt coerced into a process that he felt would label him and, since a tentative early diagnosis of Asperger's syndrome, he was resistant to any input from mental health services. Lifey felt that he was "getting on alright" without all of this attention. As Lifey talked about past health interactions, he explained the resentment he felt about talking with people who were continually misunderstanding and judging him. Lifey believed having to meet with the CAMHS team was unfair, and that the healthcare professionals on these teams were often "nasty" and "snide" towards him. Lifey felt that the whole process was a "waste of time". How Lifey entered into mental health services has largely affected his perception of the healthcare professionals he meets, and his interactions with them. Meeting a healthcare professional is part of "fighting to stay in education". Lifey believed himself failed by a system that didn't

know his background, failed to make any efforts to understand him and was continuously making judgements about him.

3.9.7 Paul

Paul was 18 years old when we met and preparing for university interviews. We got to know each other and chatted about his range of interests, his course and upcoming exams. We initially spent time talking about things Paul wanted to talk about and, when ready, Paul started the interview. Although nervous at first, Paul was keen to talk with me about his past experiences, and was open and forthright about his range of health appointments for monitoring and managing his lifelong condition. Paul explained he had "sudden death syndrome", a condition he'd had since childhood, where his heart could "stop at any moment". In addition to a past operation, Paul had regular EECG scans and ongoing health reviews to monitor his diagnosis of Long QT Syndrome. Paul had come to dread meeting health professionals, stating he wasn't a strong person because of his fear. When asked to elaborate, he provided the following explanation: "When I'm in college and at home, I see myself as a normal person. And every year I'm forced to go back to this hospital and be tested on it. It kind of throws you back and makes you realise that you're different and it kind of upsets the balance of things." For Paul, health professionals reminded him of a condition he had become adept at forgetting in his everyday life.

I found Paul to be intuitive and, as I asked questions, he paused to compose himself before giving answers. Paul reflected on the questions I asked and demonstrated good insight into the dynamics of his health interactions. Paul had very supportive parents and, over the years, Paul had come to rely on them to manage health interactions. Paul avoided direct contact, and since transitioning from paediatric to adult services he would continue to defer all health

communication to his parents. All Paul said he required was a "you're fine" at the end of a consultation. Paul felt conflicting emotions about the strategies he had developed for interacting with healthcare professionals, identifying his need to develop his independence as he would be moving on to university soon. Paul was quite fearful of what becoming independent would entail.

3.9.8 Zara

Before going into the interview room with Zara, I was pulled to one side by one of the service managers. I was cautioned that Zara could be a lovely girl, but if anything happened I should just get out of the room as soon as possible. In the interview, Zara didn't bother with preliminary conversation, instead focusing on getting the interview started. Zara presented as open and earnest, and was not reticent in self-disclosing her past experiences with healthcare professionals. Zara had been involved with the CAMHS team since school for ongoing depression and self-harming behaviours. Zara had been bullied throughout school and college and, during her low periods, would hit walls or use sharp rocks and glass to take the skin off her fingers and knuckles. Zara felt a lot of shame for her self-harming behaviours, but explained it had been the only way to get through her moods. After quitting college at 17, Zara had returned to college at 19 to gain a diploma qualification.

Zara had only positive experiences of healthcare professionals, working extensively with mental health nurses to challenge negative thoughts, understand self-harming behaviours and to identify better coping strategies in times of her low mood. Zara explained that the nurses had been flexible, led family sessions with her mother and had sought Zara's input to meet her specific needs as they occurred. Zara felt comfortable using the service and knew she could talk to the nurses about anything if she needed to. Zara openly talked about getting advice

that worked, and of finding better ways to deal with her problems. Zara "took on board what they were saying" and reported it had helped her "move on considerably since the bad days".

3.9.9 Lucy

Lucy was a 16-year-old girl preparing for her GCSEs when we met. We talked about her upcoming exams, and she returned questions about the study and myself. Lucy appeared at ease with me and conversation occurred naturally. As we chatted, Lucy sat opposite me with her sleeves pulled over both hands and clasping her fingers together to keep the sleeves in place. She explained she was having ongoing consultations with a neurologist to manage neuropathic pain, and was in the process of deciding whether to have a cosmetic operation for the "creeping web space" between her fingers. Lucy explained she had a fire injury on her hands and arms and, because of this, she had explained there was "something wrong with my nerves and he's got to do something with three nerves in my hand". Lucy could not draw on the medical terms used within her past health interactions, but was able to provide a detailed account of the interactions and how these had informed her understanding of her condition and prognosis. Lucy drew on healthcare professional strategies discussing her condition, and how she had adapted her behaviours in her interactions to understand medical terms and knowledge. Lucy noticed when healthcare professionals adapted their style in response to her new strategies and could comment on the efficacy of these approaches. Lucy believed that it was important to be proactive in her health interactions, drawing on her need to understand the risks for deciding on an operation. She explained she could only do this if she understood "what the doctor was on about".

3.9.10 MarilynM

MarilynM went out of his way to talk to me when I was on site. He would tell jokes to make others laugh and offered me sweets whenever I saw him. In his interview, MarilynM gave an account of the night-time incontinence he had experienced over the past few years. MarilynM had conflicting feelings about using continence services at the age of 13, and was very conscious as to how he was treated when using the service. MarilynM had seen various healthcare professionals over the past few years as part of his ongoing treatment, using a combination of medication, alarm therapy and sleep hygiene routines to monitor and manage his night-time bed-wetting. MarilynM had strong opinions about the healthcare professionals he met, in particular the continence nursing team, which he disclosed as a source of irritation each time he spoke with them. MarilynM saw himself spoken to in a condescending manner "like a little kid", believing the reason for this treatment was due to using a service which "normal kids" didn't use. MarilynM reported seeing a high percentage of children with profound disabilities in the waiting room when using the service and he felt this was why he was mostly "spoken at" rather than spoken to. MarilynM accepted that being treated that way was inevitable, stating that he'd "like it to change but it's like one of those things".

3.9.11 Rihanna

Rihanna was a small, 13-year-old girl who chatted freely and answered questions by drawing on what she had learnt in her health and social care classes at the school. As part of Rihanna's education at school, she was learning about infection control, the transition of pathogens and the importance of hygiene in a hospital setting. As part of this module, the schoolchildren were taken into hospitals to supplement their learning, and Rihanna drew on the observations from these trips to explain her beliefs about what was right and wrong in the hospital setting and to justify her opinions on health professional behaviour. Rihanna explained she had

generally good health outside of GP visits, but interacted frequently with healthcare professionals on behalf of her mother. Rihanna's mother often had periods of "not being well" and, during these periods, Rihanna would provide informal care during these periods of illness. As a young carer, Rihanna identified many interactions with health professionals on behalf of her mother, and these interactions greatly influenced her thoughts about them. Rihanna emphasised difficulties in communicating with healthcare professionals when they didn't understand her situation, and explained how "you have to keep telling them to get your point across".

3.9.12 Beyoncé

Beyoncé came to her appointed interview time with a friend and, despite being informed of the interview procedure the previous week, she wanted to bring her friend into the interview room with her. I explained this wasn't a good idea, and she became upset and would not speak. After giving her the option to come back another time when she had composed herself, she stated she wanted to do the interview there and then, but only if her friend could come into the room with her. Drawing from previous young people's interviews, it was apparent young people would take friends to health appointments to draw on their support. Due to Beyoncé being 13 years old, I was initially cautious, but suggested that we could continue with her friend in the room if that was her choice. I advised her she shouldn't disclose any sensitive personal information in the interview. Throughout her interview, Beyoncé did not engage well, mocked questions, and made inappropriate statements where she would turn to her friend and laugh. Beyoncé claimed she had punched a nurse in the face because she had been hurt when being giving an injection. At the end of the interview, Beyoncé was thanked for her participation and observations of the interview were recorded and included for analysis.

3.9.13 Roberta

Roberta was a quiet, 13-year-old girl who smiled nervously throughout her interview and would ask "is that OK?" after giving an answer. Roberta was often concise in her answers, but would earnestly elaborate when asked. Roberta was generally healthy, using primary health services for minor ailments. She discussed visiting her GP with her mother, but mainly focused on the 'needle nurses' who she had visited for her HPV vaccine. Roberta explained how her first visit hadn't been successful due to needle anxiety, requiring a second visit with a different nurse to receive the vaccine. Roberta drew parallels between the two experiences to identify good and bad practice. Her first experience was of unfriendly behaviour and being compared against braver children who'd had the injection earlier that day. For Roberta, these interactions exacerbated her anxiety, which in turn caused such distress that the vaccine was not able to be administered. Her second visit saw her meet the "nice nurses", who acknowledged her fear and gave advice on how to manage her anxiety. On the second visit, Roberta freely gave her arm "explaining it wasn't as bad as I thought it would be". Roberta explained she would often get "properly scared" when she met healthcare professionals, but some weren't as bad as others.

3.9.14 Sarah

Sarah was a 13-year-old girl who came to her interview slot without a signed parental consent form. She said she had forgotten it, but had taken the initiative to ask the school to call her parents. I was handed a signed note from the school secretary on a school headed compliment slip explaining that her parents had been called and they had consented over the telephone. As a doctoral researcher, I was uncertain if the interview could proceed as it deviated from the statement of procedures agreed within ethical approval. I contacted my supervisor, who confirmed this was not possible and another date should be negotiated where the slip could

be returned. After explaining this to Sarah, she became upset, stating she didn't understand why she couldn't be interviewed the same as her friend had been earlier that day. She said I was being stupid as the receptionist wouldn't lie, and it wasn't fair as the school "backed her up". I explained I could not proceed without receiving consent from her legal guardian and suggested another interview to allow her time to obtain written consent. Sarah refused to make another appointment and withdrew from the study. Reflective notes from the interaction were made for analysis within the study.

3.9.15 Tara

Tara took time to build a relationship with me. In the early stages, she would walk over to see if I had any sweets that day, but as time passed she became more at ease with me. Tara was 15 years old and, as we got to know each other, she told me about her love of singing, and her ambition to go to college to do music studies. Tara consented to be interviewed and was given a full debrief about what the interview entailed. In the interview, Tara's demeanour and attitude changed once I placed the Dictaphone on the table. Where before Tara had been speaking freely, she sat stiffly and picked at her fingernails. Tara remained silent throughout the first few questions and I suggested stopping the interview. After turning off the Dictaphone, Tara visibly relaxed and she was willing to discuss the situation. Tara explained she hated being recorded, as she had been recorded by healthcare professionals when she was being placed in care and was afraid of "saying the wrong thing again". Tara agreed to be interviewed as long as it was without the recorder. She talked about her difficulties trusting healthcare professionals, and how developing trust was difficult as she had been "moved around a lot" after being placed on a care order by child protection services. Tara explained healthcare professionals were "tricky" because they all said they wanted to help her, but then did things that ended up causing more trouble. They didn't really take time to listen to her

situation and she was always the last to find things out. Tara explained she didn't usually trust healthcare professionals until she knew "what they were about".

3.9.16 Rebecca

Rebecca was the final young person to be interviewed and was keen to contribute to the study. At 16 years old, Rebecca was in her final term at school, and explained she wanted to continue studying health studies at college so that she could eventually train to be a nurse. When asked about her interest in becoming a nurse, Rebecca told me in a clear and level tone it was because of how her mother died, and that no one should go through what she had to. Her mother's early health complaints had been dismissed, which resulted in a late diagnosis of emphysema of the lungs. Due to the lateness of the diagnosis, a lung transplant was not possible. As an inpatient at hospital, her mother was accidentally overdosed, resulting in her suffering from a fatal heart attack. Rebecca was angry about the shortfalls in healthcare that she had witnessed throughout her mother's illness. In addition, Rebecca had a previous childhood diagnosis of ventricular septal defect, and received cardiac surgery six years prior to the repair of the ventricle chamber. Rebecca drew on a range of interactions with healthcare professionals throughout her interview, some for her healthcare and management, and others from the observations of her mother's care. Rebecca explained that it didn't matter what the experience was; she had learnt about healthcare professionals from what she saw and had expectations of what a health interaction should be because of them. Rebecca held strong convictions about healthcare professionals and believed that many would "place themselves on a pedestal", thinking themselves more important than the patients they interacted with.

3.10 Chapter Summary

This chapter provided an overview of the methodology and methods employed in the study. The philosophical and theoretical aspects of grounded theory were presented to situate ontological and epistemic underpinnings, and the general background of the grounded theory method explained. The research design was influenced by a constructivist grounded theory approach, guided by an exploratory research question and four supporting research aims. The design of the data collection methods included semi-structured interviews and was driven by theoretical sampling, as is the normal procedure for a grounded theory study. The young people of this study were recruited from educational support services within secondary and further education, and the recruitment process adhered to procedures stated within ethical approval, which were upheld whilst on site at all times. A phased entry was utilised for accessing the research sites, and non-coercive practices were used to allow young people to approach the researcher on their own terms. All participants had a health interaction within the past 12 months; however, young people often drew on childhood experiences, as well as observations and stories of others within their family network, to form answers in their interviews. The study participants disclosed a variety of home backgrounds, a wide range of health needs and variable experiences of their interactions with healthcare professionals. Whilst exploring the phenomena of engagement with the young people, some were content to describe their perceptions and feelings of interactions with healthcare professionals, whilst others reflected on past interactions to form a rationale for events that occurred. Fourteen of the young people identified both good and bad interactions with healthcare professionals, and would discursively switch between these contrasting experiences to frame their understanding of healthcare professional practice. One young person reported only having negative interactions, whilst another young person reported having only positive interactions.

Chapter 4: Data Analysis

4.1 Introduction

As identified in Chapter 3, a constructivist grounded theory approach situates the researcher as interpreter of data, active in translating and representing participants' lived experiences and covert social processes (Charmaz, 2003a). It has been suggested that rigour is implicitly built into the grounded theory method, and that transparency of application is essential to denote credibility (Cooney, 2011). Furthermore, maintaining researcher reflexivity throughout the interpretation and theoretical construction is a fundamental ontological premise within a relativist paradigm (Lincoln and Guba, 1985). This chapter presents a description of the methods used throughout data analysis, drawing on the guidance of Charmaz (2006) to code and integrate theory. Initial coding was used to label and form early minor conceptual categories, with focused and theoretical coding driving analysis towards theoretical category development. Axial coding was then used to determine the properties and dimensions of theoretical categories, denoting the relationship and interaction between concepts. In addition, a Conditional Relationship Guide developed by Scott (2004) was used to explicate data patterns, providing contextualised insights and fostering theoretical maturation. Throughout the analysis, a flexible approach was utilised, as is normal practice within constructivist grounded theory (Charmaz, 2006). The following section provides a transparent overview of how findings were developed to account for the final theoretical rendering of Chapters 5 and 6.

4.2 The Contention of Coding

The methods used for data analysis have been a subject of considerable contention throughout the development of grounded theory. Traditionally, three levels of coding occurred over two distinct stages: an initial stage of systematic coding and category

development; and an 'emergent' stage, where theory surfaced through the explication of categories through memo writing (Walker & Myrick, 2006). Coding worked between inductive and deductive inquiry, with emergent theories developed from analytical processes to explore data, and theoretical explanations validated by comparing and contrasting back to grounded data (Charmaz, 2008; Walker & Myrick, 2006). The division between Glaser and Strauss saw a divergence of methodological procedures, with Strauss developing systematic coding processes to facilitate theoretical development and integration (Strauss & Corbin, 1990), whilst Glaser (1978) retained the premise that emergence occurs naturally through successive and subsequential deep data immersion. Strauss sought to tackle methodological obscurity to facilitate theoretical development, whilst Glaser maintained overly procedural methods were akin to thematic analysis, 'forcing' analysis, and thus compromising theoretically sensitive analysis (Glaser & Holton, 2004). Theoretical emergence became a contentious issue that stimulated debate on the nature of grounded theory inquiry.

Consequently, the emergence/forcing debate has proliferated scholarly discourse, ensuing in methodologies being philosophically situated to define the paradigmatic location, and to critique the analytical tools drawn on that generate theoretical statements (Kelle, 2007; Boychuk Duchscher & Morgan, 2004). Emphasis was placed on ontological and epistemological foundations to shape coding and guide research, as opposed to methodological rhetoric. Charmaz (2008) supports this perspective, suggesting research methods are tools driven by ontological beliefs, with epistemic value not independent, but rather implicit, in their use. This position implies that a Glaserian perspective of emergence is based within a positivistic assumption of objectivity, and that, by shifting focus to the researcher's relationship with data, emergence is possible by explicating 'construction'.

Chamaz (ibid) summarises this point by stating, "strategies are just that – strategies for creating and interrogating our data, not routes to knowing an objective reality" (p.401).

The way that data is treated throughout the coding processes distinguishes constructivist grounded theory from other methodological approaches (Mils et al., 2008). Constructivist grounded theory requires methods to be consciously selected to resonate within the philosophical positioning of the methodology, and that those methods are acknowledged as the tools whereby meaning emerges (Charmaz, 2006). Charmaz (2000) firmly situates her methods for conducting grounded theory within a relativist ontology, inferring that the "'discovered' reality arises from the interactive process and its temporal, cultural, and structural contexts" (p. 524). This approach naturally resonated with the research question of this study and fostered exploration of what the experience of engagement consisted of for young people in healthcare interactions. The following section provides an explication of methods, transparently acknowledging theoretical construction as a product of working with data to generate meaning.

4.2.1 Transparency

Charmaz (2008) identifies that the precepts of grounded theory require researchers to minimise presumptions about data, build theory through iterative data collection, and remain open to varied explanations of the data. These central tenets remain at the heart of the grounded theory method, and are implicit in process and procedures. Unlike quantitative research methods, which seek to subsume concepts into quantifiable means within a hypothetical-deductive framework, qualitative methods assume an interpretivist stance, utilising methods to explore the constructs of human behaviour and meaning of experience (Tuli, 2011; Thornberg & Charmaz, 2014). This matter is further complicated by the wide spectrum that interpretivist inquiry exists upon, with issues of quality standards being widely

debated (Mays & Pope, 2000). For instance, Hammersley (2007) identifies that focusing on observable procedural indicators can be reductive, whereas gauging quality on circumstance and context can be complex in nature. How to assess quality in qualitative research is recognised as a multifarious debate, yet researcher transparency, and the documentation of key decisions which shape qualitative study, remain an overarching and implicit indicator of quality (Hannes, 2011). Methodological and interpretive transparency is both valuable and necessary to make the researcher's presence, techniques and practices explicit to facilitate critical evaluation (Hiles & Čermák, 2007).

Within grounded theory, the use of robust procedures that trace the researcher's relationship with data provide a point of access into theory development, offering insight into the development of coding, and the rationale of final theoretical conception (Corbin & Strauss, 1990). In this sense, accounting for analytic choices facilitates analytical development, but also provides transparency into the means theory created (Charmaz, 2008). Such accounts of methodological rigour are advantageous as they bolster confidence in researcher credibility and the study findings (Bowen, 2009). In terms of this study transparency was especially pertinent for credible exploration of young people's reports of their meetings with healthcare professionals. The following sections account for the procedures used throughout the study, with examples provided to clarify how such methods were employed.

4.2.2 The Constant Comparison Method
Comparative analysis is an essential feature of grounded theory, intensively working with data to develop a conceptual awareness of embedded social processes within a phenomenon (Strauss & Corbin, 1998). Charmaz (2014) succinctly defines the constant comparative method as an iterative process to compare data with data, data with code, code with code, code with

category, category with category, and category with concept (p342). Comparison constitutes each successive stage of analysis, with the researcher concurrently collecting, coding and analysing data (Strauss & Corbin, 1998; Charmaz, 2000; Charmaz, 2006). Through simultaneous data collection and analysis, the constant comparative method determines, integrates and explicates theoretical categories, whilst ensuring findings remain grounded in data (Charmaz, 2014). As the study aimed to understand young people's perceptions of involvement in the healthcare interaction, the constant comparison method was instrumental in developing an abstract rendering of social process derived from young people's narratives.

As previously stated, the guidance provided by Charmaz (2006) was used within the study to compare data against data, contrast analysis across multiple cases, and develop abstracted categories for organising labels and classifying memos. The advocated methods were developed for use within constructivist research, enabling in-depth exploration into young people's perceptions of interactions with healthcare professionals, and generating insight into how such perception of events influenced engagement within interactions. The following sections account for how the constant comparison method was used throughout initial coding, focussed coding, theoretical coding, and axial coding, and theoretical integration. Examples are provided throughout this chapter to demonstrate how data sets, codes and categories progressed until theoretical sufficiency occurred.

4.2.3 Memo Writing

Memo writing is an integral part of data analysis and theoretical construction, drawing out meaning implicit within data, whilst also defining how the researcher interprets data (Charmaz, 2003b, 2006). In the initial stages of analysis, memo writing stimulates initial coding and facilitates tentative category formation, providing early insight into what is happening

within the data (Charmaz, 1990; 2006). Later, memo writing elaborates on existing categories, examining the sufficiency of codes to developing insight into the relationship between categories and define emerging patterns (Tweed and Charmaz, 2011). Within the final research stages, memo writing supports sorting and conceptual integration, bringing together abstracted analysis into a conceptually robust account of the phenomenon (Thornberg & Charmaz, 2014). Memos are an intrinsic feature of iterative analysis, being drawn on to refine meaning, shaping the eventual grounded theory (Strauss & Corbin, 1998). Memo writing drew on guidance provided by Charmaz (1995; 2006) to explicate data content, enhance emerging codes, and direct the data collection and analysis process. Hence, memo writing was used throughout data collection from the first young person's interview, and continued throughout data analysis until the study completion.

Initial memos were kept by using a journal to summarise interviews and make initial connections between units of action across cases. Memo writing was supplemented by writing in a fieldwork journal, as this is known to be a useful tool to log reflexive observation, record initial thoughts for future action, and chart on-site activity (Annells, 2006). This became especially useful in the later stages of data collection, as previously recruited young people would initiate ad-hoc interactions whilst on site; in these instances, memo writing became an essential tool to record exchanges, record meaningful excerpts from conversations, and develop memos to clarify meaning and are drawn on extensively in chapters 6 and 7 to explicate theoretical development. As data analysis progressed, strategies such as free writing, the process of engaging in automatic writing on a subject without regard to content and composition, was employed to make meaningful connections between data sets and develop a reflexive attitude to analysis. Memo writing and reflexive tools became an implicit

part of the data analysis process, and was used extensively to draw conclusions on theoretical direction.

4.3 Initial Coding

Initial coding is the preliminary stage of data analysis, where labels are systematically assigned to segments of data to allocate units of meaning. Line by line analysis was used as a strategy to fragment participant narratives with labels, highlighting the meaning underlying the narrative that would normally escape the researcher's attention (Charmaz, 2006). Gerunds, the noun forms of verbs, were used to label blocks of text to preserve action and make meaning explicit as it unfurled within the data (Charmaz, 2012). Initial labels were mostly descriptive, recounting the action of a line in concise terms. Exceptions occurred when gerunds were substituted for in vivo codes, the words or phrases used by the young people such as 'they don't listen', 'just putting up with it' and 'not worth the effort'. In vivo codes acted as a significant feature of coding, derived directly from the language of the young people to encapsulate and emphasis problems in a way that was meaningful to them (Charmaz, 2006). In vivo codes were useful as they progressed theoretical insight into the direct experience of the phenomenon without requiring further abstraction (Strauss, 1987).

As early data patterns were identified, audio recordings and field note transcripts were revisited to ensure analysis was indicative of the data. This provided a second layer of analysis to explore implicit meaning derived from the interview context. By returning to original sources, initial assumptions made from the coding process can be challenged and possible bias addressed (Strauss & Corbin, 1990). Revisiting data also encouraged new interpretations of young people's narratives, encouraging new codes that encompass plurality of meaning (Charmaz, 2006). Deep immersion in data, and repeated reading of transcripts, fostered

sensitivity towards the young people's attitudes within healthcare interactions, enabling a full picture to develop of their beliefs, and how such beliefs impacted on action. Constant comparison of preliminary data sets facilitated early category formation, identifying features specific to each interview transcript. The Word 2010 highlight feature became a useful tool to form early categories by using a simple system of colour coding (Figure 3). This allowed large amounts of data to be reduced into general descriptors of action, facilitating comparison between different features of the data.

Data section 7	Action: Rationalising not going
So I went to this medical professional that said there's a good chance you have got it [autism]. They gave me all these questions and interviews and whatnot and said there's a good chance I have got it. Anyways so they send a letter back out saying when to come in for a follow up. Well, when I got the letter through the door, the date had already passed. I didn't have any credit on my phone or a house phone to ring them to reschedule, so I just didn't go to it.	Receiving a potential diagnosis Being tested for diagnosis Being sent communication Having an appointment Missing the appointment Not going to the appointment
Data section 12	Action: Fighting the process
So I went back again and the follow up said that, what was it? Said you most likely do have autism whether it be Asperger's or whatever. You probably do have it. It's a high chance because of the things I've been doing. And the symptoms that I've been showing of it and again they sent a letter out, but when I got it through I thought to myself why the fuck should I have to do this? You know I don't see the point in them telling me I have to go see a professional so I didn't go. I fought it this time and luckily I won.	Going to appointment Receiving potential diagnosis Having diagnosis related to actions Being sent communication Anger at receiving appointment 'not seeing point' of appointment Fighting appointment
Data section 15	Action: On-going reassessment
I told them basically what I told you. I didn't come back the first time because of the letter and the second time I didn't feel I needed to and she basically said well you're wasting our time then. If you don't want to do it then what's the point in being here and I said because my college is making me. So I said fine we will refer you to see someone. So they referred me and I came back and there was this man who was really nice. He basically asked me all these questions and gave me all these tests to do. And he said to come back after he's evaluated. He sent me a letter. I came back and he said you are borderline Asperger's. However we don't have the funding or the technology to actually diagnose you of it so we'll have to refer you to someone else so I said okay then and he said we're going to send a letter to your doctor, my GP I think it were and he said when I send did letter out to him I'll send one to you as well, so you know when to go see the doctor and I'm still waiting for the letter and that's was months and months ago.	Missing appointment Not wanting to go to appointment Being told time wasting 'Made' to attended appointments Referred to new appointment Liking health professional Being tested for diagnosis Being sent communication Receiving potential diagnosis Referred to new appointment Doctor sent communication Being sent communication Waiting for communication Indeterminate waiting
Data section 14	Action: Shutting off
So, like, the fact that I've been to get this done and it's not come back you know it suits me to the ground because I don't really want it done. I don't care if I got a mental illness or whatever it's called. I mean, you know, I've gotten through life so far all right you know. It's not like I'm suicidal or threatening to kill people or anything like that	Waiting for communication Not wanting diagnosis Not caring about diagnosis 'getting on alright' Not doing anything bad

Figure 3: Example of comparative analysis within a single narrative

Line by line coding of data transcripts broke narrative into blocks of action, which facilitated a deeper reading of how interactions unfurled. Labels were compared and contrasted against similar labels, forming common categories that represent lager chunks of data (Charmaz, 2001). In Figure 3, three patterns emerged: communication with the system (yellow); on-going appointments (green); and on-going diagnosis (blue). These patterns were evocative when contrasted against the action within the narrative, which clarified how shutting off engagement became a way to fight a system in which the young person had no control. The conceptual grab of fighting to be forgotten was embellished using a cluster diagram to develop a better understanding of process, and to raise the analytical level of developing categories (Figure 4).
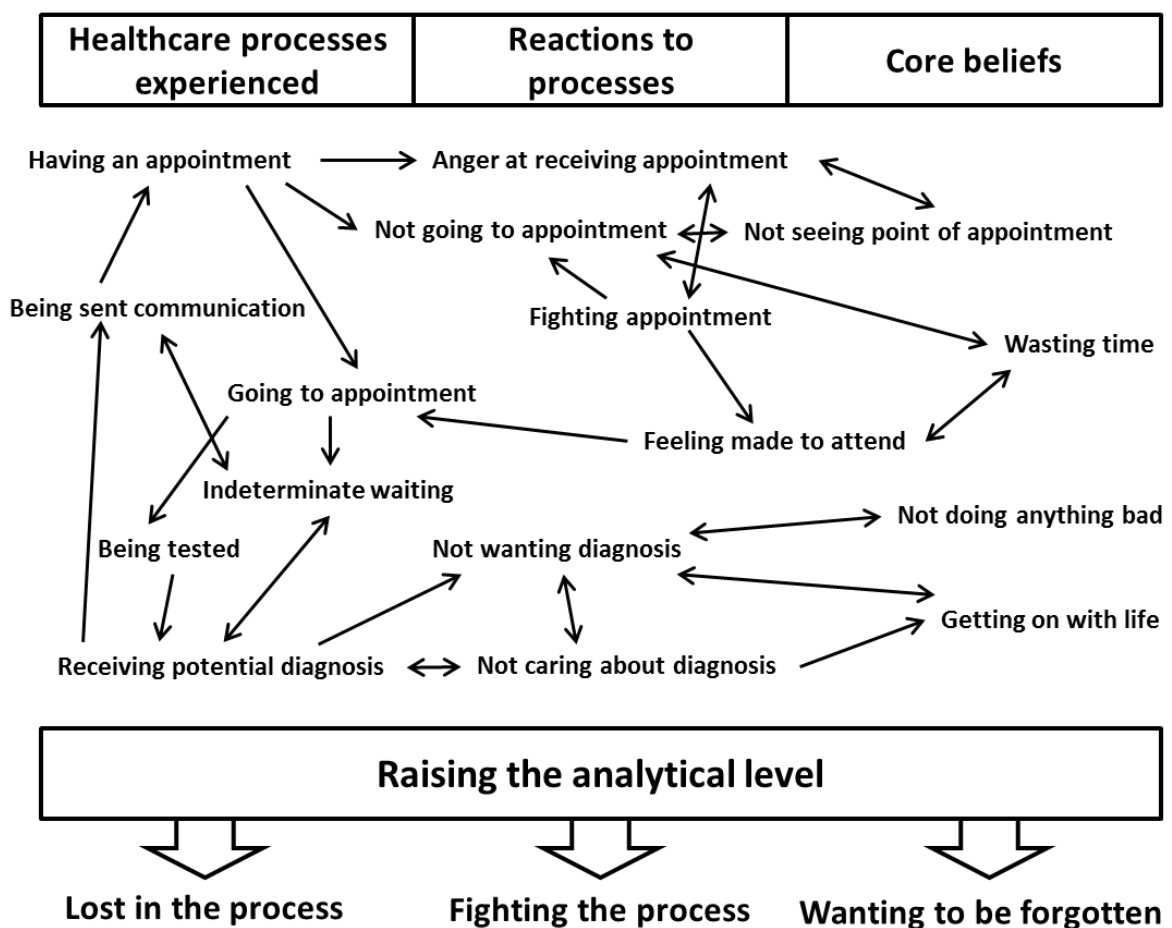
Figure 4: Example of conceptual mapping with cluster diagram

Figure 4 demonstrates the application of cluster diagramming, distributing codes across a page and reassembling them into meaningful arrangements. Cluster diagrams proved a useful technique by which to identify natural groupings of data codes, raising the analytical level of categories to form unexplored connections (Charmaz, 2006). The patterns identified using coloured highlights were redefined to provide a general account of action, namely healthcare processes experienced, reactions to process, and core beliefs. This provided a greater level of insight of the experience the young person had, identifying how reactions to healthcare processes were motivated by a conflict with the young person's core beliefs. Developing early minor conceptual categories emphasised the relationship between being 'lost in the process', 'fighting the process', and 'wanting to be forgotten', which became useful codes to facilitate comparative analysis. These early categories became significant as the analysis progressed, identifying the substantial role that emotion played in motivating behaviour, which later led to insight into how impulsive reactions negatively impacted on engagement.

As initial coding progressed, the comparison of incident against incident provided new insights across a range of topics, whilst also beneficially refining codes and developing categories (Charmaz, 2007). Coloured highlights continued to arrange significant features of the data, whilst coding became subsequently refined (Figure 5).

Rebecca: Data section 22 (RE cardiac surgery)	Initial codes	Early codes	Minor conceptual categories
They were very good. They didn't, like, say this is going to happen. It was would you agree with this or how do I feel. It was never biased. It was always a really good conversation I had with them all the time. It was really good. They drew me a diagram of what my heart looked like and of all the tubes that were going in there. I had three holes. So they drew the holes and said right, this is going to be patched up. And these two were small so they'll close on their own. And I had a crushed ventricle and they said for this, we're going to open it up with a balloon. And it's like that's fine, I thought, "Oh balloon! Yay!" Yes. They were so helpful. Yeah I understood it a lot better from talking with the nurses.	Not being 'spoken at' Being included Having conversations Showing not telling Showing not telling Showing not telling Showing not telling Being explained to Understanding Improved understanding Talking 'with' nurses	Meaningful communication Insight into own understanding Understanding what's happening Reflections on communication	Seeing how your spoken to
Jane: Data section 14 (RE receiving a prescription from her GP)		Response to communication methods	Responding in kind
They've explained it like I didn't really know what they was going on about. And I've asked them to give me more information about it but they've not, so like I was a bit, obviously I'm not going to do it because like you've not given me proper information. So then I've like went to the pharmacy and got something form there.	Not understanding info Being ignored 'Not going to do it' Not trusting advice Getting trusted advice	Having/loosing faith	

Figure 5: Example of data comparison between different narratives

Coding highlighted four common processes: young people observed how they were communicated with (yellow); statements indicative of their comprehension of communication (blue); reactions to communication (pink); and perceived outcome of communication (green). Initial codes were refined into six codes that were useful for comparative analysis between data sets. As the study progressed, these codes shaped the development of minor conceptual categories that reoccurred throughout study data.

4.4 Focused Coding

The second stage of coding requires the researcher to refine analysis to synthesis and explain larger segments of data (Charmaz, 2006). Focussed coding is an iterative process that seeks to identify the most salient and prevalent themes within the field of study and subject them to a higher level of abstraction (Charmaz, 1983). Minor conceptual categories from initial coding are used to sift through and categorise data in order to determine their usefulness at an analytical level, rather than as a descriptive account (Charmaz, 1995). Through comparison of data against pre-existing categories, and categories against newly-refined categories, their adequacy can be challenged to ensure their worth within the analytical process (Charmaz, 2006).

Each transcript and was revisited and reread carefully, then contrasted against early categories which had been identified from initial coding. These early labels were then contrasted against new data, sifting through transcribed interviews to develop meaning. As codes were used to examine various perspectives of young people's experiences, alternate explanations were sought, often resulting in multiple headings to describe all aspects of the unfurling content. For example, the code 'being listened to' was also labelled as 'having your say' and 'being understood' to reflect the subtle interplay of meaning as data analysis progressed. This process became beneficial for conceptualising multiple perspectives of young people, whilst ensuring common meanings within the phenomena of engagement were defined. Concurrent memo writing merged categories, expounded analyses and built on emerging insights. As focussed coding progressed, the driving questions of the thesis were kept in mind, focusing on what engagement consisted of for young people from their perspective. Focussed coding continued through constant comparative analysis, and was maintained alongside theoretical coding until all theoretical categories were identified.
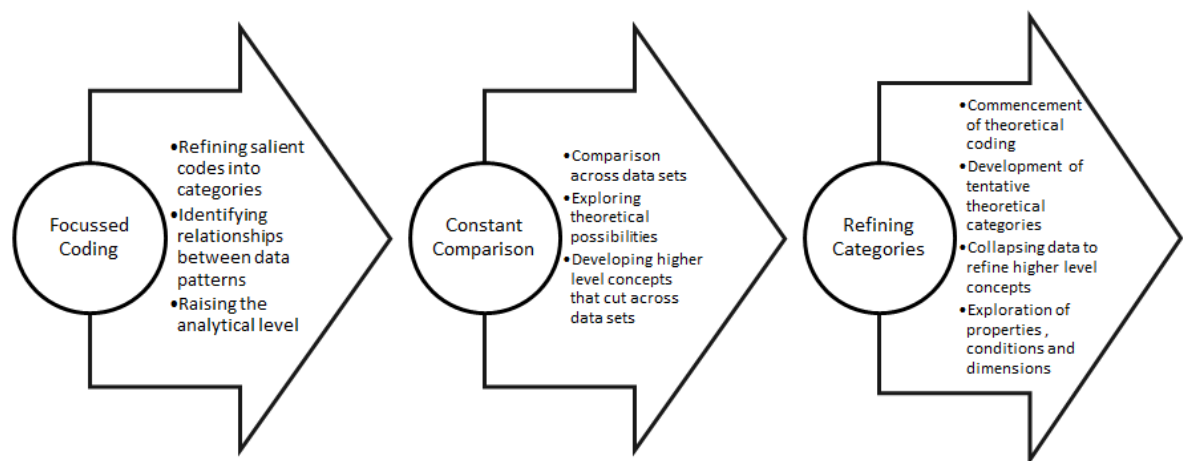
Figure 6: Development of categories

Figure 6 represents the analytical stages to develop and refine data within this study. The following sections provide details of theoretical coding and the development of theoretical categories.

4.5 Theoretical Coding

Theoretical coding entails the refinement and merger of concepts into theoretical categories that characterise the social reality of the phenomenon (Charmaz, 1990). As such, theoretical coding provides an insight into the relationship between concepts in order to develop an integrated theory (Charmaz, 2006). Intensive comparative analysis was a defining feature of this stage of the analysis, contrasting category construction back to code, and code back to data, to ensure a faithful representation of participant accounts. Analysis became a dynamic process, recombining data into configurations to develop greater understanding into tacit social processes. The theoretical category 'prejudgement' is used to illustrate how such analytical processes occurred.

Past experiences were identified as common reference points that young people drew on to form expectations about future scenarios, suggesting previously learnt 'lessons' shaped how future events were understood. Within the context of the study, analysis explored the covert beliefs young people held prior to healthcare interactions, and compared these to the expectations they formed about future events. This approach highlighted the influence belief had on healthcare interactions and expectations. Interestingly, not just first-hand experiences influenced young people, but a range of sources was also cited. Common labels such as "hearing from others", "learning from the [media source]" and "what happened to [known person]" commonly reoccurred throughout analysis, demonstrating that young people relied on multiple information sources when faced with ambiguity about future healthcare

consultations. This denoted young people were actively trying to understand future events by forming expectations by drawing on first-hand and vicarious schematic representations of the healthcare meeting. This early insight was meaningful, as it suggested that how young people formed expectations could inadvertently influence how a young person approached interactions with a healthcare professional.

As initial coding progressed into focussed coding, sensitivity increased towards how young people consciously thought about health professionals, and the function of assumptions as a way to draw on the 'known' to understand the unknown. As categories were developed, codes were revisited and refined through continued comparative analysis. It became apparent that forming expectations was a common practice prior to a healthcare interaction that prepared the young person for their future events. In addition, expectations did not solely centre on the healthcare professional, but also were indicative of the young person's sense of efficacy. Cluster diagramming became a useful approach to draw together these disparate concepts, providing a visual medium to strengthen theoretical category development.
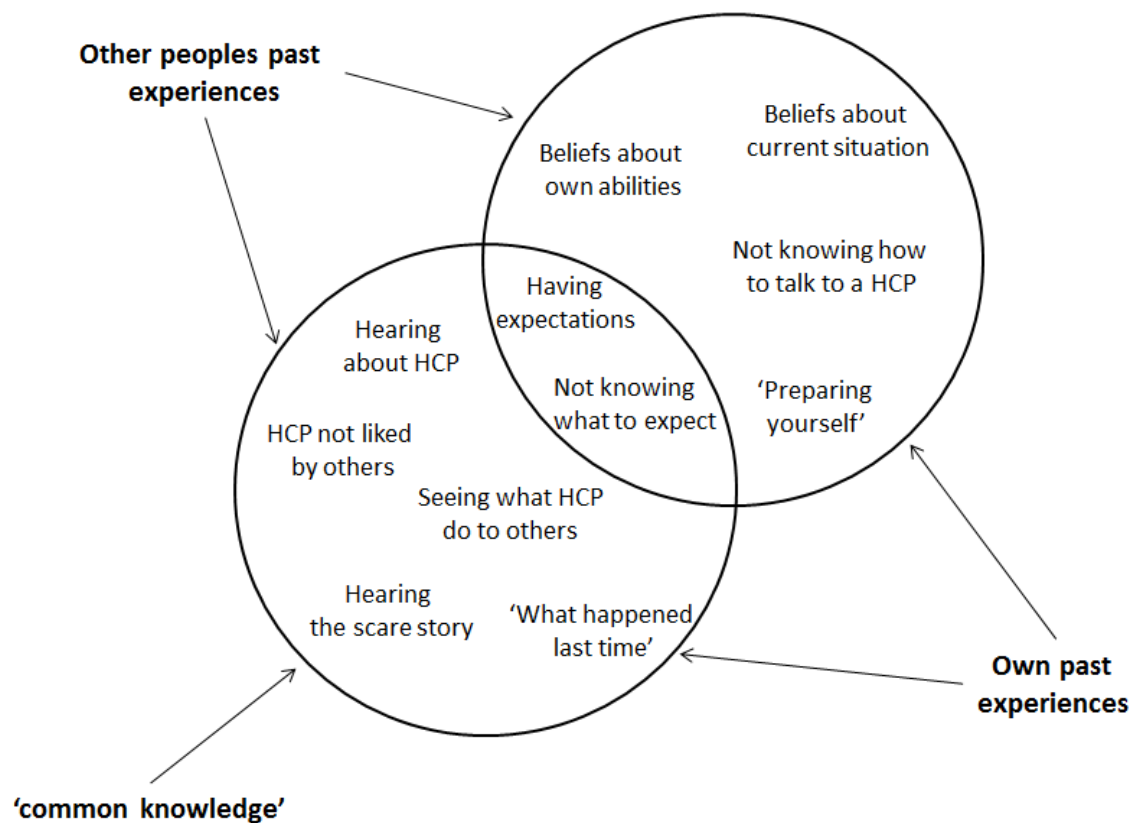
Figure 7: Cluster diagramming for thematic development

Figure 7 illustrates how categories were developed from codes, and the relationship between information-seeking behaviour and self-concept expanded. The upper circle assembled codes relating to self-perception, implying locus of control played a role in anticipatory belief formation. The lower circle highlighted 'ways of knowing', identifying that young people actively sought to understand upcoming meetings with healthcare professionals through a variety of means. Surrounding these two circles were the direct, vicarious and mediated sources of information that young people drew on to validate the expectations they held about future events. The overlapping area between these two circles suggested a tension existed between not knowing what to expect, and the development of beliefs about what will happen in the future. The analytical interplay between uncertainty and expectancy was suggestive that prejudgement had the potential to influence how young people acted in future

interactions. As theoretical coding progressed, the meaning of what it was to prejudge a healthcare interaction was developed through memo writing.

Memo 1: Example of memo use

Prejudgement appears be a specific way by which young people prepare themselves for health interactions that they are to enter into. Data indicates two forms of such prejudgement: the prejudgement young people make about healthcare professionals, and the prejudgement young people make about and how they will manage [in] interactions. I think prejudgement is a significant theoretical category that explains how young people make sense of unknown future scenarios. What is interesting is how young people appear to filter through direct and vicarious information to substantiate their expectations. This seems to be a preparatory act, a way to manage uncertainty, rather than a core conviction. As beliefs influence action, and behaviour is known to impact on engagement, prejudgement seems to be especially noteworthy. My initial impression is that it's like the young people create a personalised schema that influences their motivation towards their health interactions. Developing a greater understanding of prejudgement in terms of how young people develop and frame expectations would benefit analysis. Further exploration is required.

The above memo identified the need to raise the conceptual level of analysis by developing higher-level concepts. Higher-level concepts identify inherent commonalties across scenarios, determining the theoretical fit and relevance between overlapping concepts (Birks & Mills, 2011; Morse, 2004). In the example of prejudgement, codes that centred on self-belief and self-concept cut across instances. Returning to the upper circle of Figure (7) above, it became apparent that the anxieties young people held about their own skills and abilities to successfully interact contributed towards the prejudgement they formed about future events. Upon identifying 'prejudgement of the self' as an area of significance, interview transcripts

were reviewed to check for statements of self-efficacy and personal causation. The beliefs young people held about their ability to control future events appeared to be influenced by their self-perception. Young people who were self-assured of their ability to exert control in a future event held positive expectancies about future consultations with healthcare professionals. In contrast, being less self-assured of one's own ability to engage on preferred terms was affected by uncertainty, undermining confidence to employ efficacious behaviour, or the assumption that future participation would be automatically restricted. Theoretical coding coalesced these disparate lower-level concepts into a meaningful, higher-level concept, defining the self-agency of an imagined future self as being determined by a young person's 'prejudgement of the self'. Development of higher-level concepts was useful in order to provide new insights into prejudgement as theoretical coding progressed.
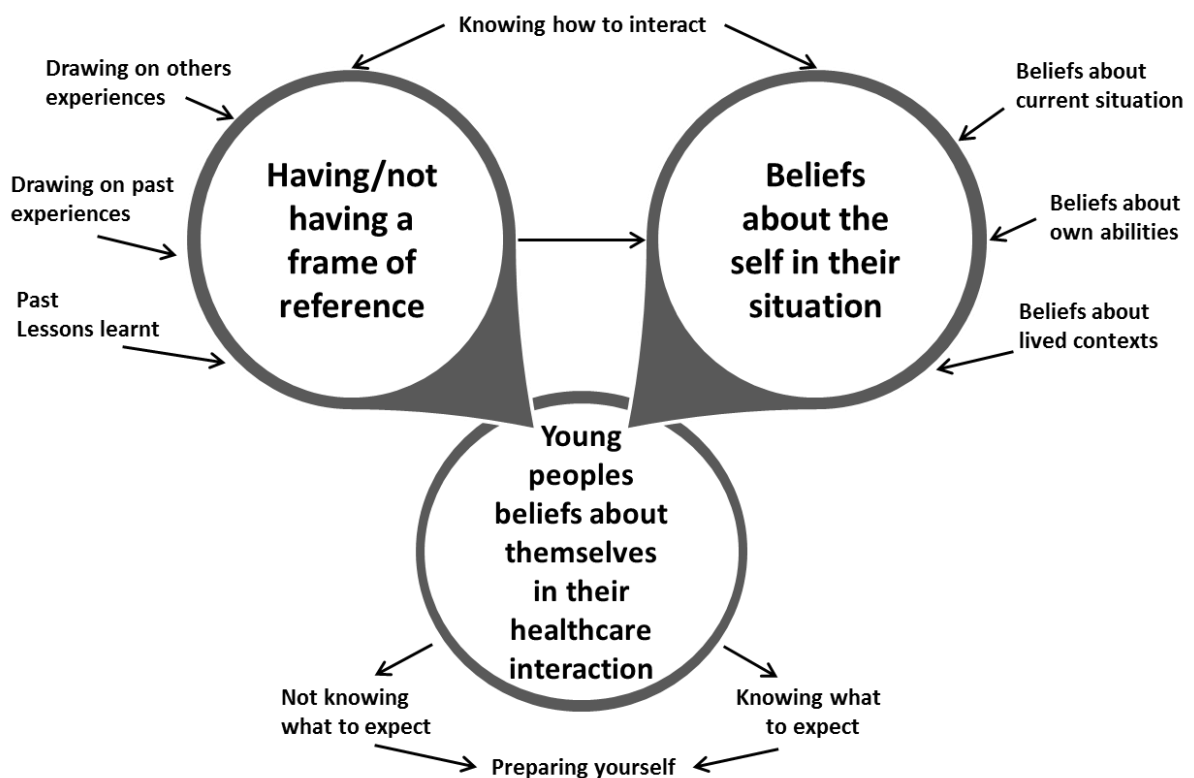
Figure 8: Integrating higher-level concepts

Exploring the interactions between higher-level concepts generated theoretical explanations to unified abstracted categories, which contributed to theoretical category development. Figure 8 demonstrates how 'prejudgement of the self' and 'frames of reference' led a greater insight into expectancy-forming behaviours. The above figure illustrates how self-perception (right circle), and frames of reference (left circle), influenced young people's expectations about future events. The text surrounding the upper two circles indicated the contributing facets of these higher-level concepts, with past experience (direct and vicarious), and young people's beliefs of personal agency, contributing to levels of (un)certainty about the self as a social actor in the healthcare interaction. Both factors were significant for influencing young people's beliefs about personal competency (lower circle). The text below the lower circle highlighted that: uncertainty led to information-seeking strategies about healthcare interactions to attach meaning to the future event; and that 'knowing' what to expect influenced how young people prepared themselves for their expectations. Both 'knowing' and 'being uncertain' contributed towards prejudgement. As comparative analysis developed, robust theoretical categories with clearly defined concepts, properties, dimensions and conditions were expounded using axial coding.

4.6 Axial Coding

Axial coding explores the relationships between codes and categories, bringing intricacies of the phenomenon to the fore by clarifying properties, conditions and dimensions (Mills et al., 2008; Charmaz, 2006). As such, axial coding defines the characteristics that bring about the occurrence of the phenomenon, whilst providing analytical depth into how the phenomenon operates on a meaningful continuum (Strauss and Corbin, 1990). The iterative nature of comparative analysis meant axial coding occurred concurrently alongside previously mentioned stages: as such, axial coding influenced, and was influenced by, the development of theoretical categories. As early

relationships were identified within theoretical coding, axial coding elaborated on these features, defining specific patterns of data to explain how categories operated. As the study progressed, a Conditional Relationship Guide devised by Scott (2004) was used to provide contextualised insights into data and foster theoretical maturation (Table 9). The Conditional Relationship Guide is purported by Scott (2004) to bridge the gap between the subsequent stages of coding, progressively developing depth to analysis. Similar to the coding paradigm developed by Strauss and Corbin (1990; 1998) to develops insight into context, action and consequences, the Conditional Relationship Guide asks successive questions of data, exploring "those patterns that contextualize a central phenomenon and the International relationships among the categories from which those patterns are constructed" (Scott & Howell, 2008, p.4). In terms of the study, focused codes, in vivo labels and higher-level concepts were listed as they were created, enabling in-depth scrutiny to elaborate on analysis.

Table 9: Use of the Conditional Relationship Guide

Category	Deciding whether to trust	Being believed or not	Belief in own ability
What	Decisions based on whether HCP actions align with expectations of a trusted person	Evidence gathered to justify feelings of how HCP place faith in their voice. A way to make sense of feelings	The self-determining beliefs surrounding skills in interactions
When	During face to face interactions	Often after interactions (reflective analysis of event). Can be in context if an overt issue	Can occur before, during or after interactions
Where	Within health interaction (Environment can be a factor) (Experience of service culture can influence perception)	Discussion with others (family, friends, trusted people). Upon reflection of the interaction. Gauged against outcomes of interactions (interpersonal as well as health based). (Can contribute to shared beliefs within support networks)	Prior to entering an interaction In moments of conflict (can affirmed or challenged) In determining the meaning of interaction through reflection
Why	Because HCP actions are interpreted as intentional signifies of their intent. (Perceived as obstacles or facilitators to trust) (Interpretation affects in context reactions)	Because feelings of being believed influenced perception of interaction (Contribute to belief formation about roles) (can be a form of justification of own behaviour)	Because past experiences contribute to self-efficacy. Because behaviour is learnt. In response to feelings of (dis)empowerment
How	By gauging how HCP present and interpreting meaning. By assuming a positional response to perceptions of interaction dynamics. (Learning through doing)	By reflecting on the extent they felt or heard. Gathering feedback through attitudinal behaviour. By justifying quality of interaction against self-determined outcomes	By inclusion/exclusion in interaction disorder. By forming judgements of expected behaviours. By playing out expected role.
Consequence	Situational and contextual engagement related behaviour	Belief formation about own voice. Development of expectations for future interactions	Role-playing and performance. Conflict between beliefs/interaction. Projecting onto future events.
Action	Relates to <u>validation</u>. Explore as a <u>dimension</u> alongside categories properties.	Relates to <u>learning to be a patient.</u> Explore as a <u>property</u> which influences young people's decision making.	Relates to <u>prejudgement</u> Explore as a <u>property</u> of self-efficacy

Initially, use of the guide proved useful to generate deeper insights into coding, whilst stimulating supplementary memos to refine the meanings. However, in later stages the guide did not progress analysis, but became a laborious tool when working between it and theoretical memos. To expedite analysis, an additional column labelled "action" was added to the chart to progress theoretical development and direct the emerging analytical structure. By developing additional techniques to track development, enhancement of procedural transparency is possible (Fram, 2013). Use of the Conditional Relationship Guide progressed analysis by making properties, dimensions and conditions explicit for theoretical synthesis, and prompted further investigation into areas that were theoretically thin. Axial coding continued throughout analysis until completion of the study.

4.7 Theoretical Sufficiency

Theoretical saturation is traditionally understood as a fundamental feature of grounded theory that signals study completion. Saturation occurs once no new theoretical insights can be derived from analysis, and new data can no longer generate original codes (Glaser and Strauss, 1967). Theoretical saturation customarily has been understood to generate a dense theory, without gaps, and relevant to the field of study (Glaser, 1992a). Yet, the assumption that saturation concludes a study has been criticised, as these connotations "imply that the process of generating categories (and their properties and relations) has been exhaustive" (Dey, 1999, pp. 116-117). Moreover, proliferation of sample size to achieve theoretical saturation can be argued to resonate with the positivistic assumptions; such assumptions that are epistemologically flawed within an interpretive paradigm. Developing greater insight into the processes used within saturation, as opposed to an external marker of completion, can be understood as a plausible approach to overcome this barrier (O'Reilly & Parker, 2012). Howarth (2012) purposes a similar method, drawing on Corbin & Strauss (2008) to suggest

that saturating concepts within a study, as opposed to saturating the sample, is a more appropriate way to mark study completion. By reframing the notion of saturation as being an analytical process, as opposed to the result of data generation, theoretical sufficiency redefines theoretical saturation as a form of textual analysis that encourages multiplicity of meaning (Dey, 2007).

Due to the constructivist nature of the study data, analysis aimed to saturate concepts, using a layered analytical approach until theoretical sufficiency was achieved. Focused coding identified recurrent conceptual patterns, with comparative analysis continuing until textual analysis ceased to generate new insights. Once theoretical categories were well-defined, comparative analysis continued until they were sufficiently supported with comprehensive theoretical codes, detailed axial codes, and thick description of integrative memos.

4.8 Conclusion

Criticisms levelled at grounded theory cite a lack of transparency in analytical processes and theoretical development (Cooney, 2011). This chapter provided insight into how the methods of data analysis were employed. A flexible approach, drawing on the guidance of Charmaz (2006) to develop initial, focussed, theoretical, and axial codes, was used to work with the data. The methods of coding and comparative analysis were discussed, with examples given to demonstrate a transparent account of theoretical development. Scott's (2004) Conditional Relationship Guide was used to develop greater analytical insight, and its application demonstrated how it was used to identify properties, conditions and dimensions. The study identified its compilation through saturation of theoretical concepts, as opposed to saturation of the sample, to achieve theoretical sufficiency. Chapters 5 and 6 detail the findings attained

from the methods stated above, synthesising analysis into a theoretical account of young

people's engagement with healthcare professionals.

Chapter 5: Study findings

5.1 Introduction

This chapter presents the construction of theoretical categories using the design and methods detailed in Chapter 4. Data analysis constructed three theoretical categories, providing insight into the processes that influenced how young people interacted and participated with healthcare professionals. These were: 'prejudgement', the beliefs with which young people enter into health interactions; 'learning to be a patient', the means by which young people learn and adapt to in-context stimuli within healthcare interactions; and 'validation', the meaning young people attach after an interaction that validates their perception of events. The properties of the phenomenon, the specific conditions, and the dimensions that determine range and variation to young people's experiences are described in order to explicate the processes observed within the study (Strauss and Corbin, 1990).

5.2 Construction of Theoretical Categories

Similar to other grounded theory approaches, category development provides insight into how the phenomenon operates at a higher abstracted level, thus providing insight into action, interaction, and the operation of tacit social processes (Straus and Corbin, 1990). However, a constructivist approach strives to understand the experience of the phenomenon by those within it through a theoretical rendering which "describes, explicates, and synthesises multiple statements and observations" (Charmaz & Mitchell, 1996, p.295). Insight into the phenomenon is gained through the reconstruction of multiple narratives, and the researcher aims to ascertain the conjunctural character of causation, illuminating underlying psychological processes that invest the phenomenon with meaning (Dey, 2004). However, interpretive analysis is often criticised as ambiguous, and theoretical constructs as

questionable, thus compromising the credibility of resulting theoretical assertions (Gasson, 2004). Critical and reflexive analysis is, therefore, essential to "expound the representational techniques that permit an explicit examination of the relationships between data elements, on a periodic basis and to constantly question the assumptions that led us to search for those relationships" (ibid, p.91).

Although a comprehensive report of theoretical category construction would not be feasible due to the iterative methods that generate in-depth analysis, this chapter endeavours to account for how analysis developed, leading to the final presentation of findings. The findings emerged by extensively working up and down the analytical coding hierarchy, with insights occurring through manual indexing, sorting and memo writing (Charmaz, 2006). Figure 9 provides an account of the decision-making processes employed during the data collection and comparative analysis that contributed to the findings.
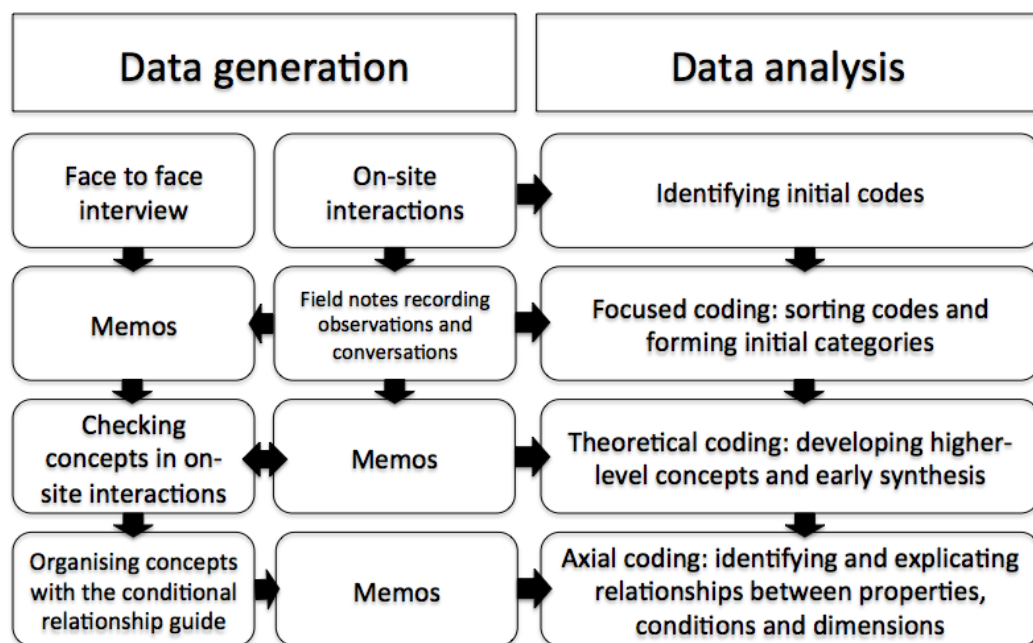
Figure 9: Process of data generation and analysis

The following sections provide a theoretical account of the processes that influence young people's interactions with healthcare professionals; this process account was enhanced by clarifying the interpretative processes to enable a critical examination of the analysis.

5.3 Theoretical Category One: Prejudgement

The first theoretical category recognised 'Prejudgement' as the expectations that young people developed about healthcare interactions that were developed in advance of actual experiences with healthcare professionals. These beliefs influenced young people's perceptions of future interactions and, in turn, appeared to influence the approaches they employed to prepare themselves. Each young person within the study described their thoughts about meeting healthcare professionals and gave reasons as to why outcomes were pre-empted. Initial analysis gave prominence to the beliefs young people held, which influenced perception of future events. The following excerpts provided two contrasting narratives that demonstrate how such beliefs operated:

Excerpt 1.

"I know she'll be a bitch when I see her [referring to the CAMHS nurse]. I spoke to my sister about it and she even said that they will have made their minds up already. There's not really any point to it but I have to go, you know, so I'll just ride it out. I'm not really looking forward to it."

Lifey

Excerpt 2.

"Oh it'll be fine [referring to her upcoming neurology appointment]. I know that they'll want to help as much as they can and stop try an' stop pain and stuff. They'll explain to me everything that's going on and they tell me what they're going to do and check I get it. I don't really worry about it if I'm honest, I just get on with it these days."

Lucy

Lifey talked about the judgemental CAMHS nurse and how this resulted in him assuming his next interaction would be pointless, ultimately having to '*ride*' out the experience. The CAMHS nurse was perceived as a major issue for Lifey, and was mentioned in both his initial interview and post-interview interactions. It became apparent that his preemption of an upcoming interaction was based on the beliefs founded regarding the CAMHS nurse, which reduced his motivation towards future interactions. Conversely, Lucy clarified her belief that healthcare professionals '*want to help*' and that she feels there is no cause to worry. Lucy was assured that her interaction would be a positive experience, which appeared to influence how she approached her interaction. The insights from these two narratives were significant as both young people assumed to 'know' what to expect. As comparative analysis progressed, a relationship was identified between the beliefs young people formed about their upcoming events and their perception of upcoming interactions. Theoretical sensitivity towards assumption-forming behaviours became an overt feature of analysis. It became apparent that the young people not only thought about healthcare professional in their upcoming interactions, but also how they foresaw their future self in upcoming interactions. The belief the young person held of their interactions influenced whether they thought they would passively '*ride*' out an experience, or actively '*get on with it*'. Analysis recognised a clear relationship between beliefs and expectations, and the potential influence this held on future action. A memo was developed to expound the process within the developing concept (Charmaz, 2006).

Memo 2: Explicating prejudgement

What is prejudgement	What is being assumed by young people
The attitudes or beliefs formed before healthcare interaction. Young people enter into interactions with these beliefs and have expectations that are projected onto interaction discourse. Appears to influence how the young person approaches an interaction.	Assumptions of what will happen next are being made. Young people's assumptions appear to be very much tied to how young people think about the healthcare professionals they are to meet with.
What is going on	What connections can I make?
Assumptions formed as a protective element in moments of fear/uncertainty. Similar process forwarded where a young person feels secure or confident of upcoming interactions. Beliefs tied to anticipation of what will happen next.	It is becoming apparent that prejudgement influences initial engagement. How?

Collectively, young people were seen to form assumptions about upcoming interactions that would allow them to pre-empt how those interactions would unfurl. This form of '*knowing what will happen'* allowed young people to prejudge interactions based on their beliefs and plan for interactions based on what they '*knew'*. As further cases were compared against the emerging category, it became apparent that young people would also prejudge healthcare interactions when there was ambiguity or uncertainty. A discussion with Jane provided insight into this feature.

Memo 3: Exploring Jane's narrative

As I was talking with Jane, I realised that I didn't understand why uncertainty was a key feature of prejudgement. It was apparent from other young people that past experiences of something 'good' or 'bad' were a key feature in the beliefs they formed; yet the role of uncertainty remained ambiguous. Jane clarified this when she explained why she always tried to get healthcare professionals she was familiar with. "I try to get the same ones [*referring to obtaining GP appointments*] because like I hate it when you get someone new and you're not sure of them like. It's not like you know what's going to happen or if you can trust them or 'owt. It's like you know there's bad ones 'coz there's ones like that nurse last year with the bags of drip, so I need to know them a bit before first, to like know what they're like. So I'll just sit there quiet until I'm sure." New healthcare professionals were a source of uncertainty for her, related to the ambiguity surrounding what will happen, and feeling that it's not possible to place trust. Jane explained that her fear was that she knew some healthcare professionals were 'bad ones'. Jane made reference to the 'nurse with the bags of drip' who killed people, which was her justification of why uncertainty was difficult. Jane stated that, if she met a healthcare professional who was new, she would sit quietly and not engage. I realised that my focus throughout analyses has been on how young people create expectations from past events, but this approach disregards other factors that also influence beliefs. Jane made me realise that beliefs are not contained to the context of young people's direct experiences, but can be derived from disparate sources. Analysis would benefit from exploring this in greater depth.

The discussion with Jane was influential as it identified anxiety surrounding the unknown could also influence future behaviour. In not having a basis for her anxiety, Jane rationalised that *'bad ones'* existed, citing the 2011 Stepping Hill scandal where saline drips injected with insulin caused patient deaths. Jane drew on the information she saw as reliable, opting to withhold active involvement until she was able to *'know what they're like'*. Jane's wariness of healthcare professionals was complex and occurred due to a variety of factors. However, it

identified that prejudgement also occurred when uncertainty surrounded events, and that

young people actively sought to anchor meaning to their interactions. This meaning-making

process appeared to psychologically prepare young people, whilst enabling them to develop

approaches for their interactions. To progress theoretical momentum, cluster diagramming

was used to organise focussed codes and determine how prejudgement operated in terms of

pre-engagement behaviour (Figure 10).
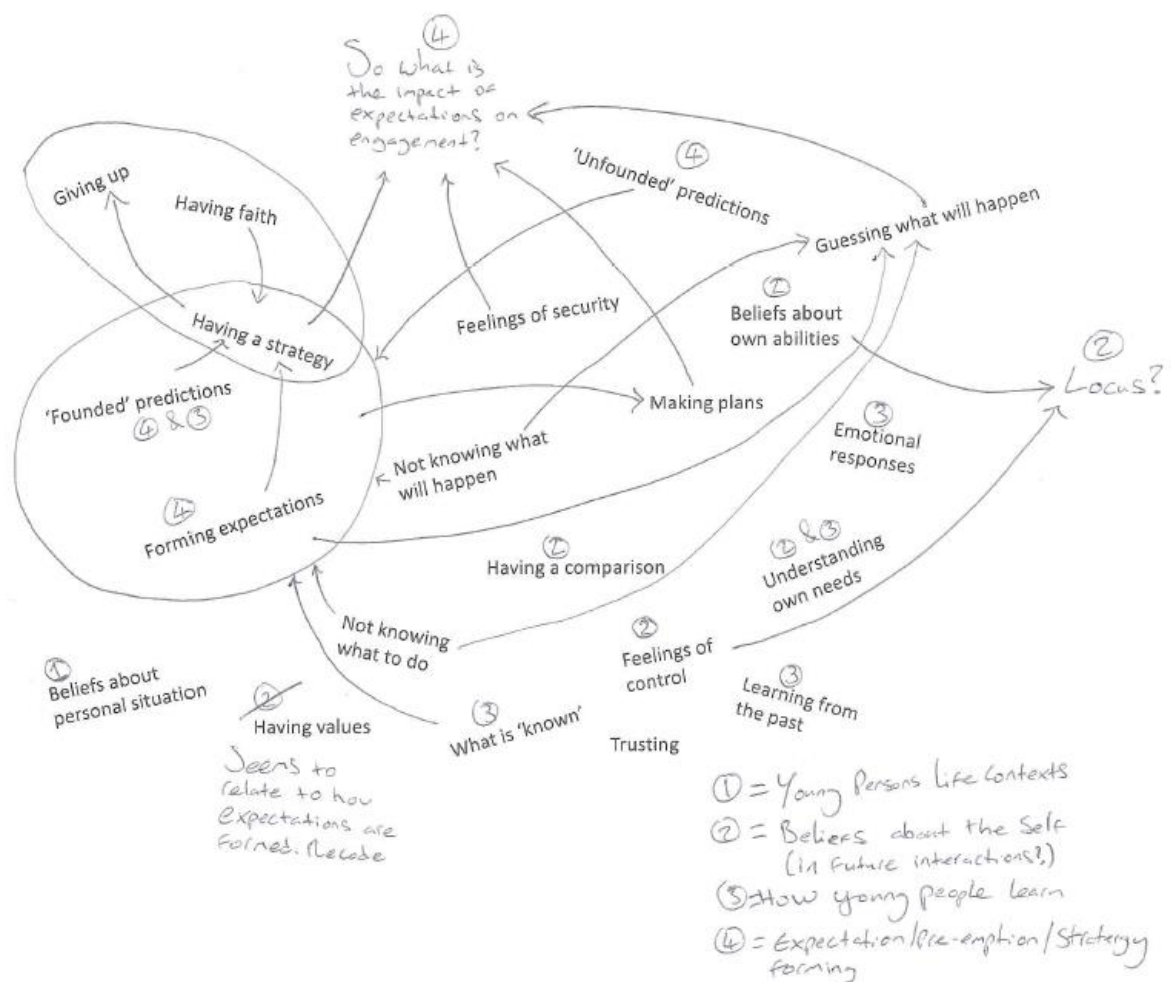
Figure 10: Messy mapping exercise

Codes were naturally arranged on a document, and free writing used to form meaningful

associations between the data (Morse et al., 2009). The resulting 'messy mapping' exercise

identified significant connections between codes and developed a wide-ranging theoretical

framework to understand the interrelationship between analyses. Circles were drawn around central codes and connected with lines, whilst numeric labels were used to comment on disparate codes to classify relationships. The circles joining codes together in the top left of the diagram tentatively identified the impact prejudgement held over the approaches young people used in their interactions. A significant relationship was identified between the expectations young people formed, and the approaches young people developed in their healthcare interactions, providing insight into the effect prejudgement had on actual engagement in interactions. Axial coding was used to provide structure to the category, ultimately establishing a framework by which the emerging concepts could be understood (Straus and Corbin, 1998). Properties, dimensions and the conditions that affected the prejudgement were clarified and compared against data sets until theoretical sufficiency was achieved. As prejudgement became a theoretically robust category, the components were charted to infer the interrelation between the different aspects of the category (Figure 11).
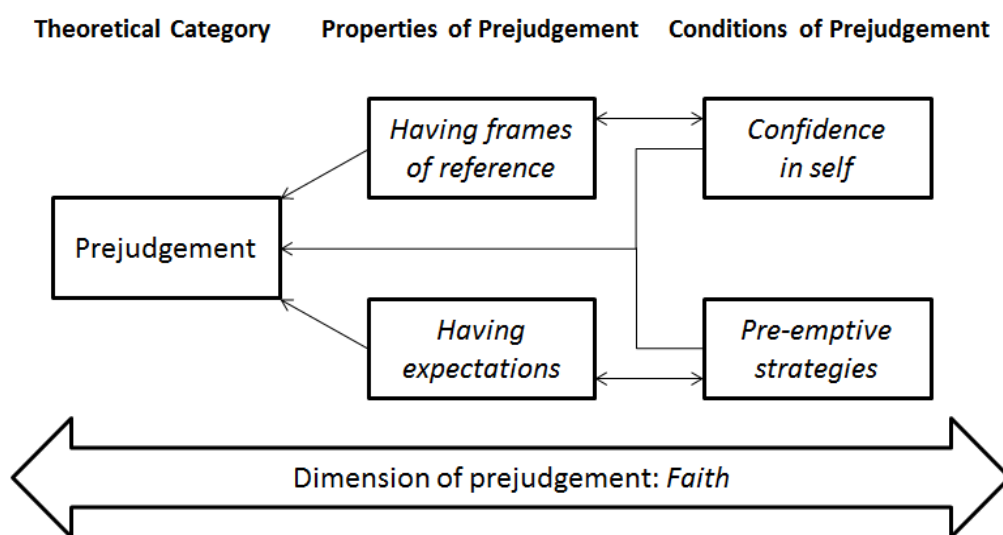
Figure 11: Properties, conditions and dimension of prejudgement

Properties were identified as 'having frames of reference' and 'having expectations', both of which were an essential feature of how young people formed prejudgements towards their

healthcare interactions and healthcare professionals. Properties were influenced by two conditions: the 'confidence in self' that the young person had, and the 'pre-emptive strategies' each young person employed to plan for upcoming interactions. Prejudgement was seen to exist on a dimension of 'faith' that the young person felt able to forward to their upcoming interactions. The following sections provide an account of these aspects of prejudgement, relating findings back to the participant's narratives in order to convey the meaning that young people attached to their experiences.

5.3.1 Prejudgement: Properties, Conditions and the Dimension
The following section details the properties, condition and dimension of prejudgement. Two properties, 'having frames of reference' and 'having expectations', emerged from comparative analysis, elucidating characteristics of prejudgement and the influence on healthcare interactions. 'Having frames of reference' identified the means by which young people drew on a variety of information sources to frame the beliefs they held, and to articulate their perspectives about healthcare interactions.

Excerpt 3

"[When asked why he thought his next appointment would be 'pointless'] I know because of what happened before at [hospital name]. They asked questions about breathing and health and how I'm feeling but I can't bring up anything. They'll have their plan and stick to it. It'll be the same."

Mark

Excerpt 4

"*I went to get the contraception rod put in my arm and like my sister went and got it a couple of weeks later and like with mine they just put a needle in and put it through. But on my sister's, they've slit her arm a little bit, when they weren't really meant to do that. I was thinking like, why've they done that? That's wrong, they're only supposed to put a needle in and then like pop it in.*"

Jane

Excerpt 5

"When he came to mum [referring to the ward doctor] he was supposed to have his shirt rolled up, but he didn't have it rolled up, but he had his watch on and everything on when he shouldn't have, because we learnt in school that could have been infected and then he's passing on germs to everyone."

Rihanna

Excerpt 6

"It's like it's in the paper when they aren't doing their job properly. Not slacking basically, but if someone was calling for the nurse and they just looked up and ignored them and got someone else to do it. And then you see them just standing around [referring to the ward nurses] and you think are you really as busy as you say you are?"

Paul

The above collection of quotes represent influences to data analysis. Initial codes from excerpt 3 such as '*following their agenda', 'not having input'* and '*sticking to their plan*' identified that Mark drew on past experiences of interactions which he perceived as being protocol-based to predict the future subjugation of his voice in the next appointment. In excerpt 4 Jane makes comparisons between the same procedure both she and her sister had. Initial codes such as '*being able to compare', 'knowing what should happen'* and '*being told about mistakes'* were influencing factors in Jane's perception of wrong doing and unnecessary harm. Codes in excerpt 5, such as '*knowing good practice'* and '*seeing bad practice',* illiterate Rihanna's judgement of practice based on what she had previously learnt. By drawing on previous health and social care lessons, she identified the infection control risk the ward doctor posed. Excerpt 6 draws on codes such as '*hearing the worst in the paper'* and '*nurses confirming the worst'* to identify that mediated stereotypes could influence a young person's perception of his nurses. Individually, the above excerpts contained different narratives, consisting of contrasting beliefs and judgements formed about the interactions young people found themselves in. However, collectively they evidenced that the formation of judgement was a multifaceted

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phenomenon, 'constructed' from a range of sources to confirm assumptions. The relationship between what young people knew, and what they assumed based on what they knew, highlighted a unique insight into the basis of expectation formation.

To develop sensitivity towards expectation, extant literature was explored to determine the theoretical resonance it held as a key concept. As acknowledged in Chapter 2, the introduction of extant literature requires justification to be philosophically aligned with the research approach; hence, constructivist grounded theory research explicitly acknowledges the role of literature in its contribution to theoretical development (Charmaz, 2006). Introduction to literature at this stage of the analysis is not problematic, as initial findings have been firmly grounded in the data; therefore, extant literature is viewed as additional data, incorporated into analysis to address the study research questions (Charmaz, ibid., p. 35). As such, the comparison of findings against a priori concepts is acknowledged as a useful tool to aid conceptual development and clarify ideas for theoretical maturation (Charmaz, 2014). In terms of 'prejudgement', the notion that young people's interactions with healthcare professionals are influenced by preconceived feelings and assumptions has been recognised in the healthcare literature, and was useful to expound the role of expectation in young people's engagement. For example, a recent literature review exploring children and young people's participation in healthcare services identified that previous exposure to healthcare professionals and services could contribute to preconceptions and influence participation (Moore and Kirk, 2010). In the same vein, Beck (2006), in a survey of young people's perceptions of mental health services, suggests that a negative preconception of services could be a deterrent to young people's health-seeking behaviours. Bias and stigma can be understood to be a factor that influences participation, yet little is known of the role these

factors play in engagement. Exploration of how young people formed assumptions became a key concept that influenced theoretical progression. The below memo elucidates this concept.

Memo 4: Exploring the role of assumption

The young people in the study were clearly able to articulate that they drew on a range of sources to 'fill in the gaps' about their expected encounters. These influences appear to be wide ranging, but were consistently used to frame beliefs and assumptions. For young people with long-term conditions, it was easier for them to draw on '*what happened last time*'. The notion that a patient's knowledge about their condition, and their empowerment in the processes surrounding their care, is an implicit feature that defines patients as the experts of themselves (Donaldson, 2003). I think that, if it is recognised that knowledge gained from past experience can improve participation, it is feasible that the lessons learnt from interactions with healthcare professionals could also contribute to the formation of maladaptive behaviours that impact on engagement. If we assume lived-experiences can be a positive impact, then it could also be hypothesised that negative experiences also influence how professionals are perceived and assumptions are formed about their healthcare. Yet, I find it interesting that analysis infers beliefs and assumptions are more than past experience alone. For young people with less exposure, '*hearing about what happened*' or talking about mediated sources of information seem just as relevant to the expectations they construct about future encounters. This suggests that even the news and stories in the general public domain may also influence how young people form perceptions about healthcare professionals. It appears that the basis of young people's prejudgement may be more complex than satisfaction levels of prior contact alone, and that insight into how such assumptions are constructed would be beneficial.

As analysis developed it became apparent that the frames of reference young people drew on impacted on their perception of upcoming healthcare appointments. Previous experience appeared to be important as it provided a direct comparison on which expectations could be

based; however, lack of prior experience did not mean expectations were not formed. Focussed codes such as '*making a point*', '*comparing against*' and '*substantiating doubts*' were useful to explore why having a frame of reference was important. Frames of reference appeared to be related to how young people formed beliefs about their interactions, whereas expectations appeared to be based on such beliefs. Rebecca made this insight explicit. In her interview, Rebecca made it known that she had experienced many interactions with healthcare professionals due to a congenital heart condition. However, a later discussion clarified that it was through observations of her mother's care that defined her approach to healthcare interactions.

Excerpt 7

> "*When my mother was in terminal care I met a lot of them [healthcare professionals]. I got to see a lot of what they did and how they acted. I think that made me realise you have to say what you mean and get your point across when you speak to them.*"
>
> Rebecca

Rebecca identified that as a voyeur to her mother's care she made connections between what healthcare professionals *did* and developed insight into how they *acted*. This was significant as she developed a belief about healthcare professional behaviour associated with an expectation of having to try hard to get her *point across*. Knowledge was acquired from observations and transferred to how she believed she had to act within a healthcare context. As comparative analysis progressed, the 'frames of reference' cited in young people's accounts were sorted into categories to explicate the property. Focussed codes were revisited and sources categorised (Table 10). Revisiting focused codes became meaningful for comparative analysis across cases, compiling initial codes into abstracted descriptions evocative of knowledge acquisition. By integrating focussed codes into higher level concepts,

three types of experiential learning became apparent: *learning from the past*, the direct experiences relating to the self in interactions with healthcare professionals; *learning through seeing*, the first-hand observations of others care; and *indirect learning*, the second-hand accounts or knowledge sources young people drew on.

Table 10: Categories of 'learning'

Focused codes	Initial categories		Higher level concepts
Defining the interaction	Drawing on the process		Learning from the past (First-hand experiences)
Explaining the system			
Emotional responses	Drawing on interaction outcomes		
Citing effectiveness			
Citing satisfaction			
Seeing care of family	Vicarious learning	Watching others' in care	Learning through seeing (first-hand observations)
Seeing aftereffects of care			
Learning in school		Being told	Indirect learning (second-hand information)
Hearing others' experiences			
Learning from the Internet		Mediated stories	
Learning from the news			
Hearing others' opinions			

Vicarious learning became an overarching category that identified the means by which information was drawn on, and given meaning to, without first-hand experience. A range of experiences, both direct and vicarious, influenced how young people interpreted future scenarios. 'Frames of reference' appeared to act as an access point by which young people orientated themselves in regards to future events, and determined baseline expectations to ward against the unknown.

Analysis of the first property directed insight into a closely related second property, 'having expectations'. Patient expectations are known to be a key determinant to satisfaction of care, and patient-centred approaches benefit from understanding the individual desired standard for care and beliefs of what will happen within interactions (Avis, 1994; Ramfelt et al., 2005; Kravitz, 1996). Moreover, expectations may influence patients' evaluation of care, suggesting prior anticipation can influence how healthcare professional behaviour is perceived (Sofaer & Firminger, 2005; McKinley et al., 2002; Dawn & Lee, 2004). Values and beliefs about care quality are closely related to how expectations are formed, implying that insight into these factors is essential in order to improve care quality and health service delivery (Davis, 2005; Dawn & Lee, 2004). Findings support the idea that expectations influence beliefs and perceptions of care, and these factors played a key role in how young people prejudged their health interactions. The role of expectations first became explicit from comparative analysis of young people's beliefs. Expectations appeared to define how the young person made sense of future situations and enabled them to pre-empt future interaction.

Table 11: Explication of young peoples' expectations

Young person	Codes - past experience	Associated expectation
Mark:	- They'll be busy - Not being able to speak	- 'Not expecting much different.'
Zara:	- Being listened to - Being given good advice	- 'We can sort things out.'
Sid:	- Not being listened to - Being misdiagnosed -Requests being ignored	- 'Won't listen.' - 'Have to keep asking.'
MarilynM:	- Nurses being 'fake' -Made to feel stupid	- 'Just like that next time.'

Table 11 illustrates an early exploration into young people's perceptions of past experiences, and the effect these appeared to have on their expectation of future events. It became

apparent that the young people were forming expectations based on previous received care, with judgements about the future working being based on the probability that these events would reoccur. Analysis also indicated that these expectations were firmly based on what the young person perceived as good or bad. Prediction of outcome is recognised as a key function to expectancy formation, with probability and value both implicit in the complex cognitive processes, modified by a range of experiences (Bowling & Rowe, 2014). It became evident that gauging probability, and value beliefs, was influencing young people's perception of future care. The following memo explores these two elements:

Memo 5: Exploring Jane's perception of future care

> Jane mentioned that she found GP appointments difficult because she knew she wanted to participate, but expected to be disappointed in future interactions. Jane stated *"You <u>want to be involved</u> and <u>have a point of view</u>. F<u>eel like you have a say</u> in the things that happen, <u>but you know it won't be like</u> that when you go. <u>It'll be that</u> <u>in out thing with you just nodding along."</u>* Interestingly, Jane highlighted a belief that, in future events, what she perceived as important would be ignored. This is seen as very important, as expectations seem to not just identify what young people want from their interaction, but also their belief in whether their wants will be met.

Reflecting on Jane's value expectations ('*be involved*', '*have a point of view*', '*have a say*') clearly identified what she wanted from her healthcare interactions, which was a stark contrast to her prediction of future events. Jane indicated through the demonstrative adjective '*that',* that passivity is something she had experienced previously and expects to be '*just nodding along'* again in her future interactions. Jane had formed an expectation of probability, based on her past experiences, and used this to predict her own passivity as a

reaction to being disappointed. This seemed to signify that expectations were an essential feature of prejudgement, and that the past experiences were essential as a framing device.

Analysis progressed by seeking variance to young people's expectations to ensure all cases were accounted for. Initial codes such as *'worried about what happens next'*, *'feeling lost'*, *'listening to others'* and *'filling in the gaps'* contributed to the development of the focussed codes such as *'fear of the unknown'* and *'making sense'*. Where young people had no previous experience to draw on they appeared to form expectations based on other frames of reference as exemplified in the memo below.

Memo 6: Unpicking 'frames of reference'

Today, Roberta provided me with a new insight into the importance young people attached to knowing what to expect in interactions. Roberta chatted with me on her midday break and revisited a conversation we had about nurses. "It's like you don't know them [*referring to the inoculation nurse*] or what they're like, you're just told to go for the injection because everyone has to have it to be healthy and stuff. So that's pretty scary anyway. And then when you ask the ones who've had it, they said it's like this big [at this point she *raised her hands and holds them apart to indicate an exaggerated needle size*] and they grab you and stuff to make you have it and then you end up being really scared because they're gonna hurt you." Roberta identified that not knowing what to expect before she met the inoculation nurses was 'scary', which was amplified by stories from others who had the injection before her. The conversation was interesting as Roberta explained how drawing on others stories contributed to an anxiety provoking experience and an expectation that nurses *'hurt you'*. It appeared to suggest that second-hand accounts (in this case, childhood teasing) are also drawn on when there is no other frame of reference. This information appeared to act as a basis for her fear and substantiated the expectation of being hurt.

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The emerging analysis identified that expectancy was a key feature of young people's accounts and was significant, as it appeared to shape how young people thought about future events. When drawn on to define healthcare interactions, it appeared that expectation held influence of belief, anticipatory assumptions, and initial behaviours. Understanding what expectancy meant for young people enabled deeper readings into how expectation influenced pre-engagement behaviours. Memo writing was used to further explore the concept in relation to findings.

Memo 7: Explicating the role of expectancy in 'prejudgement'

> The relationship between what a young person thought would happen, and how they acted in response to these beliefs, is significant and requires elaboration. Outcome expectancy theory was useful in order to understand what the young people are experiencing in their accounts. The beliefs formed by a person are based on an attributed valence to an expected outcome (Rotter, 1954). Expectations influence how an event is thought of, and how behaviour is shaped, in response to beliefs about future events. The young people of the study were explicit in stating what their expectations were, and how this influenced how they thought about the expected outcome of their future healthcare interactions. Interestingly, Rotter also identifies that the behavioural construct of an expectation is dependent on the social experiences that inform such assumptions (Rotter, 1966). In this sense, specific instances lead to generalised expectations. The social learning insight into expectancy-forming behaviour is tied to each person's individual history of reinforcement, shaping future expectations of what will happen (Bowling et al., 2012). Expectancy-forming behaviours appeared to be related to the first property 'frames of reference', suggesting that both properties are closely connected in young people's prejudgements of healthcare professionals.

The association between findings, and the work of Julian Rotter (1954; 1966; 1982), provided new insight into the role expectation played in young people's future healthcare engagement. Motivation towards action is based on the expectation of what follows from said action, with expectations based on specific events developing generalised expectations for future scenarios. Young people with long-term conditions drew on a range of past experiences to frame future expectations due to their increased familiarity with healthcare services. In contrast, young people with little prior contact appeared to use a similar mechanism to frame their expectations, but without specific experiences vicarious frames of references were used to support their expectations. Both direct and vicarious frames provided specific experiences, which were translated into general expectations for future outcomes. The association between motivation and expectation became a useful sensitising device, inferring young people's future engagement was influenced by expectation of entering into the interaction, but also that a young person's frames of references were significant in forming and reinforcing such expectations. As the property became saturated, it became apparent that 'having expectations' and 'frames of reference' were interrelated in young people's pre-engagement behaviours.

As axial coding developed, two conditions were identified, which provided insight into the factors that affected the development of young people's prejudgement-forming behaviour: 'confidence in self' and 'pre-emptive strategies'. 'Confidence in self' refers to the beliefs young people held about themselves, their abilities, and the effect they believed they had on the external factors of their future interactions. As such, 'confidence in self' operated as a causal condition, determining the internal psychological processes that bring about the occurrence of a young person's prejudgement.

Memo 8: Developing insight into 'confidence in self'

> As I compare analysis back to the data, it becomes increasingly apparent to me that the young person's confidence in their skills and abilities is instrumental in how their prejudgement manifests. It is clear from analysis that frames of reference and expectations are key components of prejudgement, yet this sense of self-efficacy impinges on the young person's beliefs about future events. For example, James commented on the insecurity he feels voicing an opinion that conflicts with the doctor's perspective.
>
> *"How am I supposed to say I think I should have this over that [referring to GP's decision making]? They're doctors, so who am I to say what I want is better?"*
>
> James summarises this as being because "They're doctors, so who am I to say what I want is better?" In contrast, other young people expressed they had no hesitation in asserting themselves. For example, Lifey explained he had no problem contradicting healthcare professionals.
>
> *"I'll just say no [referring to his reaction to possible future assessment]. I'm used to hearing the same old bullshit, so it's not like saying no will change how they think of me."*
>
> Both young people voiced their confidence in asserting themselves. James expressed that he lacked confidence when contradicting the authority of the doctor's opinion, stating '*who am I to say what I want is better?*' In contrast, Lifey is contradictory, as he has the confidence to '*just say no*', but the election of noncompliant behaviour appears to be due to his assumption that he lacks the ability to change the healthcare perception of him. Both data excerpts exemplify how the confidence the young people had in themselves contributed to how they perceived they would interact in the future interactions.

As analysis progressed, it became apparent that 'confidence in self' was intrinsically tied to the insight the young person had of their own needs, and how they best thought these needs

should be met. Where young people felt that input from healthcare professionals did not align with their current situations, they demonstrated that they were less certain of themselves in their interactions. Conversely, young people who felt more secure in themselves and their lived situation were more likely to feel certain of their abilities to become involved in their interactions. Focussed codes such as '*feeling unsure', 'being in control'* and '*feeling confident'* resonated with the health locus of control theory (Wallston et al., 1978) in that the approaches a person forms about their health behaviours are dependent on how in control the person feels in effecting change to alter outcomes.

Excerpt 8

> "*I used to do what they wanted because I was a bit scared of them and how they were always around [referring to past interactions with healthcare professionals]. Now I know what they're about, I just think to myself I'll do what I thinks best for me because no one should make decisions for me*."
>
> Tara

Tara, who previously declared herself as 'suspicious' of healthcare professionals' agendas, indicated how confidence in her abilities altered the perception of herself. Excerpt 8 identified Tara's subservience to what she perceived as the healthcare professionals' wishes over her own. Tara indicated that when she was '*scared of them'* she would comply with '*what they wanted',* suggesting a lack of confidence to assert herself and her preferences. She followed with the assertion she had learnt had since developed an understanding of what healthcare professionals 'were about', and because of this she was able to act in a way that was best for her. Having the confidence to assert herself allowed her to make sure that no one made decisions for her, and her ability to effect change was related to the locus of control she believed herself to have. As the meaning of the condition consolidated, it became apparent that young people's perceptions of their abilities influenced how they could interact in their

future meetings with healthcare professionals. The confidence the young people had in their own abilities held a bearing on the prejudgement young people had about them in future interactions, and influenced how healthcare interactions operated.

The emerging relationship between frames of reference, young people's expectations about future events and a young person's perception of themselves highlighted a second condition of prejudgement, 'Pre-emptive strategies'. This category recognised the interaction between the properties of prejudgement, and a young person's personal agency which, in turn, influenced the methods young people developed in anticipation of future interactions. 'Pre-emptive strategies' was originally derived from codes such as '*opting out*', '*preparing a comeback*' and '*planning ahead',* recognising a relationship between the expectations formed about healthcare consultations and potential future action that could impact on engagement.; this was explored in the below memo.

Memo 9: Exploring the personal meaning of Paul's narrative

I'm starting to understand that personal competency is associated with a young person's perception of future events, and having a strategy to manage such expectations appeared to be a way of coping. Intrinsic features relating to motivation, as well as extrinsic social influences that informed beliefs, are meaningful for understanding how young people attach meaning to the future events and developed preparatory mechanisms. Paul highlighted how pre-emptive strategies coalesce with the Frames of Reference (FoR) the young person drew on, the formation of expectations, and the beliefs about the self in future interactions.

"It's like when you're a kid you get shown books and TV and things of doctors and nurses who are all smiles and helpful and stuff. And when you're in there [referring to the hospital ward] that doesn't happen. They're too busy to help and acting all put out if you pressed the buzzer. I think you just have to learn to get on with it because it's not like you can change it or make them do different. It'll always be like that unless someone tells them different".	Learning from media Learning their traits Facing reality Conflicting FoR Developing strategy 'I can't change it' Others in control

Paul identified how a childhood-mediated image of the 'friendly' and 'helpful' healthcare professional contradicted with a direct experience of the healthcare professional being 'too busy to help'. These two conflicting frames of reference were compounded by the belief he had formed about his own abilities, stating he does not feel he can change it. The expectation formed by Paul is that not being helped in the hospital environment is a status quo that can't be changed. Paul develops a passive approach to participation by 'get[ting] on with it', helping him cope in a situation that will 'always be like that'.

As comparative analysis progressed, the influence preemptive strategies had on how young people prepared to enter into future meetings was deemed as a significant factor that mediated a young person's prejudgement. This appeared to imply the possibility that young people's behaviour in interactions might have been influenced by anticipatory beliefs.

As the theoretical integration of prejudgement approached the final stages, data were explored for dimensions to situate properties on a meaningful continuum, delimitating range

and variance to theoretical development (Strauss & Corbin, 1998). Focussed codes such as *'believing what they say'*, *'not trusting their integrity'* and *'being suspicions'* provided insight into how young people were able to invest trust in healthcare professionals, and the belief that their interactions would provide them with satisfactory outcomes. 'Faith' became defined as the levels of confidence that a young person believed they could invest in their upcoming events. Comparison between two narratives provided insight into how this occurred.

Memo 10: Exploring 'faith through Lucy and Paul's narratives

Across analysis, data consistently inferred that the meaning young people placed in upcoming healthcare interactions was important to understand prejudgement and the variance between young people's narratives. Lucy and Lucky provide two examples that clarify how this occurs. In Lucy's case, she explained how her past interactions were initially difficult, however she had since developed strategies to overcome these obstacles that she found improved communication with the neurology team. Her explanation that she believed she could rely on the healthcare professionals if pain ever caused her issues was underpinned by a faith in a team that *'wants to help'*. However, the interesting part of our dialogue was when she summarised her experience with the statement *'it's not something she really thought about before'.* The faith placed in the healthcare team seemed to have a basis in past interactions where she learnt to feel secure, resulting in an instinctive faith that future interactions would provide the same outcome. This high degree of faith repeatedly occurred when a young person held positive expectations. In contrast, Lucky provided insight into how poorer expectations brought about by reports of negative past experiences resulted in a loss of faith. Lucky observed a marked difference to healthcare interactions if an adult was present. When attending GP appointments with his legal guardian, he noticed the issues he reported were taken more seriously than if he attended appointments alone. Lucky concluded from these interactions that he could not place faith in the healthcare professional providing quality interactions unless there was some form of adult observance to raise the quality of standard. The contrast between these two narratives is illuminating, as it appears to provide a way of understanding the impact that a person's level of faith could have on their healthcare expectations.

Across all narratives, the confidence the young person expressed about their certainty of beliefs in upcoming healthcare interactions was demonstrative of the faith they had of the outcome of the interaction itself. How young people judged past events, therefore, influenced faith, and what value-based predictions of young people's expectations were made were based on their certainty of belief. As analysis progressed, the narratives of young people were explored in terms of axial coding and were visually organised to represent how faith influenced their future interactions (Figure 12).
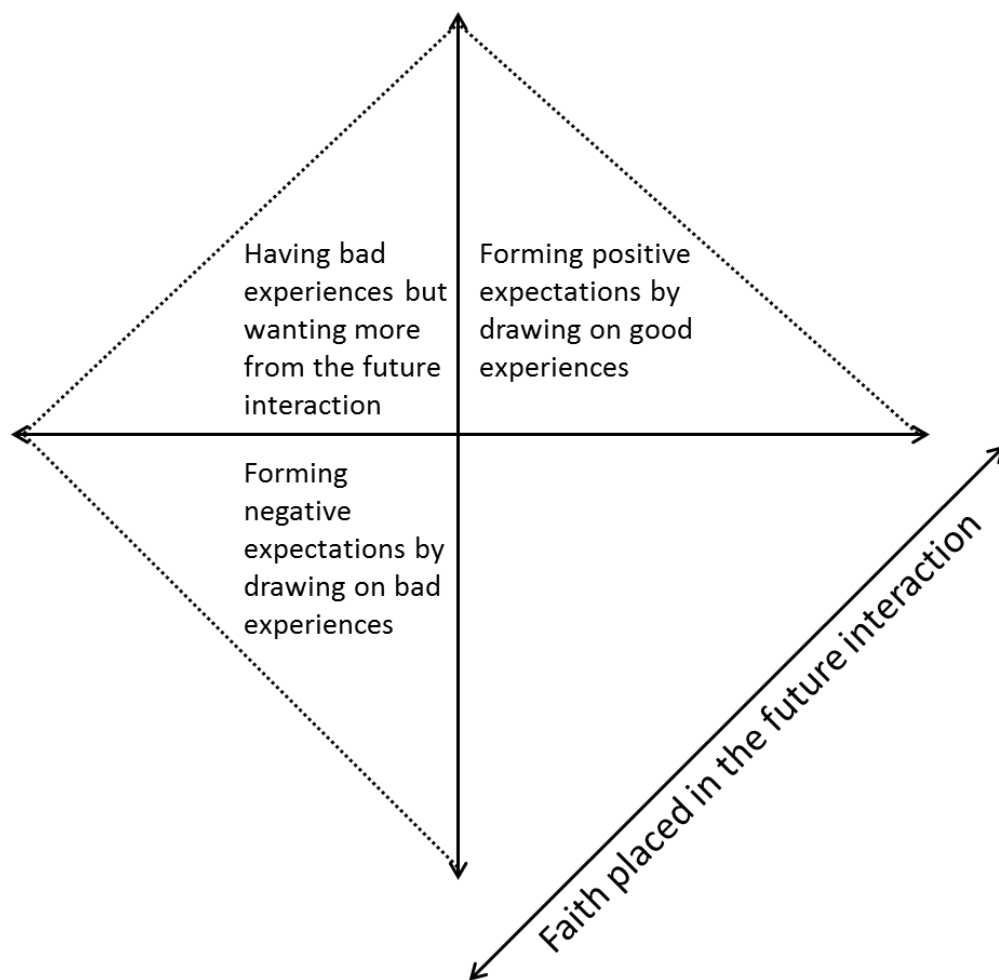
Figure 12: The properties of prejudgement on a dimensional range

Figure 13 conveys how the dynamic interaction of properties operated on a dimensional range. Where young people drew on frames of reference that were based on bad experiences,

they would develop poor expectations based on these experiences (lower left of the diagram).
In these scenarios, young people felt that they could forward little faith to their future
interactions. On the opposite side of the continuum, young people who spoke highly of past
experiences stated positive expectations about their future interactions (upper right of the
diagram). No data was indicative of young people having good experiences, but with negative
expectations for future interactions (lower left of the diagram), suggesting perceived good
experiences have no relationship with poor expectations of future outcomes. The exception
to this sliding scale were the young people who reported having negative experiences, but
knew to expect more from their interactions (upper left). In these cases, young people could
articulate that they believed a bad experience was an exception and drew on opposing frames
of reference, such as advice from others, to form higher expectations for future care. The
following excerpt explores this dynamic:

Excerpt 9.
*"My mum explained that they're not all like that [referring to the inoculation
nurses] and that they was wrong to do it [try to hold her arm]. When she said
I had to try again I didn't want to at first, but then I thought about it and I
thought it's not like they'll all be like that. So we decided to go to (clinic name)
and I'm glad I did 'coz the nurses were really nice."*

Roberta

Roberta drew on her past experience with the inoculation nurses, identifying it as a bad
experience. Drawing on her mother's reassurances, Roberta realises that she experienced a
bad interaction, but echoes her mother's words by stating *"it's not like they'll all be like"*.
Roberta placed faith in her mother's advice and was able to transfer this faith to her
expectations for future care. Roberta effectively drew on an additional source of knowledge
to alter her expectations for a future interaction. As faith consolidated as the dimension of

prejudgement, it became apparent that the continuum of faith was intrinsic to the properties

of prejudgement, and was useful for interpreting how prejudgement operated prior to a

young person's contact within a healthcare interaction.

Analysis of prejudgement was significant as it identified that prejudgement was complex,

personal to each young person's specific situation, and occurred as an interplay between the

properties, dimensions and conditions identified from constant comparative analysis.

Prejudgement appeared to influence how young people formed beliefs, and drew on such

beliefs to prepare themselves for upcoming meetings with healthcare professionals. The next

section discusses the construction of the second theoretical category, exploring how young

people interacted within interactions, and how being in interactions shaped their engagement

behaviours.

5.4 Theoretical Category Two: Learning to be a Patient
The second theoretical category that emerged was termed 'Learning to be a patient' and

identifies how young people develop their approaches for interacting with healthcare

professionals. Findings suggested that the ways that young people learnt these approaches

were based on their contextualised understanding of real-time interactions, and the means

by which they responded to events in the interactions. Focussed codes such as '*taking it in*',

'*giving back a piece of mind*', '*figuring out how to play it*' and '*figuring them out*' were example

aspects of coding which the category was built around. As comparative analysis further

identified the in-context process of interpretation and adaption as a significant feature of how

young people interacted, 'Learning to be a patient' became defined as the process by which

young people acquired methods for an interaction based on what they learnt within the

interaction context. This analysis framed young people's behaviours as a product of the

patient/professional dynamic, and was dependent on whether the young person viewed their engagement within the interaction as good or bad. This is demonstrated in the following excerpts:

Excerpt 10
[Reporting on a consultation with her GP for suspected iron deficiency] *"She kept saying it was probably just alopecia like that was supposed to make me feel better. I kept telling her that my friend had it [iron deficiency] and I had all the same symptoms, but she kept saying it was because of stress and my GCSEs and she had the final word. So she gave me the shampoo and a few weeks later when it hadn't got better I thought right, I'm not having this. I was losing loads of hair so I decided to make her listen, so I saw her and made her do blood tests"*.

Rebecca

Excerpt 11.
[Reporting on her second attempt to have the HPV vaccine] *"Because I'm really scared of needles, they calmed me down* [the nurses]. *They let me take my time because I was a bit, like, jumpy. They didn't force me to have my needle. They told me to calm down and just think about something else and pretend you're not here. And they started talking to me and started chatting to me. So I put my arm out and they did it so it was really nice. They're really nice people, speaking like calmly"*.

Roberta

In both data excerpts, the young people demonstrated how they gauged their interactions with healthcare professionals, and responded based on their assessment of the scenario. In excerpt 10, Rebecca identified that, after having her suggestion of iron deficiency dismissed and her hair loss worsen, she decided that she had to 'make' her GP investigate her suspicions. In contrast, excerpt 11 demonstrates how Roberta built enough trust with the 'nice' nurses to put her arm out to receive the injection. Despite her previous experience with her reports of 'nasty nurses', Roberta found a new way to interact with healthcare professionals to overcome her needle anxiety. As previously identified, Roberta was able to enter the

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interaction with a positive outlook due to reassurances from her mother. However, it was in the interaction itself where Roberta gauged the nurses' qualities and responded with a favourable clinical outcome. Both cases identified the young people were active in interpreting the attitudinal aspects of their interactions, and such interpretations influenced how the young persons altered their approaches to the healthcare interaction.

The early stages of comparative analysis were meaningful as they identified that a young person's interpretation of an event influenced the approaches they adopted within the interaction. This was significant, as it inferred a relationship existed between a young person's interpretation of an event and how they engaged; additionally, this relationship appeared to be important as it influenced how a young person located themselves in relation to the healthcare interaction. Building on the connection between event interpretation and engagement was meaningful for theoretical development as it led to the understanding that young people were learning engagement behaviours in response to the event. This suggested that learning could be deemed as a largely reactive process, challenging the notions that patient engagement exists on a continuum of active or passive behaviour. This subtle shift of thinking was important, as it moved the focus of analysis away from viewing a young person's engagement as a sequence of actions that could work towards or against a health-related goal, and instead implicated the healthcare professional as a variable that young people formed behaviours in response to. Consequently, early analysis highlighted that the relational dyad between the young person and healthcare professional was significant as it influenced how the young person understood healthcare situations, and shaped the reactions young people formed to manage their perceived scenarios.

Similarities can be drawn from the literature, for example methods of communication and behavioural traits of a healthcare professional have been previously identified as a limiting barrier to young people's participation in their healthcare interactions (Curtis et al., 2004). Young people can be directly influenced by the character traits and interpersonal behaviours of healthcare professionals, or feel constrained by the lack of options forwarded to them in an interaction itself (Kilkelly & Donnerly, 2011). Kelsey & Abelson-Mitchell (2007) suggest that such features of dyadic interactions can have a psychological impact on young patients, resulting in young people feeling anxious and excluded from the communication process. Similar findings are reported by LaValle et al. (2012), who identified through a rapid review that young people felt they were failed by healthcare professionals when they believed they were not made to feel involved in the interaction or included in communications about their healthcare. The influence of a healthcare professional's attitudinal traits on how young people define their patient role was explored through memo writing.

Memo 11: The importance of young people's perception of healthcare professional behaviour

Young people repeatedly unpick healthcare professionals' behaviours to justify why they feel they are not involved, or feel that they have disengaged from meaningful interaction. In contrast, young people draw on positive traits when defining why they feel included or able to participate on equal terms. Young people appear to not only intuit behaviours, but actively respond to them in the interaction itself. This is interesting as it differs from current literature. Research exploring young people's perceptions of healthcare give the young person the opportunity to disclose how they feel in response to being treated in certain ways. However, this does not identify how young people respond to being treated in such a way in the context of the interaction, or how it influences how they seek to engage thereafter. Study findings suggest that young people are actively involved in their own process of responding to their perception of the healthcare professional, and how they were treated.

As comparative analysis progressed and concepts began to be consolidated, it became apparent that, in learning how to interact, young people were active in interpreting healthcare professionals to unpick meaning:

Excerpt 12

"*I do feel like maybe they need to be a bit more personal. I think because sometimes for them it's doing their job and I understand that and they want to help, but at the same time they find it difficult to speak to me for some reason, like in general, and the words they use sometimes can confuse you, like when they're talking about certain parts of your heart and everything, so I always say I'm not interested. Well, I say I don't let it stop me from doing anything. So I don't need to know what's wrong with me. So I let my mum mainly decide what happens with my health and everything. I just go there, you decide mum, you can decide. Because I'm not interested*."

Paul

Paul sought to understand why he perceived healthcare professionals as having difficulty speaking to him, rationalising their impersonal behaviour as that of someone *'doing their job'*. In this statement, Paul intuited a difficulty in connecting with the healthcare professional, and muses that there is '*some reason*' that this difficulty occurs. Paul ascertains that these difficulties are part of his 'general' experience of the interaction, and is suggestive that the confusion he feels further alienates him from his interactions. Paul responds by withdrawing his active engagement, stating a lack of interest and prefers to defer autonomy within the interaction to his mother. This analysis indicates that Paul learnt from the difficulties within the interactions, the perceived awkwardness and alienating language, and responded by developing a lack of interest about his congenital heart defect.

As analysis progressed and sensitivity developed across cases towards how young people interpreted their interactions to situate their responses, attention turned to the means by which young people arrived at decisions as to whether to trust healthcare professionals. Early theoretical coding created *gauging approachability* as a tentative theoretical category to identify the process by which young people observed healthcare professionals to determine their genuineness and trustworthiness. However, as continued comparison progressed, this category did not achieve theoretical sufficiency and an additional layer of analysis was required to account for young people's reports of their behaviours in interactions. Previous initial codes such as *Testing the water*, *Interpreting feedback, Making a judgement, Getting through it*, and *Learning what's expected* were revisited and compared against data until focused codes were achieved. As analysis progressed, 'learning from them' was developed as a higher level concept and integrated with existing data until a new category emerged.

Table 12: The development of learning to be a patient as a category

	Theoretical memo	Initial codes	Focused codes		Memo	
Gauging approachability	The issue is that the category is static and does not allow for the young person to develop or change. At present this does not fully reflect the in-context engagement disclosed by young people. Rereading data suggests that 'learning from them', which was originally coded under the third theoretical category, will resonate better in the second category.	Testing the water / Seeing what happens	Gathering information	Higher level concept: learning from them	Collapsing the initial data from the higher level concept 'learning from them' provided new insight into how data within 'gauging approachability' is interpreted. Suggests that young people learn to be the patients they are through the interactions they have. Adapting the code for the theoretical category might be appropriate to represent this new element	Learning to be a patient
		Interpreting feedback / Making a judgement / Deciding what to do	Assessing the situation			
		Learning from feedback / Trying things out	Working out approaches			
		Getting through it / Finding your place / Learning what's expected	Learning what works			

Table 12 represents the emergence of 'learning to be a patient' as a final theoretical category. Guided by memo writing, the data corresponding to the higher level concept '*learning from them*' provided an additional feature to the category, which included learning as an essential aspect of young people's interactions. Upon reaching theoretical saturation, axial coding was performed to clarify the properties, condition and dimensions (Figure 13).
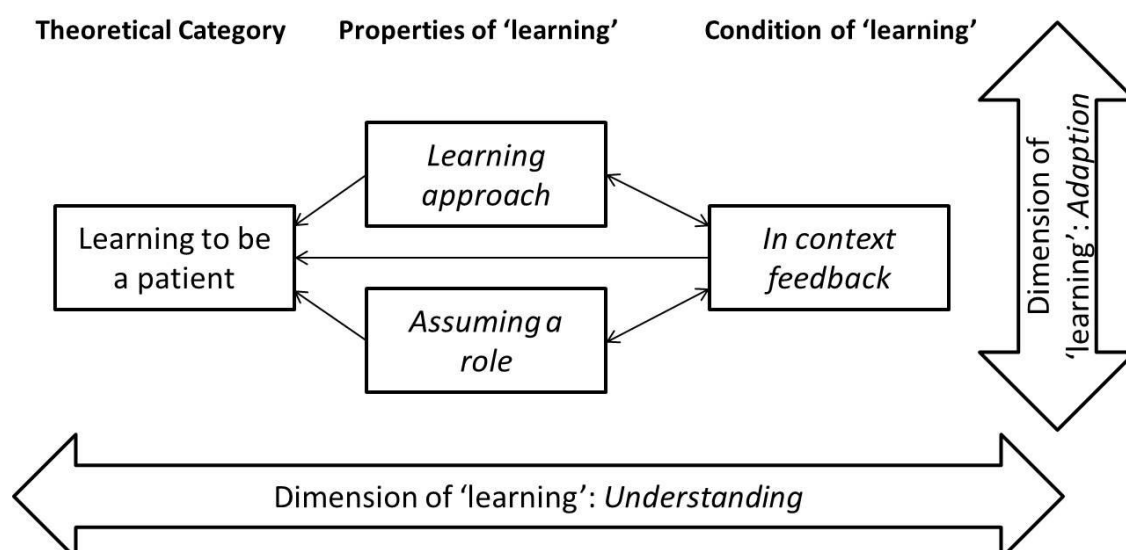
Figure 13: Properties, condition and dimensions of 'Learning to be a patient'

Properties were identified as 'learning approach', identifying the means by which young people process and learn from information from interactions, and 'assuming a role', signifying how young people position themselves in response to the relational dynamics within interactions. The intervening condition affecting these properties was the 'in-context feedback' that young people gained from participation in interactions, which influenced their behaviours. Two dimensions emerged from axial coding: 'Understanding' identified the level of insight that the young person had in the context of the interaction; and 'adaption', the means by which young people altered their means of interaction when faced with new information. The following sections detail these properties, condition and dimensions.

5.4.1 Learning to Be a Patient: Properties, the Condition and the Dimensions

The following section details the different components of the theoretical category, 'learning to be a patient'. 'Learning approach' was identified as the first property, delimiting the process by which young people drew on information from healthcare interactions to form responses to healthcare professionals. Throughout young people's accounts of real time interactions,

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young people disclosed reasons why they responded in certain ways to their interactions. This highlighted that young people effectively 'learnt' from their interactions to shape their approaches to engagement. For the purpose of this thesis, learning approach was defined as the patterned behaviour demonstrated by young people when processing information in interactions, and how their responses developed patient behaviours.

Early analysis indicated that the means by which young people reacted in their healthcare scenarios was significant. Throughout initial coding, young people were explicit in asserting what worked when they '*got on*' with healthcare professionals. Labels such as '*staff being friendly*', '*given time to trust*' and '*being treated nicely*' indicated key behaviours that young people felt ameliorated interactions and improved their satisfaction of outcomes. As analysis progressed, negative cases were identified which highlighted young people with different preferences to their healthcare interactions. The following excerpts provide examples of such young people's preferences of healthcare professional behaviour:

Excerpt 13
"I want them to be professional. No messing around. Someone I can trust and be in and out with so I'm not worrying about it later."

Lucky

Excerpt 14
"It's like to quote the film Seven Pounds with Will Smith. Rule number one, tell them what they need to hear. Lesson number two, you tell them. Lesson number three, you don't bullshit, you just tell them. You don't sugar coat it. You just tell them what it is, because you sugar coat it and it's like you don't know what to think. Your mind is sort of like that [makes clenched gesture with hands], whereas if you give me a straight answer. It's straightened up, it's done. Then they give you advice and what to do."

Lifey

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Excerpt 15

> *"I think they [healthcare professional] should treat them [young people] like they're bringing them into their home like a visitor. Make them feel at home. Offer them a drink or talk out of context a bit. Have a chat. Make them feel nice about themselves. Just talk to them. Talk to them like a normal human being."*

<div align="right">MarilynM</div>

In excerpt 13 Lucky identified he had a preference for authority figures he felt he could trust. He wanted to be able to place faith in the healthcare professional so he could be '*in and out*' without having cause for reflection later. Lifey explicitly stated in Excerpt 14 that he had a strong preference for a '*straight answer*', favouring replies that weren't sugar-coated so as to avoid confusion. In excerpt 15 MarilynM suggested that interactions that were far removed from clinical behaviours were his preference for interaction style, suggesting that feeling like '*a normal human being*' was important so young people could feel '*nice about themselves*'. The difference between young people's preferences to what constituted the best behaviours to facilitate their interaction became an area of conflict in early analysis. The majority of cases identified preferences for similar interaction styles from healthcare professionals; however, this conflicted with other young people's opinions. This suggested that merely collecting young people's views on preference would not provide an inclusive account of all young people's narratives. The dissonance between young people's preferences of interaction format was explored through memo writing.

Memo 12: Exploring interaction preference

Getting caught up in exploring young people's preferences seems to be a 'red herring'. It provides a superficial account of perceived preferences, but provides no insight into how young people engage. Also, young people's preferences differ widely and lack a definitive consensus. Generalisations of the majority of accounts suggest '*staff being friendly*', '*given time to trust*' and '*being treated nicely*' are important, yet this does not account for negative cases. Preference listing seems to be a redundant approach by which to read the data as it: a) would result in an ever-increasing list and b) it would identify the mean preferences, yet would exclude exceptions. What has developed insight is viewing young people's preferences as an expression of the sum of their experiences to date. By comparing data back to each narrative, these preferences were seen in the context of their past interactions:

Lucky	Interactions with healthcare professionals limited to minor ailments. Believes he has been treated poorly in past interactions by '*moody*' healthcare professionals who acted disinterested or were not bothered. States he doesn't like being messed around.	**Comments** Prefers quick and professional interactions from those he can trust to be good at their job
Lifey	Undergone serial appointments with CAMHS healthcare professionals for review and mental health assessment. Feels judged because of his cause for referral and frustrated by lack of answers being given to him. Lifey resented being 'forced' into having assessments to stay in college.	**Comments** Prefers '*straight speaking*'. Felt messed around and favoured direct answers rather than '*fake*' HCP that didn't tell him the truth.
MarilynM	Main interactions were with incontinence team nurses for nocturnal enuresis. Viewed interactions as patronising as he believed he was spoken to as if he were a young child. Attributed this to his perception that the service was for younger children or '*kids with disabilities*'.	**Comments** Preference for being treated as '*normal*'. Believed that being spoken to rather than '*spoken at*' would improve the situation

It became apparent that preferences were an expression of what the young person believed could improve on, based on what they had learnt from their past interactions. Young people were actively reading interactions and interpreting their events. Analysis would benefit from exploration into the different means that young people do this to understand how it relates to the theoretical category.

Early memo writing brought to the fore the means by which young people learnt from experiences to interpret, and to ultimately form opinions on, healthcare interactions. Memo writing also identified that further insight into how young people learn was necessary. This provided a theoretical turn for comparative analysis from therein, shifting focus away from the constant comparison of young people's interaction preference, instead allowing for a deeper reading into how the stated preference resonated with their self-reported narrative.

Returning to the data, the specific accounts where young people sought meaning from their interactions were analysed and focused codes identified such as *'proving them wrong'*, *'pushing away', 'taking it in'* and '*being suspicious'*. These self-reported attitudes provided insight into how the young person approached their interaction, based on what they had learnt from previous contact. As theoretical momentum developed, theoretical coding became a useful tool to form abstracted overviews of approaches identified in the data, consolidating the key attributes reported across young people's interviews (Table 13).

Table 13: Categories of 'learning approaches'

Theoretical codes	Learning approach	Description of traits
Fearing what will happen "Once bitten twice shy" Interpreting with bias	Avoidant	Drawing on worst-case scenarios and projecting these onto the interactions. Wanting to escape or pull away from that which is perceived as a threat. Drawing on safety behaviours to develop a self-protective approach.
"Wait and see" Seeking meaning/asking why	Cautious	Approaches interactions hesitantly and with lack of certainty. Careful not to 'give too much away' until sure of the situation. Tendency to seek out reasons and analyse meaning. Wants to understand what will happen next and lack of certainty creates anxiety.
Listening and understanding Actively asking/seeking clarification Willing to self-disclose **(minor category)**	Receptive	Shows interest in understanding the interaction and the information given to them. Reports higher likelihood of controlling emotional responses and moderating the influence of this on behaviour in interactions. Will attempt to seek clarification and ask questions. May share information in response to interactions where they are at ease.
Deciding quickly/being sure Quick judgement forming Thinking in black and white terms	Self-assured	Certain of their interpretation of interactions. Make judgements about things quickly and confident about interpretation of interactions. Willing to commit to the behaviour they think best meets the needs of a situation. Difficulty in seeing other perspectives. Prone to impatience.

Table 13 details the learning approaches identified from theoretical coding, and provides an overview of how these approaches operated within interactions. Column one draws on theoretical codes, which led to the formation of learning approaches listed in column two. Column three provides a description of the learning approach traits that were compiled by

comparing theoretical codes back to young people's reports of their interactions. Young people who demonstrated an avoidant learning approach found healthcare interactions overwhelming or threatening, interpreting information from interactions as a rationale for partial or full disengagement. Cautious learning approaches were entered into interactions with trepidation, and initially regarded the information within interactions with wariness or suspicion. Young people with receptive learning approaches demonstrated a tendency to reflect on information in their interactions, weighing up information in interaction before making decisions on how to proceed. Finally, a self-assured learning approach saw young people making quick judgements on the information within their interactions and acting on it immediately and with certainty. As the property became saturated, similarities were identified throughout codes relating to 'having expectations', and focussed codes such as *'believing nothing will change'*, *'knowing that they'll help'* and *'knowing I'm right'* became significant for developing insight into the data. The identification that expectations held influence over a learning approach was refined through memo writing to clarify the emerging concept.

Memo 13: Exploring the relationship between expectation and 'learning approach'

> Young people's learning approaches are reminiscent of the expectancy-forming behaviours identified in 'prejudgement'. These learning approaches seem to reflect the fact that the beliefs the young people have prior to an interaction are in effect used to filter through information within the interaction. When the original data sets were returned to, strong associations were clearly seen between the learning approaches that were used and the expectation the young person stated they had prior to that interaction. In effect, the beliefs appeared to have continued a selection bias when processing information and forming responses. The traits of these approaches had clear implications on the behaviours young people stated they had in their healthcare interactions towards healthcare professionals.

Memo writing clarified how young people drew on information through a specific approach, which filtered their understanding of the healthcare interactions and influenced how behaviours were formed in the dyadic relations with the professionals they met. As coding developed the second property, 'Assuming a role' was identified as closely related to 'learning approaches', and was significant to how young people learnt typified behaviours within their interactions. Early codes such as '*knowing your place*' and '*figuring out expectations'* identified young people who demonstrated a self-consciousness to what was expected from them when meeting a healthcare professional. Young people's perceptions of the roles they thought they were expected to take, and their assumptions of what was expected of them within that role, affected how they interacted with a healthcare professional. For the purpose of this thesis, the property 'assuming a role' was identified as the characterising beliefs young people developed about their position within the relational dyad within healthcare interactions. It encompassed what they assumed they should do within an interaction, and how they responded to such beliefs. How young people understood a role was significant as it reflected what they thought was expected of them in healthcare interactions. The following excerpt demonstrates Rebecca's understanding of the patient role:

Excerpt 16

> "*I think they put themselves on a pedestal a lot [referring to GPs]. I don't know, they must just think that we're the patients and they're the doctors so let them deal with it instead of us, like, dealing with it as well. I think that's the right way to say it.*"

> Rebecca

Excerpt 16 identifies that, what Rebecca believes is expected from her in interactions with GPs, is for her to passively let the '*doctors deal with it'*. In Rebecca's statement, there is the belief that GPs want to be on an authoritative '*pedestal'*, and that Rebecca is expected to relinquish her right to contribute to making decisions. Rebecca identified that she believed

she was expected to assume a passive role in the relational dyad of that interaction. The concept of social role assumption, by both the patient and a healthcare professional, is a well-established concept in healthcare literature. Parsons' (1951) seminal work on the institutionalisation of roles assumed in the healthcare interaction emphasises the social nature of this relationship, as well as the patterns of behaviour that are formed by involvement in the healthcare interaction itself. Specifically, social induction into medical context requires specific behaviours adopted by patient and healthcare professional for both roles to achieve a successful outcome. Memo writing was used to expound this concept in terms of how Rebecca's responded to her healthcare interaction.

Memo 14: Exploring Rebecca's observation on power dynamics

> Rebecca makes explicit observations about the power dynamic in her GP appointment. Her observation that GPs want to be on a pedestal is suggestive that she believes her GP knows best, and that the GP wants to be the person who 'deals' with decisions. I find that the parallels between Parsons' theory of socially-constructed roles, and Rebecca's observation of implicit power dynamics, very striking. If the roles of the patient and professional are in fact a prescribed social construct determined by the function of the interaction itself, then Rebecca appears to be commenting on her introduction to the societal expectations demanded of that GP consultation. Parsons (1951) argues that the patient and healthcare professional role are complementary in that a patient, seeking the expert knowledge of the professional, is expected to comply to have a 'cure' bestowed on them. Rebecca appears to express that her compliance was an expectation by her GP. If it can be assumed that there are implicit power dynamics and role expectations in a healthcare interaction, then the question is 'to what extent are young people aware of such social inductions and, if so, how does this awareness impact on their engagement-related behaviour?'

As comparison across young people's accounts continued, additional cases increased the insight into how young people perceived the roles expected of them in the healthcare interaction:

Excerpt 17
"[On being asked why he wouldn't report pain whilst in hospital] It's not like it was so bad, I mean there were some people there in a worse state an' so you don't want to be a burden when they're all doing stuff. I did tell one, but she told me to wait for the rounds with the doctor so I just got on with it after that."

Paul

Excerpt 18
"[referring to doctors' appointments] They want you to tell them everything and open up, like you have to be all yes and no and stuff. An' I think why should I, you don't have the right."

Tara

Excerpt 19
"[Referring to the CAMHS nurses] They ask me to sit down and we just talk and they listen and we both say our bits. It's just good really because I know they want to listen to what I have to say and I can get things off my chest, and then they'll give me advice and stuff, like about not doing it [self-harming] and I know it'll help."

Zara

The above excerpts identified how young people drew conclusions from their interactions about what they believed their role was as a patient. In these excerpts, the young people formed clear responses as to what they believed was expected of them within that relational dyad. In excerpt 17 Paul identified that he observed nurses always '*doing stuff*', suggesting that they always appeared involved in tasks that couldn't be interrupted. Paul confirms this observation, stating that when he did eventually '*tell one*' about experiencing pain he was told to '*wait for the rounds with the doctor*'. Paul perceived the tasks the nurses busied themselves with as more important than his pain, which made him a '*burden*' on their time. Paul states he '*just got on with it*' in response to this belief. In excerpt 18 Tara identified that she perceived

her interaction as being inquisitorial in nature, stating that she felt expected to '*open up*' and comply with answering questions as part of her role in that interaction. Tara is indignant about being placed in this decision, questioning why she should assume such a role and believing that doctors '*don't have the right*'. In contrast, Zara believes her role in the interaction is to take part in a dialogue where both parties say their '*bits*'. Excerpt 19 identifies that, by taking part as an equal partner, she can get advice that she knows will help.

As analysis progressed, variations in young people's perceptions of the patient/professional relationship were explored, and insights were formed into the roles young people believed they were expected to assume. Focused codes indicative of how young people gathered information about the interaction and made assumptions about role expectations, such as '*noticing attitude*', '*sensing cues*', '*watching and learning*' and '*locating self*', further consolidated the property. A significant feature which arose from the data was that, in addition to having assumptions about their expectations in the interaction, young people responded to such beliefs by resisting or conforming to their interpretation of the patient role. As axial coding progressed, a diagram was developed to represent this dynamic.
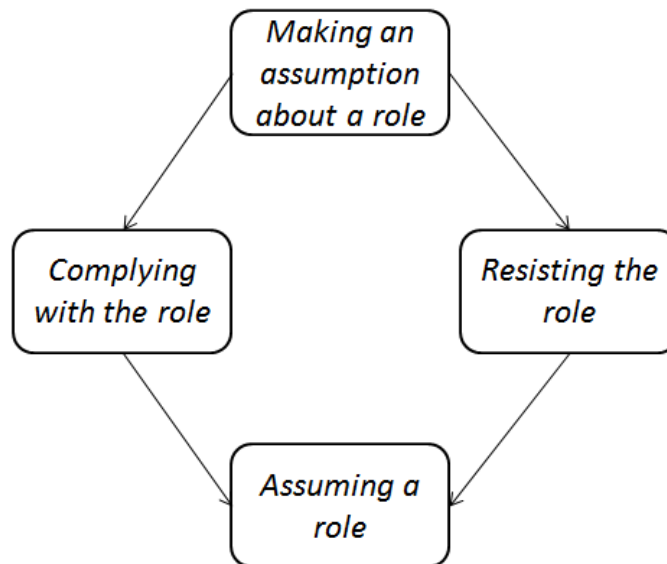
Figure 14: Assuming a role

Figure 14 represents how young people determined a response to the expectations they perceived in a relational dyad with their healthcare professional. The initial interpretation made by the young person was indicative of the perception they formed in that healthcare interaction (top box). Young people responded to these perceived role expectations by either conforming to their interpretation of the role (left box), or resisting what they believed the role to be and forming a new patient behaviour in the healthcare interaction (right box). In accounts where young people stated they resisted their perceived understanding of the role, it was suggested that the young people felt coerced into a passive role within the relational dyad and believed they were *'sticking up for themselves'*. In contrast, young people who identified that they conformed to a perceived role did so for two reasons: the young person perceived that the existing interactions with the healthcare professional met their needs; or that the young person resigned themselves to what they believed to be their role as they believed the status quo an unchangeable dynamic. Memo writing was used to refine the conceptual process of role assumption.

Memo 15: Refining the concept of 'assuming a role'

> How young people understand their own experiences of healthcare interactions, and how they position themselves in response to what they thought was expected of them, seems crucial in order to understand how they construct actual roles. The fact that young people develop notions of what is expected of them as a patient, as well the role of the professional and the outcomes, has been recognised as influencing young people in therapeutic mediums (Watsford & Rickwood, 2012). These notions also extend to the outcomes that will be achieved from the act of involvement (Watsford & Rickwood, 2013). If young people are developing awareness of their roles in relation to the healthcare professional's role, then it may not be unreasonable to assume that their assumptions play a key part in how they choose to engage. If there is a conflict between young people's perception of role expectation, and their internal locus which denotes if a young person will accept or reject such perceptions, then understanding their 'choices' could generate insight into how young people eventually engage.

A young person's individual beliefs, and the normative expectations the young person held of the healthcare context, appeared to influence how young people responded in their patient role. 'Assuming a role' emerged as a key process, whereby young people constructed an approach to the healthcare interaction based on the assumptions formed about the context, and themselves, as a social construct. In this sense, it can be argued that the young person's engagement in the healthcare interaction is an act of being structured by, but also structuring, the circumstances they enter into. This concept of reciprocal healthcare socialisation is addressed by Varul (2010), who suggests that it is the exchanges that occur between the patient and healthcare professional, within their predetermined roles, whereby socialisation of behaviours occurs. Varul (ibid) draws on Gerhardt's (1987; 1989) interpretation of Parsons (1951) to support his position, identifying that the healthcare inaction is an "exchange' entailing 'the relentless obligation to conform to others' role expectations" (p. 74). This

implies that it is not the assumption of a role that is meaningful in itself, but rather how roles are used to navigate the self in relation to others. This resonated in relation to the analysis of this study, as 'assuming a role' recognised both the young person and healthcare professional in a reciprocal system, each dependent on the other's action in that relational dyad. The extent to which the young person assumed a 'patient' role appeared to relate to how perceived attitudes, values, and norms attributed to that role were internalised, and the degree to which these attributes resonated with their sense of self. As one young person (Lifey) phrased it, "I'll only go along with so much 'coz if what they're saying isn't what I want why should I do what they say? They can't make me do what I don't want. I won't let them push me around." Such insights informed analytical readings of the data and led to exploration of how young people developed behaviours.

As axial coding progressed, an intervening condition, namely 'in context feedback', emerged from analysis, locating young people's reception of information, in the context of the healthcare interaction, as an external influence that shaped behaviours with healthcare professionals. 'In context feedback' provided young people with information in their healthcare interactions about how the healthcare professional was receiving their actions, which could both mitigate or exacerbate the behaviours young people formed in these interactions. For the intent of this thesis, 'In context feedback' identified the information that young people received about their participation in interactions, within the interaction itself, which influenced how young people sought to interact. Lucy demonstrates the impact in context feedback in the following excerpt:

Excerpt 20

> *"The first time I went [to the neurologist] I was on my own and I didn't understand what they were saying to me, and then someone came with me one time and I think they realised then that I wasn't understanding them because the person I went with, he was explaining it to me after the doctor was saying it. So after that they started explaining it fully to me and asking me questions what I wanted to know, and now if I don't understand them I actually tell them instead of going home and telling someone what they said."*

Lucy

Excerpt 20 demonstrates the impact *in context feedback* has in providing young people with intervening information to inform their perception of an interaction. Lucy suggested that, in her initial interaction, the healthcare professional's language was inaccessible. Rather than seeking clarification from someone who used words that deterred her, Lucy opted to bring an adult into her next meeting to act as a translator. Here, Lucy participated via mediation. Lucy later explains that, in a following interaction, she observed that the healthcare professional *'realised'* she *'wasn't understanding them'*. Upon seeing the neurologist making continued attempts to explain *'fully'* and check understanding, Lucy responded with direct participation. Lucy concludes she will *'tell them'* when she needs clarification rather than seeking translation through a third party. In Lucy's account, she can be seen picking up cues from the healthcare professional and deciding how the information informed the interaction. Cutting across cases, young people reported similar instances of being sensitive to the nuances of interactions. As the condition became saturated, it became apparent that *in context feedback* referred to young people's reception of information, which in turn informed their understanding of relational dynamics.
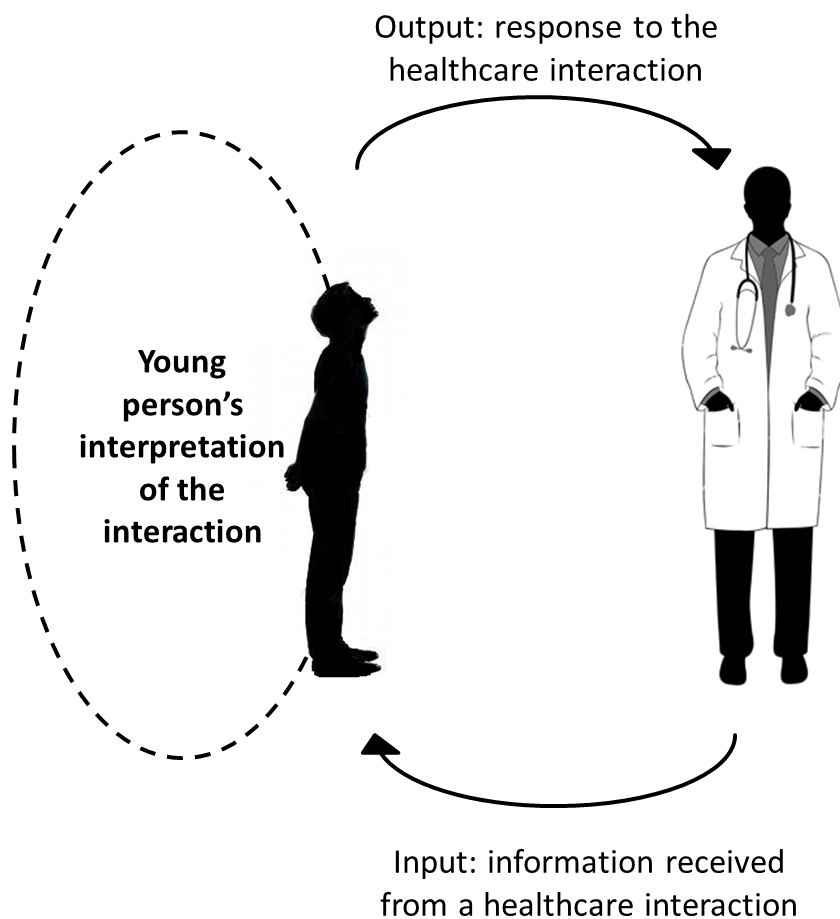
Figure 15: Representation of how 'in-context feedback' operates as an interpretive process

Figure 15 portrays the interpretive process which occurs when young people receive in context feedback from healthcare interactions. Information received from interactions is interpreted and the young person responds through behaviours and actions based on their interpretation. As comparative analysis progressed, it became apparent that information was not restricted to verbal feedback that affirmed or negated the young person's actions, but also nonverbal and interpersonal cues that young people intuited. Focussed codes such as *'watching their behaviour'*, *'being made to feel wrong'* and *'seeing them take it in'* indicated that young people drew on a variety of methods to determine how they were received. As such, the condition was noted as a constant that was present throughout a healthcare interaction, and intervened throughout interactions as affecting how young people interacted

as part of a dynamic, ongoing process. The identification of 'in context feedback' as a key aspect of young people's learning behaviours was significant as it identified how young people formed behavioural responses within real time interactions. This highlighted that young people demonstrated their involvement in a perceptual-interpretive process, where the young person is continually responding to the behaviour of the healthcare professional and the demands of the situation.

As analysis progressed, 'In context feedback' strongly resonated with systems theory, situating the person as a self-regulating system responding to external stimuli. Systems theory has been used throughout a range of disciplines in the healthcare sciences, influencing biopsychosocial approaches that include the synthesis of mental health perspectives within medical models of healthcare (Engel, 1977); the significance of this approach was the recognition of both physical and psychological factors in sickness, health and recovery. Another example within occupational science utilises systems theory to view human function as a complex relationship between personal and environmental contexts (Kielhofner, 1986); this approach expounds the complex nature of adaption within physical, social and cognitive function, constantly fluctuating in response to cues and stimulus. Collectively, perspectives relating to systems theory in healthcare view the person as a complex self-organising 'system' that is constantly responding to multiple sources of internal and external stimuli. In relation to the patient professional interaction, both parties (the patient and the healthcare professional) are recognised as being involved in a process of interpretation and meaning sharing when working towards common goals (King, 1981). The parallels that emerged between findings, and such existing interpretations of systems theory, provided theoretical clout to the analysis (the significance of systems theory is discussed in greater detail in section 6.2.1).

As axial coding of 'learning to be a patient' neared completion, two dimensions, *understanding* and *adaption,* emerged, providing both depth and breadth to the theoretical category. Both of these dimensions ran alongside the theoretical category and delineated the process by which young people developed individual patterns of behaviour to interact with healthcare professionals. *Understanding* identified the scope of insight the young person had of their actions, and of the relationship they formed with the healthcare professional. *Adaption* denoted the adjustments young people made to their behaviour when interacting with healthcare professionals. Both of these dimensions operated as parallel continuums, whereby young people learnt from interactions to developed methods of participation which they believed worked best within the context of the interaction.
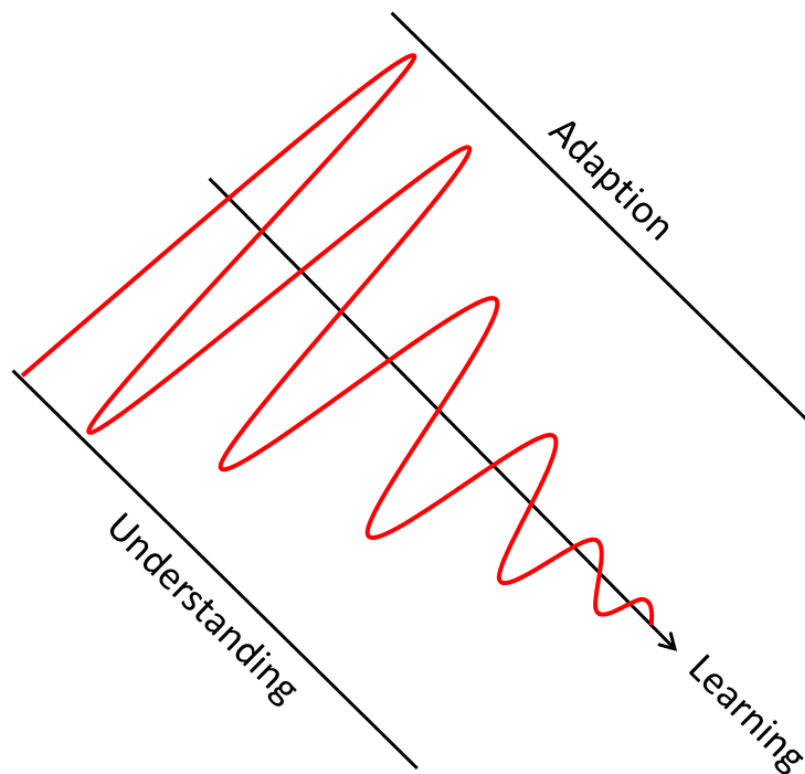
Figure 16: Adaption represented as a key feature of learning

Figure 16 shows how the dimensions of *understanding* and *adaption* interacted as young people learnt from their interactions. As the young person (red line) entered an interaction, they spent a great deal of effort interpreting the interaction. Their efforts to understand the interaction (left line) saw them adapting their approaches (right line). As the intervening condition provided in context feedback, the young person experienced learning through continually interpreting and responding to stimulus (centre arrow). As an interaction progresses and set behaviours become reinforced, there is less of a requirement to interpret and respond to an interaction. The red line became less pronounced as the young person's beliefs were mediated and the behaviours they had committed to were validated. The beliefs about the relational dynamics within the interaction became engrained, requiring less pronounced adaption. Through this process, the young person learnt their current 'patient behaviour' based on their experiences from the interaction. From this perspective, learning was a feature of all young people's narratives, regardless of the levels of participation they reported or their involvement of their health-related outcomes. This process was significant as it suggested that young people participated through means of learnt behaviour.

5.5 Theoretical Category Three: Validation

'Validation' emerged as the final theoretical category of the study, characterised by closely related components which elucidated how the experience of a healthcare interaction was judged by young people. For the purpose of this study, 'validation' refers to the meaning making process that occurs after an interaction with a healthcare professional. Through this meaning making process, young people drew on various experiences from interactions to define and justify their interpretation of the event. As such, the young people sought to validate their experiences with the information that they saw as the most important. Excerpt

21 provides an example of how information in interaction was selected to validate their perception:

Excerpt 21

Jane: *[On why she didn't trust a locum GP] "Like he was a bit shady, I just didn't like trust hi..*

Jason: *"What do you mean he was shady?"*

Jane: *"He didn't say 'owt about who he was, like, or anything and he was asking about home and stuff like that. I didn't feel I could trust him like because I don't, like, know him and he could like say something to my aunty".*

Jason: *"Did he say anything to try and make you feel comfortable?"*

Jane   *"Well yeah he was like smiling and like polite an' stuff like that, and he said like everything's confidential and stuff, but they have to, don't they?"*

In the above exchange, Jane demonstrated how she selected and prioritised elements of the healthcare interaction, which she used to validate her statement that the GP was '*shady*'. Jane explains that the enquiry into her living situation at her auntie's house was confounded by her fear '*he could like say something*'. When the GP questioned her welfare, Jane identified this as a key reason as to why he was '*shady*'. When asked if there were any attempts made by the doctor to reassure her in that interaction, Jane conceded 'he was like smiling and like polite an stuff', implying that there were overt attempts made by the GP to put her at ease when pressed to think past her initial impression. Yet, these actions were disregarded as something that they 'have to' do. Jane demonstrated she was involved in selectively drawing on information to validate her perspective. As comparative analysis progressed, this process of validation reoccurred across cases. The below memo drew on data and initial codes to refine focused codes.

	Data abstracts	Initial codes	Focussed codes
Mark	"Last time I was with him [*referring to the vascular specialist*] he talked about me for ages with her [*his auntie*] and I was just there just going like, oh right. They're always the same that way so I just get on with it."	'being talked about' 'not being included' 'being left out' 'dynamics not changing' 'accepting passivity'	'Selecting negative incidences' 'believing not included' 'Developing in context pretences' 'disregarding own actions' 'Disregarding HCP attempts at inclusion'
	"He was like trying to explain about why I needed it [*referring to a diet plan*] so I kept saying right 'coz I don't want to hear it.	'being addressed' 'being spoken to' 'pretending to listen' 'not wanting to hear it'	
Lucy	"It's a really easy experience, so if I want anything they're always eager to help and she said [*the nurse*] I can call anytime"	'Interactions being easy' 'always being helped' 'helped at anytime'	'Focus on positive incidences' 'Belief in the HCP' 'Belief will be helped' 'Disregarding incident that conflict with belief'
	"[*Referring to difficulties contacting the neurology nurse*] Yeah, well the line was always busy and when I finally got through I had to wait for an appointment and I had a lot of pain [*in her hands*] at the time."	'difficult to contact nurse' 'Try over a duration of time' 'have to wait to be seen' 'being in pain'	

Focused coding was useful to identify selection biases for validating belief about healthcare interactions. Within Mark's interview, he stated he held a largely negative perspective of his healthcare meetings. Mark gave examples of feeling excluded and indicated he used a passive approach to manage this, yet he also acknowledged attempts made for his inclusion, which he chose to disregard. Similarly, Lucy held an unshakeable faith in her neurology teams, disregarding information contrary to this belief. The bias young people formed appeared to be drawn on affective interpretations of the interaction, and information was selected to substantiate these perspectives.

The above examples highlight how young people drew on information from their encounters to validate their interpretation of the interaction. Focused codes such as '*Selecting negative incidences'* and '*Focus on positive incidences'* highlighted how young people favoured certain

aspects to form opinions of an interaction, whilst disregarding others. As the analysis progressed through constant comparison, the theoretical category became saturated, and the final schema of 'validation' was organised through axial coding (Fig 17)
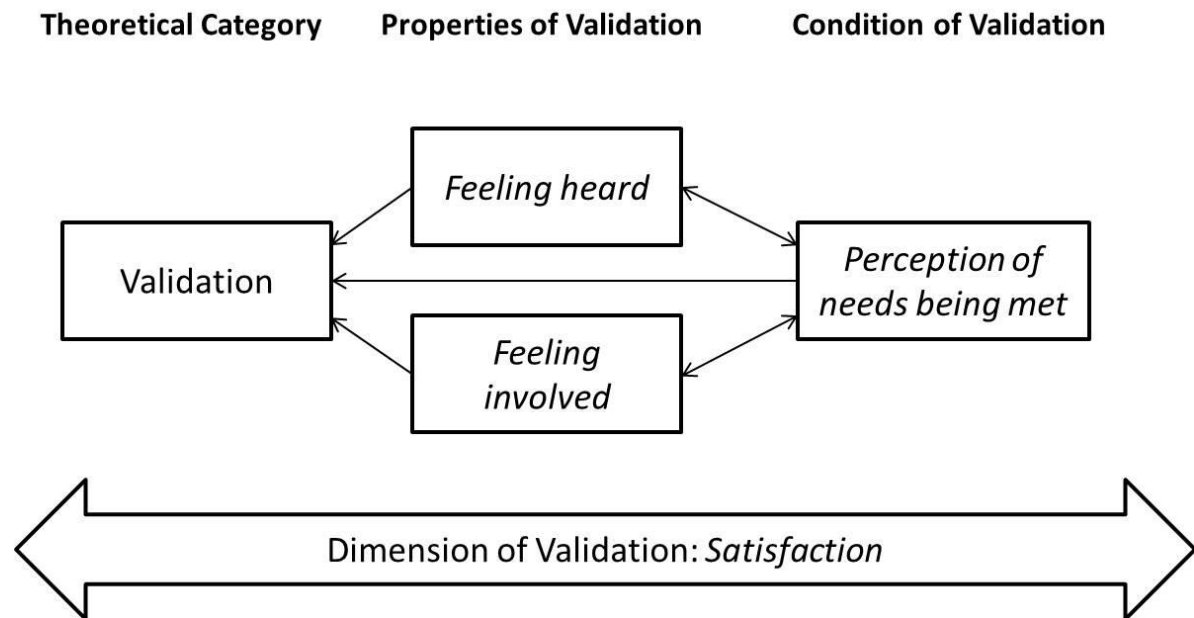
Figure 17: Properties, condition and dimension of 'Validation'

'*Feeling heard'* and '*feeling involved'* were identified as two closely related properties which defined how the selection of information was attributed, whilst '*perception of needs being met*' emerged as the condition that influenced how interactions were validated. These elements of validation operated on a dimensional range of *satisfaction*, identifying the sense of fulfilment the young person derived from the interaction they participated in. The following sections provide a description of these aspects of the theoretical category.

5.5.1 Validation: Properties, the Condition and the Dimension

Two properties of 'validation' emerged that identified the criteria by which young people gauged their perceptions of healthcare interactions: 'feelings of being heard' characterised

the means by which young people believed the extent they were listened to; and 'feelings of being involved' delineated the means by which young people perceived they were included in the discourse of the interaction itself. Both categories were closely related throughout the analysis, and ran alongside each throughout coding as meaning emerged. The following excerpt exemplifies the interconnectedness of the two properties:

Excerpt 22

> *"I went through a stage of pushing my fist against walls and rocks and stuff to take the skin of and it was the [CAMHS] nurse who saw that it was happing a lot and sat me down. I thought she was gonna get upset with me an' that, but she didn't, she just listened and let me get a lot off my chest an' that helped. After we talked about what we could do and that was really good 'coz she just listened and then we like figured out what was making it happen and sort out what I could do when I wanted to do it [self-harm]."*
>
> Zara

In excerpt 22 Zara clearly identified that feeling heard and involved in the interaction were key aspects of what worked for her. Zara explained that her feeling that the nurse listened to her experience of self-harm was both cathartic and an instrumental feature of the interaction that "figured out what was making it happen". Zara believed she was heard and involved in the discourse of the interaction, resulting in her believing the experience was '*really good'*. Interestingly, these properties of feeling heard and included were used as a standard by young people when they believed these aspects were lacking:

Excerpt 23

MarilynM   *[On being asked to recount an experience where an interaction wasn't perceived as good] The one who kept treating me like that [referring to feeling patronised by the urology nurse] "it was the one who was coming into the waiting room and putting on the false voice like [mimics fake saccharine tone] "how are you today?" I was like thinking do you even care about the answer?"*

Jason   *"Ah right. Is that why you thought it wasn't a good experience?"*

MarilynM   *"Well, it wasn't like really bad, like bad bad. I mean the medicine was helping [with night time incontinence] and that's what I wanted, but she just treated me like I was thick or something and everything was just something they expect you to go along with."*

In excerpt 23 MarilynM identified that the extent to which he felt heard or involved was important to how he determined the qualities of the experience with the incontinence nurse. MarilynM emphasised that, although the interaction wasn't '*bad bad*' because the medicine was working, the interaction itself made him feel that the nurse didn't '*even care*' about his responses. Without having the opportunity to be included or heard, he perceived the experience as something he was expected to passively '*go along*' with. These perceptions validated his belief of being '*treated like a kid*'.

As coding progressed, the properties reoccurred throughout data sets, suggesting feeling heard and feeling involved were key indicators as to how young people validated their perceptions of their interactions. As the properties became saturated, the 'perception of needs being met' was identified as a condition which interacted with these properties. The perception young people held of whether or not their needs were met affected the young person's sense of being heard and involved. The properties of validation were closely linked to whether the young person felt that specific needs were met, and how the process of

validation developed after a specific healthcare interaction. The below excerpt demonstrates the relationship between the formation of good perceptions in relations to the belief that needs were met by the interaction:

Excerpt 24

[on describing her opinion of interaction quality with the sexual health nurse]
"At the time I was, like, a bit worried like, 'coz I didn't know if I was or not [pregnant], and we was just like talking about options like, and what if and stuff and how I could like have options and like stuff like that, which helped. Then I got the results and I wasn't, which was lucky [laughs], but like knowing stuff now helps 'coz I know what to do in the future, like if it happens again and that I would go back for help."

Jane

Excerpt 24 identifies how Jane's positive account of an interaction with a sexual health nurse was developed by certain criteria she saw as important being met. Jane identifies that the indicators which improved the interaction were those that she found '*helped'*. Jane identifies that her initial anxiety was '*helped'* by being talked through scenarios and given options. She later identified that having such information '*helped'* her as she would know what to do in future situations. Perceiving her needs being met, Jane validated the experience by stating she would go back '*for help*' if needed. The repetition of the term help was significant, as it was closely tied to how Jane validated her experience of the interaction. Being '*helped'* entailed openly talking with the nurse to allow her to explore and understand her options. Being heard in the discourse and feeling included in exploring her options both reduced Jane's initial anxiety and empowered her for tackling future scenarios. In contrast to Jane's account, reports of bad experiences where identified when the young person felt they were disregarded, excluded from discourse or when their views were not sought. Initial codes such as '*being let down'*, '*feeling frustrated*' and '*not believing HCP'* influenced how young people

validated their accounts of being heard or included. Continued analysis identified that good

perceptions of the interaction were closely tied to the young person feeling their needs were

met and interaction, whereas negative accounts led to reports of dissatisfaction.

As coding progressed, a third conditional interaction was observed where there was

uncertainty as to the qualities of an interaction. The following exchange demonstrates how

doubt can impact on the perception of needs being met:

Excerpt 25

Jason   *"Can you go back to what you said about your GP rushing you? Why did you think he didn't care?"*

Lucky   *"Well, it's like I said, I'm all up for it like that normally coz I don't like wanna hang around, but I guess he was just acting like I was just another one in his day and stuff, it was just like [demonstrates bored face]. It's not like I thought it was personal or anything like that and I got it [referring to a prescription for a cold], but he didn't look at me and it was dead impersonal."*

Jason   *"So what was it that was bad if you got the prescription you needed?"*

Lucky   *[laughs] "I dunno, I mean it sounds daft when you say it like that. [Pause] I guess I got what I needed, but at the same time I think what if I had something important to say next time and he was too busy to hear it?"*

The exchange in excerpt 25 identifies that, by the GP treating Lucky as '*another one in his day'*,

Lucky doubted the GP's ability to listen if he had '*something important to say'*. Despite the

interaction having a clinical resolution that Lucky saw as appropriate, the perceived

impersonal approach of the GP caused Lucky to question if he was '*too busy to hear'* in

situations requiring sensitivity. Even though Lucky stated "I got what I needed", he questioned

the GP's integrity and ability to listen to him. This doubt was validated as it was something

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that he believed might become an issue *'next time'*. This suggested that validation about the qualities of the interaction were independent of the actual clinical outcome of the interaction. Across cases it transpired that young people often drew on their emotional reactions to justify their perceptions, suggesting that they had needs when entering into the interaction which differed from clinical outcomes. Memo writing was used to develop insight into the interaction of the condition with the properties.

Memo 17: Exploring the relationship between 'validation' and perception of needs being met

> 'Perception of needs' being met seems to be important in understanding how the experiences of interactions are validated by a young person. The conditional relationship appears to be dependent on whether the young person's self-identified needs were met in an interaction. This can differ from clinical outcomes as can be seen in instances where young people got what they understood as an appropriate clinical outcome, yet still felt unhappy with the interaction itself. Whereas the properties of validation influenced how the young person gauged their healthcare exchanges, the belief that needs were met or unmet appears to influence the young person's satisfaction with the outcome.

As analysis progressed, axial coding sought to determine the dimensional aspects to the theoretical category. 'Satisfaction' emerged as a continuum on which properties and conditions operated. For the purpose of this thesis, 'satisfaction' is defined as the feelings of gratification derived from the process of the interaction, and the feelings of needs being met from that were derived from the interaction. Satisfaction of healthcare experiences is an underexplored concept with children and young people, and a difficulty in forming a fuller understanding is the paucity of evidence in this area. LaValle et al. (2012) asserts children and young people are very rarely included in NHS quality and patient experience surveys, with

focus of such research and audits centring on adult care provision. Identifying satisfaction of outcomes based on a young person's identified needs became instrumental in understanding how satisfaction operated within the construct of 'validation'. Initial codes such as *'getting something/nothing out of it'*, *'feeling good/bad on reflection'* and *'liking/hating the process'* were examples that indicated satisfaction was implicit in post-interaction readings of experiences. As analysis progressed, insights were formed into how satisfaction interacted with the theoretical category components.
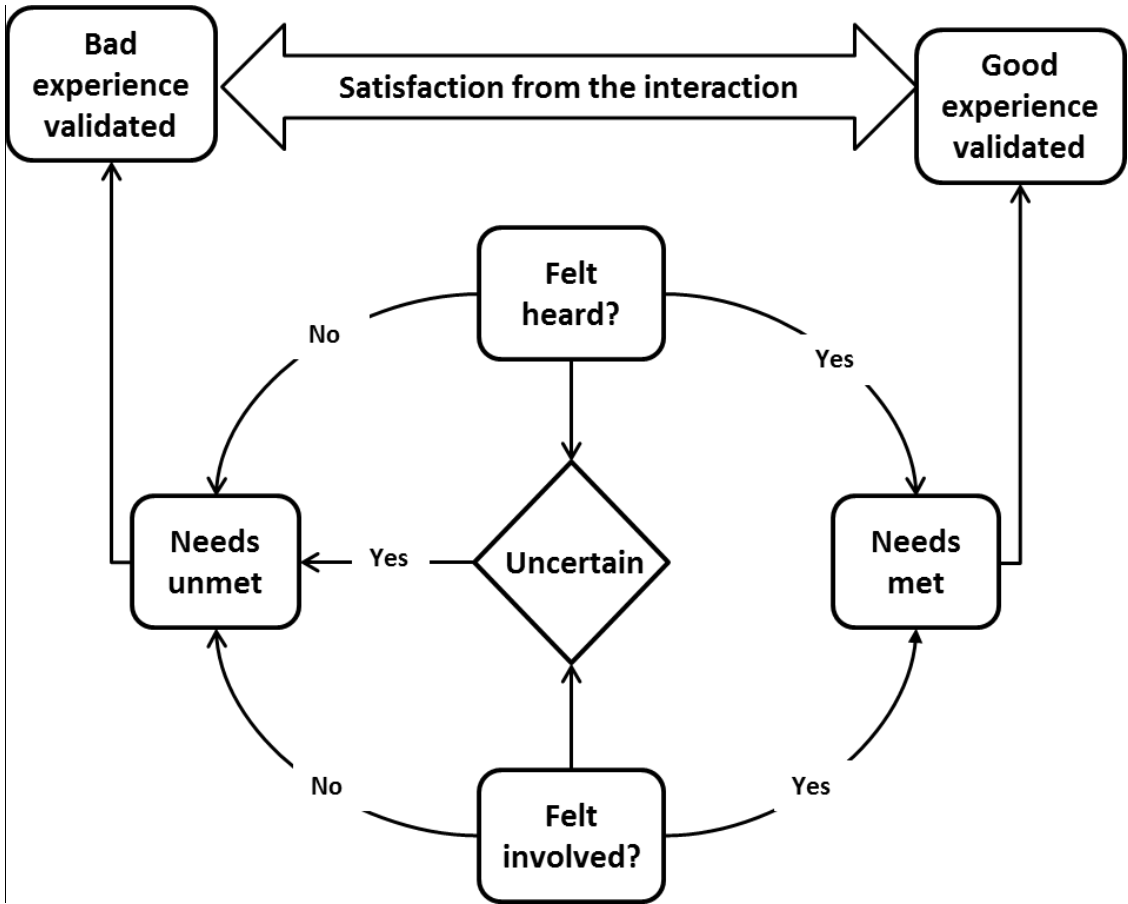
Figure 18:Explicating the dimension of 'satisfaction'

Figure 18 places the specific features of validation alongside a range of satisfaction. The process of validation of an experience occurred through young people's interpretation of

being heard and involved in their interactions. Where the young person could evidence that these feelings were met, then a perception of their needs being met validated the experiences as a positive outcome. In contrast, evidence of being excluded from aspects of the interaction, or uncertainty of the interactions' efficacy in these areas, led to the perception of needs not being met and poorer healthcare experience being validated. In terms of the study, satisfaction indicated the levels of experiences that occurred between these two poles, indicating the layers of satisfaction occurred on a scale throughout the meaning making process.

5.6 Conclusion
This chapter provided an account of the construction of three theoretical categories and the outcomes of analysis. Study findings highlighted that young people engage with healthcare professionals through psychological social processes, whereby they interpret and attach meaning to interactions to form action. Three theoretical categories were presented, identifying how young people interact in the healthcare interaction and form engagement-related behaviours: 'prejudgement' identified how young people shaped expectations prior to their interactions; 'learning to be a patient' detailed how young people develop patient behaviours through learnt responses; and 'validation' showed how meaning was attached to the young person's experience based on their perception of needs being met. The theoretical categories situated the young person within a dynamic process, whereby they perceived and interpreted meetings with healthcare professionals that influenced engagement-related behaviours. The following chapter discusses the key aspects of analysis, relating these to empirical evidence to support their theoretical resonance.

Chapter 6: Discussion of Theoretical Categories

6.1 Introduction

It has previously been suggested that a cultural shift is needed to correct power imbalances within children and young people's services to enhance a young person's participation and engagement (Royal College of Paediatric and Child Health, 2010). As such, it may not be enough to develop approaches that aim to better engage young people until the processes whereby engagement occurs are first understood. This chapter explores the key aspects of the theoretical categories presented in Chapter 5 to contribute to an emergent understanding of young people's engagement. By drawing on young people's perspectives of how they were treated by healthcare professionals, a new understanding of the social processes that affect their behaviours is possible, giving insight into what influenced how they engaged. The three categories identified above provided a preliminary step to understand these subtle social processes that shape how a young person's action in the healthcare interaction are formed; these are discussed below to expound their relevance to the concept of engagement. The theoretical categories contribute new insights into this area that might enable healthcare professionals to better understand what is happening for young people when they come to their healthcare meetings.

6.1 Prejudgement: Predictive Expectations and Their Influence on Engagement

The findings from prejudgement suggested young people formed predictions about healthcare interactions as an antecedent to actual healthcare meetings. These influenced young people's anticipations about future events. This occurred through interplay between two properties of the category, i.e. having frames of reference and having expectations, which saw young people draw information from a range of sources in order to feel prepared about

what would happen next. This appeared to suggest that the predictions young people formed were related to how they thought future events might play out. The notion that young people make predictions about themselves and their future care is interesting, as it highlighted how care recipient beliefs about the future could influence approaches to the interaction. This could equate into changing how young people act, as a young person's feelings about care can influence interrelational dynamics and participation (Kelsey & Abelson-Mitchell, 2007). Yet, despite literature exploring patient expectations receiving increased attention in healthcare literature, these studies have generally focussed on determining the effect expectations have on satisfaction of clinical outcomes of direct care (for example, see Meropol et al., 2003; Rosenberger et al., 2005). This area has yet to be extended into understanding how patient predication about care impacts on health decision-making or health-related outcomes. This is surprising as patient satisfaction of care delivery has received increased focus over the past 20 years (Bowers et al., 1994; Rosenthal & Shannon, 1997; Fan et al., 2005).

Despite the seeming lack of literature, it is helpful to turn to work that explores the relationship between concepts such as motivation, perceived control and how this influences a person's intent towards future behaviour. For example, the Theory of Planned Behaviour (Ajzen, 1986; 1991) addresses the extent a person feels in control and to how future behaviour is enacted; thus, perceptions about available resources, individual skill, and motivations toward an end goal lead to behavioural manifestations across contexts (Ajzen, 1991). Evidence supporting the utility of the Theory of Planned Behaviour has been provided in a meta-analytical review by Armitage & Conner (2001). The review appraised 161 empirical studies encompassing 185 clinical tests that explored measures of self-efficacy and perceived control over behaviour. Findings reported that current measures were useful to understand

relationships between desire, intention and self-prediction, which helped to predict future behaviour; however, it was noted that there was a variability of tools used across studies which called into question the validity of measures. Another meta-analysis by Mc Eachan et al. (2011) found similar results from the literature, concluding the Theory of Planned Behaviour was useful to understand intention and behaviour across a range of settings. Similar results have been identified with young populations, effectively predicting risk-taking behaviours such as alcohol use (Marcoux & Shope, 1997), smoking (Moan & Rise, 2006) and risky sexual behaviours (Buhi & Goodson, 2007).

Drawing on the notion that a young person's belief about future events could influence action was useful as it supported the importance of prejudgement as a theoretical construct, adding weight to the notion that, prior to a clinical interaction, a young person's cognitive processes could hold influence. Moreover, it seemed that an expectancy-value relationship (Montano et al., 2008) was present when young people were considering what they would do in future events; hence, the perception of outcomes of future meetings appeared to influence chosen behaviours. In this sense, predictive expectancies became meaningful to a young person's prejudgement of their situations. Generally, the predictions a young person made about their care helped them understand a future event, which appeared to aid them in figuring out how to approach what would happen next. Such expectations appeared to help the young person to manage uncertainty by determining what they thought would happen based on their rationalisation of events. By developing a belief about perceived control in future scenarios, young people appeared to be considering their volitional control in future events; this could relate to a social-cognitive perspective of health behaviour, as self-efficacy beliefs can determine outcomes and the ability to change (Bandura, 1997).

Although literature within social-cognitive psychology was useful to emphasise the emergent relationship between prediction and potential future action, there were few sources within healthcare extending this into anticipation of care and the potential impact on health-related behaviour; yet, as above, connections can be made. For example, Tuchman et al. (2008) observed that young people's anticipation of transferring from paediatric to adult care could evoke affective arousal resulting in feelings such as nervousness and unpreparedness. This was mainly due to not wanting to move on from long-term relationships with healthcare professionals; however, it was also noted that other patients' negative accounts contributed to fears. This seemed to reflect how hearing from others resonated in study findings. Similarly, in a systematic review of young people's perceived barriers in mental health services, Gulliver et al. (2010) identified young people had many fears surrounding help-seeking; these fears could deter a young person from using services. Interestingly, it was also noted that familiarity with services could also act as a protective factor when the service was viewed favourably, with young people who had prior contact reporting less anxiety about future contact. This could be due to young people with prior contact experiencing less uncertainty about what mental health services entailed; as such, having direct past experiences could be said to enable a young person to make predictions more easily about their future healthcare contact. These studies provide some support for the notion that frames of reference can inform anticipation about future events, which could be argued as influencing plans for future behaviour; hence, learning from the past, learning through seeing, and indirect learning may be useful constructs to understand expectation formation and predictions about future events.

As previously emphasised, the shortage of direct research in this area limits insight into how young people's expectations of care impact on their engagement. Where literature does exist, it explores expectations in relation to perceptions of received care and satisfaction of care quality; for example, in a prospective study of young service user's satisfaction of the mental health services' they use, positive expectations prior to use were identified as closely related to higher satisfaction levels of the service and of mental health professionals (Garland et al., 2000). The study's reported findings were similar to trends within adult care services, with expectations being a key predictor of levels of satisfaction. In a similar approach, Haller et al. (2007) conducted a cross-sectional study of Australian adolescents' expectations of GP visits, and reported that a young person's expectation for receiving good-quality treatment and communication was a high priority. However, reported expectations were derived from qualitative interviews using the Short Explanatory Model Interview, which is not known for its psychometric validity for patient expectations. In addition, the authors did not specify whether the measurement of expectancy was about preference for care, or about assumptions of care. This has been identified as a critical distinction as it determines whether it is values or beliefs that are being explored (Bowling et al., 2012). However, Haller et al. (2007) did observe a mismatch between young people's expectations prior to contact and a mismatch upon service receipt, suggesting that the study explored the young people's values for preferred care. In this respect, the findings of Haller et al. (ibid) were dissimilar to the findings within this thesis, as assumptions of upcoming care were significant in influencing a young person's behaviour towards future action.

Collectively, the theoretical category prejudgement highlighted that predictions about future experiences were useful to young people as a preparatory action. Identifying between

different expectancy constructs heightened the significance of prejudgement as a precursor to engagement, which was further enhanced by acknowledging predictive expectations of work on normative principles that determine consequences, relationships and contexts (Griffin & McClish, 2011). This resonated with the findings of this study, as young people were constantly gauging what healthcare professionals might do based on what they already knew about their situations. Moreover, predictive expectations have been said to encompass complex affective and cognitive processes that shape subjective interpretations of probability and causality (Bowling et al., 2012, p.5). Again, this was apparent, as young people were concerned with how they might feel based on what they already knew about what participation in healthcare interactions made them feel; in this sense, affective appraisals were a way to moderate behaviour in relation to an anticipated future-self. For the young people in this study, prediction of future events was situated in their world view, influenced by how they saw themselves, and contextualised by the sources of knowledge they drew on to shape their assumptions about future events. This helped them to prepare themselves in relation to their beliefs about event outcomes and potential consequences from meetings.

6.2 Learning to Be a Patient: The Significance of Contextual Influence

The theoretical category 'Learning to be a patient' highlighted various processes that enabled a young person to understand and adapt in healthcare interactions; this was emphasised as having a dynamical nature, whereby engagement was shaped by learning and adaption. Moreover, how young people situated themselves as a patient in relation to their experiences was significant as it encapsulated the tensions a young person felt within the healthcare context. This echoed findings from a literature review by Doherty & Stavropoulou (2012), who found patients could assume passive approaches in healthcare interactions due to a fear of

being seen as "difficult"; this was due to a belief that clinicians may respond negatively to being questioned and deference was a way to protect personal safety. Similarly, the finding of this study suggested that passive behaviour was an adaptive response to perception of interaction dynamics and a young person's individual beliefs. This reflected a common theoretical theme in the study in terms of how young people formed their action and shaped behaviour in situations unfamiliar to them.

Enactments of social roles are considered to be unique expressions of the self, which are informed by an individual's interests, beliefs, values (Keilhofner, 2008). Cultural, institutional and socioeconomic constraints are also understood to make demands of an individual's expression of the self and set expectations of what actions can be performed in any given context (Kinébanian & Stomph, 2010). Social roles can, therefore, be understood as complex manifestations which occur through an interaction between individual ability, contextual expectations and socio-environmental constraints; hence, roles are contextualised sociocultural phenomena that occur through individual perception of self-efficacy and environmental mastery (Nelson, 1988). Moreover, within a life course perspective, adolescence has been argued as a transitional period marked by a crisis between identity integrity vs. role confusion, with new behaviours emerging alongside social skill development and one's own self-perception (Erikson, 1963; 1980); hence, there is a relationship between what a young person does and their self-perception of whom they are. This resonated with the theoretical category, as young people's narratives suggested 'figuring it out' was important to their learning and understanding. How young people performed their social roles could, therefore, be argued as important to their future self, emphasising a linearity between their existential states and potential becoming and sense of belonging (Wilcock, 1998; Hitch,

2014). Enactment of the patient role informed the way the young person engaged, which shaped patient behaviours in present and future events.

In addition to the psychosocial aspects of role development and enactment, another important aspect to consider is how Individual personality traits impact on authentic self-expression and a person's self-organising behaviour. Psychology literature has broadly researched these concepts in relation to five general personality domains: neuroticism, extraversion, agreeableness, openness and conscientiousness. This five-factor model has been widely reported as influencing self-expression, interaction formation, relationships development and goals attainment (Roberts & Robins, 2000; Sheldon et al. 1997; Steger et al., 2008). The significance of this area of psychology has had far-reaching consequences in terms of how personality is understood to influence behaviour. Empirical studies have further demonstrated how expression of an individual behaviour operates within a five-factor model, as underlying traits influence how a person presents. An example of such work is best demonstrated by Digman (1997), who concluded from a meta-analysis of the literature that social navigation and integration could be understood through alpha and beta super factors; these factors were interpreted as two higher-order personality dimensions known as stability and plasticity, which determined how adaptive responses form in relation to situational stimuli. Such studies could potentially be useful to provide insight into why the young people of this study responded to healthcare interactions as they did; however, it can also be argued that a limitation of this interpretation is that poor engagement is a result of a young person's personality traits. Such a reading could be deemed superficial and would not account for context.

Following on from the five-factor model of personality, there has been some debate as to the significance that environmental context has in understanding behaviour in contrast to static personality traits; for example, Fleeson & Wilt (2010) explored two hypotheses to investigate the relationship between personality and behaviour. The first hypothesis explored trait consistency and behaviour as congruent, whilst the second hypothesis drew on the assumption that behaviour is context-dependent and separate from an individual's character. Through a series of studies in both laboratory and natural settings, Fleeson & Wilt (ibid) found the hypothesis that behaviour is context-dependent held true, whilst a congruence between trait consistency and behaviour could not be verified. Another investigation by Szymczyk (2010) that explored the relationship between behaviour and environmental context found similar findings, suggesting individual presentation of the self is accentuated or moderated across settings and social contexts. Collectively, this suggests that behaviour may be more related to psychological states within given contexts as opposed to a personality trait congruence across events, supporting prior criticisms of a five-factor approach to personality variation as merely an observational account of personality 'clusters' rather than workable models to understand behaviour (Bloc, 1995; 2001; 2010). In relation to this grounded theory study, this may mean that a greater awareness of context, and dynamics within such contexts, are important to how a young person enacts their engagement, as was reflected by the identification of four learning approaches (avoidant, cautious, receptive, and self-assured). However, further investigation would be required to confirm that such a relationship occurred.

6.2.1 A systems Approach to Learning

The feedback a young person received and responded to in interactions was a key aspect that shaped motivation towards, and regulation of, behaviour. This feature of analysis was significant as it highlighted a complex interface between young people and context, whilst

enhancing sensitivity towards engagement as a complex processes, continuously developing through the experience of action. This interpretive-adaptive process identified that young people intuitively formed and actioned responses to stimuli, suggesting behaviours were instinctive and self-organising within the healthcare context. As pointed out earlier in this chapter, this appeared to replicate a dynamic systems perspective of human behaviour as action is motivated, patterned, performed or constrained through the interaction with physical, social and cultural environments (Aldrich, 2008).

Systems theory has been expounded across different professional literatures, while variants of it have been used within young people studies to offer insight into individual-context relations, behaviour and adolescent development. This is largely due to efforts within psychology and the behavioural sciences to understand intrinsic motivation and resulting action when faced with environmental feedback (Schneider, 2001). For instance, within the education and adolescent development arena, Spencer et al. (1997) used an ecological systems theory approach to explore the academic competence of African-American middle school students aged between 14 and 17. Analysis focused on the risk factors associated within the school contexts, whilst coping strategies were explored in terms of reactive or stable natures. The study findings suggested that systems theory was useful for gaining insight into young people's perceptions of contextual situations such as social support, which shed light into beliefs and behaviour enactment.

Other variants of systems theory used within developmental sciences draw on a developmental-systems approach to adolescent maturation and change across the early life course (Urban et al., 2011); for example, Albrecht et al. (2007) explored adolescents'

perceptions of parents' psychological control over a two-year period to investigate the effect on young people's behaviour. Findings found correlations between self-reported behaviours, such as aggression, and perceived parental control. The study findings suggested a relationship existed between these two factors, with aggression exacerbated by perception of increased control. This appeared to support the notion of a dynamic relationship between young person and context, which influenced actual behaviour. Within a health behaviour context, versions of systems theory have been used to understand how social contexts can influence healthcare behaviours. Knauth et al. (2006) tested the credibility of Bowen's family systems theory (1966; 1978) as an appropriate method for identifying young people's risk behaviours. Findings confirmed that a systems approach was useful for identifying cognitive factors relating to a young person's differentiation of self and social problem-solving behaviours. Anxiety, motivation and self-management skills were correlated with risk-taking behaviours such as drug use and sexual activity, confirming that lower levels of self-differentiation were related to higher risk-taking behaviours. However, the study used a convenience sampling strategy, which has limitations in terms of transferability of results. Despite this, it is interesting to note that the systemic relationship between context and health behaviour held true.

In relation to the findings in this study, theoretical and empirical literature appears to support the notion that young people's engagement was influenced by perceptions of their healthcare context, whilst behaviour was organised and produced in response to in-context stimuli. A key aspect to the analysis of learning to be a patient was the dynamic system relationship that influenced how learning approaches were used and how roles were adopted. In relation to understanding engagement, the theoretical category identified that learning was a feature of

this process, with positive and negative reinforcement impacting on engagement dynamics. Equally, when a young person had already learnt how to interact within a given context there were less demands placed on them, requiring less active interpretation and adaption. These features of the data could be said to be due to the young person's interpretive meaning-making process becoming less pronounced as the young person's understanding of events became consistent with their expected feedback; hence, behaviour naturally adapts within a systems interface (Hamdani et al., 2011). The findings of the second theoretical category provided insight into this occurrence in relation to how young people developed their behaviours, ultimately shaping a sense of self in the patient role.

Collectively, the category 'learning to be a patient' suggested that engagement occurred within the context of each healthcare meeting, but also developed over time. Developing insight into the healthcare interaction as a dynamic system could provide significant benefits for understanding how healthcare professionals approach interactions with young people; however, further investigation would be required to determine the application of systems thinking to young people's healthcare engagement.

6.3 Validation: Having Needs Met
The final theoretical category 'validation' explicated a relationship between the meaning young people attached to the healthcare interaction experience based on a perception of needs being met. This can differ from a healthcare professional's perception of a patient's needs. For example, in a literature review for a medical centre case study that details the use of a novel problem-solving model, Tracy & Ceronsky (2001) identified that healthcare professionals prioritise patient needs differently from the patients themselves. Drawing on literature of care in complex settings, Tracy & Ceronsky suggested that, although healthcare

professionals may rate patient health needs, similarly patients themselves hold different priorities and place greater emphasis on communicational and international dynamics. The incongruence between these perceptions of needs may have wide-reaching consequences on care delivery and the patient experience, which was reflected in the findings of this study; for instance, an important aspect of the category was the importance for young people to feel heard and feel involved in healthcare processes.

The relationship between perception of needs and validation of perspective emerged as an important aspect as to how engaged a young person felt following their interaction. A young person's experiences of being included in communicational and decisional aspects of care can often be a difficult, suboptimal to those of adult patients; this was demonstrated by Hargreaves and Viner (2011), who conducted a comparative review of the experiences of children and young people (<24) and adults (25+) from national surveys over a ten-year period. Analyses of data used a binary system identifying care outcomes as positive or negative experiences to enable statistical comparison between the two age groups. Findings identified that, unlike adult populations, children and young people often felt excluded until the age of 20; however, after 20 years of age no significant statistical differences occurred between older age groups. Results could be interpreted many ways; for example, a developmental perspective of skill acquisition may suggest that, after this age range, young people had become more autonomous, thus improving their interaction experience; another interpretation may be that, in later years, young people were treated differently by a healthcare professional. However, caution is advised when interpreting results in such a way as there may be many additional factors that contribute to findings. Despite this, it is pertinent to note that young people experience less satisfaction in relation to being included in aspects

of their care, and that a disparity exists between what young people want from care and what they receive.

In relation to qualitative literature on the subject of young people, young people will have both positive and negative experiences from healthcare interactions, which is largely due to how they are treated by their healthcare providers. In a grounded theory study of hospitalised children aged between 9 and 15 (n=11), parents (n=10) and nurses (n=12) across four paediatric wards in two English hospitals, Coyne (2006) found that the children and young people largely desired to be consulted on and about their care. This translated into children and young people wanting to be involved in decisions about care, and having their opinions about care and treatment listened to; this resulted in higher satisfaction levels of and increased self confidence in themselves as a person with "rights". Conversely, reports of "lip service" were associated with a lack of involvement and tokenistic gestures of inclusion that resulted in feelings of anger and frustration. Similar findings were reported by Colton et al. (2004) in a qualitative study of young women (n=19, age range 12 to 17) from two inpatient eating disorder units. Interpretive phenomenological analyses identified "collaborating in Treatment vs Being Treated" was a valued aspect of treatment that included being involved and being heard in therapeutic care. Although this theme also included personal tensions of control within the recovery of their eating disorder, the degree to which young people perceived healthcare professional collaboration was stressed as an important aspect of their narratives. In the same vein, a meta-analysis of qualitative research (studies n=14) exploring looked-after children's views of mental health services was conducted by Davies & Wright (2008), who found that the experience of being heard and understood was an important feature of effective care and impacted on treatment responsiveness. Due to the vulnerable

nature of looked-after children, and given that previous interactions with adults may potentially have been damaging, this feature of analysis was stressed as highly significant. Although of a highly specific context, the study of Davies & Wright (ibid) identified perceptions of being heard as a key aspect of good care, and was important for young people to build feelings of trust. However, a lack of transparency in this work compromises systematic rigour; for example, both child and adolescent participants were included in the study, yet the actual age range and distribution of the meta-analysis were not reported. Caution should be used when interpreting results specifically in relation to young people.

Interestingly, not all literature provided a consistent perspective. Van Staa et al. (2011) reported that, within an inpatient hospitalised setting, Dutch children and young people ranked being heard as low importance when admitted into care. The study used a mixed methods approach that drew on semi-structured interviews to collect detailed information about conditions and care receipt, which was later thematically sorted into a questionnaire in which young people ranked preferences of service delivery. The development of this tool enabled young people to prioritise aspects of care that were most important to them. It could be argued that these seemingly conflicting findings reflect a young person's concerns within the hospital context, meaning immediate health concerns took precedence in their current situation. As such, the findings of Van Staa et al. (ibid) may mean that, when acutely ill, a young person places lower importance on interpersonal aspects of care and that feelings of sickness/wellness may influence preference in different settings. However, a critique of these findings is that the mode of data collection and analysis may have created a methodological constraint; for instance, ranking preference of what is important to young people may provide an askew perspective when a young person is acutely ill. Although a young person may rank

'being heard' as less important than 'avoid pain and discomfort' or 'keep in touch with home', this does not necessitate that the ability to be heard was not important. Rather, immediate needs for avoiding discomfort and feeling secure became more relevant at that specific time. As such, a subtle presentation bias may have occurred that presents "being heard" as "low priority".

In relation to the findings of this study, the literature supported that being heard and involved is important for young people as it was associated with their perception of met needs, and such perceptions shaped opinions of care. This suggests that understanding such needs, and how to work with young people to meet these needs, could improve relationships with healthcare professionals. However, no studies were found within healthcare literature that could identify why validation was important to a young person in terms of healthcare engagement and, in this respect, this grounded theory study provided a novel insight into this process. The analysis of validation highlighted the healthcare interaction as an experiential learning endeavour consisting of reflection on the event. This provided insight into how young people understood engagement on a personal level, elucidating a meaning-making process which they developed from their personal experience. Collectively, the three theoretical categories provided an understanding of key processes that occurred within interactions with healthcare professionals, providing insight into how levels of engagement were developed and experienced by young people in the study.

6.4 Learning to Engage: A Collective Account of Theoretical Categories

Listening to young people's perspectives about care delivery and quality is acknowledged as being of vital importance in order to improve and develop youth-friendly services (Department of Health, 2006; 2007); this is emphasised by core values such as beneficence,

justice and respect for autonomy to ensure young people receive quality services that meet their needs. Equally, the views of young people need to be fully understood in order to have any significant impact on improving care quality (Royal College of Paediatric and Child Health, 2013). From a wider perspective, involvement of young people in youth-friendly services should work around a young person's individual needs and takes into account their views. However, this is not always the case. For example, cultural barriers in the NHS can lead to young people and their families struggling to be involved in their care, whilst the communication and information that surround care delivery can inhibit their understanding and subjugate participation (Kennedy, 2010). As such, the findings from the theoretical categories are significant as they were derived from young people's perspectives to demonstrate how young people experienced and responded to the services they received. Moreover, genuine engagement of young people in care has been acknowledged as vitally important for young people to become actively involved in their health-related goals, whereas false participation and tokenism can inhibit such participation (Royal College of Paediatric and Child Health, 2010). This study found similar themes throughout the patients' narratives; young people felt anger, frustration or patronised across a range of issues such as referrals, jargon and perceived coercion by the healthcare professional. Moreover, feeling judged, ignored or not listened to were universally acknowledged as upsetting features of care delivery, which has been previously identified as a deterrent to a young person's engagement in their healthcare (Kapur et al., 2014; Robinson, 2010).

Collectively, the findings of the theoretical categories supported the notion that young people were learning about themselves in their patient role. The theoretical categories provided a clear account of how young people learnt in and from healthcare interactions, which

influenced action for healthcare meetings. Building on the theoretical categories provided insight into how such action was stimulated and shaped; hence, how a young person experienced and understood the healthcare interaction were key factors as to how they engaged. Drawing on a systems theory perspective strengthened this account of findings, as it highlighted engagement as an ongoing learning process. This also fit with a developmental perspective of adolescent learning, as young people are developing cognitive control systems to moderate social-affective processes (Crone & Dahl, 2012). Alternatively, the findings could be understood within a social-cognitive perspective of health and behaviour, which would emphasise the importance of belief constructs about the self, the social environment, and the consequences of action on behaviour (Conner & Norman, 1996; Conner & Norman, 2005; Armitage & Conner, 2000; Baiocco et al., 2009). This may provide some support as to why self-agency and perception of locus of control were important to the young people in this study, which would situate the young person as "self-organising, proactive, self-regulating, and self-reflecting [as] they are contributors to their life circumstances not just products of them" (Bandura, 2006, p.3). In this respect, motivation towards behaviour is a product of habit and the contextualised beliefs about the self (Bandura, 2004).

The summative account of analysis suggests that engagement developed for young people as they learned to respond in the healthcare context; in turn, this appeared to shape their understanding of themselves in their patient role. Turning to a pragmatist perspective of learning, Dewey (1938) suggests learning occurs as an experiential cycle, within a process of continual feedback, which transforms direct experience into purposeful action. This is explained as follows:

"The formation of purpose is, then, a rather complicated intellectual operation. It involves: (1) observation of surrounding conditions; (2) knowledge of what has happened in similar situations in the past, a knowledge obtained partly by recollection and partly from the information, advice, and warning of those who have a wider experience; and (3) judgement, which puts together what is observed and what is recalled to see what they signify. A purpose differs from an original impulse and desire through its translation into a plan and method of action that is based upon foresight of the consequences of action under given observed conditions in a certain way."

(Dewey, ibid, p.69).

The above explanation suggests that learning occurs as continual processes from engagement with context, internal processes that form meaning within an event, and planned action. This model is useful to elucidate the interaction aspects that shape personal meaning making when formulating action; indeed, even though Dewey's account of learning focuses solely on conscious and deliberative thought, it may also be useful to understand learnt behaviours. For example, the interplay between recollected past experience can, in relation to present surrounding conditions, may contribute to 'feeling upset', 'being angry' or 'fearing for the worst'; hence, the action that follows may arise due to an automatic reaction based on past experience and present concerns. Returning to Dewey's account of learning is useful in order to explicate how personal meaning making develops:

"When we experience something we act upon it, we do something; then we suffer or undergo the consequences. We do something to the thing and then it does something to us in return: such is the peculiar combination. The connection of these two phases of experience measures the fruitfulness of experience. Mere activity does not constitute experience."

(Dewey, 1916, p. 104).

Dewey (ibid) suggests that action alone does not denote meaning, but rather it is the consequences of action that shape how meaning is formed. This would certainly fit with the

findings of the study, which suggest that engagement is both an immediate outcome from the reciprocal actions within an interaction, but also a complex process that spans across time, context and life stages. The meaning a young person ascribes to engagement can, therefore, be argued as existing on both micro and macro levels.

6.5 Conclusion
This chapter explored the key aspects of the three theoretical categories presented in Chapter 5, and discussed some of the social processes that shape how a young person's action within a healthcare interaction is formed. First, predictive expectations were explored, drawing on the literature to expound how beliefs about future events influence a young person's behaviour and, potentially, their engagement. Second, the enactment of behaviour within the healthcare interaction was discussed in relation to context dependant psychological states; this led to an exploration of how learning approaches were used and how roles were adopted from a dynamic systems theory perspective. Thirdly, the perception of needs being met was discussed in relation to the young person's personal meaning-making processes of validation. The chapter concluded by discussing the healthcare interaction as an experiential cycle in which learning occurred. Collectively, the three theoretical categories provide new insight into some of the key processes that occur when young people interact with healthcare professionals. The following chapter builds on these findings to identify a core category from the data, which will be shown to underpin a substantial theory of young people's engagement in healthcare interactions.

Chapter 7: The Core Category

7.1 Introduction

Theoretical construction concludes with the identification and integration of the core category. The core category provides insight into the dynamic occurrence of a phenomenon and the circumstances by which it is shaped, thereby shedding insight into how human behaviour is patterned within the processes of social interaction (Birks and Mills, 2011). By exploring the meaning that a person attaches to their experiences, and by determining how a person understands a phenomenon or encounter forms their action within a social context, it is possible to gain insight into the volitional motivations within a person's worldview (Charmaz, 2006; 2000). It is through defining how and why social processes occur that the nature and origins of the phenomenon can be understood, providing an explanatory schema to understand the occurrence of social process (Mills et al., 2008). In this chapter, heuristic processes that rely on affect are identified as a core feature of study data. The chapter first provides an overview of the core category and follows by detailing theoretical construction to document the conceptual rendering of data. Analyses revealed that affect may shape a young person's intuitive reactions, influencing perception of, and behaviours within, interactions. The following sections explicate a dual process perspective of cognition as a core process of how engagement is enacted by young people, raising this concept into a substantive theory of affect-mediated engagement.

7.2 Locating the Core Feature of Analysis

The findings presented in Chapter 5 expounded three processes that explained how young people within the study formed interactions with healthcare professionals. The data revealed insight into young people's descriptions of both good and bad experiences, with analysis

suggesting that engagement is a complex occurrence involving interpretation, adaptation and skill development. The theoretical categories were achieved by exploring young people's perceptions of their interactions and the beliefs that they formed surrounding interpersonal relationships with the healthcare professionals with whom they met. The first theoretical category, prejudgement, inferred that young people anticipate interactions with preformed notions. These notions influence beliefs and expectations about healthcare professionals and healthcare interaction. The second theoretical category, learning to be a patient, suggested that young people develop behaviours in interactions as an adaptive learning process. The third category, validation, identified that young people reflected on interactions in terms of whether they believed that their health care needs were met or unmet. The theoretical categories provided insight into the meaning that young people attached to interactions with healthcare professionals, and explicated how such meaning shaped their perception and enactment of engagement. Overall, analysis suggested that healthcare interactions are a dynamic occurrence, with engagement facilitated or inhibited throughout the interaction process. To determine a central feature of analysis, it became essential to weave back together theoretical concepts to create a unifying narrative. Figure 19 (below) provides an overview of the analytical processes which led to core identification.
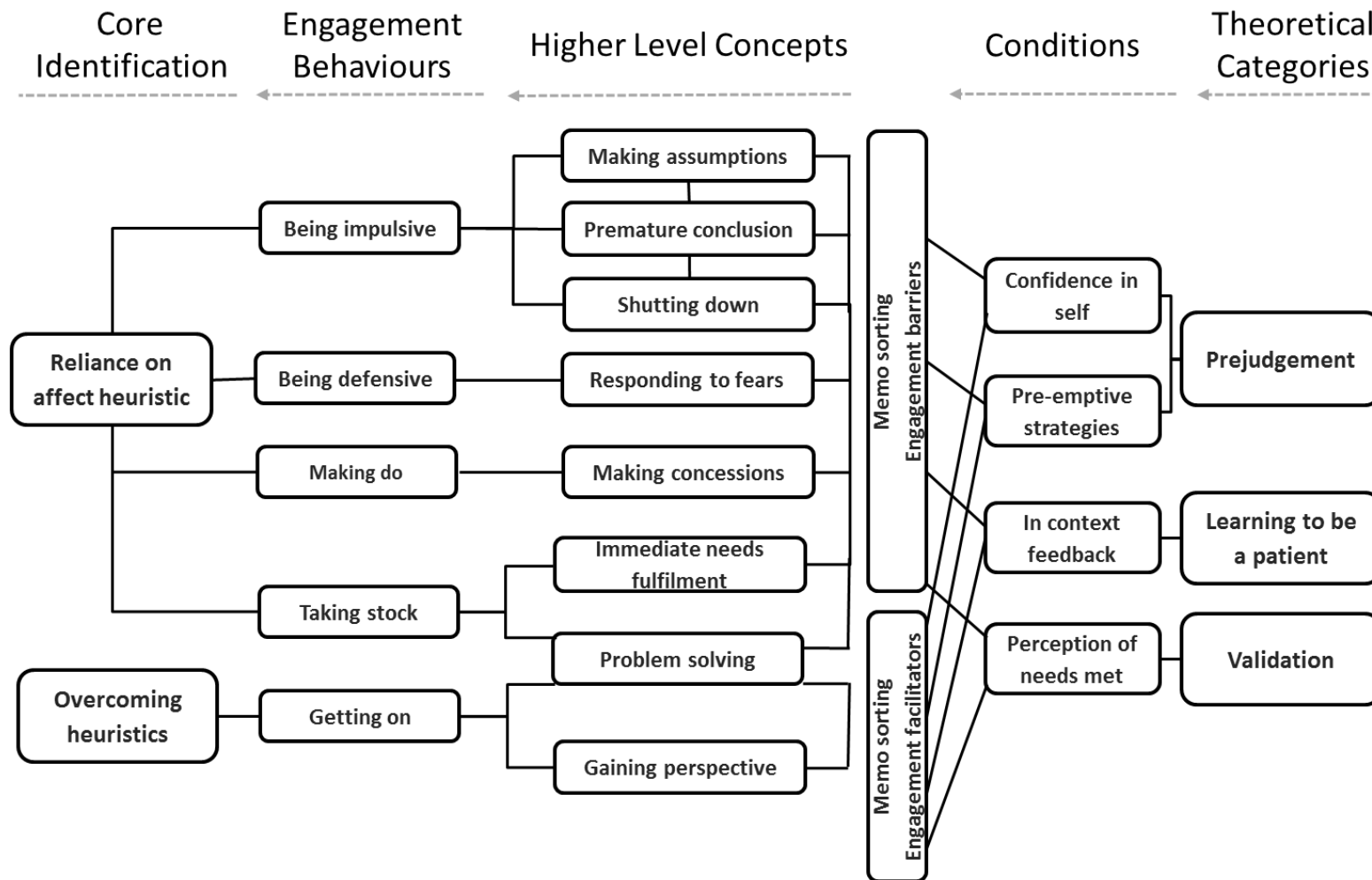
Figure 19: Analytical synthesis leading to core category integration

Revisiting coding, transcripts and memos from theoretical category construction provided insight into how young people perceived their interactions and formed beliefs within their interactions (right). Throughout analysis, codes such as 'feeling frustrated', 'feeling lost', 'being made to feel wrong', or 'being let down' exemplified and encapsulated the use of emotive language, illuminating how affect, the feeling state associated with emotion, influenced perception and belief about participation. By becoming immersed in data, coding and theoretical memos sensitivity was fostered, expounding how covert psychological processes operated when young people engaged or disengaged. Next, memos were sorted theoretically to make distinctions between young people's perception of barriers and facilitators to engagement (centre right). From these processes, the visceral nature of affect emerged as a core feature of data, enabling insight into attitudes and behaviours that affected the outcome of interaction participation (centre left). The experience of emotion, or the feeling state associated with emotion, emerged as being significant to young people's narratives about meetings with healthcare professionals. Heuristics, the cognitive processes described as instinctive mental shortcuts (Alhakami & Slovic, 1994), are said to be adaptive psychological processes that simplify information to aid in problem-solving situations. The core was identified as a young person's reliance on, or ability to overcome, heuristic processes stimulated by the experience of affect (left). The role of the affect heuristic will be discussed a length in section 7.2.2. As the final stages of analysis reached theoretical maturation, the features of the core category were clarified through memo writing.

Memo 18: Explicating heuristic approaches as a feature of the core category

<table>
<tr><td colspan="2">The heuristic approaches that young people employ in response to conflict situations appear both to be facilitated by affect, and to result in validated beliefs based on their emotional response. These processes impact how young people behave, manage, moderate, navigate or protect themselves in interactions, which ultimately impact on behaviours demonstrated in interactions, ergo influencing how they engage. The perceived immediacy of emotion can take precedence over the interaction outcome itself, resulting in heuristic processes that mediate engagement. The heuristic process can, therefore, be said to be significant as they drive and legitimate young people's responses.</td></tr>
<tr><td>What connections can I make?
A connection exists between the heuristic processes that young people draw on, and the behaviours that they employ. When young people responded with negative urgency, lower reports of participation occurred. Conversely, young people who self-regulated engaged better.</td><td>What is the core feature of the data?
Engagement is influenced by young people's reliance on, or regulation of, the affect heuristic. These automatic cognitive processes influence how young people participate and engage.</td></tr>
<tr><td>What is the impact of this feature?
The affect heuristic can produce negative outcomes when strong emotion is present. Conversely, affective regulation may be a means by which affect is overcome, facilitating engagement.</td><td>What does this suggest?
Negative affect formed in healthcare interactions seems to be related to how young people shape their behaviors. How young people manage these emotions influence levels of engagement. Engagement appears to be mediated by the role of affect within interactions with young people.</td></tr>
</table>

The identification of 'the affect heuristic' as the core category initiated a line of inquiry into how the experience of strong emotion can influence, develop and define a young person's behaviour when working towards engagement. Elaborating on the analysis highlighted the mediating influence that affect had on young people's behaviour, shedding insight into how emotion may operate as an intrinsic barrier or facilitator when forming relationships with healthcare professionals. This appeared to suggest that young people's ability to develop and maintain engagement in healthcare interactions was dependent on their ability to moderate the experience of emotions and develop regulatory mechanisms for management of affect.

The analytical procedures used in the study became a significant feature that refined and integrated the core category. This analytical process supported the development of the core category and provided an abstract rendering of data, which was important to identify the central variable of the data that unifies the theoretical schema (Strauss & Corbin, 1990; Stanley & Cheek, 2003). The following sections detail the development and theoretical integration of the core category, as depicted in Figure 20, situating heuristic processes based on affect as central to young people's development of behaviours that facilitate or inhibit engagement.
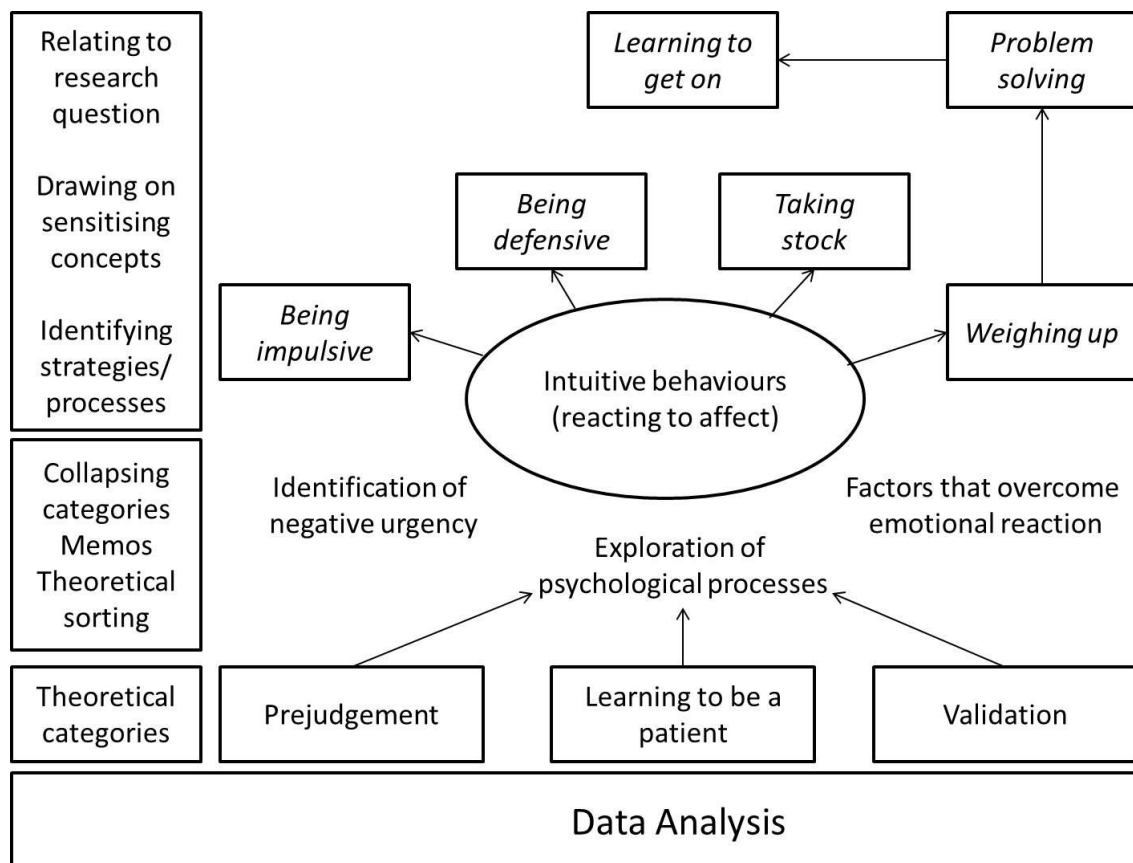
Figure 20: Development of the core category

In order to develop the core category memos were written throughout, and analyses revisited and sorted into themes such as 'managing conflict', 'being treated unfairly', 'learning to cope'

and 'getting on with them'. Memos were labelled and compared against other memos, with further memo writing being undertaken to develop new theoretical formulations and bring early theoretical insights to maturation (Charmaz, 2006; Corbin & Strauss, 2008). As identified in the previous section, strong emotion was a significant feature of the data. Early stages of analysis focussed on subsuming common features of previously analysed data to explore relationships between emotional charge (i.e. how young people felt about in their experiences) and reports of their actions (i.e. their approaches towards interaction participation). Initially, 'having strategies when upset' was identified as a key process that linked together young people's feelings about events and how such feelings influenced their participation. Other category groupings identified 'impulsive reactions' as meaningful to how young people responded when feeling upset, typifying instinctive reactions in response to strong emotional charge. Categories such as 'giving in' characterised the relationship between emotion and believing oneself unable to effect change, whereas 'defending against being hurt' identified protective behaviours developed in response to fears. Interestingly, early memos relating to 'getting on' with healthcare professionals shed light on 'figuring things out', explicating young people's role in developing approaches to manage emotions and working with healthcare professionals. As the analysis progressed, 'having strategies when upset' was renamed 'reactions to affect' as the term 'strategies' inferred that young people made conscious choices when upset. Memo sorting became a crucial aspect of theoretical development, consolidating disparate theoretical explanations development into a unifying narrative. Sub-categories were refined as 'being impulsive', 'being defensive', 'taking stock', 'weighing up' and 'problem solving'. These are discussed in detail in the following sections. As sorting and refinement progressed, it became apparent that emotion played an instrumental role in how young people participated and was an important feature that could impact on

engagement. The relationship between emotional charge, and the processes that brought about engagement, became important to explore.

Memo 19: Exploring the significance of affect in engagement

From the start of core category analysis I've been conscious of the need to develop a deeper insight into what is happening when young people interact with healthcare professionals. The theoretical categories provided insights into the processes young people moved through as they met up with and interacted with healthcare professionals, yet after this analysis an ambiguity remained as to why such processes occurred. I became conscious of the need to move past descriptive accounts of social process and revisit data to explore underlying mechanisms that act as a motivational force for engagement. Highlighting the experience of emotion as integral to young people's engagement seems very relevant, as it provides a new way of looking at data to identify psychological mechanisms as to why engagement occurs. As comparative analysis progresses, it seems to suggest that a hermeneutic function is present when young people experience emotion in the context of a healthcare interaction, influencing event appraisal, interpretation of interactions, and decisions about participation. Identifying this process seems important as it highlights how young people attribute meaning when forming responses. I think the predominance of emotion is in itself unsurprising, as adolescence is known to be a period of rapid psychosocial, neurocognitive and hormonal change which influences both mood and emotion (Steinberg, 2011; Albert & Steinberg, 2011). I think it's also important to acknowledge that social exploration and behavioural experimentation is a marked feature of psychological maturation, providing young people with a way to develop new skills and independence (Coleman & Hendry, 1999). It seems reasonable to explore emotional management as a key component of young people's engagement experience, as young people are learning how to manage an emerging independent self within an unfamiliar context. My current thinking is that, if young people are learning how to develop independence as an autonomous patient, then there is an interplay with building relationships with others whilst also learning how to become autonomous in healthcare meeting. It seems important to develop a better understanding of the role emotion plays.

Ultimately, the association between how emotion was experienced and the role played by emotion in a young person's engagement coalesced around core category analysis.

7.2.1 The Emerging Role of Affect
There is an area of research that explores the specific function of emotion within cognitive systems, delineating and defining how emotion influences event experience and behaviour. Affect has broadly been explored across research areas such as cognitive and behavioural psychology, and decision making. This has been suggested as an important shift away from viewing cognition as a reasoned process for maximising utility to improve outcomes, and instead as a complex interplay between automatic processes and higher-level thinking (Evans & Frankish, 2009). For example, in a seminal text contesting emotion as a product of reasoned cognition, Zajonc (1980) argued that affect is instinctual and automatic, influencing perception, judgement and decisions. In this sense, the experience of emotion does not just influence how a person feels, but is also a feature of how a stimulus is evaluated in terms of goodness or badness (Kahneman, 2011; Slovic et al., 2002). As such, a feeling state influences decisions about that with which an individual is interacting (Epstein, 1994). Zajonc (1980) exemplifies this concept, explaining that "We do not just see 'A House': we see a 'handsome house', 'an ugly house', or a 'pretentious house'" (p154). Affect can, therefore, be understood as something that shapes perception and the manner in which evaluations are formed about a source of stimulus. Other authors, such as Peters et al. (2004), advance this definition to suggest that emotional valence influences risk perception and judgement, asserting that how a person feels about something dictates how they make choices. As such, decisions about risks and benefits interplay between affective appraisal and conscious choice. Slovic et al. (2007) provide a synthesis of these views, defining affect as "the specific quality of "goodness" or

"badness" (i) experienced as a feeling state (with or without consciousness) and (ii) demarcating a positive or negative quality of a stimulus" (p1333). The general consensus within the literature on affect is that it functions as an automatic process that precedes awareness and influences conscious thought. Affective states are, therefore, said to be experiential in nature, fluctuating across time, circumstances, and degrees of intensity (Timmermans et al., 2010).

It has been acknowledged previously in research exploring patient engagement that there is a need to develop new insight into psychological processes through which patients become engaged and motivated towards active participation in care (Barello et al., 2012). In terms of the study, affect was acknowledged as being significant as it precedes rational thought processes in situations instigating emotional arousal (Kahneman, 2011; Slovic et al., 2002). This related to core category analysis, as it became apparent that the way in which young people experienced emotion was an important psychological process in their experience of engagement, and ultimately influenced how they interacted with healthcare professionals. Moreover, it has been argued that the previous research into engagement focusses on engagement as an outcome measure of the care process that a patient experiences; however, this approach can neglect to explore what it means for a patient to become involved in their care (Barello, 2014). Affect, as a process that could potentially influence young people's interpretation and response to stimuli, provided a possible explanation as to why young people develop attitudes that can facilitate or block participation. Early sensitisation to these aspects of the data underpinned theoretical advancement. For example, the definition of affect provided by Slovic et al. (2007) as feeling states associated with "goodness" or "badness" that influence positive or negative perceptions could explain how a young person's

emotional state might influence how healthcare professional actions are interpreted, and judgements and decisions made thereafter.

The narratives of the young people demonstrated a connection between emotional valence as a result of an incident (i.e. feeling good about being included in decision-making, feeling bad about being made to feel like a child), and their demarcation of positive or negative qualities regarding the healthcare professional or interaction. The emerging construct of affect as an influencing facet of engagement inferred a relationship between emotion and reactivity, raising the significance of early labels developed from the memo-sorting process that explicated how young people responded to emotion. Moreover, the findings presented in Chapter 5 further supported the notion that feeling states influenced perception and the development of social action interactions, such as when young people articulated prejudgement based on fears, adapted behaviours based on in-context impressions, and actively sought to confirm beliefs following an interaction. By revisiting data, it became apparent that the feelings associated with interacting with a healthcare professional (e.g. feeling fear, being angry, or feeling secure) were key motivators. Developing insight into how affect operated in terms of inhibiting or facilitating engagement drove analysis to explore how young people intuitively navigated their interactions.

7.2.2 The Affect Heuristic

Identifying affect as a core feature of analysis called into question how the experience of emotion impacted on engagement. Throughout coding and categorisation, emotive terms such as 'nasty', 'bitch', and 'shady', and phrases such as 'they don't care' and 'they think they're better' revealed that a feeling of 'badness' was a feature of how negative affect was experienced. Drawing on a symbolic interactionist perspective, interpretation shapes personal

meaning, and personal meaning influences action toward objects and others (Blumer, 1969). The terms and phrases uttered by young people highlighted that negative affect was associated with the experience of interacting, influencing action thereafter. However, drawing on Blumer to elucidate meaning conflicted on a key aspect, namely that interpretation is considered as a largely conscious mechanism in the development of meaning (Da Silva, 2007). This is conflict with the results of this analysis, as young people's accounts suggested that their responses to affect were automatic, influencing interpretation and action that impacted on engagement. This led to further analysis to understand how meaning was formed in response to affect, as can be seen in the below memo.

Memo 20: Exploring affect as an automatic reaction

It is becoming clear to me that there is an association between the meaning young people attribute to scenarios when interacting with healthcare professionals, and the affective state which shape the interpretation of these events. Taking Lifey's case to elucidate this point, he reported feelings of anger and resentment about having to interact with his CAMHs nurse. Lifey "knows" that in his meetings with the "bitch" he will be marked as a difficult and dangerous patient. The term 'know' suggested he has developed a conviction in his belief, whilst the expletive 'bitch' is a highly emotionally charged term that provides insight into his valence (a negative affective state of anger), and blame ('badness' was externalised and projected onto the nurse). What is interesting about Lifey's explanation of events is that his anger can be reframed (especially when deciphering the role of valance in determining the meaning of external stimuli) to understand how affective associations influence engagement. Drawing on the concept of embodied meaning (Ruthrof, 1997), a neuroligusitic process of meaning making (e.g. normative neural mechanisms that acquire and store knowledge shape comprehension of the world) does not fully explain how external stimuli is interpreted, as embodied corporal sensations also contribute to how meaning is generated. Corporal experiences (such as valence) arise instinctively as a biological feature and contribute to how context is understood and meaning is generated. In this sense, external reality is not a neutral interpretation, but it is also a representation of what it means to exist as a feeling subject in that context. By exploring embodied meaning within young people's experiences, new insights can be made into how affect influences interpretation in healthcare interactions. To expound this point further, what it meant for Lifey in his interaction was that the anger associated with being judged resulted in the interpretation of the nurse as bad (a bitch). Interestingly, this also appeared to motivate his future action, for example Lifey made clear statements that he was planning to be obtrusive in his next meeting. In this sense, embodied meaning was useful to understand how his feeling states influenced his interpretation of events. As such, affect is clearly automatic and preconscious, but also highly relevant to understand how young people interpret healthcare interactions.

The notion of embodied meaning enhanced phenomenological insights into the direct experience that affect had for young people and the personal meaning allocated in the context of healthcare interactions. However, grounded theorists move beyond descriptive account to understand how such meaning operates within the context of action, interaction and the substantive setting (Corbin & Strauss, 2014). As comparative analysis progressed, it became apparent that how a young person felt about interacting with a healthcare professional aided them in making decisions about their interactions, although this relationship was often largely not recognised. For example, in Paul's case he deferred judgement about his condition to healthcare professionals due to 'them knowing better'; yet, in his interview, he explained how fear of 'getting things wrong' could be paralysing. This feature of the data was illuminating, as it suggested that emotion played an important role in participation. However, although this revealed that affect could influence some aspects of how young people may engage, it was still uncertain as to why this process occurred.

To draw out the analysis, literature from cognitive and behavioural psychology was explored to elaborate how heuristics operated as an automatic cognitive process that influence judgement and decision making. Researchers have argued heuristics to be useful in expediting the decision-making process in expert judgement (McDonald, 1996) and improving satisfaction with decisions (Slovic, 2007). These processes are purported to operate by substituting attributes of a stimulus deemed to be difficult for other aspects of information that are easier to process and understand (Kahneman, 2002). This process of attribute substitution is deemed to be a heuristic process, as easily understandable information is given precedence to provide a reasonable approximation of a situation (Kralik et al., 2012). By drawing on heuristics in complex situations, it is possible to satisfice immediate needs;

namely, to accept the first resolution that satisfies needs held to be most important, as opposed to seeking an optimal outcome (Simon, 1957: 1959). These processes are largely unconscious, but can also lead to implicit bias and cognitive error (Tversky & Kahneman, 1974; Gigerenzer, 2007; Anderson, 2005). In terms of the study, the relationship between affect and implicit reactions appeared to relate to a heuristic process termed the affect heuristic. This process draws on valence to determine intuitively how to interact with a source of stimuli. As with the concept of embodied meaning (Ruthrof, 1997), heuristics have the potential to operate as an unconscious process, intuitively influencing behaviour. The affect heuristic emerged as an important concept to describe intuitive judgements and/or behaviours that influenced how young people form their interactions.

7.2.3 Expounding the Relationship between Affect and Heuristic Processes

The concept of heuristic processes influencing young people's engagement provided greater insight into young people's accounts of engagement, and how meaning was constructed around interactions with healthcare professionals. As previously discussed in Chapter 3, the final stages of analysis sought to saturate concepts that arose from comparative analysis by relating theory back to data until no new insights occurred. The emerging construct of the core category implied that heuristic reactions are a key influence to how engagement is enacted by young people. This appeared to be significant, as it inferred that engagement levels may be influenced by affect. When validating concepts, Charmaz (2009) advises to check inferences against data to determine their place within the final theoretical rendering of a grounded theory. By doing this, their worth as an accurate representation of the phenomenon can be determined (Charmaz, 2006). Repeated reading, coding and memo sorting occurred until five categories were developed that accounted for variations in response to negative affect. The first four categories, 'being impulsive', 'being defensive', 'making do', and 'taking

stock' provided insight into how reactions to negative affect can inhibit engagement (Figure

21, below). The fifth category, 'gaining perspective', will be discussed later in this chapter.

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                        ┌──────────────┐
                        │   Reacting   │
                        │  to affect   │
                        └──────────────┘
```

| Being impulsive | | Being defensive | Making do | *Taking stock* |

Making assumptions	Premature conclusion	Shutting down	Responding to fears	Making concessions	Problem solving
'Generalising'	'Jumping to conclusions'	'Pushing them away'	'Negative filtering'	'Sacrificing needs'	'Saying what they want to hear'
'Polarised thinking'	'Knowing better'	'Keeping safe'	'Assuming the worst'	'Denial of abilities'	
'Knowing what will happen'	'Not believing'	'Not trusting'	'Feeling vulnerable'	'Constant compromising'	'Going along with it'

Figure 21: Organising the concepts of 'reacting to affect'

From bottom to top, Figure 21 provides insight into the coding hierarchy that led to category construction. The bottom row provides an example of code groupings of how young people were responding to stimuli in interactions. In the following row, groupings were theoretically labelled to capture and define action in response to stimuli. The next row up denotes analytical progression by developing higher-level concepts, defining the utility of reactive behaviours in the context of a healthcare interaction. The top row identified the core process which undercut analysis, inferring affect-based heuristic processes underlay a young person's engagement behaviour. Analysis aided in making meaningful theoretical connections between affect and behaviour, providing insight into the role that heuristics played in a young person's experience of their engagement. Interestingly, although reaction to affect was a common feature of data, the variance between young people's reactions also shed insight into a spread of experiences within the study (Table 14, below).

Table 14: Categories; reacting to affect

Being impulsive	Immediate, instinctual, and spontaneous reactions to affect. Occur without deliberation or evident metacognitive processes in response to negative affect. Impulsivity seems to manage experiences of negative affect, changing the relationship to a source of upset. This may be by pushing away the source ('refusing to participate', 'not going to appointments'), or by confronting what caused the upset ('having to fight', 'proving them wrong'). Marked by strong emotive reactions such as anger or frustration.
Being Defensive	Similarities with being impulsive. Young people also draw on immediate, instinctual, and spontaneous processes; however, young people appear to retract from stimulus as opposed to pushing stimulus away (i.e. 'being quiet', 'not saying anything', 'not wanting to speak'). Defensive behaviours were marked by emotional arousal such as anxiety or fear, yet the focus seems to be on developing protective behaviours.
Making do	Appears to have similarities with satisficing to meet immediate needs (i.e. settling/'putting up' with a situation). Young people may 'make do', or 'make the best' from a situation when they feel there is a lack of involvement, or the possibility for interactions to work a different way. This may occur due to external stimuli (e.g. within paternalistic healthcare interactions, where young people feel led), or due to lack of faith in own abilities. Appears to be associated with feeling helpless, frustrated or overwhelmed.
Taking stock	'Taking stock' differed from the above three categories in that there is some self-awareness that the emotion is being experienced, or that it may be influencing behaviour. This appears to suggest that there are some metacognitive processes at play. However, a key condition here seems to be whether the experience of negative affect overcame early metacognitive processes (e.g. 'not caring' or 'not wanting to listen'), or if the young person was able to regulate the experience of emotion. As such, 'taking stock' appears to act as a gateway for instinctive reactions or self-regulation.

By revisiting data transcripts to explore the emerging theoretical constructs, the notion of affect as a mediating force to engagement became saturated, hence the concept earned its place as a theoretical representation of the data. In addition, the categories allowed young people's narratives to be revisited to explore reoccurring patterns across analysis. This fostered a deeper reading into case by case scenarios of affect and the influence it had over

participation. For example, Rebecca's account of not being listened to or believed by her GP was heightened after 'being reactive' was identified as a key feature of her narrative.

Memo 21: Exploring Rebecca's account of not being believed

Comparison of theory back to data is proving useful to explore the relationship between affect and a young person's action. Rebecca's account of having to 'fight' with her GP to be heard was more meaningful after comparison against the category 'being impulsive' (as discussed in Chapter 5). Rebecca experienced doubt after her suggestion that an iron deficiency may be causing hair loss was dismissed. After an initial diagnosis of alopecia, Rebecca felt both anger and resentment after using a medicated shampoo that did not improve her condition. From Rebecca's perspective, the anger she experienced was due to her condition not improving following her GP's advice, but also that her opinion was dismissed. 'They think they know better' was meaningful to analysis as it highlighted a key assumption that she had developed. For Rebecca, anger resulting from having an opinion discounted contributed to how she interpreted her GP's choices, and ultimately understood her interaction. Rebecca went to her following consultation believing she had to 'fight'. This resonated with the category 'being impulsive' for two reasons. Firstly, her interpretation of her situation was related to her embodied meaning of anger, which influenced beliefs about her GP. Secondly, Rebecca developed a course of action to change what was upsetting her by preparing to 'fight'. Comparing the category 'being impulsive' back to the data was interesting as it furthered my understanding of how negative affect can foster intuitive reactions as specific behaviours. This appears to differ from young people who take overt planned action, which seems to relate to codes such as 'problem solving' and 'gaining perspective'.

The development of the categories aided analysis by exploring the basic processes that occurred when negative affect was experienced. Together, these categories appeared to support an early insight into the role of valance in stimulating intuitive reaction. These findings were significant because they identified a relationship between the young person's cognitive

processes and social action. This made a new connection between the young person's meaning-making processes that interpret affect, and the development of behaviour. As concept saturation progressed, memo writing became a useful tool to refine and hone theoretical progression.

Memo 22: Understanding emotional reactivity

It's apparent that emotional reactivity is an umbrella term that accounts for a wide range of reactions based within heuristic processes. Data transcripts show that emotional reactions are common when young people experience conflict or difficulties in healthcare interactions. Studies such as Pham (2007) and Slovic et al. (2002) have shown that negative affect can activate heuristic processes; hence, judgement and behaviour can be affected. In this sense, revisiting data was useful as it became very clear to me that affect also influenced young people in a similar fashion. Higher level concepts highlighted how young people satisficed in interactions to appease the experience of negative affect. This could be by means of an angry retaliation (being impulsive), refusal to volunteer information for fear of saying the wrong thing (being defensive), or choosing to be passive for fear of saying the wrong thing (making do). The analysis to data appears to support the premise that affect can influence both thoughts and action (Krank and Goldstein, 2006; Rooke et al., 2008). Analysis also appears to support the notion that relational dynamics are a key aspect of meaning making, and it is that through the process of coaction that heuristics are triggered. Interestingly, the data which led to the fourth higher level category, 'taking stock', provided another new insight. Taking stock identified that awareness of affect, and how it was impacting on participation, could be a factor that altered this processes. However, overcoming these feelings only occurred when the drive to meet immediate (emotional) needs could be self-managed. This leads me to believe that trait urgency, the tendency to act rashly when upset, may also be a factor that impacts on why heuristics are triggered. My current interpretation is that heuristic processes occur partly because young people find negative affect overwhelming, and affect heuristics enable simpler means to understand their situations, but also that focus changes to tending to this emotional need. This may mean that making 'bad' feelings better becomes more important than the health goal of the interaction.

Reflecting on analytical process was useful as it fostered consideration into why automatic responses to affect were significant. As identified in the above memo, trait urgency was postulated as exaggerating heuristic responses. The notion that being upset caused reactive behaviour appeared to be supported by literature exploring adolescent risk-taking; for instance, after a review of relevant studies, Cyders and Smith (2009) hypothesised a relationship between emotionality and rash behaviour. Negative urgency, or acting rashly in response to the experience of negative affect, has also been shown as a key predictor in a range of risk-taking behaviours in young people such as alcohol use (Dick et al., 2010), drug use (Kaiser et al., 2012), and risky sexual behaviour (Deckman & DeWall, 2011). The notion that adolescents develop adaptive responses intuitively to make themselves feel better corresponded with young participants' narratives about 'getting by' in interactions. This in vivo code was illuminating, as it suggested that coping was a key feature for managing negative affect, which could infer that coping mechanisms were employed in upsetting scenarios. In essence, analysis was furthered as sensitivity towards a young person's emotional valence increased, providing insight as to why negative affect was such a prominent feature of data analysis.

In contrast to the above four categories, a young person's insight into their emotions, and having comprehension of the impact of emotional-expressive behaviour on outcomes, emerged as meaningful facilitators to engagement. As data was refined and synthesised, the key processes behind emotional reactivity and self-regulation were explored. The ability for a young person to adapt and self-manage within a situation, eliciting constructive behaviours to develop their interpersonal dynamics, can be understood as an essential developmental

feature for social skill acquirement (Saarni, 2000). Whereas, as self-regulatory skills have a positive impact on interpersonal skills and intrapersonal wellbeing, the inability to self-manage can result in maladaptive responses and emotional and behavioural difficulties (Saarni et al., 2008; Saarni, 1999). Within the context of the healthcare interaction, this appeared to be especially pertinent, given that health-related outcomes are dependent on the extent to which a patient complies with medical advice and participates in healthcare dialogues. Figure 22 provides an insight into how category construction identified 'not reacting to affect' as an important trait for young people to overcome heuristic processes.

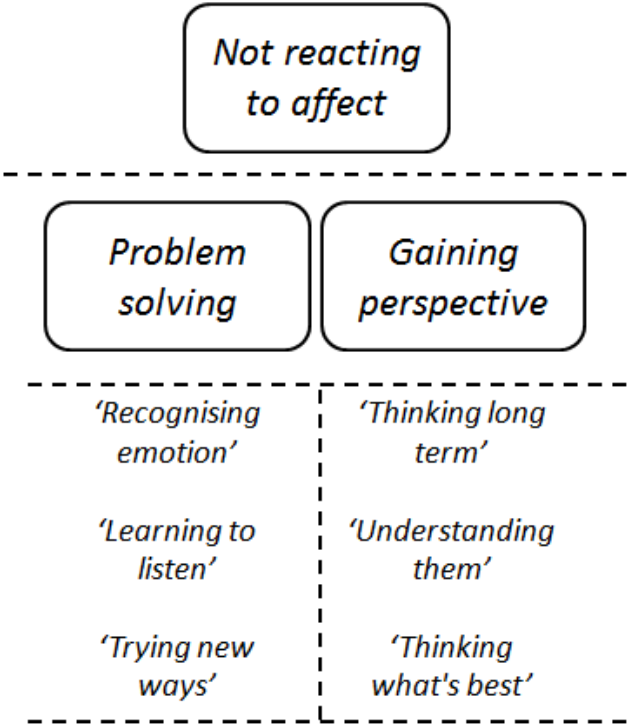*Figure 22: Organising the concepts of 'not reacting to affect'*

From bottom to top, coding and categorisation highlighted the ways in which young people became more active in their participation to improve working with healthcare professionals. The categories 'problem solving' and 'gaining perspective' identified how young people developed behaviours through which they sought to understand themselves as a social

participator in the healthcare meeting. These categories were later subsumed, raising 'gaining perspective' into a category that encompassed all inner cognitive processes that facilitated engagement (Table 16).

Table 15: Category; not reacting to affect

Gaining perspective	Relates to a young person's insight into why situations were upsetting and their ability to address emotional arousal, as opposed to forming instinctive emotional reactions. 'Gaining perspective' differed from prior categories in that metacognition and intrapersonal awareness was demonstrated. This also appeared to influence a young person's ability to try new approaches and learn from situations. The ability to self-regulate emotions and understand consequences also influenced this process.

The extent to which a young person 'gained perspective' of themselves, interaction dynamics, and how to participate was raised during analysis as a crucial feature for perspective-gaining, and was a protective factor that enabled young people not to react to affect. This seemed to suggest that basic metacognitive processes such as 'recognising the impact of emotion', 'understanding the other person's perspective' and 'thinking about the best course of action' were important. A possible explanation for this aspect of the data was that early metacognition and self-regulatory behaviours occurred mutually as young people found meaningful ways to interact with their healthcare professionals. This account certainly fits with the World Health organisation's perspective of adolescence as a developmental process in which social independence is sought as self-identity emerges (World Health Organisation, 2010; United Nations Children's Fund 2011). Moreover, reasoning processes and reliance on higher executive functions normatively become a greater feature of adolescent judgement and decision-making as cognitive maturation improves regulatory competence (Steinberg, 2005). However, this explanation provided no insight into how to understand or work with disengagement behaviours that relate to 'reacting to affect'. The literature seemed to suggest

that 'gaining perspective' occurred on a continuum of development, and, until a young person developed such cognitive maturation to 'gain perspective' disengagement, behaviours would occur naturally in response to negative affect. This highlighted the importance of young people managing emotion in terms of their interactions, and that understanding how such processes are manifested may be necessary in order to develop approaches for working with young people who experience difficulty with affective self-regulation. Memo writing became a useful tool to define this point.

Memo 23: Explicating affective regulation as a feature of 'gaining perspective'

I feel that analysis is at the point where clear links can be made between the experience of emotion and the certain cognitive processes that influence participation. It seems to me that, as a large part of a young person's ability to 'get on' with a healthcare professional is due to valence, strategies that seek to engage young people should account for the impact affect has on participation. Positive experiences may stimulate positive affect, which in turn may improve participatory behaviours. This was exemplified by Roberta's explanation of 'nice nurses' overcoming fears of past experiences with 'bad nurses'. Yet, experiences of negative affect seem to be more problematic, especially if a young person struggles to independently initial emotions if they are to maintain a focus on their health-related goals. In this sense, 'gaining perspective' provided a way of thinking about the relationship between emotion and cognition that was not apparent in 'being impulsive', 'being defensive' and 'making do'. Similar to literature espousing dual process perspectives of cognition (Albert & Steinberg, 2011; Mayer & Salovey, 1997; Salovey & Mayer, 1990), overcoming the experience of negative affect may largely rely on the young person's ability to engage in rational and process-orientated thinking. This would overcome heuristic processes generated through affect through self-regulation of impulsive behaviours. The difference between these two features of the data ('reacting to affect' and 'overcoming affect') may be because different methods of appraisal exist between rational approaches to problem solving and the reliance on heuristic processes (Evens, 2007)

The two processes observed within the study elucidated why heuristic responses were such a prominent feature of the data, and why overcoming emotion was related strongly to engagement.

7.4 Dual Process Theory and Systems of Cognition

In the previous sections, it has been explained how analysis led to the identification of two distinct processes relating to how young people understood and responded to healthcare interactions. This was closely related to a dual-process theory of cognition and reasoning. A dual-process perspective purports that how events, situation and phenomenon are understood depends on how the experience is processed cognitively. These two cognitive processes relate to automatic heuristic responses that are largely unconscious or deliberative cognitive processes which draw on higher executive functions of analysis and critical thought (Todd & Gigerenzer, 2000; Reimer & Rieskamp, 2007). A number of researchers have suggested different terminologies for these two systems, such as the unconscious and conscious (Wilson 2002), the intuitive and rational (Kahneman, 2003), the experiential and analytical system (Slovic et al., 2004), or System 1 and System 2 (Evens, 2013; Stanovich, 1999). These differences have largely been due to semantic debates about what these processes entail. For example, Wilson (2002) draws on the terms unconscious and conscious to distinguish between levels of awareness, whereas Kahneman (2003) and Slovic et al. (2004) employ terms denoting the absence or presence of logic. However, such terms have been criticised as being biased in their taxonomies, implying that heuristic processes are the result of cognitive errors, when both processes are an important feature of human cognition (Evens, 2013). Although heuristic processes occur automatically without voluntary control whilst deliberative processes utilise concerted mental efforts, both terms are neutral discerptions of processes that operate in response to stimulus. Accordingly, the terms system 1 (heuristic

processes) and system 2 (overt reasoning processes) are used here as they are neutral in their taxonomy.

Following the proponents of dual-process theory, the notion that judgement and decisions operate on both conscious and preconscious levels resonated with the core category analysis. The theoretical connections made between 'reacting to affect' and the rapid and the intuitive processes of system 1 processes of cognition provided insight into young people's tendency to react impulsively to negative affect. Evans (2013) suggests that heuristics are separate to, and precede, analytic and sequential processes, and system 1 cognition enables instant decisions by utilising information to hand. These processes are useful to relieve the cognitive burden of deliberative thought and enable fast, contextual decisions. A similar position is provided by Gigerenzer & Goldstein (1996) who suggests that system 1 processes are fast and frugal mechanisms that filter through information, drawing on salient information perceived as being relevant to a problem, whilst discarding that which is seemingly irrelevant. The experience of negative affect appeared to influence young people in a similar way, acting as an evaluative tool to appraise the interaction. Another interesting feature of the analysis was that, when experiencing negative affect, young people's appraisal of events appeared to be myopic. For example, 'being treated like a child' featured as a prominent aspect of MarilynM's accounts, despite at one point conceding that the continence interventions had greatly improved his dry nights. This was interesting, as how he felt patronised in healthcare interactions was a greater aspect of his narrative than 'being helped'.

Following a dual-process theory perspective, the above insights could be understood as occurring because of the instinctual nature of affect-based heuristic processes preceding

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system 2 thought processes. As system 1 processes demarcate positive or negative qualities to a stimulus to direct judgement and perception (Slovic et al., 2005), feeling patronised appeared to influence MarilynM in his appraisal of the continence service. It is also noteworthy that intense emotion is known to inhibit system 2 activation (Bechara, 2004), resulting in more extreme reactions to stimuli than system 2 responses (Pham et al., 2001), and to contribute to parochial perspectives of reward and consequences beliefs (Pham, 2007). Collectively, the physiological state of being upset may sharpen focus, yet draw attention to that which is perceived as the cause of upset. In terms of the study findings, this may explain why young people focussed on an 'immediate need fulfilment' of appeasing feelings of upset. System 1 processes appeared to match 'reacting to affect' and further supported the role of affect as a central feature of the study.

In contrast, data relating to 'not reacting to affect' appeared to be in line with literature acknowledging system 2 processes as the conscious cognitive mechanisms that can challenge and suppress heuristic responses. System 2 processes are described as rule-based and analytical processes that draw on "normative rules, such as probability calculus, formal logic and risk analysis… [and is]… relatively slow, effortful and requires conscious control" (Slovic et al., 2004, p. 311). Rather than being separate to system 1, system 2 cognition processes are correlated and play a key role in awareness and volition (Evens, 2008). Evens (ibid) summarises these processes as "a form of thinking under intentional level control, supported by unconscious processes in system 1 that deliver percepts [and] memories" (p. 258). This resonated with the fifth category, namely 'gaining perspective', and the development of young people's self-awareness in the interaction dynamics. Being able to identify affect is a key feature of metacognition and emotional self-regulation (Klaczynski, 2005), which may

explain why this was an initial step for young people who worked towards engagement. For example, Lucy explained that the first time she went to the neurologist alone she was confused and anxious due to not understanding the consultant's language. Recognising this as inhibiting her participation, she actively sought out support from an adult to 'translate' the interaction. Interestingly, this behaviour demonstrated an ability to recognise anxiety and confusion caused by the healthcare professional's language, and rather than develop unhelpful behaviours as discussed above she was able devise a strategy to overcome this barrier. As a result of Lucy actively seeking support, her consultant recognised her difficulties and developed more inclusive consultations thereafter. Relating this to the precepts of system 2 cognition, recognising the impact of affect is a key feature for asserting effortful control over system 1 processes (Slovic et al., 2004: 2007; Gerrard et al., 2008), which can improve interpersonal relationships (Mayer & Salovey, 1997; Salovey & Mayer, 1990) and increase a person's perceived control in a situation (Loewenstein & Lerner, 2003). By recognising her anxiety and problem-solving in her interaction, Lucy improved the relationship with her healthcare professional, whilst also becoming more confident in the patient role.

Becoming sensitised to system 2 approaches was important to the analysis of the core category as it provided further insight into why 'not reacting to affect' improved engagement. However, despite the similarities between data analysis and literature relating to system 2 processes, it was not clear why some young people were able to 'gain perspective', whilst others continued with 'reacting to affect'. From a developmental perspective, young people normatively demonstrate increased abstract and analytical reasoning due to prefrontal cortex maturation and formal school-based education (Dansereau et al., 2013). However, such forms of self-regulation can be overestimated as a form of behavioural control, as social, emotional

and environmental situations are complex and may not facilitate these behaviours (Sheeran, Traiimow & Armitage, 2003). In this sense, although cognitive processes similar to system 2 processes within a dual-processes perspective of cognition were identified, it remains unclear if self-regulation was a consistent feature of engagement with young people who demonstrated such behaviours, or if such behavioural controls were due to a facilitative environment. In this sense, it was not possible to distinguish between self-regulation as an internal or external form of regulation through data analysis.

Despite lacking a full picture of how the management of negative affect operated across time and context, relating data analysis to the concept of dual process theory proved useful to enhance theoretical sensitivity towards young people's engagement. This enabled greater insight into how young people constructed meaning about interactions with healthcare professionals, why disengagement may occur when a young person is upset, whilst identifying system 2 processes as a protective factor that may facilitate engagement. Relating the core category to dual process theory also provided insight into how cognitive processes influenced young people's behaviours in interactions, providing a means to understand how and why they engaged as they did. They enabled a better understanding of how negative affect can influence a young person's perceptions of healthcare participation, which supported the development of a substantive theory.

7.5 Affect-Mediated Engagement

The final stage of a grounded theory method is to explicate the social psychological processes observed within the study. Such low-level theories are interpretations of the specific experiences of participants in the phenomenon, and seek to provide new insight into substantive areas (Straus and Corbin, 1990; Charmaz, 2006). Unlike formal theory, which is

concerned with general processes that apply across substantive contexts, a substantive theory aims to understand and expound a specific issue within a substantive setting (Hallberg, 2006). Within the study, contact substantive theory development was concerned with developing insight into the relationship between affect and engagement as social action. As identified above, young people's reactions to affect as a feature of intuitive system 1 processes that preceded rational thought were explored. Emotional distress is known to impact negatively on self-regulatory behaviours and goal prioritisation (Tice, Bratslavsky & Baumeister, 2001), so it followed that affect, operating as an influencing force in engagement formation, fitted well with the interpretation of findings.

The notion that emotion could trigger system 1 heuristic processes was useful to understanding that feeling states influence decisions about that which is being interacted with (Epstein, 1994), and affective appraisal, influence interpretation and action with said stimulus (Kahneman, 2011; Slovic et al., 2002). Moreover, affective appraisal of stimuli can influence the weight that is given to information, greatly swaying judgement formation and decisions. For example, Alhakami & Slovic (1994) identified an inverse relationship between risk/benefit perception and affect, with affective appraisal being a major predictor of evaluation and judgement. The association between affective appraisal and perceptions of risk/benefit can have a significant impact on how situations are understood and interpreted. As such, it became useful to understand system 1 processes as a response to stimulus, but also as an active process of interpretation. The way in which young people responded to negative affect was understood as potentially having a direct impact on engagement as an outcome. Memo writing was useful to understand young people's behaviours in response to affect.

Memo 24: Defining the impact of affect on engagement

I find working across young people's narratives illuminating as it shows variation as to how young people behaved when upset, but underneath this the core category seems to bring everything back together. I think that the notion of affect as being a trigger for engagement/disengagement is useful as it supports the view that affective appraisal of risks and associated benefits influence behavioural outcomes (Slovic et al., 1993). In relation to the study, it's not just the feelings of goodness and badness it projected onto a healthcare professional that influences engagement, but what the young person believes it means to interact under these beliefs. If this is the case, then it would be a heuristic response, automatically occurring, and would provide a tentative explanation as to why affect influences behaviour. I find this interesting, as the relationship between a young person's perception of being further upset (perceived risk), and the associated beliefs surrounding continued participation (a risk reward trade off) seems to be an important feature as to how engagement plays out. I think it's also important to note that this seems to be consistent with a normative neurodevelopmental perspective, as reward gratification traits increase with pubertal maturation around adolescence (Steinberg, 2004). This is mainly due to the fact that cognitive structures develop faster than control systems within the prefrontal cortex, and emotional arousal can be a stronger driving force than rational assessment (Steinberg, 2008).

Whilst the interplay between emotionality and rationality are both acknowledged to influence behaviour, Wang (2006) suggests that a "hedonic framing of choice outcomes [has] a stronger influence on the emotional preference than rational preference" (p.1146). In this respect, the immediacy of emotion can hold greater influence over how behaviour is moderated and how a person decides to engage (Damasio, 1994). The interplay between inhibitory control mechanisms and emotional arousal can, therefore, be a determining factor of how risk/reward decisions are made (Steinberg, 2011; Albert & Steinberg, 2011). Furthermore, affective appraisal may have an impact on how people make forecasts about future

events. For example, Wilson and Gilbert (2003) highlighted an impact bias of disproportional length and duration when affect was a feature of a person's predictions. How this relates to young people is that affect can be understood as a strong motivator that may be based on heuristic processes that misrepresent their situation. Although this cannot be confirmed in this study, the connotation does seem to suggest that affect can act as a hidden barrier for young people who do not draw on system 2 processes. Both system 1 & 2 processes were associated with emotional arousal in situations young people found challenging, yet the variation to engagement appeared to be associated with the cognitive approaches young people utilised.

The memo drew on affect as a system 1 response to stimuli that also influenced meaning ascribed to interacting with that stimuli. This was significant to understanding engagement as it located affect as the intervening factor influencing how young people formed judgements and behavioural responses to healthcare professionals when conflict arose. Relating this back to comparative analysis, the cognitive processes that a young person drew on shaped behavioural responses to feelings of negative affect. The cognitive processes that mediated the experience of affect had the potential to alter heuristic appraisal and to develop new judgement and behaviour. Affect could result in a young person employing self-regulatory approaches, or continuing with judgement and behaviours that focussed on immediate needs fulfilment (Figure 23). Understanding the relationship between affective appraisal, risk/benefit perception, and behavioural responses was useful in finalising the analysis.
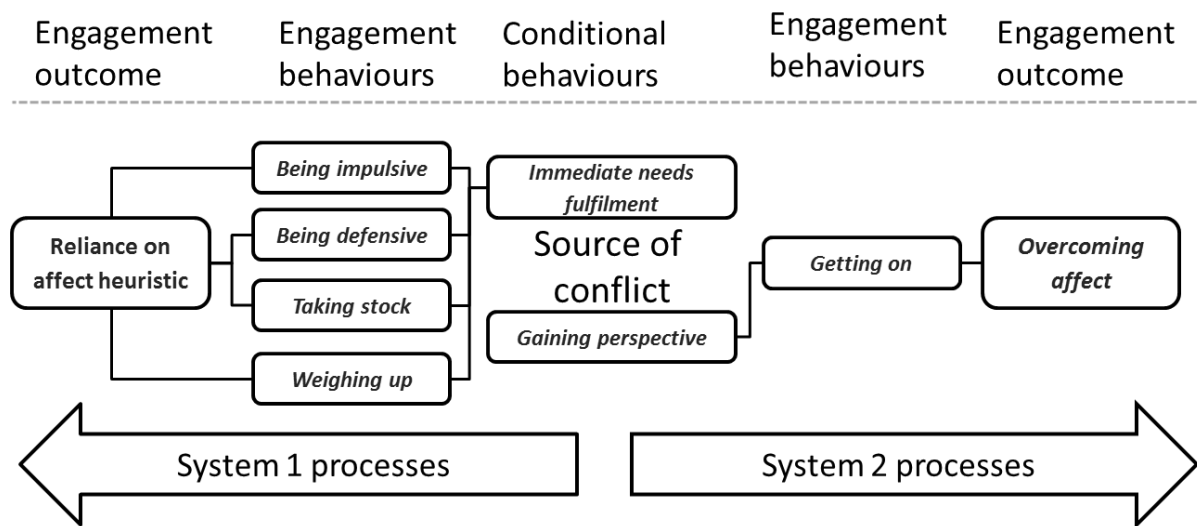
Figure 23: Explicating the mediating role of affect

Figure 23 conveys the systems of cognition that could potentially explain the mediating impact of affect on engagement. Engagement outcomes appeared to be dependent on whether affective appraisal persisted in interactions, resulting in 'being impulsive', being defensive', 'taking stock' or weighing up, or whether self-regulatory traits associated with stem 2 processes overcame heuristic responses. Hence, affect could be argued to have a mediating role on engagement, influencing perception, judgement formation and behaviour enactment. The core category suggested affective-mediation as an emergent theory that defined an underlying mechanism that operates separate from, or concomitant with, system 2 processes, which encourage engagement. Hence, the mediating role of affect may have the potential to shape a young person's prejudgement, affect in-context learning that contributes to emergent patient behaviour, and influence the validation of the healthcare experience through the perception of needs being met (Figure 24).
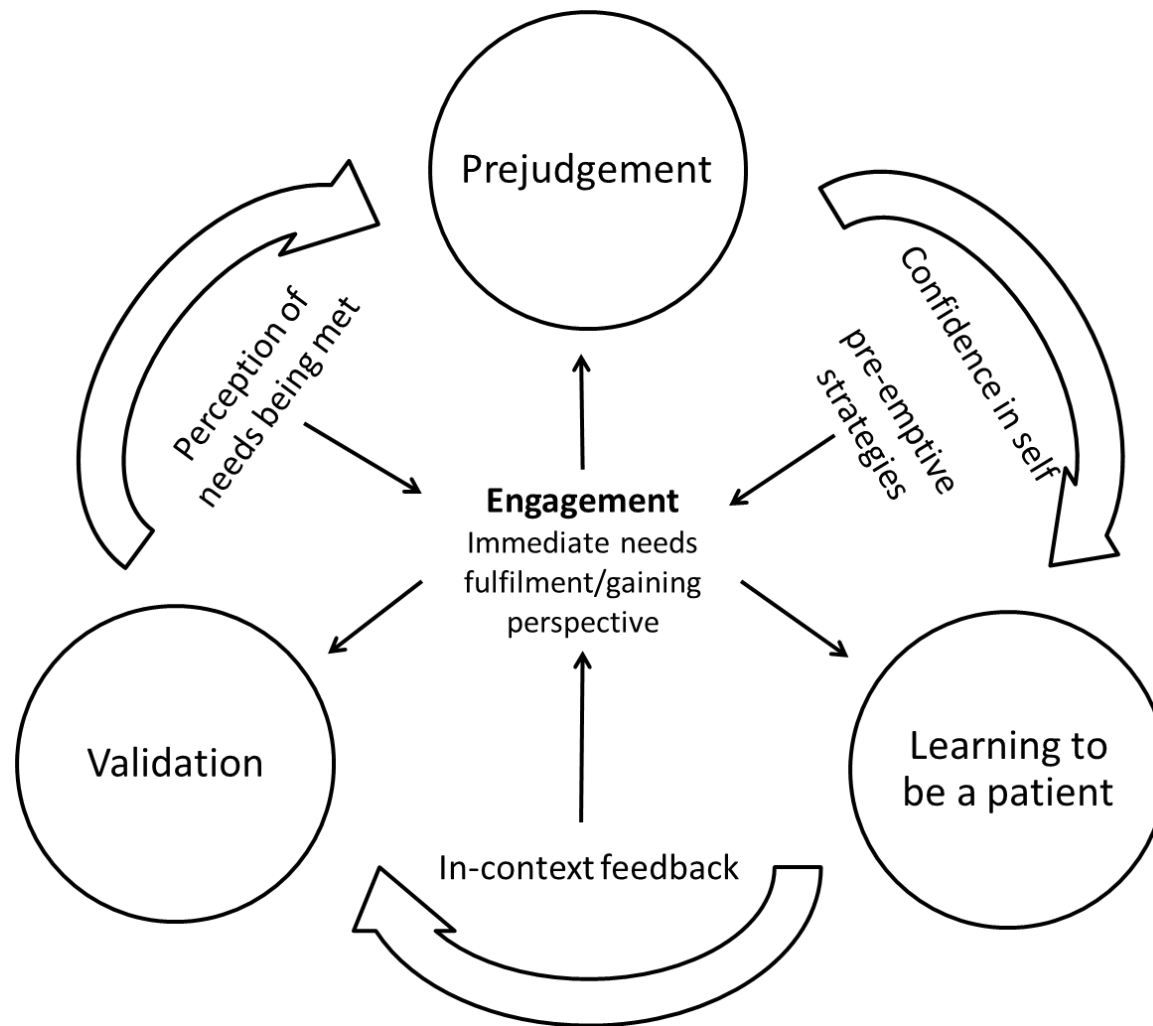
Figure 24: The mediating role of affect in the experience of engagement

Figure 24 provides a collective account of the theoretical insights from the study, bringing together theoretical categories to denote their relationship to affect. The core categories, depicted by three circles, are represented of the figure as an experiential learning cycle (as previously discussed in section 6.4); this conveys the notion that engagement is a continual process that is manifest from beliefs prior to the healthcare consultation, adaptive behaviour learnt within the healthcare meeting, and post-event interpretation. The young people's responses to the experience of affect, as a drive to fulfil perceived immediate need, or through the metacognitive intersection of system 2 processes, played a key role in shaping intention and action within the social processes of engagement. Yet, the complex mediation of engagement can be best understood as a continual tension, as phenomena "are not conceived of as static but as continually changing in response to prevailing conditions" (Corbin and Strauss, 1990, p.419). This is shown through black arrows leading from the specific conditions that cause, and contribute to, the experience of affect, which in turn feeds back into the young person's experience of prejudgement, learning, and event validation. Through this process, young people, as social actors, are "seen as having, though not always utilising, the means of controlling their destinies by their responses to conditions" (Corbin and Strauss, ibid).

Developing theoretical insight into how affect had the potential to mediate young people's experiences of engagement provided new insight into a key process that potentially blocks engagement within young people's healthcare interactions. Moreover, a working theory of affect-mediated engagement inferred that such barriers can potentially be overcome by a young person developing deliberative problem-solving strategies. This has meaningful implications for working with young people, and reflects a strategic shift in promoting positive patient behaviours to improve health outcomes. For example, in 'Applying Behavioural Insight

to Health', a discussion paper produced by the UK Cabinet Office, both behavioural science and behavioural economics are drawn on to identify the need for new public health policies that understand how health behaviours manifest (Behavioural Insights Team, 2010). Such approaches have the potential to recognise heuristic processess as part of a patient's decision-making approach: patients are empowered by facilitating a shift from automatic processes to one of intentional cognitive control (Nilsen et al., 2012). This could be argued to be a valuable approach for working with young people, as behaviours developed within adolescence are believed to have a significant impact on future health beliefs and habits (Spruijt-Metz, 1999). By aiming to understand patient behaviours, as opposed to seeking compliance with positive health behaviours, a greater focus is placed on the causal factors influencing behaviour rather than determining behavioural consequences. This would be meaningful for facilitating patient interactions, as health outcomes alone do not address the complexity and subtle nuances of patient behaviour (Sharp & Currin, 2006). By acknowledging affect as a mediating factor of engagement, it was possible to bring cognitive processes to the forefront of analysis to explicate young people's engagement behaviours.

7.6 Core Category: Discussion

This section provides a discussion of the core category by relating key aspects of findings to relevant literature. As stated above, the core category coalesced key insights from theoretical category construction to identify how young people responded to affect. This was then aligned with a dual-process perspective of cognition to explore affective arousal from the perspective of young people's engagement. The core category found that responses to affect influenced young people's reactions and behaviours. Engagement in interactions was mediated by system 2 psychological processes that managed the experience of affect, or defaulted to system 1 processes that relied on heuristics. This section discusses key aspects of the core

category in relation to literature to discuss these theoretical constructs. First, affect is revisited in order to understand how the literature defines such instinctive reactions in young people. Then, the suggested substantive theory of affect-mediated engagement is related to a dual process perspective of adolescent cognition, and discussed in terms of personal meaning and the impact that this exerts on participation. Finally, the discussion is concluded by appraising the quality of the study using appraisal criteria advocated by Charmaz (2006).

7.6.1 Young People and Affect

The findings of the core category suggested that affect, emotional reactivity, and emotional regulation were core components to a young person's engagement within the substantive area. As indicated above, the experience of affect appeared to fit alongside a developmental perspective of cognitive maturation; this viewpoint suggested that cognitive-control system development was a key component in the regulation of affective arousal, impulse control, and competency in emotional self-management. Steinberg (2007) suggests that, from a neurological perspective, this is due to an interplay between prefrontal cortex maturation and subcortical socio-emotive processing, as competing systems that drive a young person's behaviour and decision-making become more pronounced through psychosocial factors. The underdevelopment of adolescent cortical areas may explain why emotional reactivity and impulsively persist, even when intellectual capability is considered to be of a reasonable capacity for problem-solving and comprehending cause and effect (Casey et al., 2008). Cyders (2008) draws on research from animal studies (Barbas, 2007) and research with human subjects (Bechara, 2005) to expound this point, suggesting that reactivity occurs as a complex relationship between subcortical processes aligned with the limbic system and higher cortical activity, with cortical areas interpreting the "emotional meaning of stimuli" which, in turn, modulates amygdala responses. The role of affect has been argued as twofold in such

processes, by creating a myopic perspective to heighten focus on that which seems to be most pertinent in that given time, and guiding judgement and arousal as a source of secondary information (Peters et al., 2006).

In relation to this study, the crux of the core category analysis was the identification of young people's responses to affect, which ultimately influenced perception and behaviour of interactions with healthcare professionals. This was a significant finding as it suggested that engagement was mediated by the experience of affect. In relation to the literature, there is little direct empirical evidence to support the relationship between affect and healthcare engagement; however, connections can be made to studies that explore the role of affect in coping behaviours and their impact on health outcomes. For example, Shrier et al. (2014) explored the experience of emotion preceding marijuana use in young people aged 15 to 24 who were regular recreational users of the drug. The study findings suggested positive affect did not significantly alter within the 24-hour period prior to marijuana; in contrast, negative affect peaked prior to marijuana use compared to other times. This suggested negative trait urgency was strongly correlated with marijuana use. Shrier et al. (ibid) suggested that a new approach that considered trait urgency as a motivator for behaviour was required in health promotion and management strategies. Similarly, a literature review by Kuntsche et al. (2005) found a comparable trend in young people's coping strategies for negative affect (i.e. to escape, avoid or regulate unpleasant emotions). Kuntsche et al. (ibid) concluded that drinking as a coping mechanism was associated with heavy drinking and other alcohol-related problems due to the underlying causes of negative affect remaining unaddressed. The findings of Shrier et al. (2014) and Kuntsche et al. (2005) both supported the notion that poor trait self-control was associated with higher mental health issues, likelihood of substance abuse and

lower self-reported subjective well-being. This appears to be consistent with the results of a systematic meta-analytical review by Penley et al. (2002), who concluded from a review of the literature that characteristics associated with trait self-control were positively correlated with health outcomes, whilst strategies associated with reacting to negative affect were correlated with poorer health outcomes.

Perhaps the strongest support for a relationship between trait responses to affect and behavioural reactions was found by Boals et al. (2011), who identified a significant relationship between undergraduate college students' levels of self-control and their coping styles. The study reported that lower reports of self-control predicted higher rates of coping traits, whereas the reverse was true for higher reports of self-control. Self-control was a significant predictor of health outcomes across measures for physical and mental health. The authors suggested that the trait self-control played an important role in mediating participants' coping styles, enabling predictions for health outcomes. These findings provide some support for the core category presented within this study, namely that behaviours employed in response to affect were mediated by a young person's ability to control affective reactions. This suggests that trait self-control may be akin to the code '*managing affective responses*' identified in this study. However, although Bolas et al. (ibid) made many associations to literature concerning adolescent development, it is important to note that the reported mean age of 20.94 years was derived from a range of 18–52, no standard deviations of participant demographics were provided. Although the mean age indicates that that the sample was weighted at the lower age range of participants, it is important to note this age most commonly refers to young adulthood as opposed to adolescent populations; therefore caution is advised when relating

findings to younger populations. Replication of the study with younger age ranges would be beneficial to determine if this relationship remains consistent with younger years.

The available literature appears to support the notion that a person's responses to affect influence both behaviour and outcomes; hence, engagement may also be influenced by such a relationship. It may, therefore, be valuable to understand how heuristic responses stimulate trait urgency and detract from a young person's engagement, while the reverse is true when self-regulation occurs. Interestingly, Phillips et al. (2009) explored the relationship between urgency traits in response to the experience of affect, providing some evidence that heuristic processes are present when young people experience strong emotion. The study tested the hypothesis that young people with high urgency traits would be more likely to draw on the affect heuristic than young people with low urgency traits; findings demonstrated that the hypothesis held true, as young people high on trait urgency consistently drew on affective associations for binge drinking. Phillips et al. (ibid) suggested this showed that young people high on trait urgency drew on on an affect heuristic whereas, in contrast, young people low in trait urgency drew on rational cognitive processes. However, the studies' use of a cross-sectional design is a limiting factor when interpreting these results as causality cannot be isolated. Again, it would be useful to test if such a relationship held true in relation to young people and their healthcare engagement.

In terms of this study, it was identified that there may be value in exploring the notion that heuristic responses can negatively influence a young person's engagement, whereas the opposite may be true when self-regulation occurs. To date, the relationship between affect, trait urgency and engagement appears to be unexplored; accordingly, considering the growing

attention that affect and trait urgency have received in relation to health behaviours, it may be useful to extend these concepts to develop insight into engagement.

7.6.2 Aligning Dual-Process Theory with a Theory of Affect-Mediated Engagement
The substantive theory suggested in this chapter provided a tentative link between affect as an experiential state and cognitive processes that triggered automatic reactions; this tentative theory provided a novel approach for understanding young people's engagement in healthcare interactions through a dual process perspective of adolescent cognition. This link was made by drawing parallels to intuitive system 1 processes preceding rational thought as an explanation for how young people responded to negative affect. Conversely, system 2 processes appeared to explain strategies young people used to overcome the experience of affect. This perspective was useful to situate the mediating impact of reactions to affect (as suggested in 'being impulsive', being defensive', 'taking stock' or weighing up) within system 1 processes, or system 2 processes if heuristic responses were suppressed (as suggested in gaining perspective). However, at this present stage this theory remains explanatory of the data and would require testing, as is normal on inductive/deductive continuum of grounded theory research (Strauss & Corbin, 1990). The notion of affect-mediated engagement highlighted that, by understanding underlying heuristic responses that operate separate from, or concomitant with, system 2 processes, a young person's engagement in their healthcare interactions would be better understood.

As mentioned above, cognitive development occurs through maturation of the prefrontal cortex which enables rational and metacognitive processes; these processes precede emotional self-management and, along a normative development trajectory, insight develops into the self, context, and consequences of their actions (Zimmerman, 2000; 2007). However,

cognitive maturation does not necessitate system 2 approaches are utilised, and heuristic processes motivate a young person's behaviour due to age, competence, experience or skills (Klaczynski, 2004) and may well extend into adult life (Amsel et al., 2008). However, it is recognised there is a little literature expounding how metacognitive intersection (the ability to reflect and inhibit heuristic responses) occurs across developmental trajectories (Barrouillet & Gauffroy, 2013). Again, this proves problematic; however, literature exploring dual process theory within young people's studies provides an insight into this area.

Klaczynski (2001) demonstrated that the task performance of young people was dependent on two processing systems when provided with a series of analytical problems: an analytical system, which enabled task decontextualisation that required rational logic, and a "cognitively cheap" heuristic system that influenced responses conflicting with expected norms. The findings confirmed a two-factor hypothesis of cognition, namely system 2 processes, which were correlated normatively correct responses, and non-normative responses, which were associated with heuristic system 1 processes. This suggested that, although an increase in age could lessen the heuristic response, system 2 processes remained ubiquitous across age ranges. This supported the findings within this grounded theory study, namely that heuristic system 1 responses were a key motivator to engagement. Similarly, in another experimental design, Klaczynski & Cottrell (2004) explored the relationship between normatively correct and non-normative logic through two studies that explored whether young people utilised formal reasoning in problem-solving scenarios. Collective findings demonstrated that the young people tended to utilise a "sunk cost heuristic" for deciding future action (decision based on feelings associated with spent resources such as time or money) as opposed to logical appraisal of cause and effect; additionally, it was noted that age-related improvements

did occur, suggesting a heuristic reliance may diminish with age. However, as study participants were not included over the age of 15 years it is unclear whether such improvements continued past this age range. Despite this, the study supported the notion that a dual process perspective of development may be useful to understand dual cognitive processes young people utilise in decision-making. In relation to the findings of this grounded theory study, it is helpful to note that these two distinct cognitive processes have been shown to influence how young people understand problems and make decisions about information, although further instigation would be required to demine if this holds true for heuristics based on affect.

Although limited evidence is building for a dual-processes perspective of adolescence development, there appears to be no direct studies that explore how these systems of cognition operate in relation to young people's engagement. Further investigation would be useful as it could provide insight into how dual processes of cognition influence young people in building reciprocal behaviours; despite this, current research is useful to form links with how a dual-process perspective of cognition operates in terms of affect-mediated engagement. For example, Jacobs & Klaczynski (2006) posit that the activation of heuristic processes is often due to situational cues; and, as system 1 processes are automatic and largely unconscious, they are often associated with "feelings of rightness" or "gut feelings". Such learnt responses may be a part of childhood development and inform the strategies young people utilise when trigged by stimuli (p.41).

This grounded theory study has argued that system 1 responses to affect mediate a young person's engagement as it initiates behaviours that detract from the young person/healthcare

professional relationship. This notion is not farfetched, as theorists expounding a dual process perspective of cognition have identified health decisions are often based on heuristic instincts (Slovic et al., 2002); this may be due to the emotions attached to health and illness. In addition, system 1 processes are known to be triggered by affective arousal and are often associated with "feelings of rightness" that foster myopic perspectives and increase conviction in perception of events (Thompson, 2009). This would also support the notion that, when experiencing affect, system 1 processes may be an inhibiting factor to a young person's engagement. In contrast, the activation of a system 2 process may well facilitate engagement, as metacognition (system 2 processes) is known to be associated with higher order reasoning and problem-solving strategies in adolescent development (Kuhn, 2006). This would support the notion that a system 2 process would supress affect, hence engagement would be moderated leading to potentially better outcomes. Collectively, a dual process theory of adolescent cognition appeared to provide some support for the theory of affect-mediated engagement; however, further research would be required to confirm this association.

7.6.3 Engagement as a Personal Construct

As stated in Chapter 1, the overarching aim of this thesis was to understand what exactly engagement was for young people within the healthcare interaction; this resulted in in-depth exploration of the young persons' perspectives of the healthcare interaction, views of healthcare professional behaviour and insight into the consequences of these factors on young persons' actions. This perspective suggested that learning how to engage was important form a developmental perspective of learning. Considering cognition as on a developmental trajectory, learning is known to occur across a period of neural proliferation, with activity-dependent plasticity occurring through myelination and pruning (Fields, 2005). In terms of this study, this may suggest that how young people learn to engage may potentially

influence future engagement, as learnt responses occur through functional neurological plasticity. In addition, the individual experiences young people have within the healthcare interaction could also be said to reflect how young people redefine their sense of self as an autonomous and independent being within an emerging adult role; hence, skills development for psychosocial interaction in the healthcare interaction may be increasingly important through this transformative period. The key features of this grounded theory study highlighted that young people experienced engagement as a personal construct; this suggested that the young person's engagement behaviours were formed in response to their subjective perspective of the healthcare professional/young person dyad.

It is acknowledged that person-centred care places the person at that core of their healthcare experience; this is acknowledged to be a highly individual experience that occurs by affording dignity and respect within interactions, is personalised to individual needs, and supports the person in developing strengths and skills in relation to their health needs (The Health Foundation, 2014). As such, acknowledging that subjectivity in these experiences is important for independence to be encouraged in helping the patient to develop health management behaviours (Richards et al., 2015). Within services for young people, this has been said to occur by understanding the young "inner dimensions" alongside developmental and environmental considerations (Botbol, 2010). This shift recognises that psychological constructs behind action are important, suggesting how meaning is constructed is as important as the action a person takes. Reed et al. (2010) suggest it is only through the elucidation of personal meaning that the lived experience can be understood, and that the subjective components behind behaviour shed insight into motivation towards action, the experience of participation, and the possibilities and potentials of a future self. Further, Reed et al. (ibid) suggest that, if

personal meaning as a construct is understood, then the processes and outcomes of care can potentially be transformed.

Drawing on Ziehe (2009) became useful to elaborate this aspect of findings, situating personal meaning within a social constructivist perspective of youth learning. Ziehe suggests that, for a young person, personal meaning can be understood in terms of "meaning horizons", and that the range of possibilities available to a young person are ameliorated or constrained by the subjective value they invest in such possibilities. Meaning horizons occur through an interplay of cultural, institutional and environmental constructs that socialise a young person, whilst individual mental processes shape their understanding of such constructs. The value a young person places on themselves occurs through an interplay between potential meaning horizons, the socialising constructs they exist within, and the young person's individual interpretation of self-concept. Ziehe contends that this process presents issues in relation to how young people learn and adapt in their given contexts, as young people may develop behavioural habits (such as avoidance) when in situations that challenge their self-concept. This process may also influence a young person's motivation for a "preferred content" of learning, which may also limit "meaning horizons" when a situation is seen as alienating. Ziehe concludes that a key challenge to a young person's learning is in developing a "motivational competence", which fosters new ways of doing things that may counter their initial inclinations towards preferred content.

In terms of this grounded theory study, Ziehe (ibid) proved a useful concept to contextualise how a young person's individual experience of healthcare interactions influenced their engagement. The personal meaning young people ascribe to their situations is important for

engagement to occur. Young people enter into institutional environments of the healthcare interactions, which socialise the young person with normative assumptions about boundaries and conduct; how a young person reacts in these settings may well enhance or impinge on the young person's health and wellbeing as their meaning horizons. In addition, future engagement could also be said to be a meaning horizon of health behaviour, and may well be influenced by the extent a young person feels valued in their patient role; hence, learning to becoming a patient may well be dependent on the personal meaning ascribed to individual experience. Developing awareness of the subjective perspectives of the young person may well be essential to engage a young person; in so doing, it is potentially possible to encourage behaviours and habits that see young people actively working towards their participation within interactions, health behaviours and health-related goals. Involvements in such processes may also be essential to encourage the young person to explore new ways to interact in their role of a valued individual. Collectively encouraging practices that explore personal meaning may be important for the better engagement of young people in their healthcare interactions.

7.7 Conclusion

This chapter detailed the construction of the core category. The analytical processes of memo sorting and conceptual synthesis of categories were presented in order to provide a transparent account of theoretical development. The visceral nature of affect was recognised as an important feature of young people's experiences of healthcare interactions, whilst embodied meaning influenced how young people reacted to affect. The experience of negative affect was identified as triggering automatic heuristic mechanisms, which influenced young people's participation. Five categories relating to the core category were identified that explained how young people responded to the experience of negative affect in their

healthcare interactions. This was later related to the dual process theory to elucidate the nature of affective arousal and the management of affect. Core category analysis suggested that the experience of affect was central to analysis and that affective appraisal of interactions influenced reactions and behaviours. Finally, the core category supported a substantive theory of 'affect-mediated engagement' which was discussed in relation to the literature. The following chapter completes the study, discussing the credibility, originality and resonance usefulness of findings in relation to theory, practice, and suggestions for future research.

Chapter 8: Thesis Dénouement: Quality, Key Messages and Study Limitations

8.1 Introduction

Dénouement refers to the unravelling of complex action so that disparate elements can be drawn back together, explained and resolved. This section focuses on the outcome of the study, clarifying the theoretical worth of findings and further impact. Chapters 5 and 6 identified prejudgement, learning to be a patient, and validation as significant processes whereby young people approached healthcare interactions, formed behaviours in the interaction to navigate their meetings with healthcare professionals, and validated their interpretation of the healthcare experience. Chapter 7 drew on the above three theoretical categories to identify that heuristic processes were triggered by the experience of affect; this led to the development of an emergent substantive theory of affect-mediated engagement situated within a dual-process perspective of cognition. The study provided a novel insight into what constitutes a young person's engagement through its delineation of key interpretive processes that young people draw on to understand the healthcare interaction; this provided insights into how young people formed behaviours in response to the healthcare professional, and subsequently inform how young people behave as an outcome of the healthcare interaction. The below thesis dénouement draws together these findings in relation to the following areas. First, the quality of the study is discussed using the specific criteria of credibility, originality, resonance, and usefulness as suggested by Charmaz (2006) for a constructivist grounded theory study; second, three key messages are proposed, providing suggestions for application of findings and recommendations for future research; third, study limitations are acknowledged in relation to research design and data collection methods. Finally, this chapter concludes the thesis by summarising the study and study findings.

8.2 Quality

Scientific rigour is of critical importance when determining the worth of empirical research; however, qualitative research has often been contested due to its lack of generalisability and objective measures (Myers, 2000). Seminal thinking such as Kuhn (1970) have shifted this argument into one of "paradigms", instead acknowledging that each distinct field of research hold its own assumptions about the world and how it is understood. Although attempts have been made to apply positivistic criteria such as reliability and validity to naturalistic research (Golafshani, 2003), it is generally accepted that, within a qualitative paradigm, ontological positioning informs epistemic claims; for example, Mays & Pope (2000) suggests that studies within an anti-realist paradigm are distant from a positivistic ontology and, therefore, are exempt from such measures. As this research was conducted using a constructivist grounded theory approach, a relativist ontological position was maintained that placed emphasis on the construction of meaning (Mills et al., 2008). To determine scientific rigour within this study, the specific criteria of credibility, originality, resonance, and usefulness as advocated by Charmaz (2006) was used to appraise quality. Moreover, it is acknowledged that, through a strong combination of credibility and originality, the resonance and usefulness of a piece of work are enhanced (Charmaz, 2014); hence, transparency and trustworthiness are important to acknowledge future application in the substantive area. The following sections discuss the credibility, originality, resonance and usefulness of this study, providing examples of how these criteria were met. The criteria of usefulness is later incorporated into the messages from the study (sections 7.3 – 7.5).

8.2.1 Credibility

To determine credibility, Charmaz (2006) suggests that a sufficient familiarity with data is required to warrant insight into the participants' experience of the phenomenon and to make empirical observations. Furthermore, the narrative of the participants should be made explicit throughout comparative analysis and the researcher's presence maintained; this is to ensure a transparent account of the theoretical rendering is attained. Credibility was maintained in this study by providing a transparent account of the analytical methods in Chapter 4. This chapter gave examples of how systematic comparisons were made within data sets, across data sets, and ultimately developed into theoretical categories. Moreover, a detailed and faithful profile of the participants was provided in Chapter 3 to maintain the presence of the young people who took part in this study; this provided a context to the young person's narratives and kept their experiences of interacting with healthcare professionals at the forefront of the study. Throughout Chapters 5 & 6, analysis was linked back to young people's accounts to ensure these observations remained grounded in the young people's experiences; these were supported by memos written in the first person to trace theoretical insights made throughout the constant comparison processes, and to provide a rationale for the resulting theoretical constructs. Analytical transparency was maintained throughout analysis, leading to the construction of a substantive theory of affect-mediated engagement. Credibility was further enhanced as saturation of concepts was achieved upon theoretical and core category completion.

8.2.2 Originality

The worth of a grounded theory can be said to be the analytical insights made within a substantive area; hence, novel ideas are of significance if they can further thinking, research and practice (Charrmaz, 2006). As identified in Chapter 2, there is very little health science

research that defines engagement or provides a direct empirical basis for how engagement occurs for a young person in a healthcare interaction. Furthermore, definitions that do exist are vague and often used interchangeably with other terms. This is worrying, as engagement is said to be a necessary component of healthcare practice with young people to improve health-related outcomes and facilitate positive lifelong health behaviours. This thesis provides a new understanding of how engagement occurs from the young person's perspective. Four novel insights previously unidentified in healthcare literature have been identified within the theoretical constructs of this study. Firstly, predictive expectations may potentially influence a young person's engagement, as opposed to ideal expectations which are commonly used to understand satisfaction in services and care delivery. Secondly, young people are learning how to engage through their participation in healthcare interactions; this suggests that the young person's interpretation of healthcare interactions is significant for forming contextual behavioural responses. Thirdly, young people found meaning in interactions based on their perception of needs being met; this highlights the importance of understanding a young person's individual needs to facilitate engagement. Finally, the core category insight into a dual-process perspective of how young people managed affect, hence engagement was mediated by different systems of cognition.

Understanding young people's engagement within healthcare interactions is highly important if practice is to be improved. The findings of this thesis are especially significant considering the scarcity of empirical evidence within this area. Healthcare professionals have a unique role as agents who can incite change and modify patient health and risk behaviours (Wiggers & Sanson-Fisher, 1994). Findings suggest that young person's engagement behaviours are associated with how they learn from involvement in their interactions; healthcare

professionals may, therefore, be well-suited to incite change in engagement behaviours and improving their participation. This research adds new insights in these areas and may well stimulate further debate.

8.2.3 Resonance

The criterion of resonance relates to how the fullness of the studied experience was portrayed, encompassing the researcher's action to convey the lived experiences of those within the phenomenon, whilst explicating the covert social processes that drove their action (Charamz, 2006). It is now commonly acknowledged within the sociology of healthcare that expectations of conduct and behaviour are key components of the patient role (Parsons, 1951); hence, an implicit power disparity exists between the role of the patient and the healthcare professionals' role in delivering services (Budd & Sharma, 1994). Explicating the young person's voice was essential to ensure their perspectives were engrained in strategies to improve engagement and the healthcare interaction experience. As stated in Chapter 4, the research method sought to give preference to the young person's narrative to develop a new insight into engagement. Current perspectives lack these insights and the paucity of literature in this area would benefit from the young person's perspective in order to develop patient-centred practices. Sensitivity to the young person's voice was developed and enhanced by deep immersion into the setting; this allowed young people to build trust and rapport when disclosing their narratives, which heightened researcher sensitivity into their experiences. This enabled young people's experiences to extend into explanations of how interactions were navigated and personal meaning was formed. Furthermore, the criteria of resonance relates to the extent the research 'makes sense' of narrative, requiring insight the co-construction of meaning as in identifying social process (Charmaz, 2014). Frequent onsite accesses enabled regular contact with the young people, affording them discussions into the study and research

outcome; this enabled young people to learn about the concept of engagement as concepts were being checked. This was useful as it heightened young people's awareness about their experiences and developed a greater understanding of their healthcare experiences. Memo writing was especially important in this process, identifying how meaningful narratives were interpreted by myself and used to direct theoretical moment. However, it is important to note that the final theory was not fed back to young people due to time restrictions. Furthermore, many students were in their final year of formal education and preparing to graduate at the time of interviewing, posing additional problems for checking individual concepts. However, this is not problematic within a grounded theory approach as it is acknowledged theory development occurs along a continuum of induction to deduction (Strauss & Corbin, 1990). As a result, the theory proposed in this thesis will lend itself to empirical testing of worth in additional studies.

8.2.4 Usefulness

The criteria of usefulness relate to the extent that the findings can influence the lives of people in the phenomenon, and the extent theoretical renderings stimulate further enquiry. This specifically relates to how findings contribute to further knowledge and shape a better world (Chamaz, 2006). Chamaz (2014) summarises usefulness as follows:

"When born from reasoned reflections and principled convictions, a grounded theory that conceptualises and conveys what is meaningful about a substantive area can make a valuable contribution"

(p.338).

This sentiment emphasises that the process of scientific enquiry, when deemed credible, original and having resonance within the substantive area, may prove valuable to understand the phenomenon and effect change. The previous chapters elucidated rigourous methods of

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qualitative coding that led to the identification of psychological social processes young people experienced when working with healthcare professionals. Theoretical categories identified three distinct stages whereby young people formed expectations, developed in-context adaptive responses, and sought validation of their beliefs. From these, a core category was identified that led to a potential substantive theory of affect-mediated engagement, highlighting two distinct systems of cognition that influence a young person's engagement in healthcare interactions. Chapter 7 argued that the processes that led to the construction of these systems of knowledge were credible, provided original insight into the area, and had resonance with the young people of the study; it was also identified that resonance could be further developed in post-doctoral studies. The usefulness of this grounded theory lay in the identification of affect as a key influence to a young person's engagement, that heuristic processes are a potential mediating factor to engagement, and that the knowledge derived from this study could be useful to reconceptualise how healthcare professionals conduct healthcare meetings with young people, and how young people are worked with to enable them to manage affect in their health behaviours.

The following sections discuss usefulness in terms of three key messages. The first message from this study suggests that young people may automatically draw on heuristic processes when experiencing affect, and knowledge of this is useful when developing youth-friendly approaches. The second message from this study identifies that a dual-process perspective of engagement could potentially aid healthcare professionals when working with young people to remove barriers to engagement. The third message from this study identifies the importance to understanding a young person's perspective of engagement is to stimulate new lines of enquiry into healthcare engagement; hence, developing an under-researched area.

8.3 Message 1: Recognising Affect as a Developmentally Normal Aspect of Adolescence is Useful to Develop Youth-Friendly Policy and Services

It has become increasingly important to get it right when working with young people in healthcare contexts. The Department of Health (2011) Quality criteria for young people-friendly health services explicitly emphasises that healthcare professionals and other health workers should have the knowledge and skills to understand, engage and communicate with young people to promote healthy attitudes and values. Such expertise is considered essential to facilitate a young person's decision-making and enable them to feel listened to during engagement with health services (Department of Health, 2007). The World Health Organisation (2010) report on youth-friendly health policies and services in the European Region identifies considerable progress has been made in the United Kingdom in developing youth health services. These developments have been made possible due to a range of policies that have focused on developing services that have the right people, with the right skills, in the right place, at the right time to meet young people's specific health needs, provide early intervention, and target the health inequalities young people experience in the adolescent period. Yet, despite progress, challenges remain. The report suggests that a key challenge is the growing recognition that it is not possible to change young people's health and health behaviours until young people are engaged in their services; this places an emphasis on "getting services right for users, and so encouraging young people's autonomy and self-determination in respect of lifestyle choices [to] create a strong foundation upon which the health of the young nation can flourish" (World Health Organisation, ibid, p.198). The findings of this study can, therefore, be understood as useful as they identify that affect is a developmentally normal experience for a young person, and that reactions to affect may exist on a normal continuum of cognitive change and social/behavioural development. As such,

defining engagement as a process that evolves as young people develop cognitive control systems in self-management could be argued as important to understand what we should expect of young people at a service engagement level. Interestingly, this suggestion is already in line with current health delivery approaches; for example, The 5–19 Healthy Child programme (Department of Health, 2009a) emphasises this point:

"Changes in neurological structure and function relate to developmental changes, and how areas of the brain responsible for executive control and decision-making continue to mature until the mid-20s….[by] understanding neurological development [we] may improve our ability to understand young people's perspectives and better engage with them about the health choices they make."

(P.20)

By acknowledging that adolescence is a distinct developmental stage that impacts on health and health behaviours, it is possible to extend this notion to the health behaviours young people form in managing their healthcare interactions. Hence, the findings of this study have implications for three key areas.

Firstly, recognising affect as a developmentally normal experience of adolescence could inform how services are structured to accommodate affective reactions within healthcare service provision. Adolescence is a marked period of significant change, where learning about one's self in the world occurs alongside pubertal, emotional, social and cognitive development (section 6.4); how young people learn to respond to these changes is important in regards to how they develop their engagement behaviours within the healthcare interaction. This thesis showed that young people are learning how to manage emotions that arise, when interacting with healthcare professionals, within the healthcare context (section 7.2.3); how young people navigated these experiences was based on competing systems of cognition that shaped their interpersonal reactivity (section 7.4). It would, therefore, be useful for youth-

friendly services to acknowledge that the healthcare interaction is as much about how the young person develops the ability to manage emotions in such new experiences, as it is about achieving positive health outcomes within that meeting; hence, behaviours in healthcare meeting, whether conducive or disadvantageous to engagement, are influenced by the young person's self-regulation competencies when experiencing negative affect (section 7.5). Service provision may benefit from this knowledge by incorporating emotional intelligence training and self-management strategies into care delivery for young people; this would require a shift from condition-based service delivery, which focusses on specific health needs within set service provision, to a holistic perspective that promotes active collaboration and engagement as a positive health behaviour, alongside specific service provision to meet young people's health needs. This approach may be further enhanced by joined-up working across primary and secondary healthcare services, school-based services and community health programmes to ensure parity across young people's services.

Secondly, the findings of this thesis are advantageous from a health education perspective, and may be potentially useful to empower all stakeholders in young people's health. This could be done by promoting insight, independence and voice to assist young people in developing positive engagement behaviours. These are detailed as follows:

I. **Promoting insight**. The roles of affective states and urgency behaviours have been shown to impact on young health and health behaviours; similarly, metacognitive intersection has been identified as a key protective factor for regulating trait urgency and moderating choices that could negatively impact on health and health outcomes (section 7.6.1). Educating young people, parents and care workers on how affective

states influence choices relating to engagement within the healthcare interaction could potentially promote insight into causes of disengagement, and provide a foothold to reengage young people when disengagement occurs.

II. **Promoting independence**. This thesis contended that affect is a developmentally normal aspect of adolescence and, as such, should be reflected in the way one works with young people. Therefore, promoting positive engagement could be said to potentially have positive effects within young people's transitions to adulthood; this could prevent mid to long-term health complications forming or progressing, instil an awareness of the importance of health and tackle negative health-related behaviour. This could be achieved by health professionals targeting negative reactions to affect, when such behaviours occur, but also by educating young people and parents as to how healthcare interactions can be negotiated when perceived conflict occurs. Such strategies would be beneficial to empower young people as an active participant in their care, rather than a passive recipient of care.

III. **Promoting voice**. Healthcare literature shows that a range of factors surrounding the healthcare interaction, in addition to the dynamics of the healthcare interaction itself, can make young people feel disempowered and marginalised in the healthcare interaction (section 2.8); such perspectives can contribute to young people's (dis)engagement with healthcare professionals. Educating young people on how to recognise and overcome negative reactions that arise within the healthcare interaction would be useful to help young people constructively assert themselves when feeling their needs are not met, and promote young people to develop their own voice for active collaborative with the healthcare professional.

Finally, it would be useful if young people are consulted with these strategies to ensure individual and collective participation in decisions that affect them. As suggested in section 2.8, concepts such as engagement have been developed through professional discourse, and such knowledge, developed through expert opinion, can be imposed on young people without gaining their perspective or understanding of what such terms mean to them. Similarly, the development of services that aim to facilitate young people's self-management strategies for emotional regulation would benefit from the young person's perspective into how these services could be developed and implemented so that they are accessible, acceptable, appropriate, effective and equitable (World Health Organisation, 2009). By collaborating with young people to understand their needs, these criteria can be useful for developing and improving responsive healthcare services that meet the needs of the young people who use them (World Health Organisation, 2012). Ultimately, services that are aware of young people's emotional needs, and work with young people to overcome the impact of negative affect on a young person's engagement behaviour, may well empower young people in becoming active stakeholders in their own health.

Greater insight into how young people engage has the potential to act as a bridge between national policies and drivers and healthcare delivery that seeks to engage young people in their healthcare. This approach would be useful to rethink how strong systems within services are designed to be developmentally appropriate, and delivered to meet the emotional and behavioural needs of young people as they age into adulthood.

8.4 Message 2: A Dual-System Perspective of Engagement Would Be Useful for Healthcare Professionals Seeking to Engage Young People

It is known that, as a population, young people are less likely than other age groups to visit or engage with healthcare professionals, and that new approaches are needed to make health programmes and health services more teen-centred (The Chief Medical Officers Report, 2008). As identified in Chapter 6, a dual-processes perspective of adolescent cognition emerged that recognised the impact of heuristics in relation to the experience of affect and how such heuristics were employed in the management of trait urgency; these experiences were suggested as being moderated by the cognitive control systems the young person employed. Knowledge of such processes would be useful to shape how healthcare professionals work with young people to accommodate the experience of affect, potentially enabling young people to become adept at managing affect. Working with young people may, therefore, be enhanced by helping young people develop positive behaviours for their lifelong relationships with healthcare professionals, as opposed to the presenting problems alone. However, this would require healthcare professionals to understand that engagement as health behaviour is a complex phenomenon. Furthermore, the implication for health outcomes and future health behaviours should engagement not occur is equally important; for instance, the Chief Executive Summary (2008) iterates the importance of developing good health behaviours early in life as these have a lifelong influence on health habits in later years.

A dual-processes perspective of engagement is potentially beneficial for healthcare professionals working with young people, as it may allow for strategies that target emotional regulation when disengagement occurred. Self-regulation in healthcare behaviour has been identified as a key aspect in goal prioritisation and attainment; hence, enabling self-regulation is beneficial in the strategic mobilisation of thoughts and feelings as an agent in volitional

health behaviours (De Ridder & De Wit, 2006). By designing healthcare interactions that are sensitive to the young person's experience of affect, and utilising strategies to assist the young person in developing cognitive processes associated with system 2 cognitive deliberation, young people could potentially work through problems alongside their emerging autonomy. The benefits of such an approach may mean that young people receive healthcare interactions that are personal and personalised, which would go some way to meet a young person's expectations for age-appropriate healthcare receipt. The implications of this for healthcare professionals working with young people are as follows:

I.   **Equipping healthcare professionals with the skills to engage young people.** Patient-centred care is widely recognised as a professional core competency, requiring healthcare providers to understand patients' needs, involve patients in joint decision-making, and facilitate patients in making good health and lifestyle choices (Greiner & Knebel, 2003). When working with adolescent populations, healthcare professionals draw on a range of specialist skills and knowledge to place the young person at the centre of their care to encourage them to become active parties in their own health and wellbeing. However, it is important to recognise that young people receive care from a wide range of professional identities, each with specific knowledge, skills and strategies relating to their field of practice. This thesis suggested a dual-process perspective of adolescent cognition may be useful for healthcare professionals to understand how young people experience engagement in the healthcare interaction; as such, professions that draw on psychology and mental health literature may find the thesis findings more accessible, and easier to translate into practice, than those who work in biomedical contexts. In this respect, it would be helpful for healthcare professionals to have training provided in relation to the theories relating to dual

processes of cognition, affect, and the role of heuristic processes in judgement and decision making; this may enable a greater insight of discrete cognitive processes that underlie young people's express needs, decisions within the healthcare interaction and health and risk behaviours. Such training could be supplemented by using standardised assessment tools, such as the Adolescent Self-Regulatory Inventory II (Moilanen, 2007), to equip healthcare professionals with the skills to recognise self-regulatory abilities of young people in order to determine those at risk of disengagement from their healthcare interactions. It would be beneficial to explore what training would be required with key stakeholders to determine the feasibility of this suggestion.

II. **Working with young people to overcome negative affect.** Young people are at a pivotal life stage where they are learning new skills, responsibilities and new behaviours; the shift from dependency on others to relative autonomy is a marked feature of their development, and the ability to self-regulate emotion is a key feature of successful psychosocial functioning in later life (Zeman et al., 2006). This thesis highlighted that self-regulation, when under the experience of negative affect (section 7.5), may play a pivotal role in how young people engage in their healthcare interaction; for this reason, it may be useful for healthcare professionals to work with young people to improve their ability to self-regulate in order to engage them in their healthcare. This could be done by working with young people to develop their cognitive and social-emotional self-regulation, as such approaches are thought as beneficial for encouraging metacognitive intersection, the ability to recognise and alter maladaptive behaviours when experiencing negative affect, reflection, the capacity for developing insight into the consequences of decisions and behaviour, and delaying gratification, the means to overcome trait urgency to develop constructive behaviours (Bandy & Moore, 2010). By

helping young people to become aware of thoughts that precede actions, and to explore the consequence of behaviours, it may be possible to help young people develop constructive approaches for engagement within the healthcare interaction. Additionally, this approach may be supplemented by healthcare professionals collaborating with young people to develop metacognitive nudges as a means to activate rational cognitive processes when experiencing negative affect (Dansereau et al., 2013). These strategies could enhance young people's experience of the healthcare interaction, and assist young people in developing a mastery of their health and health behaviours.

III.   **Educating parents and stakeholders.** The findings of this study suggest that young people develop their own approaches to navigate their healthcare interactions through their participation in their healthcare meetings (section 5.4); however it would be wrong to suggest that young people develop these behaviours in isolation, as they draw on competing sources to construct their understanding of the healthcare professional and the healthcare interaction (section 5.3.1). It may, therefore, be useful to disseminate findings to parents and other key stakeholders in young people's health and wellbeing to better prepare young people for their healthcare experiences. By encouraging parents, schools, and wider communities to recognise and understand the role of emotion on young people's information processing, judgement forming and decision making may stimulate a discourse into how young people can be supported to improve their health behaviours, and actively participate in their health decisions. This could be further enhanced through consultation and further research with key stakeholders (as will be explored in section 8.5).

Such strategies would complement current guidance for working with young people. For example, the National Service Framework for Children, Young People and Maternity Services (Department of Health, 2004) acknowledges a need for a fundamental shift in the way we think about children's and young people's health, suggesting that holistic approaches should focus on early identification of problems and preventative action to best meet young people's future needs. There is great potential to better engage young people in their care by developing a greater insight into the dual processes of cognition that influence how young people engage, and it would be useful to further explore how such knowledge can inform practice.

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8.5 Message 3: A Young Person's Perspective is Useful to Understand Engagement and Stimulate New Lines of Enquiry

This study explored how young people experienced engagement within their healthcare interactions from the perspectives of 16 young people who had a health interaction within the past 12 months. The young people came from a variety of home backgrounds, disclosed a wide range of health needs, and had experienced variable experiences in their interactions

with healthcare professionals, as well as the observations of others people's experiences within their family networks. In-depth interviews generated rich data, which were later analysed using the constant comparison method as is usual with a grounded theory study. The results of this method of enquiry provided detailed insight into how young people experienced the phenomenon of engagement with healthcare professionals, whilst enabling identification of the psychological and social processes which brought this phenomenon about. The study findings resulted in a tentative substantive theory that suggested affect may be mediated through two systems of cognition; hence, providing a novel way to understand how young people engaged. Further research would be required to test that the substantive theory held true by exploring these concepts in additional studies. This could be done in the following ways:

I. Concepts raised from this grounded theory study could be investigated with young people in similar substantive settings. This approach would be useful to validate the concepts that emerged from comparative analysis whilst further enhancing the resonance of findings.

II. Concepts raised from this grounded theory study could be investigated with young people in dissimilar substantive settings. This approach would be useful to develop the concepts that emerged from comparative analysis by determining their originality across populations of young people and usefulness within different settings.

III. Concepts raised from this grounded theory study could be investigated with other key stakeholders in young people's health (for example, healthcare professionals, parents, service managers). This approach would be useful to explore the resonance of concepts that emerged from comparative analysis whilst gaining insight into the usefulness of these theories for practical implementation.

IV. The above steps would enable the development of a formal theory of affect-mediated engagement which would be useful for applications across settings and healthcare contexts with young people. The development of a formal theory would then be

subject to further enquiry to determine the falsifiability of the theory as a robust and workable model of young people's engagement.

In addition to the theoretical development of findings, this thesis identified that there is a gap in the literature on how engagement is understood, specifically from a young person's perspective. Further research in this area could include the development of a qualitative questionnaire to survey young people on their experiences of healthcare interactions and beliefs about engagement within interactions in order to understand what barriers and facilitators are experienced across a bigger data set. Additionally, this research area would also benefit from mixed methods investigations to draw together associations into young people's perspectives correlated across different research paradigms.

300 words on the need to stimulate further enquiry within this area

Identifying and understanding young people's perspectives as a valid perspective to understand the difficult concept of engagement would be a crucial step in developing greater insights into this area. It would be beneficial to develop new perspectives from a range of young people across social backgrounds, reflecting the fact that young people are a heterogeneous population, and establishing the views and perspectives across a wide spectrum of backgrounds would strengthen a global understanding of the core features of what it is – for a young person – to engage within the healthcare context. This would require research to move beyond seeking views beyond that of the experience of healthcare receipt, instead delving into how young people form meaning in their worlds, and shape decisions on such interpretations of their world. Such approaches would enable a shift from confirmation of existing knowledge through the young person's voice, to one that values the young person's voice as a way of shaping and defining meaning within the healthcare context. The above steps

would be useful to develop the evidence base to aid healthcare professionals working with young people. This would also provide a means to understand why young people engage with, or disengage from, the healthcare interaction, and facilitate working with young people to develop regulatory strategies when experiencing negative affect, which would contribute to their development of positive health behaviours.

8.6 Study Limitations
Identifying the limitations of a study is of great importance within empirical work as these place findings in context, provide insight into the potential errors borne from methods of data collection, and determine the relevance of the work for other substantive areas. Moreover, it is important that study limitations are properly identified in order to generate debate on the topic and stimulate further research. Yet, scientific studies do not always appropriately acknowledge limitations, resulting in the extrapolation of flawed findings due to the lack of transparency in such reports (Ioannidis, 2007). Given the constructivist nature of this grounded theory, the acknowledgement of limitations is essential to demonstrate reflexivity with regards to research design, data collection, and the application of findings. This study acknowledges three limitations. Firstly, the research design did not include a healthcare professional's perspective into the engagement of young people in the healthcare interaction. This was a purposeful delimitation in order to give preference to the young person's perspective, thus exploring an area not previously researched. Therefore, it might be argued that, due to this approach, the study does not fully encompass the young person/healthcare professional-relational dyad. However, this limitation in scope of inquiry is not problematic, as the development of a substantive theory does not claim an objective truth, but rather aims to provide new insight into how the phenomenon is experienced and operates by those who contributed to it. As such, it is acknowledged that the substantive theory developed in this

study pertains to the young people's perspectives of the healthcare interactions, but would readily lend itself to further investigation with healthcare professionals to develop greater insight into these concepts.

Secondly, the findings from this study were derived from young people's retrospective accounts of healthcare interactions. Young people were not limited to the type of experiences they should draw on to determine how they understood engagement, which meant that often young people disclosed events from their childhood, and from the healthcare experiences of family members. This approach could be potentially criticised as lacking clear parameters of what constituted a 'young person' health interaction. However, it is essential to note that the constructivist nature of this thesis seeks to understand how participants construct meaning; hence, it was imperative to allow young people to draw on their own associations when forming their accounts of the phenomenon. In this sense, engagement became viewed as a continual process of learning, which undoubtedly influenced theoretical construction. Again, this is not problematic; however, the additional approaches for future research listed above will undoubtedly add to the rigour of future scientific enquiry. As such, credibility of findings would be enhanced through future postdoctoral research.

Finally, at present there is limited scope for this study to make direct inferences into other substantive areas. This limitation pertains to the direct application of findings as a means to explicate young people's engagement within the healthcare interaction as a global concept. This grounded theory study focussed on the generation of rich data to develop a contextualised insight situated in young people's perspectives of care, and was achieved through continued processes of comparative analysis and abstraction until theoretical

maturation occurred; this resulted in the identification of a core category central to the observed phenomenon. However, there are confines to the extent this research can be applied to new contexts, as the study did not engage in further testing of the emergent substantive theory. For example, it has been suggested that the end product of a grounded theory is its systematic replication, requiring confirmatory evidence in support of initial findings (Hussein et al., 2014). Hence, confirmation of a new theory would require it to determine its use to explicate real world events. Yet, even latter stages of deductive inquiry are not without issue, as further research is arguably verifiable, but not necessarily reproducible. Corbin & Strauss (1990) elucidate this point, as follows:

"One can take the propositions that are made explicit or left implicit, whatever the case may be, and test them. However, no theory that deals with social psychological phenomena is actually reproducible in the sense that new situations can be found whose conditions exactly match those of the original study, although major conditions may be similar. Unlike physical phenomena, it is very difficult in the social realm to set up experimental or other designs in which one can recreate all of the original conditions and control all extraneous variables impinging upon the phenomenon under investigation."

(P.15)

Drawing on Corbin & Strauss (ibid), a grounded theory is generalisable to the extent that process of action and interaction can become known, and the conditions that impinge on, or bring about, the phenomenon can be understood. However, the theory may never be truly replicable as new conditions will constantly arise across social contexts; as such, theory may always require adaption as new conditions and variations are discovered. In relation to this study, the further testing of theory would be useful to develop a robust and broad theory, useful across a range of situations; however, as new insights are discovered, the adaption of existing theory may be required to reconceptualise the phenomenon of young people's engagement within their healthcare interaction.

8.7 Thesis Conclusion

In conclusion, this study has provided clarification as to what engagement in a healthcare interaction is from the young person's perspective, and consequently provides an initial step to understand engagement as a process and outcome of the young person's healthcare meetings. The rationale for this study arose from the scarcity of empirical work in this area, resulting in a conceptual ambiguity of what engagement is, and how it is enacted. The findings of this study have the potential to positively influence how engagement is understood for healthcare professionals who work with young people. Findings echoed current conceptual definitions of engagement in that engagement was a result of reciprocal actions between a healthcare professional and patient (Coulter, 2011), and were compatible with youth-friendly approaches for health and healthcare delivery (Department of Health, 2004a; 2004; 2007; 2008; 2009a;2011). However, this study provides new insights into the psychological social processes that young people experience when they interact, and how engagement is mediated through the experience of affect. The theoretical categories *prejudgement*, *learning to be a patient*, and *validation*, identified the psychological-social aspects of the healthcare interaction that influence how young people approach, enact and understand their patient role when meeting with healthcare professionals. Furthermore, these aspects of study findings identified that these psychological-social processes were active features of how young people elicited their engagement, regardless of the behaviours they believed they formed in their healthcare meetings. The core category identified that affect was central to these experiences, which influenced how young people responded to healthcare professionals within the healthcare interaction. Finally, an emergent substantive theory was identified to determine how different systems of cognition mediate affect when young people experience perceived difficulties in healthcare interactions. The final rendition of findings drew on a dual-

process perspective of cognition to identify that automatic system 1 cognitive processes could potentially detract from positive engagement, whereas deliberative system 2 cognitive processes may facilitate self-regulation, thereby positively contributing to better engagement. Collectively, these findings provide new knowledge to an area with a paucity of literature.

This thesis has identified that a young person's engagement in a healthcare interaction is a highly personal experience, and this experience is often not acknowledged or understood and would benefit from further empirical research. The experience of affect is arguably a developmentally normal experience, given young people's life stage, and the biological, cognitive and social developments they experience throughout adolescence. Recognising affect as a developmentally normal feature of their engagement may be useful to minimise the barriers young people face when meeting with healthcare professionals. This study adds a novel contribution to the evidence base in terms of theoretical and empirical insights through the identification of heuristic processes potentially inhibiting a young person's engagement; hence, findings deliver a new perspective into how young people engage as a process of participation and as a behavioural outcome.

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Appendices

Descriptive Info	
Author(s)/year	
Title	

Inclusion/Exclusion			
	Criteria	**Yes**	**No**
1	Clear focus on healthcare interactions between population 1&2		
2	Perceptions of population 1 engagement in healthcare by population 1.		
3	Perceptions of population 1 engagement in healthcare by population 2.		
4	Contextual factors of population 1's healthcare engagement		
5	Exploration of relational dyads between populations 1&2		
6	Exploration of communications between populations 1&2		
7	Outcome measurements of engagement		
8	Outcome measurements of health needs met through engagement		
9	Another language		
10	No focus on engagement set out in 1-8		
11	Family decision making		
12	patient and public engagement strategies		
13	Not relevant to United Kingdom healthcare		
14	Non-populations specific		

If – YES to criteria 1-8 please complete below			
	Criteria	**Yes**	**No**
1	Young person focused		
3	HCP focused (specify HCP)		
4	Qualitative (specify)		
5	Quantitative (specify)		
6	Model specific		

Notes:

Decisions

Include (if answered Yes to 1 and 2 and 3 above)	Exclude (if answered Yes to 4 or 5 or 6)	Needs Further Discussion	Exclude – But useful background info

Appendix 2: Interview Guide

- Would you tell me about the last time you met with the doctor/nurse/therapist (use pre-interview check results)
  - (Reason/length/result)

- Do you feel you were able to get across to the HCP what your needs were?

- Was there anything happening in your life at that time that made the healthcare consultation difficult?
  - (check for lifestyle issues and contextual factors that conflicted with health appointments and interventions)

- What was important that you wanted the HCP to know?
  - Did you manage to make it known?
  - Do you feel the HCP understood you?

- Can you tell me about how the HCP communicated with you?
  - How well do you think they listened to your concerns?
  - (Explore what was facilitators and barriers to the process)
  - (Was age appropriate communication used?)

- When you visit a healthcare professional what would help you to better discuss your health needs to meet how you live?
  - How do you think HCP can help you discuss your needs?
  - Do you think there's anything you could do to help this?

- What else is important to you when discussing your needs with a HCP?

- How were you involved in the consultation?
  - (seek examples)
  - (Explore approach of consultation, decision aids)

- How did the HCP take into account any lifestyle issues within your consultation?

- Who did you feel made the decisions in your consultation?

- Was the level of involvement you had in your consultation the level that you wanted?
  - (check for young person's desire for own level of participation)

- Did you feel that you and the HCP understood each other?
  - Did feel you could share more with them?

- Did you feel that you 'engaged' with the HCP?
  - (After answer ask what engaging means)

- Is there anything the HCP could have done to better engage you?

- What other things could have happened in the consultation that would have helped?
- Think about your past healthcare consultations. Can you talk me through how you feel a consultation should take place with your HCP?

University of
Salford
MANCHESTER

Introduction

I am doing this study to find out how young people from many different types of backgrounds engage with their health professionals. Engagement happens whenever a young person meets a nurse, doctor of other health professional to talk about their health needs. When people engage well with health professionals they can:

- Feel more involved
- Feel more in control
- Build trusting relationships
- Make important joint-decisions together

However, everyone is different. Only you know what works best for you. Finding out what you think will help health professionals understand and work with young people better.

Who am I?

My name is Jason and I am an occupational therapist. I'm studying for a PhD with the University of Salford. As a health professional I must always act in your best interest.

Why have you been asked to take part in this study?

- You are a young person between the ages of 13 and 19
- You have had a healthcare appointment in the last year
- There may be reasons in your life that make it difficult to interact with health professionals
- You may not have had the same access to health services as many other young people.

What is the purpose of the study?

I want to find out your views of what happens when you interact with health professionals. This will help me understand how to make this a better experience. I will use what I find to explain to other health professionals the best way to work with young people like you. To get as many points of view as possible, I will be interviewing 10 to 25 young people from a wide range of backgrounds.

Do you have to take part in this study?

It's your choice. If you do not want to take part, you do not need to give a reason. If you want to take part, I will:

- Talk about the research with you in more detail
- Ask you to take the form home to your parents/guardian
- Talk about taking part with your parents/guardian
- Ask you to return the form to me with signatures from yourself and a parent/guardian.

If you take part, but later change your mind, you can do this at any time. We will ask if we can still use the information you have given. It will be up to you, and if you say no all the data will be removed from the study.

What if my parent/guardian wants to speak with you?

If they want to speak with me after reading this information sheet they can. Ask them to contact me using the details below. I am happy to talk with them about the study and any concerns they have. If they are happy for you to take part, they need to sign and return the consent form I gave you.

What will I need to do?
Taking part involves being interviewed. Interviews will take around 60 minutes and will be done at (NAME OF THE SITE). I will bring some questions with me, but I want you to add anything important that you think I have missed. I also want you to tell me how to do the interviews better. All the interviews will be recorded so I can listen to you without writing notes. After the interview, I may ask you if you would like to come to a group meeting at the end of the research to see if you think the results sound right. We can also use this time to discuss what you think is the best way to get these messages across to health professionals.

Are there any possible benefits for you in taking part in this study?
Your voice is important, and it is important that it is heard in the right way. Taking part may help you think of better ways to communicate with health professionals. What you tell me will also be used to help health professionals understand you and run services better to meet your needs.

What are the risks of taking part in this study?
There is no physical risk. However, I understand that not all healthcare experiences are positive ones. If, at any point, you become upset we can stop. We will only continue if you want to. If you bring up issues that need further attention, there will be an opportunity for debrief after the recorder is switched, where I may advise you about the best services to help.

Will the health care professionals know what you said about them?
No. As a researcher I keep your confidentiality. This means that no details will be passed to anyone outside of this study, and what we talk about is kept private. All data will be anonymous, and no-one would ever know who had told us these things. The exceptions are if:
- You tell me that you or another person is at risk of harm
- Any illegal activities are disclosed.

In this situation I would need to pass this information onto another professional who deals with these matters.

What happens to the information and results that I get from this study?
The information will be:
- Stored under password protection on a computer at the University of Salford
- Accessed only by me and my supervisors
- Paper documents will be stored in a locked cabinet that only I have access to.

The results of the study will be:
- Submitted to the University of Salford as part of my final thesis
- May be published within health journals
- May be presented at health conferences.

What if you have any concerns?
Speak about your concerns to your parents, guardian or the service manager. If you want to complain about the study you can contact my supervisor, Dr. Jo Smith, through her direct line on 0161 295 7132.

Thank you for reading this information sheet. If you have any further questions or concerns then please do not hesitate to discuss them with me. If there is any problem with your interview slot you can text or call me on (disposable sim)

[Researcher & Supervisor contact details]

University of
Salford
MANCHESTER

Introduction

I am doing this study to understand how young people from a wide range of backgrounds engage with their healthcare professionals. Engagement happens whenever a young person meets a nurse, doctor of other health professional to talk about their health needs. When people engage well with health professionals they can:

- Feel more involved
- Feel more in control
- Build trusting relationships
- Make important joint-decisions together

However, everyone is different, and only you can know what works best for you. Finding out your views will help health professionals understand and work with young people better.

Who am I?

My name is Jason, and I am an occupational therapist studying for a PhD at the University of Salford. As a health professional I have an ethical duty to act in your best interests at all times.

Why have you been asked to take part in this study?

- You are a young person between the ages of 13-19
- You have had a healthcare appointment in the last year
- There may be reasons in your life that make it difficult to interact with health professionals
- You may not have had the same access to health services as many other young people.

What is the purpose of the study?

The purpose is to find out your views of what happened when you have interacted with health professionals in the past. The information you give will help me understand what happens when you engage with health professionals and to explain to other health professionals how to work with you better. To get as many points of view as possible, I will be interviewing 10 to 25 young people from a wide range of backgrounds.

Do you have to take part in this study?

It is your choice. I am interested in what you have to say in your own way. If you do not wish to take part, you do not need to give a reason. If you take part, but later change your mind, you can withdraw at any time. We will ask if we can still use the information you have given. It will be up to you, and if you say no all the data will be removed from the study. If you want to take part I will explain the research to you in further detail, and if you still want to take part I will ask you to sign a consent form. You will be given a copy of the consent form and this information sheet to keep.

Do you need to get your parents/guardian involved?

You are over 16 so this choice is entirely up to you. It is your right to be heard; however, I realise you may want to talk about this with your parent/guardian. You should think about this for at least 24 hours before you make your choice. If you want your parents or guardian to be involved, you can give them this information sheet with my contact details. If you choose not to include them, they will not be informed that you took part.

What will I need to do?

Taking part involves being interviewed. Interviews will take approximately 60 minutes and will be done at (NAME OF THE SITE). I will bring some questions with me to guide the interview, but I want you to add anything important that you think I have missed. I also want you to tell me how to do the interviews better. All the interviews will be recorded so I can listen to you without writing notes.

At the end of the interview I may ask you if you would like to come to a group meeting at the end of the research to see if you think the results sound right. We can also use this time to discuss what you think is the best way to get these messages across to health professionals.

Are there any possible benefits for you in taking part in this study?

Your voice is important, and it is important that it is heard in the right way. Taking part may help you think of better ways to communicate with health professionals. Your views will also be used to help health professionals understand you, and influence services to work with you more effectively.

What are the risks of taking part in this study?

There is no physical risk. However, I understand that your health is important to you, and not all healthcare experiences are positive ones. If, at any point, you become upset or distressed, we can stop the interview until you are ready to continue. If you bring up issues that need further attention, there will be an opportunity for debrief after the recorder is switched, when I may advise you about the best services to help.

Will the health care professionals know what you said about them?

No. As a researcher I keep your confidentiality. This means that no details will be passed to anyone outside of this study, and what we talk about is kept private. All data will be anonymous, and no-one would ever know who had told us these things. The only exceptions are if:

- You tell me that you or another person is at risk of harm
- Any illegal activities are disclosed.

In this situation, I would need to pass this information onto another professional with specific responsibility for such matters.

What happens to the information and results that I get from this study?

Information from the project will be stored under password protection on a computer at the University of Salford and accessed only by me and my supervisors. Any paper documents will be stored in a locked cabinet to which only I will have access. The results of this research will be submitted as my final thesis to the University of Salford, and may be published within health journals and presented at health conferences.

What if you have any concerns?

Speak about your concerns to your parents, guardian or the service manager. If you wish to complain about the study, you can contact my supervisor, Dr. Jo Smith, through her direct line on 0161 295 7132 who address this with me. If there is any problem with your interview slot text or call me on (disposable sim)

Thank you for reading this information sheet. If you have any further questions or concerns then please do not hesitate to discuss them with me.

[Researcher & Supervisor contact details]

University of
Salford
MANCHESTER

Patient identification number for _____ study

Name of Researcher: Jason Vickers

Name of participant: _____

Please initial box

1. I confirm that I have read and understand the information sheet (version 2: 30/11/2012).

2. I have had the opportunity to discuss this project and I have had a minimum
    of 24 hours to decide that I want to participate.

3. I understand that my participation is voluntary and that I am free to withdraw at any time
    without giving any reason and without my legal rights being affected. If I chose to withdraw
    I understand it is my right to have all information I have given removed from the study.

4. I have been given the opportunity to inform my parent/guardian about the study.

5. I agree to the interview being recorded.

6. I understand that the final results of the study will be presented in thesis, and may be
    included in future journal papers and conference presentations.

7. I agree to take part in the above study.

_____   _____   _____
Name of Parent   Date   Signature
_____   _____   _____
Name of Participant   Date   Signature
_____   _____   _____
Name of Researcher   Date   Signature

Dear (Contact name),

Further to our telephone conversation, I have enclosed further details of the intended study at [**site name**].

I am an occupational therapist undertaking a doctoral programme with the Department of Nursing, Midwifery and Social Work at the University of Salford. My research aims to understand and define how young people experience the act of engagement with health professionals. Young people's autonomy is an important factor for health professionals who work with young patients, and successfully engaging these young people is a recognised need within current health, education and social care policy. Poor patient engagement can produce a range of health-related needs such as reduced health-seeking behaviour, increased morbidity and low health service expectations. Developing a greater understanding of the barriers and facilitators to engagement could potentially improve early interventions, and meaningfully involve young people in becoming active stakeholders in their own healthcare. The project would involve interviewing young people.

Prior to undertaking this research, I would like to seek support from your organisation to approach young people (aged 13-19) who access your service. In order to recruit these young people, I would like to display posters and information sheets in an area young people access one week prior to undertaking any interviews. After one week, and with negotiation in relation to suitable times, I would like to be on site to make myself available to the young people to be able to provide further information to potential participants and to arrange interviews. I will not approach young people directly. All interviews will take place on site, or at an agreed safe venue. Your organisation and the university will be alerted to any off-site interviews that take place prior to the event. Interviews will last approximately one hour.

I would like to reassure you that I do not anticipate the study will disrupt the service environment, and that all information collected within this study will remain confidential. The research has been approved by the Research Governance and Ethics Committee at the University of Salford, (date). In addition, as part of the ethical procedures, I have undergone an enhanced Criminal Record Bureau Check.

My research is being supervised by Dr. Michelle Howarth and Professor Tony Long. Should you have any queries, please feel free to contact them via the university switchboard (0161 295 5000).

Kind regards

Jason Vickers
(BSc Hons Occupational Therapy)

University of Salford MANCHESTER

Name of Researcher: Jason Vickers

Name of Company: _____

1. I confirm that I have read and understand the information sheet (version 1: 15th October 2012). ☐

2. I have had the opportunity to discuss this project with the researcher and addressed any organisational concerns. ☐

3. I confirm that the organisation will support the study. ☐

Name

Position

Signature

Date

Company stamp