Experiences of Adherence Assessment in Asthma

Amy Stewart

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ABSTRACT

Background and Aims: Poor adherence to inhaled corticosteroids is understood to be one of the largest contributors to problematic severe asthma in children (Bracken et al., 2009). Researchers have sought to understand and target non-adherence and assessment of adherence is seen as crucial in this process. Recent research has championed electronic monitoring tools as the "gold standard" for accurately measuring adherence and these devices have been extensively evaluated (Burgess, Sly, Devadason, 2011). Only a small amount of literature has considered how one experiences the process of adherence assessment through electronic tools. One such device, the smart-inhaler has been introduced in the paediatric asthma team at the Royal Brompton Hospital. The proposed study aims to explore young people's experiences of having their adherence to inhaled corticosteroids assessed through a smart-inhaler. It will also explore the experiences of their caregivers and healthcare professionals.

Method: Semi-structured interviews were conducted with eight young people with asthma, aged 11-15, who had been given a smart-inhaler as part of their care at the Royal Brompton Hospital, and eight of their caregivers. A focus group with seven healthcare professionals who used the smart-inhalers in their practice was also carried out. Interviews were analysed using a critical realist thematic analysis.

Results: Three themes were identified: "they were trying to help me get better", "it's clearly just to check up" and "who is responsible?". They highlight the variety of perspectives and experiences participants had regarding the smart-inhaler. More specifically the themes highlighted the importance of participants' priorities in influencing their experiences, the impact of the smart-inhaler on the healthcare relationship and on the transferring of responsibility for asthma to young people.

Conclusions: The findings suggest that it is important for healthcare professionals to engage in a shared decision-making process with their patients when introducing healthcare interventions such as the smart-inhaler.

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LIST OF ABBREVIATIONS

"**SI**" Smart-Inhaler

"**RBH**" The Royal Brompton Hospital

"**ICS**" Inhaled Corticosteroids

"**PSA**" Problematic Severe Asthma

"**NICE**" The National Institute for Health and Clinical Excellence

"**SRM**" Self Regulatory Model

"**PAPA**" The Perceptions and Practicalities Approach

"**NHS**" The National Health Service

"**COPD**" Chronic Obstructive Pulmonary Disease

"**TA**" Thematic Analysis

"IPA" Interpretative Phenomenological Analysis

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1. INTRODUCTION

This chapter aims to review the literature surrounding experiences of electronic adherence assessment in chronic health conditions, with a particular focus on the experiences of young people with asthma. I define a number of key terms, summarising some of the historical and theoretical context to these terms and consider their relevance to healthcare. I review the existing chronic health literature concerning electronic adherence assessment and argue that further research is needed to consider the impact of electronic adherence assessment on young people and their wider systems. In particular, I make the argument that further research is needed which explores the beliefs young people hold about electronic adherence assessment and the impact it has on their experiences of taking responsibility for their asthma self-care and of the healthcare relationship. During these discussions, I introduce a relatively new adherence assessment tool called the smart-inhaler [SI], which has been incorporated into clinical practice in the paediatric asthma team at the Royal Brompton Hospital [RBH], London. Finally, I state the research questions for this study.

1.1. Literature Search

In order to collate the current research, a thorough literature search was conducted. The terms telehealth, telemonitoring and electronic adherence assessment were paired with other words and phrases (e.g. asthma, chronic health conditions, young people, smart-inhaler, experiences, feasibility, acceptance, compliance etc.) and these search terms were entered into the following databases: PsychInfo, PsychArticles, Pubmed, Science Direct, CINAHL, Wiley Online Library and Google Scholar. The search was limited to work written in the English language but included studies from across all countries. All dates were covered in the search, although with the focus of the study being on a relatively new area of healthcare (telehealth), the majority of studies concentrating on this had been published since 2000. Academic

journals, reviews, dissertations and books/chapters were included. The search also included a review of key references of retrieved studies and books, internet searches and correspondence with researchers. All studies deemed relevant to the research aims were included (research which had reviewed telemonitoring/electronic adherence assessment equipment in chronic health conditions). Papers adopting qualitative methods and those carried out in the field of asthma were prioritised for discussion in the literature review given the focus of this research being on peoples' views and experiences of electronic adherence assessment in asthma. Studies that focused on adherence monitoring but that were carried out in the field of mental health were not included in the review.

1.2. Definitions, Relevance to Healthcare and Theoretical Contributions

1.2.1. Asthma

Asthma is a respiratory condition where there is inflammation of the air passages in the lungs. This affects the sensitivity of the nerve endings in the airways so they become easily irritated. In an attack, the lining of the passages swells, causing the airways to narrow. This reduces the flow of air in and out of the lungs (The World Health Organization, 2013). Asthma is often characterised by symptoms of coughing, wheezing and breathlessness, however these vary in severity and frequency from person to person (NHS Choices, 2012a).

The World Health Organization (2013) estimates that 235 million people suffer from asthma and state that it is the most common chronic health condition in children. However whilst common, asthma is also a very complex health condition and despite extensive investigation research has been unable to identify what exactly causes asthma (National Asthma Education & Prevention Program, 2007, NHS Choices, 2014). Various factors have been identified as mediating the inflammatory process; including both innate factors (such as our genetics and our gender) as well as environmental factors, such as allergens (e.g. pets), viral respiratory infections (e.g. bronchiolitis/ influenza), exposure to irritants (e.g. tobacco smoke/ air pollution) and exercise (National Asthma

Education & Prevention Program, 2007). Psychological factors such as emotions and stress levels are also viewed as mediating factors in asthma (Asthma UK, 2015a). Taking into account the numerous mediating factors, as well as the heterogeneity in symptom presentation from person to person, it is not surprising to learn that the diagnosis of asthma is not straightforward and proves a complex challenge for healthcare professionals working in the field (Jenkins et al., 1996, Werk, Steinbach, Adams & Bauchner, 2000).

Asthma is argued to be the leading preventable cause of morbidity, mortality and healthcare cost worldwide (Heaney & Horne, 2012) and preventative medication is seen as the cornerstone of treatment (Burgess, Sly & Devadason, 2011). One of the most commonly prescribed medications for asthma is inhaled corticosteroids [ICS]. Taken regularly, ICS are understood to decrease airway inflammation, reducing the number of asthma attacks, hospitalisations and asthma related mortality (Birkhead, Attaway, Strunk, Townsend & Teutsch, 1989, Fong & Levin, 2007, Ordonez, Phelan, Olinsky & Robertson, 1998). ICS are often taken by patients through regular use of a preventer inhaler and also through as needed use of a reliever inhaler. Preventer inhalers are designed to help prevent asthma symptoms by reducing swelling and inflammation in the airways. They often contain a low dose of ICS and are expected to be used regularly by patients, typically twice a day (Asthma UK, 2015b). They differ to reliever inhalers, which are used by patients in emergency situations to provide short acting, on the spot relief from the symptoms of asthma (Asthma UK, 2015c).

Most cases of paediatric asthma are managed through ICS (Hedlin, de Benedictis & Bush, 2012). However, some children and young people experience ongoing and frequent symptoms and exacerbations of asthma despite being prescribed high doses of ICS (Bracken et al., 2009). This population are often described as having “problematic severe asthma” [PSA] and are estimated to make up just under 5% of the childhood asthma population (Lang et al., 2008). Research by Sharples et al. (2012) demonstrated that children and young people described as having PSA comprise of two different groups; those described as having “difficult asthma” (whose asthma improves without further increases in treatment when the basics

of asthma management such as adherence to ICS are addressed), and those described as having severe therapy resistant asthma (those who have ongoing severe asthma despite attention to the basics of asthma management). This is a key and complex issue in paediatric asthma teams and the consequences of stepping up pharmaceutical treatments unnecessarily has enormous implications for health, quality of life, financial cost and long-term well-being (Hedlin et al., 2012, Sharples et al., 2012). It is therefore of great important for clinicians to identify which young people fall into which group in order to avoid escalations in treatment when they are not required.

In defining asthma, it is also important to reflect on the use of the language used by professionals and researchers working in this field. Language and the way people talk about things, is viewed by many as central in the social construction of what we regard as "knowledge" (Willig, 2013). Morgan (2000) considers the power that exists in language and posits that in society people can become subjugated and oppressed by the language used. When considering the terms "problematic" and "difficult" asthma, questions can be raised about the impact this choice of language has. For instance, who is the asthma "problematic" or "difficult"? Moreover, with the terms being used predominantly in the context of distinguishing patients who are viewed as managing their asthma from those who are not, do these choice of descriptions place the "difficulty" or "problem" in the asthma or in the patient?

1.2.2. Adherence

The term adherence forms part of a wider debate within the healthcare literature related to a paradigm shift which occurred in the late nineties moving from a compliance model of healthcare to a concordance model (Segal, 2007). The aim of this shift was to move from a paternalistic model of care where a patient[1] passively followed their doctor's orders, to a model of consensual partnership and shared decision-making, where both doctor and patient views are acknowledged equally (Burgess, Wilson, Cooper, Sly & Devadason, 2006, Williams, Manias & Walker, 2008). However the term concordance has not

[1] The terms "doctor", "healthcare professional", "patient" and "user" are used throughout this thesis, typically when the literature being summarised uses them, but also for the purpose of clarity. They are also the terms most commonly used in the healthcare settings described and are also used by participants in the study.

been widely accepted and critics have argued that aside from a change in the term used, an ideology of compliance still exists in healthcare (Segal, 2007). The term adherence has also emerged during this time. Viewed as neutral and non- judgemental, the notion of adherence was introduced to emphasise a patient's right to choose whether to follow the healthcare advice of a doctor and to remove the concept of blame if they chose not to do so (Heaney & Horne, 2012). The National Institute for Health and Clinical Excellence [NICE] (2009) describes adherence as "an agreement between prescriber and patient about the prescriber's recommendations. Adherence to medicines is defined as the extent to which the patient's action matches the agreed recommendations" (NICE, 2009, p.3). This model of patient medication use can be viewed as a mid-ground between compliance and concordance, recognising the "expertise" of the healthcare professional in the relationship, whilst also acknowledging the role of the individual and any wider contributors which may influence their ability to act on these recommendations. However the terminological and conceptual differences between the three terms are complex and some have argued that in practice, the notion of adherence still resembles some of the paternalistic features of a compliance model of healthcare (Horne, 2006). Despite this, the terms adherence and non-adherence are used extensively within the chronic health literature (examples of which are included in many of the studies described below) and will be used for the remainder of this study.

1.2.3. Understanding and Assessing Adherence

Whilst non-adherence may consist of stopping medical treatment altogether, it is also acknowledged that a significant number of patients remain in treatment but do not follow their treatment regimen in the recommended way to derive the optimal benefit (Ockene, Hayman, Pasternak, Schron & Dunbar-Jacob, 2002). It is estimated that approximately 50% of patients with long-term health conditions who remain in treatment are classified as non-adherent (Jackson et al., 2014). Medication non-adherence has been linked with avoidable morbidity and mortality, medication wastage and reduced quality of life (DiMatteo, Giordane, Lepper, & Croghan, 2002, Williams et al., 2004). Within the asthma literature poor adherence to ICS is viewed to be one of the most important contributors in problematic severe asthma and recent figures suggest that only 43% of children with problematic severe asthma filled more than 80% of

prescriptions (Bracken et al., 2009). Guidelines therefore emphasise the importance of healthcare professionals assessing adherence and promoting self-management, independence and responsibility in controlling asthma (Asthma UK, 2013, The British Thoracic Society, 2011, NICE, 2013).

A variety of methods to assess adherence have been developed and evaluated. This includes patient and caregiver self-report (Milgrom et al., 1996), clinician estimate, (Mushlin & Appel, 1977), blood and lung function testing (Gillissen, 2007), prescription uptake records (Lau, de Boer, Beuning, & Porsius, 1997) and symptom control and quality of life measures (Bender & Zhang, 2008). However, it is recognised that each of these methods is limited in the extent to which it can accurately predict levels of adherence. For example in the research carried out by Milgrom et al. (1996) patients' self-reported use of inhaled corticosteroids was 95.4%, whereas the actual use was 58.4%. In the research carried out by Mushlin and Appel (1997) clinicians only predicted non-adherence accurately in 35% of their patients. Subsequently, more recent research has championed electronic monitoring devices as the "gold standard" for accurately measuring adherence (Burgess et al., 2011). There is a general consensus within the literature that developing better tools for identifying those who are poorly adherent is important, so that intervention strategies for adherence can be targeted at the appropriate individuals (Bracken et al., 2009, Gamble, Stevenson, McClean & Heaney, 2009).

Adherence to medical treatment is clearly a key concern within the chronic health literature. There is an abundance of research seeking to understand the factors that contribute to adherence and on supporting individuals living with asthma and their families to adhere to preventative medication (Bracken et al., 2009, Gamble, Stevenson & Heaney, 2011, Penza-Clyve, Mansell & McQuaid, 2004). Research has suggested that individuals' beliefs about illness and treatment shapes their asthma self-management and adherence to medication (Clifford, Barber & Horne, 2008, Horne et al., 2007), as well as doctor-patient communication (Clark et al., 1998), coping style (Barton, Clark, Sulaimain & Abramson, 2003), psychological factors (Clark & Valerio, 2003), family functioning (Bender, Milgrom, Rand & Ackerson, 1998) and the social environment (Bourbeau & Bartlett, 2008). In a review carried out almost 20

years ago, it was understood that as many as 200 factors could influence adherence behaviour (Meichenbaum & Turk, 1987).

Subsequently a number of models and frameworks have been developed which seek to understand adherence and non-adherence (see Kardas, Lewek, & Matyjaszczyk, 2013, Munro, Lewin, Swart & Volmink, 2007 for a more thorough review of these). Within the field of asthma Leventhal, Diefenbach and Leventhal's (1992) Self Regulatory Model [SRM] has been applied extensively in developing understanding of adherence and non-adherence. Within the SRM, adherence to treatment is understood as one of a number of "coping" responses that a patient (who is viewed as an "active problem solver") may adopt. This coping behaviour will represent a "common sense" response based on the cognitive and emotional interpretations the patient makes of their experiences (for example the symptoms they experience or the information they are given). These interpretations are a central feature of the SRM and will shape how the patient conceptualises their illness and the beliefs they hold about it (Horne & Weinman, 2002). Leventhal et al.'s (1992) research suggested that there are five main groups of beliefs which include beliefs about the nature (identity) of the illness, beliefs about the likely time-course (timeline) of the illness, beliefs about the personal impact (consequences) of the illness, beliefs about the causal factors (cause) of the illness and beliefs about control or cure (control/cure) of the illness. These sets of beliefs are often described as "illness representations" and have been found to be a strong predictor of health behaviours such as medication adherence in asthma and other chronic health conditions (Bucks et al., 2009, Clifford et al., 2008, Horne & Weinman, 2002, Menckeberg et al., 2008, O'Carroll et al., 2011).

More recently the SRM has been extended in order to further understand treatment adherence and non-adherence in asthma (Horne & Weinman, 2002). In addition to the beliefs a patient holds about their illness, Horne and Weinman (2002) posit that the beliefs a patient holds about the *prescribed treatment itself* will also influence their adherence behaviours. They suggest "adherence decisions are influenced by an interaction of personal beliefs about the necessity of the treatment for maintaining or improving health and concerns about the potential adverse effects of adhering to it" (Horne & Weinman, 2002,

p19). Subsequent research has supported this (Clifford et al., 2008, Menckeberg et al., 2008); correlating patients' beliefs about ICS treatment with self-reported adherence levels and prescription-uptake records. This lends support to the recommendations of Horne and Weinman (2002) who advocate for clinicians to use a "necessity-concern framework" in their interactions with patients as a useful means of eliciting and understanding their perception of asthma and its treatment, and to promote adherence through interventions which address necessity beliefs and concerns.

In addition to understanding how ones beliefs influence adherence behaviour, researchers seeking to explore the factors that contribute to non-adherence have also argued that "unintentional factors" will play a role (Horne, 2006 Weinman, 2012, Wroe, 2002). In 2006, Horne put forward an explanation of adherence behaviour referred to as the Perceptions and Practicalities Approach [PAPA]. This approach recognised that perceptual barriers such as patients' beliefs and motivations can influence adherence and can lead to intentional non-adherence. However the approach also acknowledged that patients may not adhere because of practical barriers related to their skills, ability and resources in taking their medication (e.g. forgetfulness, poor technique). This was described as unintentional non-adherence (Horne, 2006). This categorisation of non-adherence was not claimed to be watertight and it was recognised that there was a degree of overlap between the two (Horne, 2006). However the division is seen to be conceptually useful as it identifies different targets for intervention, with perceptual and practical barriers needing to be addressed differently (Horne & Clatworthy, 2010). The PAPA has also been incorporated into NICE guidelines (2009) on adherence to support healthcare professionals in responding to the different factors that influence adherence behaviour.

Non-adherence remains both a concern and challenge to healthcare professionals (Horne, 2006) and whilst the theoretical contributions described above generate a wider understanding of adherence and non-adherence, it is important to note that they do not offer causal explanations of adherence. Indeed the SRM has received criticism for not providing a fully comprehensive understanding of adherence behaviours, neglecting contributors such as

automatic processes and social factors (Jackson, Eliasson, Barber & Weinman, 2014). However, these theoretical contributions are becoming increasingly used in understandings of adherence in asthma and have aided the development of a variety of healthcare interventions aimed at improving adherence across the chronic health field. This includes a range of complex interventions targeted at the individual and wider system level including combinations of information, reminders, self-monitoring, reinforcement, counselling, family therapy, psychological therapy, crisis intervention, manual telephone follow-up, improved communication in the healthcare relationship, and more convenient, collaborative and supportive healthcare (Gillissen, 2007, Haynes, Ackloo, Sahota & McDonald, 2008, Haynes, McKibbon & Kanani, 1996, Horne & Clatworthy, 2010).

1.2.4. Electronic Adherence Assessment Tools

More recently electronic assessment tools have been introduced to the healthcare field, viewed as a more objective and accurate method of assessing adherence compared to the earlier mentioned methods (Bender et al., 2000). The SI (which is the focus of the current study) is one such electronic assessment tool. The SI is attached by a healthcare professional to a patient's usual inhaler. Once attached, sensors on the device will detect when the medication is taken and will record this information onto its memory. A healthcare professional can later access this information by uploading the recordings from the SI onto their computer. This information will show the healthcare professional the patient's frequency of inhaler use, the times and dates of inhaler use and the dose of ICS taken. They can then discuss the information recorded on the inhaler with the individual who is using it (Burgess et al., 2006). In the context of the current study, the SI was used on participants' preventer inhalers.

As well as offering a more objective means of assessing adherence, electronic methods of assessment such as the SI are also receiving increased attention as a form of healthcare technology known as "telemonitoring"; which forms part of the third generation of "telehealth" equipment (Stowe & Harding, 2010). Telehealth equipment involves the delivery of healthcare through technology. It has been implemented across the National Health Service [NHS], often

accompanied by rhetoric of promoting patients' ability to self-care and take responsibility for monitoring their own health (NHS Choices, 2012b). A variety of telehealth equipment exists, not all of which is used for the purpose of monitoring adherence. This includes web-based applications, mobile phone and alert systems and telephone and video conferencing with patients to name a few (Finkelstein, Speedie & Potthoff, 2006, Lee, Chen, Hsiao & Tseng, 2007, Pinnock, Slack, Pagliari, Price & Sheikh, 2007). Telemonitoring involves the measurement, collection and analysis of a particular form of data in a user's home (for example a user's adherence to ICS). This data can then be sent electronically to an internet portal that can be accessed by another, typically a healthcare professional, but possibly also by the user, their relatives and carers. Data can be collected continuously, but is not always immediately available to view (Stowe & Harding, 2010).

1.3. Literature Review

Electronic measures of adherence such as the SI and other variations of telemonitoring equipment have been extensively evaluated in asthma as well as a range of other chronic health conditions (See Brettle, Brown, Hardiker, Radcliffe & Smith, 2013, Chan et al., 2007, Spaulding, Devine, Duncan, Wilson & Hogan, 2012, Stowe & Harding 2010). Within the field of asthma, research has compared the accuracy of electronic devices in assessing adherence to other methods such as self-report (Bender et al., 2000) and has investigated the efficacy of electronic adherence assessment devices as part of an intervention designed to reduce non-adherence (Chan et al., 2007). They have also been used in a recent study to assess participants' adherence with trial medication (Patel et al., 2013) and in research carried out by Burgess et al. (2006), the reliability of the SI specifically was evaluated.

However, only a small amount of the chronic health literature has considered how individuals experience the process of adherence assessment through telemonitoring and the ethical and professional implications of using electronic monitoring tools in healthcare settings. To date, the SI has not been researched in this way and little attention has been afforded to understanding the beliefs patients form about the use of this equipment and the perceptual and

practical barriers that may shape their experience of using this equipment, despite the emphasis on this elsewhere in the asthma-adherence field (Clifford et al., 2008, Horne, 2006, Horne & Clatworthy, 2010, Horne & Weinman, 2002, Menckeberg et al., 2008). I will now go on to review the existing literature, with focus on the role of electronic adherence assessment and telemonitoring equipment in promoting an individual's ability to self-care/ manage their health condition. A focus will also be placed on how the monitoring process impacts on the healthcare relationship, as well as the interactions that take place in the healthcare relationship itself which influence how the process of electronic adherence assessment is experienced.

1.3.1. Electronic Adherence Assessment and Self-Care

With the introduction of telemonitoring equipment to healthcare settings, one issue which has been raised relates to its role in promoting an individual's ability to be responsible for their own self-care of their health. Fairbrother et al. (2013) describe the process of self-care as "relating to the acquisition and/or use of knowledge and skills by patients to support their own care" (p.403) and describe how the term forms part of the patient empowerment agenda. Indeed the idea of empowering or promoting one/the ability to self-care and take responsibility for monitoring their own health in chronic health conditions is increasingly recognised in the NHS, with the development of a variety of initiatives aimed at supporting self-care, including electronic assessment tools (Horne et al., 2007, NHS Choices, 2012b). Within the field of asthma it has been recognised that good outcomes rely not only on the availability of medications but also on their appropriate use by patients and their "optimal self-management" (Horne, 2006, p. 65). In a review of the existing literature of technology's role in respiratory care, Smith, Elkin and Partridge (2009) called for future research to consider whether telemonitoring in respiratory care "empowers the patient to self manage their condition" or leads to a "dependence upon advice received back in response to technology-based monitoring" (p.162). However, despite this the research literature exploring the role of electronic adherence assessment and telemonitoring equipment in promoting an individual's ability to take responsibility for their self-care is limited and contains mixed findings.

In a study conducted by Seto et al. (2012), healthcare professionals and adult

patients experiencing heart failure shared their experiences of using mobile phone based telemonitoring as part of the healthcare process. Patients were required to use the telemonitoring system to take daily weight and blood pressure readings and to answer daily symptom questions on a mobile phone for 6 months. This information was then sent automatically and wirelessly via a mobile phone to the data repository at the hospital, where a healthcare professional could access it. The system could also send reminders to ensure that the patients took their readings, and information based on their readings would be accessible securely online for both the individual and healthcare professional to see. The patients and healthcare professionals were then interviewed about their experience of using this system with a focus placed on understanding whether the system impacted on self-care. One of the findings from the interviews was that the telemonitoring system did indeed promote self-care, through increasing individuals' awareness, knowledge and confidence in managing their condition. However some participants described feeling like they were being watched long-term and concerns were raised about becoming dependent on the system and what would happen if it were taken away.

Research carried out by Fairbrother et al. (2013) has also explored the views of professionals and adult patients with chronic obstructive pulmonary disease [COPD] on self-management in the context of telemonitoring. They carried out semi-structured interviews with patients and healthcare professionals and explored experiences of using telemonitoring and its effect on the "doctor-patient relationship". The findings from the interviews with the patients suggested that telemonitoring empowered self-management by enhancing their understanding and knowledge of COPD and provided a sense of reassurance and support. Conversely, the findings from the professionals' interviews indicated that they viewed the telemonitoring process as promoting compliance with medical advice, with professionals suggesting that whilst telemonitoring encouraged their patients to exercise personal responsibility it also ran the risk of promoting the sick role and creating dependence on the system. In their conclusions, the researchers stated that whilst the process of telemonitoring empowered those living with COPD to take responsibility for their healthcare through increased access to information about their health, it did so paradoxically in that it promoted the view of a compliant self-manager who

would ultimately remain dependent on the expertise of the healthcare professional.

These studies highlight one of the emerging complexities associated with implementing telemonitoring and electronic adherence assessment tools in healthcare settings. Whilst these tools can increase the sense of responsibility an individual has for monitoring their own health and self-caring, they do so in a way that maintains a reliance on the healthcare system and on the advice of a healthcare professional. The claim that telemonitoring and electronic adherence assessment tools promote self-care and responsibility for monitoring one's own health can therefore be questioned. On the one hand it could be argued that these findings reflect the underlying ethos of an adherence model of health care, recognising that a healthcare professional will possess expertise that they can draw upon to advise their patients who can in turn (if they so wish) use electronic monitoring tools in conjunction with this advice to care for themselves. On the other hand, it could be argued that this alleged handing over of responsibility for managing ones own health is a merely tokenistic gesture and that, ultimately, patients will remain dependent on and compliant with the ideas and practices of their healthcare professional with little true responsibility for managing their own health.

This raises the additional complexity of using telemonitoring in healthcare practice and begs the question as to whether the process of electronic assessment is more closely aligned to a compliance model of healthcare than to an adherence model of healthcare. NICE guidelines on medicines adherence (2009) stress that “the purpose of assessing adherence is not to monitor patients but rather to find out whether patients need more information and support” (p.13). However Bourdin et al. (2012) argued that electronic assessment devices quantify compliance rather than adherence to a prescription. Additionally, Schermer (2009) argued that current forms of telemonitoring promote compliant self-management where a patient is merely an extension of their healthcare professional, undertaking practical tasks that would traditionally be performed by their healthcare professional rather than an individual who takes responsibility for caring for their own health.
However, this does not necessarily mean that a compliance model of healthcare

cannot be experienced as empowering by patients. The findings of both Fairbrother et al. (2013) and Seto et al. (2012) do seem to suggest that the patients involved in the monitoring process of self care did experience it as empowering; aiding their understanding, knowledge and confidence in managing their health. Additional research is therefore needed to explore the process of electronic adherence assessment tools on self-care further and to understand the mechanisms through which an approach that may simply perpetuate a traditional doctor-patient healthcare relationship of compliance, can nevertheless be experienced as empowering by users and promote self-care.

1.3.2. Electronic Adherence Assessment and the Healthcare Relationship

The role of the "doctor-patient relationship" in health outcomes has been extensively researched (Beckman, Markakis, Suchman & Frankel, 1994, Ferguson & Candib, 2002, Stewart, McWhinney & Buck, 1979). This is particularly the case within the chronic health literature, where research has demonstrated that aspects of the healthcare relationship, such as the patient's perceptions of how understood they feel by their healthcare professional, can interact with how willing they are to accept a healthcare professionals' advice (Selfe, Matthews & Stones, 1998). Research has also highlighted that an alliance between healthcare professional and patient where shared goals are developed and there is a lack of focus on negative behaviours, can improve adherence to medication in young people with asthma (Gavin, Wamboldt, Sorokin, Levy & Wamboldt, 1999). Indeed even existing guidance in asthma management stresses the importance of the relationship between patient and healthcare professional as a primary component of optimal treatment (National Heart Lung & Blood Institute, 1997). With this is mind, it seems important to consider the ways electronic adherence assessment equipment interacts with the healthcare relationship.

One particular concern in the literature related to telemonitoring and the healthcare relationship is the extent to which patients using this equipment in their lives experience this process as intrusive. The findings in the Seto et al. (2012) study highlighted that some participants did not like feeling like they were being watched long term by healthcare professionals. Additionally in their

review of the use of telemonitoring equipment in an older adult population, Stowe and Harding (2010) likened monitoring systems to a form of surveillance that could impact on one's privacy. They also considered the power differential between healthcare professionals and their patients and acknowledged that patients may accept the implementation of these tools in their lives regardless of the intrusion. Certainly, one could argue that having a healthcare professional remotely assess the amount of times you take your medication, the dose you take and the specific time you take it, is not far removed from a form of health surveillance monitoring (Bauer & Olsén, 2009). It is possible that this process could therefore be experienced as intrusive, possibly promoting feelings of distrust in the healthcare relationship.

The above is of particular concern when considering the use of telemonitoring equipment with young people who are transitioning from childhood to adulthood. Young people are often at a stage in their lives where the desire for independence emerges and this, along with rejection of adult authority can form a key stage of identity development (Erikson, 1968). As a group which already has significant experiences of living in a world where the practices of surveillance are rife (Vaz & Bruno, 2003), young people in particular may be more rejecting and suspicious of the introduction of this equipment into another area of their lives. On the other hand, it could be argued that young people might be more used to and accepting of electronic monitoring as more of their lives are lived publically via technology and various social media applications (Lenhart, Purcell, Smith & Zickuhr, 2010). In this case, young people may experience telemonitoring equipment such as the SI as an innovative addition to the healthcare relationship, which possibly mirrors other areas of their lives and encourages them to engage with the advice of their healthcare professional.

It therefore seems important for research to consider how telemonitoring and electronic adherence assessment monitoring tools such as the SI are viewed by those using them and in particular whether patients perceive them as intrusive or innovative? The extended SRM model which incorporates patients' beliefs about the necessity of and concerns about a treatment (Horne & Weinman, 2002) may provide a useful framework for understanding how patients

experience the SI. For instance, if young people believe that the technology involved in the SI provides a more modern and innovative way of receiving healthcare, are they more likely to accept the equipment then if they are concerned that it is being used as a means of surveillance? Research carried out by Tierney, Fraser and Kennedy (2013) and Rohan et al. (2013) has started to explore this. Tierney et al. (2013) used focus groups to explore users' experiences of home monitoring of health with specific regard to physical activity monitors. They interviewed 14 participants with rheumatoid arthritis who had taken part in a physical activity monitoring study and had worn physical activity monitors for seven days in their homes. They found that users' concerns about having their health monitored in the home were limited and instead their experiences of the technology were largely positive, with participants finding the equipment helpful for facilitating physical activity choices and overall unobtrusive. However, this research was carried out in an older population and the findings may differ in other age groups. For instance, research carried out by Rohan et al. (2013) interviewed six children and young people aged 5-14 and their caregivers who had participated in an adherence promotion intervention. Of these six, four families[2] responded positively to feedback on their adherence levels and were viewed to readily problem solve jointly with the healthcare professional about ways to improve their adherence. Of note however is that the two families in this study with poorer rates of adherence were described as reacting defensively to the feedback and suggested that the electronic monitoring data was not valid. The findings also highlighted that when the adherence monitoring and feedback ceased, adherence rates declined to pre-intervention levels. This raises questions about the effectiveness of monitoring tools in the long term if individuals just stop adhering once they are no longer being monitored. The authors therefore called for further research to explore healthcare professionals and patients' experiences with adherence monitoring and feedback in more detail.

These studies again highlight some of the additional complexities healthcare services face when deciding whether to implement telemonitoring and electronic adherence assessment equipment; in this case the different ways in which the

[2] Interestingly the authors did not specify whose response was positive; the young person or caregiver and instead generalised to "the family". I will discuss this further later in the chapter.

healthcare relationship can be affected. It remains unclear at this stage whether the implementation of telemonitoring equipment will be experienced as having a positive or negative affect on the healthcare relationship, although it seems plausible that one's experience will be shaped by a number of factors such as how patients view the equipment (and any concerns they have about it and whether these outweigh their views on the necessity/need for it). These studies have also started to highlight that the way information is collected through this technology, and the ways the information is used and fed back within the healthcare relationship is important. This is consistent with the earlier review of the literature surrounding interventions aimed at improving adherence, which highlighted that elements of the healthcare relationship such as the amount of support, collaboration and reinforcement given, as well as improved communication can promote adherence (Gillissen, 2007, Haynes et al., 2008, Haynes et al.,1996, Horne & Clatworthy, 2010). I will discuss this further below.

One line of thinking which has emerged within the literature on electronic adherence assessment tools is that giving feedback on adherence levels increases adherence. In research conducted by Burgess, Sly and Devadason (2010), children and young people with asthma who were given feedback on their adherence levels (measured through an electronic monitoring device) were shown to increase their use of preventive medication. Furthermore, in the research described above, some of the findings suggest that giving *positive* feedback on adherence levels may be beneficial for the healthcare relationship.

It is possible that if a doctor and patient can think together about what the findings collected on an electronic adherence assessment tool show, this may promote a sense of partnership and collaboration in the healthcare relationship and potentially promote adherence behaviours (Haynes et al., 2008, Haynes et al.,1996, Horne & Clatworthy, 2010). This seemed particularly important in the findings of Rohan et al., (2013) where four of the families (who had acceptable levels of adherence) reported positive experiences of the feedback process. Spaulding et al. (2012) have also acknowledged this. Their research evaluated the effect of electronic monitoring on adherence rates in paediatric asthma. Within their discussions they acknowledged that positive feedback from staff, or the absence of negative feedback from staff may have a favourable effect on

adherence for some children. This idea was supported by the findings of Penza-Clyve et al. (2004), where children with asthma reported that they were more likely to take their medication when rewarded for doing so. Finally, in the work of Rogers, Kirk, Gately, May and Finch (2011) it was noted that individuals can experience a sense of achievement from the monitoring process.

However, not all electronic monitoring has been found to have positive outcomes. For instance Rohan et al. (2013) suggested that the families in their study who were viewed as having poorer adherence levels reacted less positively to feedback on adherence. Consideration therefore needs to be given to how healthcare professionals approach conversations with individuals where adherence is viewed as poor. This is of particular importance when considering the PAPA model of intentional and unintentional adherence put forwards by Horne (2006), which recognised that both perceptual and practical barriers can influence one's adherence. For those who had poorer levels of adherence in Rohan et al.'s (2013) study, it is not clear whether the contributors to this were explored. It is possible that without an acknowledgement of any barriers contributing to the poorer adherence levels being recorded, any feedback could be experienced as punitive and lacking in awareness for the reasons why this occurred. Interestingly however, some researchers have acknowledged that feedback on poor adherence levels can improve adherence (Vasbinder et al., 2013). Indeed Spaulding et al. (2012) acknowledged in their research that electronic monitoring and feedback on adherence may involve negative reinforcement, where patients are motivated to use their inhalers correctly in order to avoid a clinic visit where data clearly shows non-adherence. This again fits with the earlier review of the literature surrounding interventions aimed at improving adherence, which highlighted that elements of the healthcare relationship such as the type of reinforcement given can improve adherence (Haynes et al., 2008, Haynes et al.,1996, Horne & Clatworthy, 2010). However, the impact of this on the healthcare relationship could be detrimental. McNicholl and Heaney (2013) highlighted that for some patients, overt monitoring even when done sensitively, will feel too confronting and some may then resort to trying to conceal their data or find ways around the system (for example through inhaler dumping- where someone empties the contents of the inhaler- Simmons, Nides, Rand, Wise & Tashkin, 2000). Furthermore,

Weinstein (2005) has questioned how healthcare professionals then use information about poor adherence levels. In his review of the literature concerning the reasons to carry out objective forms of adherence assessment, he considers how information on adherence is communicated to those paying for medical care such as healthcare insurance companies and whether this could lead to reimbursement for medical treatment costs being denied. Whilst this is not currently a major issue in the NHS where healthcare at this time remains free, it does raise questions about what effect having information that indicates poor adherence has on healthcare professionals offering care to individuals. Do they then feel less supportive of or motivated with individuals who are not following healthcare advice?

This all raises concerns about the long-term impact of telemonitoring on healthcare relationships, particularly for children and young people where some of these encounters could be their first experiences of forming healthcare relationships and could shape their later relationships to help (Reder & Fredman, 1996). It also begs the question of who the telemonitoring equipment is actually monitoring; the young person or the caregiver? For example, Rohan et al. (2013) focused on adherence promotion interventions for families and it remains unclear who the majority of the healthcare interactions were with and who specifically received the feedback on adherence levels. Finally, it also highlights the need for future research to more closely consider the specific processes that may play a role in adherence behaviour change. For instance is it positive feedback, or the absence of negative feedback from healthcare professionals that has a favourable effect on adherence? Or does a negative reinforcement contingency increase adherence in some patients and if so for who? Moreover, what is the impact of these processes on the healthcare relationship itself?

The findings of the literature reviewed so far also highlight the need for a clear dialogue about telemonitoring equipment in the healthcare relationship. Research by Pruette, Fadrowski, Bedra and Finkelstein **(**2013) evaluated the feasibility of a mobile blood pressure telemanagement system in children with hypertension. They explored children and caregivers' acceptance of the system, which involved self-monitoring and reciprocal exchange of medication

adherence and blood pressure measurement information between patients and healthcare professionals. The findings indicated the need for healthcare professionals to clearly communicate to families that professionals could immediately review the self-testing results. Even more important to consider for the healthcare relationship is when individuals are monitored without this being communicated to them. In research carried out by Milgrom et al. (1996) 24 children with moderate to severe asthma were prescribed ICS and monitored electronically without their knowledge. This raises a serious ethical concern about the purpose of adherence monitoring. One can question whether this process is actually about promoting responsibility for self-care and having a positive healthcare relationship, or is instead merely a way for healthcare professionals to check up on individuals and see if they are doing as told. With more and more research concluding that successful management of chronic health conditions requires a paradigm shift in healthcare relationships towards a more active partnership involving greater collaboration (Bodenheimer, Lorig, Holman & Grumbach, 2002, Fairbrother et al., 2013, Finch, Mort, Mair & May, 2008), the process of electronic adherence assessment needs further exploration as to whether it is supporting this shift or is in fact moving further from it.

From the review of the literature so far it is clear that there are mixed views on the role of telemonitoring and electronic adherence assessment in chronic health conditions including asthma. Whilst certain forms of telemonitoring can promote patients taking responsibility for self-care, through increasing awareness, knowledge and confidence in managing chronic health conditions, they can also be viewed as promoting a dependency on the healthcare system and a compliance model of care. However, the impact of this on the healthcare relationship and whether patients experience this technology as empowering self-care or not may be influenced by their beliefs about the equipment and the extent to which the perceived need for the equipment outweighs the perceived concerns about using the equipment. Additionally, particular features of the healthcare relationship may influence how the process of electronic adherence assessment is experienced. For example the way the information collected through this technology is used and fed back within the healthcare setting may shape whether or not the overall process is experienced as a collaborative

endeavour which aligns the healthcare professional and patient in an active partnership. Finally, the additional complexities involved in carrying out telemonitoring and electronic adherence assessment with different populations such as with children, young people and their families has started to emerge. I will now go on to discuss why further research is needed in this area specifically with young people and also their families and healthcare professionals.

1.3.3. Current Research with Young People and their Wider Systems[3]

As noted earlier, asthma is considered to be the most common chronic health condition in children and young people (The World Health Organization, 2013). A large body of research has acknowledged the impact asthma can have on the quality of life of young people, during what is viewed as a time of transition from childhood to adulthood (Gibson, Henry, Vimpani & Halliday, 1995, Newacheck, McManus & Fox, 1991, Rutishauser, Sawyer, & Bowes, 1998). Anderson and Coyne (1993) describe how this transition period is likely to be associated with appropriate increases in a young person's management of his or her own illness, which develop in tandem with other increases including needs for privacy, control, and peer acceptance. Cerreto and Travis (1984) suggest similarly that young people need to become personally responsible for self-care activities, while families withdraw their involvement to little more than occasional monitoring. In line with this thinking, recent research and guidance in asthma has focused on the need for young people to be supported in taking increasing responsibility for controlling their asthma as they approach adulthood (Blaakman, Cohen, Fagnano, & Halterman, 2014, The British Thoracic Society, 2011, Price, 1996). It is therefore of no surprise that telemonitoring and electronic adherence assessment equipment has begun to be introduced to and evaluated in the child and young person population. Many of the examples of research that were reviewed above were examples of this (Milgrom et al., 1996, Pruette et al., 2013, Rohan et al., 2013, Spaulding et al., 2012).

[3] The current study predominantly uses the term "young people". This term is a flexible term that can encompass a broad age range that includes those who would sometimes be referred to as "older children" or "adolescents". It does not typically include younger children who would instead be described as "children" (General Medical Council, 2014). It is used in this study when referring to participants aged 11 to 16, however it is important to recognise that it could apply to a wider age group in other contexts, including some of the other studies described.

However, evidence suggests that is common for adherence to medical regimes to decrease during adolescence (Anderson, Ho, Brackett, Finkelstein and Laffel 1997), with the cognitive changes that take place during this period making it more likely that young people will think differently about adherence behaviour then they did during childhood (Holmbeck, 2002). Furthermore, Eisner (1993) has described how potential conflicts in the shifting of responsibility to young people can occur during this period of time, with parents expressing concerns about their child's level of conscientiousness about these responsibilities. Anderson and Coyne, (1993) suggest that these parental concerns can lead to a miscarried helping process which Holmbeck et al. (2002) argue is problematic; as increases in parental control during this period of development are often linked with lower levels of autonomy in young people.

Riekert and Rand (2002) suggest that the process of telemonitoring could assist families in appropriately transferring responsibility of asthma care from parents to adolescents. However, within the existing literature there was only a limited exploration[4] into the experiences of young people using telemonitoring equipment in their lives, the beliefs they form about the equipment and the impact it has on their relationships with healthcare professionals. Furthermore, there was an absence within the literature of any research exploring the impact of telemonitoring equipment on shifting the responsibility for self-care from a parent/caregiver[5] to the young person. Further research is therefore required to explore young people's experiences and how the process of telemonitoring through devices such as the SI may contribute to the shifting of responsibility from caregivers to young people.

From the review of the literature, it is also important to acknowledge that there are multiple views regarding electronic adherence assessment tools such as the SI. This is not surprising. Research has previously demonstrated that young people and their parents have differing views on living with and managing

[4] See Hafetz & Miller (2010), however this research was not specific to monitoring using electronic equipment.
[5] The terms "caregiver" and "parents" are used interchangeably. I have used both to try and reflect my awareness that caregivers can encompass a wider group than the term parent. However, at times, usually when previous research or the participants in the current study have used it, I have written the word parent.

asthma (Jonsson, Egmar, Hallner & Kull, 2013). In this study the young people spoke about wanting to develop their own strategies for self-management of asthma, which included not always taking medication as prescribed. The parents described wanting to be met with competence and understanding in asthma care from healthcare professionals. The research concluded that developing a partnership between young people, their parents/caregivers and healthcare professionals could be a successful way to improve the care of patients with asthma. With research such as this in mind, it can be argued that exploring the views of both young people and their parents/caregivers is integral to generating a more rounded understanding of electronic adherence monitoring in asthma. This is also in line with the thinking of Horne and Weinman (2002) described earlier in this chapter, who recommended that clinicians elicit and understand their patients' perception of asthma and its treatment, in order to promote adherence.

Additionally, the literature base described throughout this chapter has indicated the added benefit of eliciting the often differing views of healthcare professionals regarding telemonitoring and electronic adherence assessment. Whilst slightly more research has been carried out in this area exploring the impact of telemonitoring on self-care and healthcare relationships in adult populations (Fairbrother et al., 2013, Hopp, Hogan, Woodbridge & Lowery, 2007, Seto et al., 2012), any further insights that subsequent research can offer to this area (specifically to healthcare with young people) will remain useful.

1.4. Research Aims

The proposed study therefore aims to explore the experiences of young people with asthma and their caregivers, of having their adherence to ICS assessed through electronic adherence assessment equipment, in this case the SI. The SI has been selected, as it is a relatively new device that has been introduced into the clinical practice of the paediatric asthma team at the Royal Brompton Hospital London. This team offers multidisciplinary care for children and young people with PSA and has one of the largest populations of children with PSA for whom poor adherence is a leading cause of sub-optimal control (Bracken et al., 2009). The SI is currently offered to all young people referred to the service as

part of the difficult asthma assessment protocol. As this protocol involves a healthcare professional viewing data collected on the SI and feeding this back to families, the proposed study also aims to explore healthcare professionals' experiences of assessing adherence through the SI (although the focus on this will be less given the attention already paid to this in the existing literature). Attention will be given to experiences of electronic adherence assessment and self-care and whether young people experience the SI as promoting their responsibility to self-care or not. To help achieve this, I will look out for the different views participants hold about the SI and the impact it has on the process of transferring responsibility for asthma to the young people. A focus will also be placed on how the monitoring process impacts on the healthcare relationship, in particular how the beliefs the young people hold about the SI influence their experiences of the healthcare relationship.

1.4.1. Research Questions

The proposed study is therefore concerned with the experiences of electronic adherence assessment in young people, their caregivers and healthcare professionals and seeks to explore how assessment of adherence to asthma medication through the SI is experienced by those involved in this process.

The research questions the study seeks to answer are:

- How do young people and caregivers experience being assessed through the SI?

- How do healthcare professionals involved in assessing adherence using the SI experience this process?

- How does the process of having ICS adherence assessed through the SI influence experiences of self-care and do participants experience the SI as promoting young people's responsibility for self-care or not?

- How does the process of being given the SI interact with the relationship between the healthcare professional and the young person/caregiver?

2. EPISTEMOLOGY AND METHODOLOGY

The purpose of this chapter is to describe the study's methodology and method. I start by outlining my epistemological position and the project's methodology and method. I then reflect on my role as a researcher and how I thought this may be influential. I go on to describe the procedure of the study, giving information about the participants, recruitment, ethical considerations and the data collection. Finally I explain how I conducted the analysis and how I planned to evaluate this.

2.1. Epistemological Position

Epistemology has been defined as "a branch of philosophy concerned with the theory of knowledge" (Willig, 2009, p.2) and is concerned with how individuals come to know information and attain knowledge. Methodology can be understood as "a general approach to studying research topics" (Silverman, 1993, p. 1)" whilst method can be understood as "a specific research technique" (Silverman, 1993, p. 1). Different methodologies will therefore be influenced by one's epistemological position and will reflect different assumptions about knowledge and the ways individuals come to know and make sense of things (Willig, 2009). One's epistemological position will also influence the amount of emphasis placed on the role and influence of the researcher in the research process and will shape decisions made about research design and methods (Carter & Little, 2007). A researcher's epistemological stance should therefore be acknowledged.

The proposed study is situated within a critical realist position, based on the view that information collected through research can indeed tell us something about the "real world", however the knowledge created is not a direct reflection of reality but reflects the subjective experiences of the participants and the interpretations of the researcher (Green & Thorogood, 2010). A critical realist approach differs from the positivist or "naive realist" view that assumes that research can provide objective and unbiased findings, which the researcher

remains outside of. It acknowledges that although research data can tell us something about what is going on in the world, it does not do so in a self-evident, unmediated fashion (Willig, 2009). This epistemological position fits with my own view of the world, in that I understand phenomena such as asthma to be "real" medical conditions that exist. However I also believe that how each person experiences and talks about such phenomena can differ and can be shaped by historical, cultural and social factors, which lead to different subjective versions of reality (Burr, 2003).

2.2. Methodology

The current research aims to explore experiences of electronic adherence assessment equipment. A qualitative approach to research tends to be concerned with how participants make sense of the world and how they experience events (Willig, 2013). Qualitative approaches provide a means for rich, in-depth descriptions of experience to be heard (Willig, 2009). Qualitative research is therefore interested in answering questions like "what it is like to experience particular conditions" and "how people manage certain situations" (Willig, 2013, p. 8). The qualitative researcher focuses on the exploration of participants' personal and social experiences (Green & Thorogood, 2010). A qualitative approach is also concerned with identifying recurring patterns and is viewed as aiding the understanding of natural phenomena (e.g. asthma), focusing on the meaning, experiences and views of participants (Al-Busaidi, 2008). It also aims to give a voice to those whose accounts are often not heard (Willig, 2009). This is particularly important for the current study, where within the existing literature there is only a limited exploration into the experiences of young people using telemonitoring equipment in their lives. Taking this into consideration, a qualitative methodology therefore seemed fitting.

2.3. Method

2.3.1. Methods of Data Collection

In order to collect data from multiple sources (young people, caregivers, healthcare professionals) I decided to employ two different methods of data

collection; semi-structured interviews with the young people and caregivers, and a focus group with the healthcare professionals. Using more than one method of data collection to gather the views of multiple sources is often described as "triangulation" and is viewed as a way of increasing understanding over and above what any method could achieve in isolation (Howitt, 2010).

Interviews offer a pragmatic means of listening to the views of participants, typically related to a particular aspect of their lives or experiences that the researcher is concerned with (Willig, 2013). Semi-structured interviews can combine relatively formal interview features such as clear roles for interviewer and interviewee and a set interview schedule, whilst also incorporating features of an informal conversation such as open-ended questions and a focus on narratives and experience (Firth & Gleeson, 2012). The importance of establishing and maintaining rapport in interviews is key and the semi-structured format selected arguably lends itself well to this, particularly for engaging the young people in the study.

Focus groups provide an alternative to semi-structured interviews and provide a more "naturalistic" setting. Here, the additional element of the group interaction can be utilised as a means of generating arguably richer information; as participants can be mobilised to respond to and add to each other's comments. Focus groups also offer a time-limited way of collecting multiple views (in the current study for very busy and time-limited healthcare professionals), (Willig, 2013).

2.3.2. Method of Data Analysis

I considered several approaches when selecting a method of data analysis (see appendix 1). One such approach was interpretative phenomenological analysis [IPA]. IPA aims to "explore in detail how participants are making sense of their personal and social world" (Smith & Osborn, 2008, p.53), whilst also acknowledging the role of the researcher and their relationship with participants (Willig, 2013). However, IPA as an approach to analysis is situated within an epistemology of phenomenology. While phenomenology is concerned with subjective, lived experience it does not address issues of materiality. Taking this into account, an approach to analysis grounded in phenomenology would

not permit for sufficient attention to be paid to the context in which the participants' experiences occurred. With the current study focusing on the broader investigation of participants' experiences with smart-inhalers, and the factors that influenced this (e.g. the ways healthcare professionals introduced the SI to participants and how this impacted on how they viewed the device), I decided that IPA would not fit with my own epistemology and the study's research questions. I therefore decided to conduct a thematic analysis [TA].

TA involves a systematic search through a data set to identify and analyse salient patterns of meaning and aims to organise and describe these (Boyatzis, 1998, Braun & Clarke, 2006). TA is comparable to aspects of content analysis, however it also aims to move beyond the observed aspects of a data set and allows the researcher to approach and examine data flexibly, rather than working solely from a theoretically driven framework (Joffe, 2012). TA can be approached from different epistemological positions and is viewed as being compatible with a critical realist epistemological position (Braun & Clarke, 2006). A TA from this perspective can therefore acknowledge the ways individuals construct meaning from their experience, as well as the ways the broader social context impinges on those meanings, whilst also retaining focus on the material and other limits of "reality" (Braun & Clarke, 2006, p. 81). TA was therefore chosen as it is seen to fit well with research questions that aim to explore "the specific nature of a given group's conceptualisation of the phenomenon under study" (Joffe, 2012, p. 212). TA was

Themes identified in TA can be developed either in an inductive manner or deductive manner (Braun & Clarke, 2006). An inductive TA works from the bottom up, with the researcher approaching the data without a theoretically informed coding frame. Here themes are seen to be firmly grounded in the data rather than reflecting the researcher's theoretical commitments (Willig, 2013). A deductive TA on the other hand involves mapping the data onto a form of coding template, usually derived from the relevant literature in order to code data and develop themes (Crabtree & Miller, 1999). It is also possible to use a combination of inductive and deductive TA, whereby *a priori* template is used to organise the data to begin with, but where novel themes are also identified from analysis (Fereday & Muir-Cochrane, 2006). The two are then integrated in

order to generate a comprehensive thematic description of the data. A combination of inductive and deductive approaches was therefore adopted for the current study in order to fit with the study's exploratory aims and critical realist epistemological stance, but to also hold in mind the current literature and the study's research questions. This combined approach enabled me to attend to references to issues that previous research has identified as important, while also enabling the data to drive the analysis with the intention of being sensitive to the possibility of identifying new and unanticipated issues

Themes identified in TA can also emerge from a manifest or at a latent level. Themes at a manifest level (also known as semantic level) refer to that which can be directly observed in the data. Braun and Clarke (2006) argue that themes identified at a manifest level are mostly associated with a realist perspective. Alternatively themes at a latent level are associated with the ideas and assumptions that may shape the manifest/semantic level and are associated aligned with a more constructionist perspective (Boyatzis, 1998). Taking into consideration that TAs often draw on both types of themes (Joffe, 2013) and the critical realistic perspective of this study, both manifest and latent themes were identified. Joffe (2012) states that a "dual deductive-inductive and latent-manifest set of themes are used together in high-quality qualitative research" (p. 210). The current study therefore adopted this approach to the TA.

2.4. Reflexivity

Willig (2013) in her discussions surrounding reflexivity acknowledges the "impossibility of remaining outside of one's subject matter whilst conducting research" (p. 10). Green and Thorogood (2010) also recognised this, arguing that objectivity in research is not possible, as both the research and the researcher exist as part of a world where subjectivity is inevitable. The process of reflexivity therefore requires researchers to explore and reflect on the ways their values, beliefs and experiences, amongst other factors, may influence their reactions to the research context and data, and impact on the eventual outcomes of the study (Nightingale & Cromby, 1999). This can be understood as "personal reflexivity" (Willig, 2013, p. 10). I felt that my position as a young,

white British, professional female (in relatively good health) might have influenced both my interactions with and my understanding of the participants' experiences.

Additionally Willig (2013) posits that one must also be concerned with "epistemological reflexivity" (p. 10), where we reflect upon the assumptions (about the world, about knowledge) that we have made in the course of the research. In developing this research project I was aware that in positioning myself as a critical realist (described above), I was aligning myself to a particular view of the world that the participants in the study may not share. I was therefore mindful that in constructing aspects of the research project such as the research questions and interview schedule, that I was constructing these in a particular way based on my view of the world, and this view may then have been imposed on the participants. Willig (2009) highlights that a power differential between researcher and participant can exist when carrying out research and that it is particularly important to acknowledge and address this. Whilst it can be difficult to remove this power dynamic, I hoped that my approach to certain aspects of the research (e.g. introducing myself as being outside of the clinical team at RBH, promoting ethical aspects of the study such as the right to confidentiality and the right to withdraw and using a semi-structured interview schedule which was guided by participants as much as possible in the interviews) helped minimise the power differential. I also kept a reflexive journal (appendix 2) during the completition of this study to help me reflect on certain aspects of the research process. I will discuss ideas around reflexivity in further detail during the Discussion Chapter.

2.5 Selection and Recruitment of Participants

2.5.1. Sample

Kendall et al. (2009) posit that multi-perspective or "linked qualitative interviews conducted with patients and their informal and professional carers can generate a richer understanding of needs and experiences than the single perspective most commonly used in qualitative studies" and that "interview dyads or tri-ads, where two or three participants are interviewed as a set or case study, can

explore complex complementary as well as contradictory perspectives, and there is considerable scope for using this method in a range of long-term conditions." (p.196). The process of adherence assessment described in the introduction involves several people; the young person asked to use the SI, the caregiver (and arguably other family members) of this young person, and the healthcare professionals using the SI with this young person as part of their clinical practice. Each of these people will have their own experience and views of the SI and these may complement or contradict that of each other. The sample selected, therefore, comprised not only of young people with difficult asthma receiving care at RBH, but also the caregivers of these young people and their healthcare professionals at this hospital.

The RBH has one of the largest populations of children with problematic severe asthma for whom poor adherence is a leading cause of sub-optimal control (Bracken et al., 2009). This is a tertiary service, which receives referrals largely from South East England but occasionally from further afield. The SI is currently offered to all young people referred to the service as part of the difficult asthma assessment protocol. These young people will have long-term asthma and will have been using ICS for at least a year.

2.5.2. Inclusion and Exclusion Criteria

The inclusion criteria for the young people recruited to participate in this study were as follows:

- Aged 11-16 years.
- Referred with difficult asthma to the paediatric asthma team at RBH.
- Issued with the SI as part of their clinical care (during the study's set time period of July 2014 to Jan 2015).

Caregivers of the young people who met these inclusion criteria were also invited to participate, as were members of staff who used the SI in their clinical practice at RBH.

Due to the financial and time limitations imposed on the study there was no funding available for translation services. Therefore only those able to understand and speak English were invited to participate in the study. However, it was not anticipated that this would neglect a particular participant group as the majority of young people attending the RBH clinic can speak English. Furthermore during the recruitment period of the study all potential participants did indeed understand and speak English.

2.5.3. Sample Size

It was intended that approximately 24 interviews would be carried out, 12 with the young people and 12 with a caregiver. This was in line with the recommendations of Guest, Bunce and Johnson (2005) who advise that a minimum of six interviews should be carried out and that data saturation "the point at which no new information or themes are observed in the data" (p. 59) can be reached from approximately 12 interviews. I therefore aimed to interview a minimum of six and as close to 12 young people and 12 caregivers as was possible during the study time frame.

It was hoped that approximately six to eight healthcare professionals would be able to participate in the study. This number was calculated based on information received from the paediatric asthma team regarding the number of staff working in their team who used the SI as part of their clinical practice.

2.5.4. Recruitment

2.5.4.1. Young people and caregivers

As the SI is given out to young people in the paediatric asthma team at RBH as part of the difficult asthma assessment protocol, it was agreed with the team that the healthcare professional issuing the SI would introduce the young person and their caregiver to the study during a routine clinic appointment where the SI was discussed. The healthcare professional asked the young person and their caregiver if they would be happy to be interviewed by a researcher independent of the clinical team about their views and experiences of using the SI. They also informed them that choosing whether or not to participate would not affect the care they received at RBH. Any young people

and caregivers who expressed an interest at this stage were then given an information sheet (appendices 3-5) with more details, and verbal consent was sought for their details to be shared with me. I then met these potential participants (for the young people this was done in the presence of their parent/caregiver) to tell them more about the study and to confirm that they would like to take part. Ahead of the interview I would go through the information sheet with them again and asked them to sign a consent/age appropriate assent form (appendices 6-8). Interviews were carried out following the appointment where the SI was due to be returned (approximately 6-8 weeks after it was issued).

2.5.4.2. Healthcare professionals

I approached the healthcare professionals of the young people who met the inclusion criteria for the study during one of their weekly team meetings at RBH. This was arranged in advance with the support of one of the Consultants in the paediatric asthma team who introduced the study to the team via email ahead of this meeting. During this meeting I gave the team more information about the study, giving them an information sheet (appendix 9) and asked those who were interested in sharing their views to sign a consent form (appendix 10). The focus group was then carried out with those who agreed to participate. It commenced by agreeing a set of ground rules, which included an agreement of confidentiality within the group, as well as some discussion around the importance of all participants' views being heard equally.

2.6. Participants

2.6.1. Young People and Caregivers

All 12 young people and 12 caregivers who attended RBH during the study's recruitment period and met the inclusion criteria were approached by the clinical team and introduced to the study. Of these potential participants, eight young people and eight caregivers consented to take part in the study and were subsequently interviewed. Of the others who were approached one caregiver declined to participate and did not give permission for their child to participate, another caregiver and young person initially agreed to participate but left the

clinic prior to the interview and another caregiver and young person also agreed in principle but requested the interview to take place at a later date which I was unable to make. Another caregiver and their child did express an interest in participating but did not meet the inclusion criteria and were therefore not interviewed.

Tables 1 and 2 (overleaf) summarise the basic demographic details of the participants who took part.

2.6.2. Healthcare Professionals

Seven healthcare professionals from the paediatric asthma team took part in the focus group. This included four Consultants, two Specialist Nurses and one Research Nurse.

Table 1: Young People Demographics

Pp No.	Pseudonym	Gender	Ethnicity	Age at Interview	Location of interview	Duration of Interview	Returned SI?	Feedback on SI Results	Joint or Separate	Feedback on Study
1	Theo	Male	White British	11	Hospital Bed	24m 15s	Yes	No	Separate	Yes
2	Sam	Male	White British	12	Hospital Bed	22m 31s	Yes	No	Separate	Not requested at this time
3	Aysha	Female	Asian British	11	Hospital Bed	20m 45s *(Total duration 35m 57s)*	No	No	Joint	Not requested at this time
4	Chanelle	Female	White British	14	Outpatient Clinic	27m 52s	No	No	Separate	Not requested at this time
5	Gary	Male	White British	14	Outpatient Clinic	26m 45s *(Total duration 45m 09s)*	Yes	No	Joint	Not requested at this time
6	Isla	Female	White British	15	Hospital Bed	35m 14s	No	No	Separate	Yes
7	Rabhya	Female	Asian British	13	Outpatient Clinic	32m 54s	Yes	No	Separate	Not requested at this time
8	Claire	Female	White British	13	Outpatient Clinic	30m 34s	Yes	No	Separate	Not requested at this time

Table 2: Caregiver Demographic

Pp No.	Pseudonym	Gender	Ethnicity	Relationship to Young Person	Location of interview	Duration of Interview	Returned SI?	Feedback on SI Results	Joint or Separate	Feedback on Study
1	Jessica	Female	White British	Mother	Hospital bed	17m 20s	Yes	No	Separate	Yes
2	Lizzie	Female	White British	Mother	Hospital bed	16m 13s	Yes	No	Separate	Not requested at this time
3	Samia	Female	Asian British	Mother	Hospital bed	15m 12s *(Total duration 35m 57s)*	No	No	Joint	Not requested at this time
4	Danielle	Female	White British	Mother	Outpatient Clinic	19m 37s	No	No	Separate	Not requested at this time
5	Estelle	Female	White British	Mother	Outpatient Clinic	18m 24s *(Total duration 45m 09s)*	No	No	Joint	Not requested at this time
6	Janet	Female	White British	Mother	Hospital bed	25m 12s	No	No	Separate	Yes
7	Nimisha	Female	Asian British	Mother	Outpatient Clinic	11m 10s	Yes	No	Separate	Not requested at this time
8	Sarah	Female	White British	Mother	Outpatient Clinic	24m 13s	Yes	No	Separate	Not requested at this time

2.7. Data Collection- Interview and Focus Group Procedures

The interviews were carried out face to face in a private setting at RBH and took place following the appointment where the SI was due to be returned (approximately 6-8 weeks after it was issued). For four of the young people and their caregivers the SI was due to be returned during a prearranged inpatient admission to RBH and therefore interviews were conducted in their hospital rooms. For the other young people and their caregivers, interviews were carried out following outpatient appointments where the SI was due to be returned. A clinical room in the outpatient department was used for these interviews. As discussed earlier, prior to commencing the interview I would go through the relevant information sheets with both the young person and their caregiver before asking the caregiver to sign a consent form for themselves and another to give consent for their child to participate. The young people were then invited to sign an age appropriate assent form. I then carried out the interviews; starting with the young person and then moving onto the caregivers[6]. The interviews were guided by an interview schedule[7], which consisted of several open-ended questions that were influenced by my research aims (appendices 11-12). Interviews lasted on average 27 minutes for the young people and 18 minutes for the caregivers. Two sets of young people and their caregivers requested for their interviews to be carried out jointly (in the presence of each other), both requested this due to their time limitations. I discussed this with my university supervisor at the time and we agreed that for the purpose of encouraging participation in the study that this request could be met. During these interviews I attended to the relationship dynamic between young person and caregiver and later made notes in my reflexive journal related to this, to help me consider whether the process of answering questions in front of each other had influenced their responses. I will come back to this in my discussion section. Following each interview, I explained to participants that they could contact me if they would like a summary of the results. At the time of

[6] Of note was that all eight caregivers interviewed were mothers. Of the other four approached, two were fathers. I will consider this absence of fathers further in my discussion.

[7] The interview schedule was piloted with a young person from RBH who had used the SI previously and their caregiver, prior to the interviews being carried out. This allowed a "practice-run" of the interview process and also generated positive feedback on the relevance and acceptability of the questions being asked.

writing four participants have requested this (two young people and their caregivers).

The focus group took place at RBH in the format described above. It lasted half an hour. The focus group was also guided by an interview schedule, which consisted of several open-ended questions that were influenced by my research aims (appendix 13). In consultation with my university supervisor regarding the limits to my time and resources in completing this study, it was agreed that the focus group would not be recorded and transcribed, but that instead I would take basic notes during the group on the main ideas and views shared. At the end of the focus group I fed back what I had noted down to the participants and agreed these notes and the main ideas generated from their discussion with them.

2.8. Apparatus

Interviews were recorded with a digital voice recorder, which was placed in view of the participants. Participants were made aware of this in the information sheet and gave consent for their interview to be recorded. Once completed, interviews were transcribed on a computer.

2.9. Ethical Issues

2.9.1. Ethical Approval

The study was granted ethical approval from the School of Psychology Research Ethics Committee (appendix 14), the University of East London Research Ethics Committee (appendix 15), an NHS Research Ethics Committee (appendix 16) and the local Research and Development Office (appendix 17).

2.9.2. Consent

Prior to any interviews or the focus group informed consent was obtained from all participants. As the young people participating were under the age of 18,

consent was sought from their caregiver. However an assent form tailored to 11-16 year olds was also given to each young person. Before giving consent participants had the opportunity to read through the relevant information sheet and were invited to ask any questions and discuss their rights (e.g. to confidentiality, to withdraw from the study and to terminate the interview).

2.9.3. Confidentiality and Anonymity

I preserved the confidentiality and anonymity of participants taking part in the study in line with the Data Protection Act (British Parliament, 1998). I explained to all participants their right to confidentiality and anonymity verbally and also outlined this in the information sheets and consent forms. I was the only person to collect data and transcribe interviews. Any identifiable data that was collected was anonymised, with participants assigned a pseudonym and a participant number. These were used when transcribing and any identifying references that were discussed during interviews were changed at the time of transcription (e.g. names, locations etc.). Consent forms (which included the participants' names and signatures) were stored in a locked filing cabinet away from all other data. All other data was kept on my personal computer, which requires a password to access. I explained the nature of the study to all participants and that this meant that my university supervisor and examiners would be able to read extracts from the anonymised transcriptions of interviews. I also advised that there was a possibility that I would develop the research at a later stage (for publication, for example). With this is mind I explained that all audio recordings would be destroyed after examination of the study, but that electronic copies of anonymised transcripts would be kept securely for three years in order for me to develop the research further.

2.9.4. Further Support

Although no adverse effects were anticipated as a consequence of taking part in the study, the information sheets highlighted that participants could contact UEL if they had any concerns about their participation in the study. In addition, as young people were involved in the study I arranged with one of the local collaborators (a qualified Clinical Psychologist) that they would be available to support me if any concerns did arise.

2.10. Data Analysis

Attride-Stirling, (2001) stresses the importance of describing how data is analysed in order to clarify how final conclusions come about and to understand the steps that were taken in reaching them. As detailed above, TA was used to analyse the data. My university supervisor provided supervision of the analysis. Themes were developed following analysis of each interview and the data set as a whole. While some participants spoke more than others, all views were of equal importance and therefore themes chosen were those which captured important elements from across the data (Braun & Clarke, 2006).

It is important to recognise that any form of qualitative data analysis will involve a level of interpretation. Interpretation involves engaging with the research data in a way to make sense of and finding meaning in it in a way that may not immediately obvious (Willig, 2013). Different interpretations will be made depending on one's epistemological position and the different questions being asked. In positioning myself as a critical realist I was therefore aware that I may have attended to and interpreted the content of the interviews differently to how another who viewed the world differently and held a different epistemological position would.

2.10.1. Transcription

Transcription can be viewed as one of the first and key stages of data analysis and there are different ways for interviews to be transcribed, which will be informed by one's epistemology and methodology (Bird, 2005, Wilkson, 2008). TA does not require the same level of detail in transcription as conversation, discourse or narrative analysis (Braun & Clarke, 2006). However the transcript should include all information from the verbal account. Interviews were transcribed at a semantic level, with attention placed on what was said rather than the way in which it was said (e.g., tone, emphasis etc.). The transcription conventions used for this study were adapted from Parker (2005) and are shown in appendix 18. To be thorough, I listened to the interviews again after transcription (Parker, 2005).

2.10.2. The Process of TA

The process of analysis was informed by the guidelines set out by Braun and Clarke (2006). Although these guidelines form a framework with which to approach the data, Braun and Clarke (2006) note the flexibility of these and stress that they are not strict rules to be followed, but should be adapted to best suit the research. They stress that analysis is not a linear process, but requires movement back and forth throughout the phases.

2.10.2.1. Familiarity with data

Braun and Clarke (2006) note that regardless of whether or not you are aiming for an overall or detailed analysis, are searching for latent or semantic themes, or are data or theoretically driven it is important to be familiar with all aspects of your data. The initial stages of carrying out and transcribing the interviews described above aided this process. Interviews were analysed individually with recordings listened back to at least twice. Initial annotations were made by hand, with notes made about anything thought relevant, for example initial thoughts about codes, content and language. This helped with generating an initial list of ideas about what was in the data.

2.10.2.2. Generating initial codes

This phase involved the identification of initial codes from the data. Codes can be defined as "the most basic segment, or element, of raw data or information that can be assessed in a meaningful way" (Boyatzis, 1998, p. 63). Coding was carried out by hand on the transcripts, with some segments given multiple codes (see appendix 18 for an example from one transcript). Coded transcripts were re-read to ensure all data segments had been included. All codes were transferred into a spreadsheet to form a "coding manual" (Joffe, 2012) with associated data segments from across the data set (see appendices 20-22).

2.10.2.3. Search for themes

This phase re-focused the analysis at the broader level of themes and involved organising the different codes into provisional themes. This was done visually using maps (see appendix 23) and involved collating all relevant coded data extracts within the identified themes. I considered "the relationship between

codes, between themes, and between different levels of themes (e.g. main overarching themes and sub-themes within them)" (Braun & Clarke, 2006, pp. 89-90). Some codes later became themes whilst others were collapsed into other themes. As suggested by Braun and Clarke (2006) a list of miscellaneous codes that appeared not to fit within initial themes was kept. At the end of this phase, provisional themes had been identified while some codes and themes were discarded. In their guidance Braun and Clarke (2006) highlight that themes can be determined by salience within each data item and prevalence across the whole data set. However, they also recognise that the "keyness" (Braun & Clarke, 2006, p.82) of a theme should not solely be based on its frequency in the data, but also through its relevance to the research question and on researcher judgement. Therefore, although repetitions of themes were assumed to be reflective of salience, these other factors also contributed to theme development. A list of three provisional themes was identified at the end of this stage (appendix 23).

2.10.2.4. Review of themes

This phase involved reviewing and refining themes (Braun & Clarke, 2006), considering whether themes are heterogeneous and that codes within themes are homogeneous (Patton, 1990). I re-read the extracts within each theme to ensure that they all related to the identified themes. I then reviewed the different themes and their extracts to ensure they were distinctive. I then re-read the entire data set in order to consider the validity of the themes in relation to the transcripts and to ascertain whether the thematic map accurately reflected the meanings evident in the data set as a whole (Braun & Clarke, 2006). During this stage, themes were merged and discarded and sub-themes developed. Themes were then reviewed across the whole data set. This was carried out with the aim of developing a set of themes that provided an accurate representation of the data. At the end of this phase, three revised themes were identified, each with sub-themes within them (appendix 24).

2.10.2.5. Defining and naming themes

Once satisfied with the thematic map of the data, the next phase in the TA process involves defining and naming the themes. This process involves

identifying aspects of the data that each theme and sub-ordinate theme capture, what is interesting about them and why. I considered the story that each theme told to help me define them. I also considered the extent to which each theme related to the research aims (appendix 25). At this point changes were made to themes and final names decided upon.

2.10.2.6. Producing the report

The final stage of the analysis was the production of the report, which is found in the following chapter and aims to provide a precise and coherent summary of the data. Numerous data extracts are given to illustrate themes and invite the reader to evaluate whether the themes and quotes are reflective of the story being told about the data. The research questions are also kept in mind.

Participants are referred to using their pseudonym. I included broad categories to describe how many participants reported certain themes; i.e. “some”, “several”. The rationale behind this was to highlight to the reader the differing responses rather than to provide a quantification of the data.

3. RESULTS

From my thematic analysis, three super-ordinate themes and six sub-ordinate themes were identified, as shown in table 3 and appendix 24.

Table 3: Super-Ordinate and Sub-Ordinate Themes

3.1.	**"They Were Trying To Help Me Get Better"**	3.1.1.	"It Feels Like I'm Kind Of Dying"
		3.1.2	"It Helps Us To Get The Basics Right"
3.2.	**"It's Clearly Just To Check Up"**	3.2.1.	"It Was A Little Bit Spyee"
		3.2.2.	"They Should Put The Tracker In Your Throat"
3.3.	**Who Is Responsible?**	3.3.1.	"As I'm Older Now She Tells Me It's My Responsibility"
		3.3.2.	"It Reversed Back To Being Us"

3.1. "They Were Trying To Help Me Get Better"

This theme highlights some of the ways in which participants' beliefs about asthma and their understandings of the risks and vulnerabilities it posed influenced their expectations of the healthcare relationship and their experience of being given the SI. It encompasses two sub-ordinate themes: "It feels like I'm kind of dying" outlines some of the beliefs participants held about asthma and the need for medical treatment. "It helps us to get the basics right " describes participants' views of the SI as helping healthcare professionals to improve patients' health.

3.1.1. "It Feels Like I'm Kind Of Dying"

Throughout the interviews, the descriptions of asthma that were shared portrayed the health condition as a scary and life threatening illness for which frequent hospital admissions and medical treatment were required. At the beginning of my interview with Aysha and her mother Samia, Samia told me about the impact of asthma on Aysha's life and some of the medical treatment she had received:

Samia: It just happens her asthma is quite an unusual case where she could be fine one minute and the next minute she could be like wheezing and can't breathe and stuff, she ended up in intensive care twice in the last year last November and last April

Amy: Gosh so that means you have to go into hospital quite a lot then?

Samia: Since June now cause she's had one of them these err asthma related injections she's been fine but before that the last two years it's been really really hard cause since she was 10 we've been in hospital once a week sometimes twice, and then she had a massive cardiac arrest on the ward as well back in November

(Samia, Aysha & Samia, 22-31)

Other participants also described similarly the severe nature of their asthma and their experiences of requiring urgent medical attention. Rabhya described just how scary asthma could be for her:

Amy: Can you tell me a bit about your asthma?

Rabhya: It makes me unwell, it's really painful, hard to breath and sometimes I have to go to A and E to get nebulizers and IVs to help

Amy: So it had a yeh a really big, it's a big deal then?

Rabhya: Yeh [coughs]

Amy: And have you had asthma your whole life?

Rabhya: Erm no mum said that I, it was discovered when I was 2 years old

Amy: Ok and whe-, so bit of a strange question but can you remember when you knew you had asthma, when you were like oh that's what that is, or did somebody tell you?

Rabhya: I think erm when I was in year 1, cause I was in hospital for a-, I went to emergency cause I had collapsed so the-, I went to hospital and got IVs nebulizer and I had to have saline put through my body [Amy: Oh gosh] yeh that's when I realised [Amy: Yeh], it was really scary as I was like really young at that time

Amy: I bet, when you're really young to have to go through that it sounds really scary [Rabhya: Yeh], and so you were saying that like up to now it's-still there's times when you have to go to hospital?

Rabhya: Even now it's still scary because it feels like to me it feels like I'm kind of dying [Amy: Yeh yeh]
(Rabhya, 1-24)

These accounts, as well as others contributed to the emerging picture of a healthcare relationship where patients go to their healthcare professional with asthma related health concerns to receive medical treatment to improve their health. Additionally many of the participants talked about what have been described by Horne and Weinman (2002) as treatment necessity beliefs, in this case the need for ICS. For example in Theo's interview, he talked about why he felt he needed to take ICS and the things this permitted him to do that he would otherwise be unable to do:

Amy: Why do you think it helps [taking your inhaler]?
Theo: Because I can do more as in when I didn't have it I tried to do like a mile race or round that and I couldn't but now like the past year when I took it before the race I could do it all
(Theo, 113-116)

Claire's mother Sarah also spoke about the necessity of ICS and how she encouraged her daughter to use them to avoid unnecessary hospitalisations:

Sarah: Yeh I mean cause the more if she doesn't forget to take it [the inhaler] then I keep saying to her the you won't have to come up the hospital as often I said and that way you know so touch wood you never hap- nothing ever happens I said but if you do keep forgetting to take it there could be an instance where you know I might have to call the numbers [emergency numbers] yeh so
(Sarah, 117-121)

Theo and Sarah's responses also highlight some of the different priorities participants had surrounding their motivations for taking ICS. Whilst in Theo's case, ICS enabled him to do things that he valued such as playing sports, for Sarah, as a mother, her priorities centred around helping her daughter avoid negative consequences such as hospitalisation.

3.1.2. "It Helps Us To Get The Basics Right"

Several of the young people described how the SI was something introduced to "help" them:

> Amy: And when they [the healthcare professionals] gave it you did they say why they wanted you to have it?
> Gary: They said so we can monitor your like usage and to see when you're taking it and when you're not taking it so we can help you with a plan of attack
> (Gary, Gary & Estelle, 126-129)

> Claire: They said that they were gonna erm record me to see if I was taking it cause I weren't really taking it before [Amy: Ok] and they said that err they were trying like to help me get better and because I wasn't taking it properly that that I needed to make sure I was taking it to get better and cause I weren't taking it yeh
> (Claire, 115-119)

Claire's words also bear resemblance to some of the descriptions above, with ICS again being viewed as something that is needed to improve health. Claire also described having "got better" since using the SI, explaining that she no longer needed to use her reliever inhaler:

> Amy: What did you think about that [being given the smart-inhaler]?
> Claire: I thought it was a good idea cause ever since I've been taking it like I've got better I don't even use the blue one cause I used to use the blue one all the time [Amy: Wow ok] but since I've been using the red one I don't take the r- blue one that much
> (Claire, 125-129).

The discussion points from the healthcare professionals' focus group also reflected the idea of the SI being associated with health benefits and illustrates their priorities as helping patients avoid negative consequences:

> Focus group discussion: One patient said this [smart-inhaler] has substantially improved her lung function too so health benefits are also a benefit of using the smart-inhaler. It also helps the patients avoid having to have more invasive treatments such as a test of steroid responsiveness which is quite invasive
> (HCP focus group, 34-38)

There was also some acknowledgement in participant accounts of the portability benefits the SI offered; extending the healthcare assessment to patients' homes and reducing the need for hospital observation:

> Amy: Yeh and in your own personal opinion what do you think it's for?
> Samia: Same kind of thing it's probably like a research that they've come up with and then they just want to like, obviously cause when they are in London and we are in [location far away] they cant really check what you're doing so it just records down everything that's been happening and then they get, they can even keep that in your records to show that this person has been taking their inhalers and that they've been on a test for 6 weeks
> (Samia, 198-204)

> Amy: So kind of yeh on the whole seeing them as a good thing that can help families and doctors?
> Estelle: Yeh yeh exactly if they can work it out instead of having (unclear 'to') it takes out the need of being in hospital under observation for a while
> Amy: Yeh that's a really good point actually I guess because I've met a lot of young people who have to be in hospital
> Estelle: =Yeh to be observed, it's just something that it just take it home and do regularly in regular life and then just plug it into a machine then that saves, takes two three weeks out of your life you know
> (Estelle, Gary & Estelle, 345-353)

Participants also highlighted that the SI results could aid medical understanding and place an onus on healthcare professionals to change their practice in

response to the results. For example, within the focus group some of the implications of using the SI in clinical practice were discussed:

> Focus group discussion: The data the smart-inhaler gives us helps to see if asthma control is bad or good and see if this is linked to their difficult asthma or not
> (HCP focus group, 7-10)

> Focus group discussion: It also avoids us having to do more invasive treatments as described above. It also helps us to get the basics right
> (HCP focus group, 49-51)

Rabhya and Sarah also described how they believed the SI results could aid healthcare professionals' understanding of the contributors to a young person's asthma and what the relevant treatment may be:

> Amy: Yeh yeh and what do you think would be good about them being able to see that you've been using it?
> Rabhya: They'll be able to get some kind of idea like because erm the-, if you're not using it then they'll be like oh because then it's a a bit like it your not controlling the asthma but if they are using it the asthma is controlled and there must be something else going on
> (Rabhya, 163-168)

> Sarah: Erm I suppose you know like if she was taking it like she took it every day and maybe they might maybe increase the dose if they thought no it's not this and their could be another reason why yeh
> Amy: Yeh cause actually it could, you could
> Sarah: = Mmm cause they're thinking you know we know she she's taking it so then there might be room for their improvement so yeh
> (Sarah, 126-128)

3.2. "It's Clearly Just To Check Up"

This theme illustrates how participants experienced the introduction of the SI to the healthcare relationship as being to monitor their inhaler use. It consists of two subordinate themes. "It was a little bit spyee" outlines how the introduction of the SI raised issues of mistrust and fear in the healthcare relationship, promoting a sense of surveillance of young people, both from healthcare professionals and from caregivers. It also acknowledges that despite these feelings, the process improved young people's adherence whilst using the SI. "They should put the tracker in your throat" illustrates the ways some participants viewed the SI as inadequate at recording real life inhaler use.

3.2.1. "It Was A Little Bit Spyee"

Across several of the interviews the idea of the SI as something healthcare professionals use to check up on young people and their families was introduced. This was very clear during the interviews with caregivers Jessica and Lizzie:

> Amy: And I guess in terms of when they set up the smart-inhaler and feeling like you're being checked up on do you think there are any other things the smart-inhaler is for?
> Lizzie: No [laughs] it's clearly just to check up
> (Lizzie, 25-28)

> Amy: What do you think the smart-inhaler is for?
> Jessica: To track his use to check up on us
> Amy: When you got the smart-inhaler what do you think your son thought it was for?
> Jessica: To check up on him
> (Jessica, 18-22)

Jessica's description of the SI checking up on both of them also suggested that there may be a blurring of responsibility for her son's ICS use, with the SI being used to check he was taking it and that she was making sure of this. For both

caregivers there was a sense of shock that healthcare professionals would need to check this and for Lizzie, the process insulted her:

> Jessica: Yeh because one of my big things is that they always question has he had his medication and of course he does I can't imagine him not I know she said last time some kids don't but I cant imagine him not or any child who needs medication not taking it
> (Jessica, 66-69)

> Amy: Ok and like you said so it kinda felt like they were checking up on you?
> Lizzie: I felt insulted
> Amy: Yeh, well I was going to ask you why you think they gave it you and how you felt about it?
> Lizzie: Well yes it is insulting and I think if it is your child's health and their life you are going to give them their inhaler and I just think it's madness it's like if you were a diabetic and you don't take your insulin you'd die I think it's ridiculous
> Amy: So it feels insulting?
> Lizzie: You feel like you are being treated like a child
> (Lizzie, 15-24)

Caregiver Danielle described suspecting that the SI had been introduced as healthcare professionals didn't believe her daughter was taking her ICS:

> Amy: So what were your views?
> Danielle: Well to be honest me and my husband's view is we're not particularly over happy with it, it's like their trying to sort of catch you out at cause if it's like she's not taking it and I administer, I'm on her all the time and you know we do feel a bit, I dunno how to explain it really you know, as if they feel well she's not taking it and I know with all doctors they like to know that the medicines working for, so I know they've got a job b-but you know it feels, I dunno how to explain it really you know m-my, well I explained it to my husband and to be honest he wasn't very happy about it and er you know, it's just I feel that they feel that she's not taking it

(Danielle 82-92)

Many participants likened the introduction of the SI to a process of covert surveillance, which raised feelings of mistrust in the healthcare relationship:

Janet: but from my daughters perspective if she wasn't taking it then that could be a quite a frightening thing to have to come and see a doctor and get told off, like big brother's watching you
(Janet, 16-18)

Amy: What did you think about that?
Sam: Hmm err it was a little bit spyee
Amy: A little bit what?
Sam: Spyee
Amy: A bit spyee! Ah! Why do you think it felt a little bit spyee?
Sam: Well because they are checking up to see if I'm taking my inhaler
Amy: And what did you think about that?
Sam: Err well I didn't really like it that much but I'm ok with it
Amy: And the way [nurse] explained it can you remember how
Sam: = She said that she said that it would record how many times I take it and that they can see you and whether whether I've been taking it or not
Amy: An so you said like it felt a little bit spyee do you think anything else about it and why you were given it?
Sam: Maybe she thought I wasn't taking it
Amy: And what do you think about that?
Sam: That she was wrong
(Sam, 87-102)

The process also contributed to a sense of fear in the healthcare relationship, with participants predicting that the information recorded could land young people in trouble, with limited opportunities to explain their side of the story:

Amy: And how does it feel for you Gary, kind of knowing that they are going to look at them in that way?

Gary: It feels scary cause whenever I don't, whenever I think of taking it but I haven't it's like oh, whenever your found or someone says you haven't done this and you plead innocence they are always gonna say that they wont believe you cause it's the results but you thi-, you say ok I'd thought I'd tooken it but I didn't know if I had and yeh
Amy: Yeh so it's kind of like feels like i- there's this thing where they are like here's some evidence and [Gary: Yeh] and that doesn't feel very nice cause like you say you're trying to plead your innocence
Gary: Yeh exactly and then say if you get more they are gonna be like why are you doing this for and then you think oh I don't know if I have tooken it so I took it again but I don't know if I took it
Amy: And is that different to before did it not fe-, did you not feel so pressured before cause they didn- they weren't able to look at it like is it any different or was there still that argument about [Gary: =No] who
Gary: = Well if I didn't have the smart-inhaler it was like oh oh they wont know so yeh I could take it then take it then take it then and then fine but then now it's like oh if I don't take it I'll be in trouble
(Gary, Gary & Estelle, 154-172)

Isla and Rabhya also raised similar issues, fearing the presence of the SI in the healthcare relationship would mean their own explanations for their inhaler use would not be listened to or believed:

Amy: Yeh yeh and like you say I guess if you'd given it in and you knew they were gonna look at it and obviously like you say you've not been able to use it all the time [Isla: Yeh] do you think that would have been like quite hard to explain or how do you think you would have managed that?
Isla: I would have explained it but I don't think like they would believe me sort of thing [Amy: Yeh ok] but I have been [laughs] I have [Amy: Yeh]
(Isla, 108-113)

Rabhya: I think they like might think like the doctor might like saying have you taken your medication and so yeh, not like shout at them but be a bit like told off like a warning like you have to take it it's not good and then I

think like kids are gonna get scared and say oh I don't like the doctor they are making me take my medication when I'm saying I don't want to take it (Rabhya, 114-118)

Interestingly however, several of the young people explained how the process of having healthcare professionals check their adherence through the SI had improved their inhaler use:

Amy: If you were thinking about using a smart-inhaler do you think knowing that a doctor, do you think that would make you more likely to use it like more often?
Isla: Probably it would make me think oh wait doctors are gonna look at this so I better use it, but yeh I think it would have made me a bit more aware that I have to do it (Isla, 229-233)

Amy: And when you thought that she might be able to see [how Sam used his inhaler] did that affect how you used the inhaler? Did it make you want to take it more or less or the same?
Sam: I just took it-well it pressured me to take it to make sure I take it all the time so it was always on my mind
(Sam 103-106)

Several of the caregiver participants also acknowledged that the SI could aid their own ability to monitor their child's inhaler use:

Amy: And do you think that the smart-inhaler helps with asthma control and management? Do you think it's something that could help to have it as part of your routine care to look at the graphs with the doctors?
Jessica: Yeh maybe it would be good to see you know, we know he takes it in the evening but it would be good to see you know when he takes it at the other times.
(Jessica, 36-41)

For caregiver Janet, this monitoring could then extend to times when her daughter was in her estranged husbands care:

Amy: And thinking generally about the smart-inhalers?
Janet: They're good as a parent to see a bit more about what she's doing and if she's taking it as she should, I'm trying to be a bit more hands off as she gets older but you know I still want to know that she's taking it and cause she's with my husband half the time so she has to be responsible for it as neither of us are there all the time especially now she's older too
(Janet, 161-121)

The healthcare professionals also described how parents had fed back to them that the SI enabled them to supervise their child's adherence better:

Focus group discussion point: Parents have said they now feel that they can supervise their child's adherence better
(HCP focus group, 32-33)

3.2.2. "They Should Put The Tracker In Your Throat"

Across the interviews it was also acknowledged that even with the presence of the SI, some just didn't believe the results:

Focus group discussion: Some parents still do not believe the graph with the results on
(Hcp focus group 66-67)

Caregiver Janet also raised this idea when thinking about how the SI results could be communicated to her daughter:

Amy: Cause do you think with these sort of things when they're then presented with evidence that they've not taken it, do you think that helps with responsibility?
Janet: I don't know if you're gonna show em a graph they are just gonna go [shrugs and pulls face], you know it's err you know you could probably tell them till you're blue in the face
(Janet, 92-97)

For many participants there was an expectation that the results would not capture how things really were because the SI was just not good enough technology. Isla described how having separate inhalers at both her parents' homes, meant that the SI (which was left at her mum's house) did not capture her inhaler use at her dad's house:

> Isla: Yeh and then I got to mum's and I used it for a few days and then like I went to dad's where, I normally live at dad's longer than mum's [Amy: Ah ok yeh] and I left it at mum's and so that missed out like two weeks and then like I came back and then it was beeping at me and I was like what ya doing [laughs] so it was really complicated
> Amy: Yeh and I guess lots of young people said that because yeh either cause your parents are in different places or they have relatives that they go stay with [Isla: Yeh] like it's hard to take it everywhere [Isla:Yeh] and then if you don't have it it's not gonna show how you've used your inhaler
> Isla: I've got like my medicine at dad's and medicine at mum's and they're separate and I don't have, I don't carry it with me
> Amy: So it's like you needed two [Isla: Yeh] one in each place?
> Isla: But then the data would be really [pulls awkward face]
> (Isla 78-90)

Jessica highlighted that the limitations of the SI technology could result in a young person being perceived as not taking their inhaler by healthcare professionals, when in fact the family's approach to using inhalers was to prepare for the different times and places one may need an inhaler:

> Amy: When you got the smart-inhaler what do you think your son thought it was for?
> Jessica: To check up on him
> Amy: And did you have a conversation about that between you?
> Jessica: Just in the fact that when he didn't take it and used another one that they'd see that as him not taking it when actually we're just prepared for different situations and have them in different places, I've got a 2 year old and we have to be out the house quickly so we have one in the car for him to use instead, we have 3 and so when I came I asked about this and

said but he uses a different one at school and she said it would be fine and it didn't matter, it would have been better if it's tracking his use then to only use one inhaler but that wasn't implied to us that would have given a better reading
(Jessica, 20-31)

During my interview with Theo, I was struck by his suggestion that the monitoring device should be put in his throat. Reflecting on this, it suggested to me that for Theo his experience of using the SI had made him feel that if he was going to be monitored using this technology, it could at least have been done properly:

Amy: Ok and so like you said while you've had it other then when you went to your dad's, have you always had it on it?
Theo: Erh yeh mainly, I have a separate one for sport at school which doesn't have it so so it's only going to show what I take in the house
Amy: That's a good point
Theo: They should put the tracker in your throat then they'd be able to see that I was taking it because when we went to the caravan I have a different inhaler there
(Theo, 147-155)

3.3. Who Is Responsible?

This theme focuses on participants' accounts of taking responsibility and ownership for their asthma and some of the complexities with this process. It comprises of 2 subordinate themes. "As I'm older now she tells me it's my responsibility" describes some of the developmental expectations that exist around taking responsibility for asthma during the period of adolescence. "It reversed back to being us" describes how the introduction of the SI reduced the level of responsibility young people possessed for their asthma. It also illustrates that even when the presence of the SI increased young people's inhaler use, this increase was short-term, with participants following the

instructions of their healthcare professional rather than taking responsibility for their asthma.

3.3.1. “As I’m Older Now She Tells Me It’s My Responsibility”

Throughout the interviews I heard about participants' own ways of managing asthma and in particular I listened to many accounts that were shaped by an expectation that the young people living with asthma should be the ones responsible for managing it:

> Lizzie: Yeh because when he was at primary school they had all his medication for him in a case but they said as he moves to high school the nurse was like no he’s got to take responsibility so if he goes out his blue inhaler he got to make sure he’s got his blue inhaler
> (Lizzie, 49-52)

> Claire: As I’m older now she tells me it’s my responsibility I’ve gotta remember I’ve gotta take part in things and make sure I do things and I’m like yeh
> (Claire, 66-68)

For Isla, her view of young people becoming responsible for their asthma influenced her perception of the appropriateness of the SI:

> Amy: And I- overall generally what do you think about doctors and nurses using these things [smart-inhalers] to check up?
> Isla: I think it’s err ok like I guess they are trying to find out i- like if parents say that you take it if you’ve got other people witnessing that and saying then I guess you know it depends, if I was like really responsible all by myself for taking it then yeh but if it was like like mum and dad sometimes help me then I don’t need it in that sense
> Amy: So it might be something that could help if that felt like the time was right to help but actually if you’ve got parents who kind of help already
> Isla: I guess at my age now would be more suitable to have it like now to like a bit older cause you’re getting more responsibility

Amy: Yeh I thinks that's what they want these to be used for [Isla: Yeh] to try help them be more in charge so that your mum doesn't have to say have you taken it because actually there's something else saying have you taken it

Isla: Yeh I think that age range maybe 13 to whatever like I don't know but like children your parents will like always make you take your medicine cause it's like a hazard but you know so

(Isla, 246-262)

These descriptions contributed to the sense of young people gradually taking on more responsibility for their asthma as they entered the period of adolescence. However not all participants shared this view and caregiver Danielle described some of the issues this period presented her with:

Amy: And so during that time your daughter was still in charge of her inhaler? It wasn't' that you kind of yeh felt like you needed to do more?

Danielle: Yeh well this has only happened recently though because I've always been in charge of her medication just because obviously she's a teenager and to make sure like she's taking it you know and yeh I've always I've always been on her case to take it because with her you know if there's a day like a morning that she didn't take it you know because her body's used to it then she'd suffer from it, and I think that now she's a teenager it's more like when she wants to go somewhere and I don't want her to go like with staying over friends and that, she's only sort of really done that recently because over the years she's had some really bad turns and she's actually stopped breathing and sort of like we worry that she's out and something's gonna happen and that that person might not b-cause my husbands had to give her mouth to mouth before so we worry that that person might not really know what they were doing and you know and it's only now and the not all the time, to be honest it is a worry

Amy: Yes, Yes I bet

Danielle: Especially now she's getting to this age now where she's wanting to do things that other children do her age and it is hard if she's gone on a sleepover I'd be on the phone to that parent to make sure that she's

actually taken it you know just for that specific reason that I didn't want her missing it you know
(Danielle, 62-81)

3.3.2. "It Reversed Back To Being Us"

However, during the interviews it became apparent that for some families, the introduction of the SI created tensions in the negotiation of responsibility, with some participants describing how the introduction of the SI had resulted in young people losing their recently acquired responsibility for their inhalers. Several of the caregivers explained how their fears about breaking what they viewed as an expensive device had led them to take on more responsibility for their child's inhalers then they had previously done:

Amy: Yes and you said earlier that your son usually takes responsibility for his inhaler and I wonder during the time you had the smart-inhaler did you feel that changed?
Lizzie: Yeh I guess usually we keep it in like a box with his medication but I thought I'd better keep the smart-inhaler high up on a shelf because we have babies and I thought they may smash it or they'll think that it's a computer and press all the buttons and confuse it so where he was more independent it removes that say the I'm going to take my inhaler now and my peak flow because we keep it with the peak flow in a box and he can just go and get that himself whereas now he has to stand on a chair to get it because he's nearly 13 you want him to have a bit more independence and say I'm taking my inhaler because he's at high school you know he has to do things like that on his own so it reversed back to being us, which I don't think is good at all because at his age you want him to be taking responsibility
Amy: Yeh and that is something I am really interested in for my research how it affects this age group in terms of them taking responsibility for their inhalers
Lizzie: Yeh because when he was at primary school they had all his medication for him in a case but they said as he moves to high school the nurse was like no he's got to take responsibility so if he goes out his blue

inhaler he got to make sure he's got his blue inhaler and then we've had to take all that away from him
Amy: That's really interesting as I guess my next question was about whether you think there are any ways the smart-inhaler helps your son take responsibility?
Lizzie: No it was the reverse as they were saying it's so expensive [puts voice on] so expensive don't break it we don't have many
(Lizzie, 33-57)

Amy: And you've said about a few conversations where you were having to take the recorder off, did it feel like she was looking after the recorder [Sarah: No] or did it feel like you were?
Sarah: It was me [laughs] yeh cause she wasn't too sure how to take it off and I was like give it here cause you're gonna break it yeh so in like that way no I dealt with most of you know taking it off
Amy: Ok so did that feel then like
Sarah: = Yeh a bit of pressure yeh I suppose cause I didn't wanna break it and I'm thinking ooh
Amy: And with that is that not usually there when the recorders not on it cause they are like her inhalers?
Sarah: Yeh she wouldn't normally care
Amy: So maybe then a-, which is interesting cause I guess if we are thinking about her taking more responsibility for her asthma [Sarah: Mmm] you're then having to get back involved?
Sarah: No exactly and charging it as well so yeh, but the charger and that it's quite good really I didn't really charge it that often so there's quite a long yeh it's pretty good I did it a couple of times but I wasn't in very often
Amy: Ah okay so that's interesting as it sounds like you were having to do the charging?
Sarah: Oh yes that's right [laughs] yeh I did all that yeh
Amy: Ok so I guess listening to you it sounds like you've had a big part to play [Sarah: A bigger role yeh definitely] which and it sound like i- you do have a role anyway [Sarah:Yeh] in managing your daughter's asthma but maybe it was a bit increased because she had the recorder on it?
Sarah: Yeh

Amy: And what do you think about that in the kind of long term would you want to have that role or do you think it is more about kind of
Sarah:= Oh no I didn't mind doing it but obviously you know I had to make sure she din't break it
Amy: So the pressure of actually having this thing [Sarah: Yeh], whereas I guess if it was yours to keep I guess it might not feel
Sarah:= Well it wouldn't be so bad but I probably wouldn't wanna break it cause [laughs] replacing it yeh mm
(Sarah, 227-260)

This reduced sense of responsibility was also evident during participants' descriptions of how the SI had led to young people questioning their own judgement and ability to be responsible for taking their inhalers. On several occasions participants described defaulting to their parents' judgement to confirm they had taken their ICS:

Amy: Yeh so it kind of like feels like i- there's this thing where they are like here's some evidence and [Gary: Yeh] and that doesn't feel very nice cause like you say you're trying to plead your innocence
Gary: Yeh exactly and then say if you get more they are gonna be like why are you doing this for and then you think oh I don't know if I have tooken it so I took it again but I don't know if I took it
(Gary, Gary & Estelle, line 164-166)

Amy: Yeh and I guess there's a few thing then so for your daughter knowing that was on there did she have any conversations with you about being watched or [Sarah: Erm] or was it something you just kind of sensed she might be worried about or did you think did it not seem that she was bothered?
Sarah: I don't think she seemed really bothered but I know that it's more that she going ah you know I don't thi-. sometimes she might have thought to herself oh did I take it this morning or did I forget and then things like that sometimes she might have worried and I say no you've taken it
(Sarah, 50-57)

Interestingly, even for those young people where the SI was viewed as something that could help them taking some responsibility for taking their ICS regularly, there was a sense that once the SI was taken away and there was no longer anyone checking, their inhaler use would reduce again. This promoted the idea that for many participants they were not taking responsibility for their asthma but were instead dependent on the actions of their healthcare professional:

> Rabhya: And I think that if they were given the smart-inhaler then they are gonna be like quite scared like oh no I'm not taking my medication I'm gonna get in trouble and then that's only when they're gonna start using it and then when the smart-inhaler is taken back then they are gonna stop using it
> (Rabhya, 93-96)

> Amy: And so you've said about this a bit already but can you tell me about any ways the recorder helps you or your family to take care or responsibly for asthma?
> Claire: It would always make me think about taking it if it was on there all the time
> Amy: But if they took it off, so have you handed it back today?
> Claire: Yeh they've took it now
> Amy: So do you think going home now that it'll feel a bit more relaxed and that you might drop off a bit in doing it, or do you think that because you've seen a difference you'd want to try and
> Claire: = I'll try and carry on but I think it'll slowly go like I just won't take it properly
> (Claire, 281-292)

4. DISCUSSION

This chapter summarises and evaluates the study's results in relation to the research questions and the existing literature. I then reflect on the study's limitations and my role as researcher, before discussing the implications of the findings.

4.1. Summary of Findings

The study aimed to explore the experiences of young people with asthma whilst having their adherence to ICS assessed through the SI. It also aimed to explore the experiences of their caregivers and healthcare professionals. In particular, the study sought to examine whether the SI was experienced as promoting young people's responsibility to self-care. The study also aimed to explore how the SI monitoring process impacted on the healthcare relationship.

The research questions posed were as follows:

1. How do young people and their caregivers experience being assessed through the SI?

2. How do healthcare professionals involved in assessing adherence using the SI experience this process?

3. How does the process of having ICS adherence assessed through the SI influence experiences of self-care and do participants experience the SI as promoting young people's responsibility for self-care or not?

4. How does the process of being given the SI interact with the relationship between the healthcare professional and the young person/caregiver?

This section summarises the results in relation to these research questions. The themes identified and discussed in the findings described the young people, caregivers and healthcare professionals' experiences of the SI. In

particular the findings highlighted that young people and caregivers experienced being assessed through the SI positively when they viewed the SI as supporting healthcare professionals' ability to take care of their patient's health. Young people and caregivers shared their views of the SI as a new and health-improving technology, which would hopefully aid healthcare professionals' ability to look after their patient's asthma. The findings also indicated that when healthcare interventions such as the SI were consistent with participants' main priorities, they were more likely to be experienced as positive and helpful then when they were not consistent with these priorities. For healthcare professionals in the study, whose main priorities were focused on improving the health of their patients, the SI was experienced as a useful tool for assessing adherence and promoting patients' health. The findings also raised the idea that as an electronic adherence assessment tool that monitors ICS use, the SI was experienced as a form of health surveillance. For many of the young people in the study, the experience of surveillance promoted feelings of mistrust from healthcare professionals, and for caregivers contributed to their experience of feeling undermined by healthcare professionals. This led to the healthcare relationship feeling somewhat fractious at times following the introduction of the SI. Finally, the findings highlighted that having ICS adherence assessed through the SI can impact on the relationship between a young person and caregiver. In particular it can impact on the transfer of responsibility from caregiver to young person, with the introduction of the SI in many cases actually depriving young people of opportunities to take responsibility for asthma related self-care.

4.2. Evaluation of Findings

This section considers the overarching issues from the three themes and six sub-ordinate themes identified. It evaluates these in relation to the current literature and outlines the contributions the findings offer.

4.2.1. Shared Decision-Making: Identifying the Different Perspectives and Priorities of Those in the Healthcare Relationship

An issue that emerged very strongly whilst developing and reviewing the themes relates to the different priorities participants had for taking care of asthma and the variety of perspectives that existed regarding the introduction of the SI.

Most participants described asthma as a serious and life-long health condition that needs to be managed through engaging with a variety of healthcare behaviours (i.e. taking ICS regularly, avoiding allergens and irritants, attending medical appointments). These descriptions resembled features of Leventhal et al.'s (1992) SRM which was described in the Introduction. The SRM assumes that an individual will hold beliefs about the identity, timeline, consequences, cause and control/cure of an illness and these beliefs will influence their health behaviours, in particular their medication adherence (Bucks et al., 2009, Clifford et al., 2008, Horne & Weinman, 2002, Menckeberg et al., 2008, O'Carroll et al., 2011). However, participants' specific reasons for engaging with healthcare behaviours varied depending on how each behaviour connected with what they regarded as most important to them. These different priorities can be seen through looking at each participant group's perceptions of the SI. For example, for many of the young people in the study, participating in activities that were important to them such as spending time with their peers and developing independence in their lives away from asthma and the supervision of their parents was one of their main priorities. For many young people this meant there were times when they hadn't taken their ICS. Subsequently, the young people's perceptions of the SI were often accompanied by feelings of fear, mistrust and blame, with the technology viewed as something that could get them into trouble. They predicted their explanations for not taking their ICS would not be listened to by healthcare professionals. For many of the caregivers in the study a main priority was for family life to run smoothly, with asthma related tasks often incorporated into the daily routines of the family. Here, the SI could be perceived as a bit of nuisance due to the limitations of the technology (which meant that it only recorded the activity of one inhaler despite multiple inhalers being used). It could also be perceived as assisting these priorities, helping family life to run smoothly by reducing the need for lengthy

hospital stays through assessing their child's health remotely. Finally, for healthcare professionals, their priorities were often focused on promoting the health of their patients, with their descriptions at times dominated by their motivations to understand and improve the health outcomes of their patients[8].

The observation of the participant groups having different perceptions compares to the findings of Jonsson et al. (2013), where young people and their caregivers held differing views on living with and managing asthma. The findings also lend support to the recommendations of Horne and Weinman (2002) for healthcare professionals to use a "necessity-concern framework" in their interactions with patients as a useful means of eliciting and understanding their perception of asthma and its treatment. However, this research has highlighted the importance of also acknowledging that different priorities can exist within the healthcare relationship, with what is most important to one member of the healthcare relationship not necessarily being that which is most important to another. The value of healthcare professionals identifying patients' preferences and priorities in relation to treatment decisions has been recognised by other researchers previously and is often viewed as an important step in the process of shared decision-making. For example Mulley, Trimble and Elwyn (2012) have advocated for healthcare professionals to communicate with patients in a way that allows both the medical expertise of a healthcare professional and the expertise of a patient on his or her priorities to be acknowledged. Through a process of shared decision-making, a healthcare professional, patient and in many cases a relative or carer, would then choose a treatment together as a team. Research carried out in an adult asthma population has also highlighted the benefits of engaging patients in a shared decision-making process and demonstrated that when healthcare professionals and patients negotiated a treatment regimen that accommodated patient goals and preferences, there were significant improvements to patients' adherence levels and other clinical outcomes[9] (Wilson et al., 2010).

[8] This is not to say that the young people and caregivers in the study did not see health promotion as important, with many in fact agreeing that the SI offered health benefits. However, for healthcare professionals in the study this appeared to be their main priority, whereas for the young people and caregivers there were competing priorities.
[9] Including improved controller adherence, asthma-related quality of life, health care use, rescue medication use, asthma control and lung function.

However, the process of shared decision-making and negotiating priorities can be complex, and challenges one of the longstanding assumptions of medicine that “the doctor knows best” (Mulley et al., 2012). The challenges associated with the shifts in healthcare between compliance, adherence and concordance models of healthcare were described in the Introduction, and it was acknowledged that in reality, healthcare practices remain more closely aligned to a compliance model of healthcare (Segal, 2007). Certainly, within the current study the fundamental view of the healthcare relationship appeared to be of one where the healthcare professional possessed the expertise and ability to bring about improvements in their patients’ health, with the caregiver and young person positioned as recipients of healthcare, acting on the instructions given to them by their healthcare professionals. These descriptions appeared to resemble a more “doctor knows best” compliance healthcare relationship, rather than one of shared decision-making. Contributors to this relationship dynamic are easy to identify, for instance many of the participants gave examples of where healthcare professionals had saved their patients’ lives through their medical skill and expertise. However, it is possible that because of this, many of the young people and caregivers in the study accepted the introduction of the SI based on their healthcare professionals priorities rather than their own. In not being entirely synonymous with their own main priorities however, many participants then experienced aspects of the SI negatively and consequently did not engage fully with the technology.

Overall these findings add to the existing literature on telemonitoring and electronic adherence assessment by illustrating the significance of participants’ priorities in influencing their perceptions and experiences of the SI. For those participants where the purposes and functions of the SI were synonymous with what was important to them in life, the technology was experienced as a valuable addition to the healthcare relationship. For those where this was not the case, the SI was more likely to be perceived negatively, for example as a nuisance or something that could lead to negative consequences. These findings suggest that for all members of the healthcare relationship to be fully engaged in treatment decisions (such as whether to use the SI), the different priorities and perspectives of each person must be acknowledged and a shared decision about future actions must be agreed upon. For this process to occur it

is likely that a shift must take place within the healthcare relationship towards interactions more closely connected with an adherence model of healthcare. For young people, caregivers and healthcare professionals where expertise is located solely within the healthcare professional, this process may be a challenge.

4.2.2. The Consequences and Complexities of Health Surveillance Technology

Another key issue identified whilst developing and reviewing the themes relates to participants' experiences of the SI technology as a form of health surveillance. This surveillance impacted not only on the healthcare relationship, but also on the relationship between young person and caregiver; specifically on the transferring of responsibility for asthma related self-care tasks from caregiver to young person.

4.2.2.1. The SI and the healthcare relationship

During the interviews participants shared their awareness of the SI's monitoring capabilities and likened the technology to forms of surveillance such as being like "big brother" or a "spy". As acknowledged in the Introduction, practices of surveillance surround individuals living in Western society and are becoming increasingly utilised in healthcare settings (Stowe & Harding, 2010, Vaz & Bruno, 2003). Unsurprisingly, young people and caregivers in the current study reported feeling checked up on by healthcare professionals due to the nature of the technology. Interestingly however, participants experienced feeling checked up by healthcare professionals in different ways. For some participants, particularly those where their beliefs about asthma were of a severe and life threatening illness, being checked up on provided a sense of reassurance that healthcare professionals were looking after and "helping" their patients. This is consistent with the findings of Fairbrother et al. (2013) whereby telemonitoring provided a sense of reassurance and support to patients. It also highlights that when participants viewed the SI as part of a standard helping process that aided healthcare professionals in their routine practices of assessment, the practice of health surveillance was far more accepted within the healthcare relationship.

However, for other participants, there was a sense of dissatisfaction in response to the introduction of the SI as a health surveillance tool. For instance several young people described the SI as being introduced because healthcare professionals didn't believe they were taking their inhaler, evoking feelings of mistrust and suspicion within the healthcare relationship. The caregivers in the study also described thinking that the SI had been introduced because healthcare professionals did not believe their child was using their inhaler and in some cases, caregivers described thinking the SI had also been introduced because healthcare professionals did not believe them as parents. It is likely that this contributed to some caregivers' feelings of shock and insult, with the SI in a way questioning their truthfulness and reliability as parents. Isla's description of the SI not being needed for young people whose parents witness them taking their inhalers and confirm this to healthcare professionals illustrates her view of her parents as reliable sources. In this sense, the introduction of the SI could be seen to undermine her parent's reliability, arguably communicating to Isla that healthcare professionals didn't believe her parents, as they needed the SI to confirm her adherence. This could create tensions in not only the relationships the healthcare professional has with young person and caregiver, but also in the relationship between the caregiver and young person. The caregivers' subsequent descriptions of hoping to use the SI to check on their child's adherence for themselves may also in part be related to this process, with caregivers possibly wanting to re-establish their position as reliable sources. The healthcare professionals' descriptions of parents now supervising their child's inhaler use better because of the SI is also consistent with this.

These descriptions paint the picture of a chain of observation, where both young people and caregivers are monitored through health surveillance technology. Whilst for some, this process was experienced as reassuring, for many, the monitoring process evoked negative feelings within the healthcare relationship. The use of the SI technology in this setting specifically, (whereby a young person's inhaler use was recorded over a period of time, then returned to a healthcare professional who could view the results themselves before sharing with a young person or caregiver) may have contributed to this experience. Without seeing the results for themselves, it is conceivable that for the young people and caregivers in the study, the monitoring process felt very much out of

their control. It was acknowledged in the Introduction that overt monitoring by healthcare professionals, even when done sensitively, will feel too confronting for patients (McNicholl & Heaney, 2013). The research findings of Seto et al. (2012) also highlighted that some participants experienced being watched by healthcare professionals through telemonitoring equipment negatively. In the face of increasing health surveillance technology, it is therefore important to acknowledge the impact technology such as the SI can have on the healthcare relationship. The multiple perspectives gained through the current study have also highlighted the impact electronic adherence assessment tools can have on the relationship between the healthcare professional and caregiver.

4.2.2.2 The SI and transferring responsibility for asthma self-care

As well as impacting on the relationship between healthcare professional and young person/caregiver, the interviews also highlighted the impact the introduction of the SI had on the relationship between the young person and their caregiver. One issue in particular that was raised related to how the process of being monitored through the SI affected the young people's ability to take on responsibility and ownership for their asthma.

The relationship between young people and their caregivers as they approach adulthood has received considerable attention in chronic health literature (Anderson & Coyne, 1993, Anderson et al., 1997, Cerreto & Travis, 1984, Eisner, 1993, Holmbeck, 2002). Recent research and policy recommendations have focused on the need for responsibility for asthma to be transferred from caregiver to young person as they approach adulthood (Blaakman et al., 2014, The British Thoracic Society, 2011, Price, 1996). In the current study, many participants' accounts were informed by this expectation, however they also highlighted that this transfer of responsibility is not always straightforward and in some cases posed a challenge to caregivers in relinquishing the responsibility for supervising asthma related tasks. Caregivers' descriptions of hoping to use the SI to help them monitor their child's inhaler use offer one example of this. The challenges associated with this period of transition have been acknowledged previously. For example, Eisner (1993) described how caregivers can struggle with transferring responsibility to their child due to their concerns about their child's level of conscientiousness regarding these

responsibilities. This struggle can be aggravated when caregivers perceive their child's behaviour or failure to implement treatment appropriately as life threatening. This conflict was clear for caregiver Danielle, who described fearing her daughter might end up needing to be resuscitated if she forgot to take medication when staying at a friend's house.

It is therefore somewhat unsurprising that in response to feeling checked up on by healthcare professionals; young people were described as having lost any recently acquired responsibility for their inhalers. In most cases this responsibility was transferred back to their caregivers, who became more involved in response to their own experiences of having their supervision ability monitored through the SI. Several caregivers explained how they took on more responsibility for their child's ICS then they had previously done. This included caregivers placing inhalers out of reach of young people, taking on the responsibility for charging up the SI and transferring the SI onto new inhalers when the ICS ran out. This behaviour contradicts the recommendations of Cerreto and Travis (1984) that young people need to take on more responsibility for self-care activities, with family members withdrawing their involvement. It also contradicts the suggestions of Riekert and Rand (2002) that the process of telemonitoring can assist families in appropriately transferring responsibility of asthma care from caregivers to young people.

In a similar vein, the monitoring process also impacted on young people's confidence in being responsible for taking their inhalers. There were several examples where young people described feeling more worried about forgetting to take their ICS following the introduction of the SI and subsequently they had sought reassurance from their caregivers around this. Holmbeck et al.'s (2002) suggestion that increased caregiver involvement can lead to lower levels of autonomy in young people trying to take responsibility for their self-care offers one possible explanation for this finding. It may be that the increase in caregiver involvement (resulting from caregivers experiences of feeling checked up on themselves through the technology) reduced the young people's autonomy in managing their asthma, leading to them becoming more dependent on their caregivers. It could also be related to the young people's fear that the SI monitoring could get them into trouble. It is conceivable that the

anticipation of negative feedback from healthcare professionals promoted young people's desire to make sure they took their inhalers regularly and to achieve this they became increasingly thorough in their own checking. This, arguably, is similar to a form of self-surveillance, which has been described by Vaz and Bruno (2008) as "the attention one pays to one's behaviour when facing the actuality or virtuality of an immediate or mediated observation by others whose opinion he or she deems as relevant – usually, observers of the same or superior social position (p. 274). This is consistent with the observation from the results that for some participants, the introduction of the SI had motivated them to use their inhaler regularly. This was also the case in the research conducted by Spaulding et al. (2012), where electronic monitoring and feedback on adherence motivated patients to use their inhalers correctly in order to avoid a clinic visit where data would show non-adherence. However, despite this, there was a sense amongst participants that once the SI was taken away and there was no longer anyone checking, their inhaler use would reduce again.

These findings emphasise that in introducing the SI to the healthcare relationship, the level of responsibility young people held for asthma related self-care tasks reduced. This decrease in responsibility was two-fold, with caregivers becoming more involved than they had previously done because of the introduction of the SI, and young people becoming less autonomous in their asthma self-care, relying more on the judgement of their caregivers then previously. This shift occurred despite young people and caregivers' awareness that young people should be taking more responsibility for their asthma. The findings also illustrated that for young people who reported that their adherence behaviour had improved during the time they had the SI and who hoped to maintain this once the SI was removed, there was still an expectation that their adherence would reduce once they were no longer being monitored.

Overall these findings have highlighted an important issue; that introducing electronic adherence assessment and telemonitoring equipment such as the SI into healthcare settings is complex and can lead to a range of consequences, not all of which are experienced positively. Whilst some participants felt

reassured by the presence of the SI and in some cases expressed an interest to continue using the equipment, other participants were unhappy about its introduction and were dissatisfied with the technology itself. How healthcare professionals present and engage families with the technology is therefore key. Additionally this research has highlighted the ways in which the SI was experienced as a form of health surveillance. This surveillance undermined young people and caregivers' confidence; depriving young people of responsibility for managing their asthma and undermining caregivers' reliability in supervising their child's inhaler use. Additionally, the unintended consequence of young people feeling less inclined to take responsibility and perhaps reverting to more ad-hoc use once the SI was gone suggests that young people ultimately remain dependent on their healthcare professional. The extent to which the SI promotes the aims of the patient empowerment agenda and the increased drive within the NHS for patients to take responsibility for their own self-care (NHS Choices, 2012b) is therefore questionable.

4.3 Limitations

Having summarised the results and considered how they relate and contribute to the literature, it is now important to reflect on some of the limitations to the study:

4.3.1. Sample

4.3.1.1. Absence of male caregivers

Within the current sample there was an absence of male caregivers. During recruitment very few male caregivers were identified, with the majority of young people attending hospital and clinic appointments with female caregivers. Researchers have stressed that important and meaningful findings can emerge when fathers are included in research designs (Phares, Lopez, Fields, Kamboukos & Duhig, 2005). However, the absence from the hospital setting and from the current research study is not surprising. Research has previously acknowledged the scarcity of fathers in clinical and paediatric setting and this under-representation poses a challenge to researchers recruiting fathers

(Costigan & Cox, 2001, Duhig, Phares, & Birkeland, 2002, Phares, 1992, Quittner & DiGirolamo, 1998, Seiffge-Krenke, 2002). I would have been interested to have heard more about the views of male caregivers and wonder what different perspectives this may have brought to the findings. Participants did at times share the views of absent male figures, and I encouraged participants to share with me any conversations they'd had and the views of absent family members regarding the SI.

4.3.1.2. Restricting the findings to the problematic severe asthma population

All participants recruited were viewed as having PSA. However only 5% of the childhood asthma population is estimated to have PSA (Lang et al., 2008). The issues and experiences this small population experience are therefore likely to be qualitatively different to the experiences of the other 95% of children whose asthma is less severe. The findings of the current study therefore need to be considered carefully and any attempts to generalise should be done so with caution.

4.3.2. Study Design and Data Collection

4.3.2.1. Research setting

When designing the study, I decided to carry out the interviews at RBH. This decision was made for pragmatic reasons, such as time and funding limitations, which amongst other things, would have made it difficult for me to travel to carry out interviews in participants' home. Furthermore it seemed excessive to ask participants, who had already travelled from their homes to RBH for their appointments, to travel further to carry out interviews in other locations (e.g. at my university). Additionally, the Research and Development team at RBH required a member of the paediatric asthma team to introduce the study and myself to participants. Whilst I made considerable effort to communicate my independence from RBH and participants' right to confidentiality, I was mindful that this process may have influenced how some participants viewed me; possibly as connected to the medical team. Consequently I wondered whether any of the participants who declined to take part might have done so as they did not feel comfortable sharing their views about aspects of their experiences at RBH with me. It is also possible that this may have influenced the responses of

those who did participate, potentially increasing the likelihood of them giving socially desirable answers.

4.3.2.2. One-off interviews

The decision to carry out one-off interviews with participants can also be viewed as a limitation of this study. Chamberlain (2012) criticises the use of one-off interviews with participants in qualitative research, suggesting they limit the scope, depth and potential of research, viewing participants as nothing more than data sources. Instead, he advocates for researchers to use more than one interview with each participant, arguing that this would deepen rapport, expanding the scope and depth of data collected and allow opportunities for reflection by both researcher and participant. When listening to the interview recordings I often wanted to speak again with participants and hear more about their experiences at different times. With all participants being interviewed at the appointment where they were due to return the SI, the insight I could achieve into their experiences stopped there. This means that what happened next for participants e.g. their experience of receiving feedback on the SI from healthcare professionals remains unknown and any reflections on the long-term implications of the SI are hypothetical.

4.3.2.3. Joint young person and caregiver interviews

Another unanticipated issue in the current study relates to the request from two sets of young people and their caregivers (Aysha and Samia /Gary and Estelle) to be interviewed at the same time. As discussed earlier, I considered this at the time with my university supervisor and we agreed that during these interviews I would pay extra attention to the interactions between the young person and caregiver and record my observations in my reflexive journal. I considered these interactions again during analysis. Through attending to these interviews in this way, I was aware that there were occasions when the caregivers would answer on behalf of the young people and vice versa and at other times there was a dialogue between them. This meant that in contrast to other participants, I was not solely hearing about a young person or caregiver's experience of the SI, I was hearing about their shared experience. I was therefore concerned that neither participant's view would be fully represented in

their joint account, possibly leading to salient information being lost. I was also aware that there might be things that Aysha and Gary did not want to say in front of their mothers and vice versa. Furthermore I was concerned that if either participant's voice was more dominant during the joint interviews, the view of the quieter participant could be subjugated. However, the shared experiences described were extremely rich in detail, with both dyads adding to and at times contradicting what each other had said. Moreover, for Aysha, as one of the quietest participants, the presence of her mother arguably helped her to be able to say more.

4.3.2.4. Focus group dynamics

The decision to carry out a focus group with staff also presented several challenges, particularly around attending to the group dynamic, in addition to listening to and making note of the content of their discussions. I was mindful that within the group there were various professionals with different histories, including senior doctors, long-serving nurses and newly employed nurses. This raised issues of power and authority and I wondered whether some group members may have felt less able to share any conflicting views they may have had with other group members. With healthcare professional views having already been thoroughly investigated within the literature concerning electronic adherence assessment, often via interviews, the experiences of healthcare professionals are not limited. The decision to carry out a focus group therefore, although raising some dilemmas, is not an overarching concern.

4.3.3. Research Journey

As a novice qualitative researcher, carrying out this research has developed my knowledge and confidence in carrying qualitative research in a healthcare setting and some of the issues this raises. For instance during the earlier interviews I would often stick more closely to the interview schedule through fear of missing questions. Transcribing each interview as I went along helped develop my confidence in asking questions in different ways and in being able to follow the accounts of each participant rather than being led by the order of the interview schedule. Consequently my earlier interviews were shorter and arguably less rich then those completed later on.

Additionally, carrying out research in a busy hospital environment with some participants having been admitted as inpatients for routine assessment whilst others attended scheduled outpatient appointments, meant that interviews were carried out in two different settings; these being the hospital bedside and outpatient clinic rooms. As well as presenting logistical challenges such as trying to limit ward noise when carrying out interviews bedside and time pressures when interviewing in the clinic environment, it also raised ethical pressures around ensuring confidentiality. I often had to be very mindful of stopping interviews quickly and at times cutting participants off when members of staff disturbed us. Consequently my own and participants' trains of thought were at times disrupted, potentially losing salient information.

Finally, having previously been a more experienced quantitative researcher, the process of conducting qualitative research has made me more alert to the pros and cons of the two approaches. Qualitative research is often compared negatively to quantitative research due to its small sample sizes, increased researcher bias and challenges in establishing validity (Mays & Pope, 1995). However, given that the current study was carried out in an emerging field, where limited research findings were available, the qualitative approach taken, whilst with its limitations, generated a valuable and in-depth understanding into participants' experiences. This would arguably have been lost were a more quantitative approach employed (Flick, 2009).

4.4. The Role of The Researcher

The role of the researcher in qualitative research has been widely acknowledged. Many authors agree that any notion of objectivity is problematic for the qualitative researcher, as their experiences, values and beliefs amongst other factors will inevitably play an integral role in the way in which their research is conducted and reported (Nightingale & Cromby, 1999, Patton, 1990, Spencer & Ritchie, 2012, Willig, 2013). There is therefore a call for reflexivity within the qualitative research field. In line with this thinking, I have tried to share some of the reasons why I have found the results I did and why they have been reported in the way they have below.

4.4.1. Reflections on Research

As I discussed in my Method, I am a young, white British, female who has been fortunate enough to experience relatively good health during my lifetime. My personal experiences of interacting with healthcare professionals are typically of visiting a doctor or nurse for the purpose of seeking their expertise on a given health concern. I also work as a trainee clinical psychologist, a position which has afforded me several opportunities to work alongside doctors and nurses in healthcare settings. My professional experiences have widened my view of healthcare professionals, as people with their own work and life pressures, values and subjective experiences. I also identify myself as a critical realist. This epistemological position fits with my view of healthcare professionals as being able to offer medical treatment for "real" medical conditions such as asthma. However, it also captures my view that peoples' descriptions of receiving healthcare interventions such as the SI can be influenced by their own and others values, preferences and experiences.

In reflecting on my own experiences and view of the world, I was struck at times by the ways my own taken for granted assumptions about asthma, healthcare professionals, medical care etc. influenced the way I approached certain tasks whilst carrying out this research. For instance when interviewing the young people I would often start with questions related to their asthma history such as "can you tell me how you found out that you had asthma?". This question was influenced by my own view that whilst asthma is a "real" health condition, children living with it may not realise they have it until someone tells them/ they are old enough to understand what it is. However, at times my wording confused young people and they would ask for more clarity or reply by saying something like "I've just always had it". On reflection I wondered whether these interactions and other similar ones might have been influenced by my own assumptions about asthma and my view of the world. In order to keep these ideas alive throughout the research process I kept a reflexive journal (see appendix 2 for examples).

In writing this report, I also became aware of the impact this research had on me. I feel it has helped me reflect on my clinical practice, especially following

the transcription process where I became aware of my tendency to ask two or three questions in one go, or to try and "help out" participants by giving them a few ideas, when it would have been less leading to have waited and see what they came up with on their own.

4.5 Evaluating the Quality of Qualitative Research

The importance of evaluating qualitative research has become increasingly recognised (Willig, 2009). Yet the idea of evaluating the quality of qualitative research is still contested by some, with concerns raised about the applicability of standardised assessment principles such as validity and reliability to qualitative research methods (Reicher, 2000). However, many have sought to evaluate the quality of qualitative research in less traditional ways (Guba & Lincoln, 1981, Mays & Pope, 2000, Yardley, 2000). More recently Spencer and Ritchie (2012) have brought together some of the recurring principles that underpin the concept of quality in order to evaluate all qualitative research, including the critical realist TA adopted for this study. These include contribution, credibility and rigour.

4.5.1. Contribution

Contribution refers broadly to the value and relevance of research evidence, in particular beyond the purpose of the study. This may be to theory, policy, practice, etc. Regardless of which, it requires an enhancement of existing understanding (Spencer & Ritchie, 2012). I have therefore summarised and evaluated the results and considered how these may relate to the existing research. The limitations of the study have also been described and I consider possible implications of the findings shortly.

4.5.2. Credibility

Credibility has been likened to interpretive validity and relates to the defensibility and plausibility of claims made by the research, not just in the believability of findings but also the ability to see how conclusions have been reached (Spencer & Ritchie, 2012). Descriptive accounts of raw data and interpretive accounts showing how data is put together to develop explanations,

reach conclusions and generate hypotheses and theories can support the credibility of research (Miles & Huberman, 1994). Some authors have also recommended the process of triangulation be used to promote credibility. Here different methods and data sources would be used during the research, in addition to peer review and respondent validation (Spencer & Richie, 2012). I used a thorough transcription process during the research to ensure that the interviews were represented as accurately as possible. In addition, numerous extracts have been presented within the Results. The multi-perspective nature of this research also provides support for the credibility of the study. Bearing in mind the critical realist approach I adopted and the social constructionist ideas this holds in mind, I did not ask anyone else to analyse the data or assess inter-rater reliability. I did, however, share a draft of my Results and the relevant appendices with my supervisor.

4.5.3. Rigour

Rigour is associated with methodological validity. It involves the careful documentation of the research process, and is linked to the appropriate research decisions, dependability of evidence and general safe conduct of the research (Spencer & Ritchie, 2012). The rigour of a study can be evaluated through a consideration of the following:

4.5.3.1. Reflexivity

Spencer and Ritchie (2012) encourage qualitative researchers to explore and reflect on the ways their role in the research and the ways their values, beliefs and experiences may influence their responses and impact on the study outcomes. I have considered this in both my Method and Discussion chapters.

4.5.3.2. Audibility

Emphasis has also been placed on the importance of documenting and reporting how and why certain decisions were made, particularly in regards to the analysis of results (Spencer & Ritchie, 2012). I have therefore documented and described many of my research decisions during the Method chapter and

have provided examples of raw data in the Results chapter. I have also included several appendices to further evidence this (see appendices 18-25).

4.5.3.3. Defensibility

Spencer and Ritchie (2012) also recommend that researchers provide a clear logic and rationale for their choice of method, design and analysis, as well as decisions around sample and consider how these helped the study to meet its aims. These have been given in both the Introduction and the Method and then critiqued in this chapter.

4.6. Implications of Findings

4.6.1. Implications for Healthcare Professionals, Services and Organisations

This research has highlighted the need for healthcare professionals to engage in a shared decision-making process with their patients when introducing healthcare interventions. This requires healthcare professionals to acknowledge and accept that their patients' priorities, preferences and goals may not always mirror their own professional view. This process is particularly important when thinking about children and young people, where other family members are likely to be involved in the healthcare relationship and may not be motivated by the same priorities as the child. Here the process of shared decision-making will involve healthcare professionals openly exploring the potentially different (and possibly conflicting) priorities their young people and family members may have for engaging with particular healthcare interventions and reaching a joint agreement about the most appropriate way forward. For some this may mean that healthcare professionals do not introduce a particular healthcare intervention, whereas for others they may do so. This would be important in the case of the SI, where there were mixed views and different priorities.

This suggestion is neither new nor radical and previous research has already highlighted the benefits of engaging patients in shared decision-making (Wilson et al., 2010). Yet at present, there is still ambivalence amongst healthcare professionals about their ability to practice in this way (Segal, 2007). One need

not look far to find stories in the media about healthcare professionals neglecting their duty of care or the advertisements of legal companies offering their services in medical negligence claims. For the healthcare professionals in this study whose main priority was to promote the health of their patients, how easy would it be to allow a patient to not engage in a particular healthcare intervention, when within the wider system they too have their practice monitored? In the case of the SI, where there is increasing pressure for healthcare professionals to accurately assess their patients' adherence levels (Bender et al., 2000), healthcare professionals would arguably need to feel supported by their service and organisation to work in this way.

4.6.2. Implications For Future Research

4.6.2.1. Sample

Future research may wish to explore the experiences of a wider sample in order to generalise the findings to other populations. This may include promoting the involvement of fathers; by focusing more effort on this at the recruitment stage, possibly contacting fathers directly or hearing their views in different ways, e.g. through questionnaires or telephone interviews. It may also include exploring the views of a child population to explore whether the introduction of the SI raises similar or different issues in the younger age group. This would most likely require more creative methods of data collection to the semi-structured interview. Finally the views of young people living with less severe forms of asthma may offer some different and insightful perspectives on the SI to those raised in the current sample.

4.6.2.2. Design

Future research could also adopt different research designs to further answer the research questions posed. As a relatively short-term piece of research, the current study cannot speak definitively to the long-term impact of SI technology on promoting young people's ability to take responsibility for their self-care and it may be that with its continued use, young people could take over some of the responsibilities involved with using the SI. Future research could adopt a longitudinal design to assess this further. Quantitative designs could also be

employed to measure whether the SI influenced young people's adherence, and whether there were differences in the experiences of those whose adherence to ICS was greater and those whose adherence was lower. Future research could also seek to recruit and meet with participants away from the hospital setting to address issues around the researcher's independence from the hospital setting. Finally, research could draw on Chamberlain's (2012) recommendations for multiple interviews to be carried out at various stages e.g. following the introduction of the SI, after feedback on the SI results are given, six months later. Whilst more time consuming for the researcher and participants, this approach would offer greater insight into the experiences of participants.

4.6.2.3. Analysis

Carrying out a critical realist TA, offered an accessible and flexible framework to explore the data obtained from participants. However, there were times whilst carrying out this analysis when I was particularly interested in how participants had talked about their experiences, especially in relation to features of the healthcare relationship and how they positioned themselves in this relationship. With this in mind, a discursive method of analysis[10] may have offered deeper insights into the more socially produced elements of participants' realities (Willig, 2013). One possibility for future research would be to audio-record the healthcare appointments where the SI was discussed. These interactions could then be analysed; with the ways participants used language to talk about the smart-inhaler being explored in more detail.

Each of the possibilities for future research described could add valuable insights to this emerging area.

4.7. Conclusions

The aim of this study was to explore young people with asthma, their caregivers and healthcare professionals' experiences of having adherence to ICS assessed through the SI. Using semi-structured interviews and a focus group

[10] See Appendix 1 for more information on discourse analysis.

offered a helpful means to explore these experiences. The use of TA to analyse experiences provided a useful framework with which themes could be identified and placed in the context of current literature. Given the limited amount of published studies, the current findings are therefore able to offer some indication of participants' experiences of the use of electronic adherence assessment and telemonitoring equipment in NHS services. However it is acknowledged that further research employing different methods of recruitment, designs and analysis is warranted.

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6. APPENDICES

List of Appendices

Appendix 1 – Choosing a Method

I considered several approaches when selecting a method including content analysis, interpretative phenomenological analysis and discourse analysis, before choosing to carry out a thematic analysis. I will give some information on the other forms of analysis I considered and why I did not choose them in this instance.

Content analysis [CA] offers a systematic and objective means of describing and quantifying phenomena and allows a researcher to distill words into fewer content related categories. It is assumed that when classified into the same categories, words, phrases, etc. will share the same meaning (Elo & Kyngas, 2007). Was the current research seeking to quantify and categorise participants' experiences of using the smart-inhaler numerically, CA may have offered one possibility for doing so. However with the current research aims in mind, this method would likely have distilled the multiple views and experiences of participants too extensively, limiting the amount of insight that could be achieved into participants' experiences.

Interpretative Phenomenological Analysis [IPA] aims to "explore in detail how participants are making sense of their personal and social world" (Smith & Osborn, 2008, p.53), whilst also acknowledging the role of the researcher and their relationship with participants (Willig, 2013). IPA would therefore have offered one possible method for exploring participants' experiences. However as this study focused on the broader investigation of participants' experiences with smart-inhalers and factors that influenced this, rather than focusing on interpreting how participants made sense of their experiences, I decided that TA was more in line with the study's research aims then IPA.

Discourse Analysis [DA] focuses on the role of language in participants' construction of reality. It is concerned with "what people do with language and it emphasises the performance qualities of discourse" (Willig, 2013, p.117). DA involves analysing naturally occurring text and talk and requires researchers to look at the language used and ask different questions about it (Hepburn & Wiggins, 2005). Had the current study been aiming to explore how participants had talked about their experiences, especially in relation to features of the healthcare relationship and how they positioned themselves in this relationship, DA may have offered an appropriate method. However, to answer the research questions posed in the current study, TA offered a more suitable method for exploring participants' experiences of the smart-inhaler.

Appendix 2 – Sample Extracts from My Reflexive Journal

Thoughts Following Interview with Gary & Estelle:

Prior to the interview starting Gary spoke about being watched by big brother in front of the nurse who'd introduced us. I thought this was interesting and I wondered if this would come across in his interview. During the interview Gary spoke a lot about the smart-inhaler as being like a lie detector, as did his mum Estelle and this promoted a sense of the smart-inhaler being used almost "legally" to catch him out (he said several times about not being able to argue his "innocence"). Similarly to my earlier interview with Samia, Estelle raised the idea of portability and the introduction of the smart-inhaler meaning less time in hospital. This got me thinking about the process of joint interviews (these being the only two where young people and caregivers interviewed together and I wondered whether both caregivers had felt a need to promote the positive aspects of the smart-inhaler whilst in the presence of their children.

Other thoughts I had during/after the interview related to the long-term implications of the smart-inhaler. This was something the healthcare professionals focus group had raised in terms of wanting to know the smart-inhaler impacted young people's adherence behaviour/ asthma control once the inhaler was taken away and in previous interviews participants had brought up this idea of the smart-inhaler being used long term and then it feeling more normal and part of health care. This made me think about when the smart-inhaler is taken away and is only has a short-term presence, it may feel a bit strange and "catchy outy" rather than part of routine health care.

Additionally this interview got me thinking about the impact of the smart-inhaler on relationships with the doctors and nurses and I thought it was interesting that even when there were strong feelings about the smart-inhaler (such as in Gary's case), that participants did not seem to think it affected their relationships when asked directly (despite implying through their responses that it had).

Thoughts Following Interview with Isla:

As my oldest young person so far I was aware that Isla appeared a bit more open to thinking more widely about the process of adherence monitoring and I was able to help her to generate ideas about what would have made the process more effective.

As an interview carried out separately, I was also aware that there were not any substantial differences in the content of Isla's answers compared to the young people who had asked to do the interviews jointly with their caregivers. For instance in response to the question "is parents involvement helpful?" Isla said similar to those who'd been interviewed with their mums present, acknowledging that it is a bit annoying, but nothing more. This was reassuring as I was worried that other young people who had been interviewed in their parent's presence may have not wanted to say more in front of them. Additionally Isla later alluded to the idea of her parents being allies somewhat when healthcare professionals question her about adherence.

The way Isla spoke about the pill box and others checking it also made me think about some of the ways adherence monitoring is taking place less formally anyway with parents and it reminded me of earlier interviews for instance with Theo and Jessica; having the school log had brought that issue up and given them proof that he was taking his inhaler.

I was also able to ask questions hypothetically/prospectively which I felt I hadn't done as much previously. However I was mindful that this was not a “lived experience”. Finally I was also mindful during my interview with Isla that I may be “giving ideas” when she said she didn’t know. In my efforts not to lead her, I therefore endeavoured to give a range of ideas e.g. were you worried about getting in trouble, did it not bother you, was it helpful.

Appendix 3 – Young Person Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator
Amy Stewart
u1235007@uel.ac.uk

My name is Amy and I am carrying out some research about young people's views of smart-inhalers for my university studies. I have put together this letter to tell you more about this research and to help you think about whether you would like to be part of it.

Research Title

Experiences of Adherence Assessment in Asthma

Research Description

I am interested in what young people think about smart-inhalers.

I would like to ask you what you think about the smart-inhaler you were given at one of your appointments at the Royal Brompton Hospital.

I'd like to hear what you think is good about the smart-inhaler and what you think is not so good about it. I'd like to know why you think you have it and how you were told about it. I'd also like to hear about your experiences of using it over the last few months.

There are no right or wrong answers. I just want to hear what you think.

If you would be happy to talk to me about the smart-inhaler then I will meet with you at the Royal Brompton Hospital when you bring the smart-inhaler back. We will meet for around 30-40 minutes in a private room in the hospital.

As I will be interviewing a lot of young people about the smart-inhaler I would like to be able to record our conversation on a voice recorder. This will help me think about all the young people's views in more detail and will help me when I write up the research for my studies.

Confidentiality of the Data

Everything we talk about when we meet will be treated confidentially. This means that our conversation is private. The only time I will tell anyone what we have talked about is if I am worried about your safety or someone else's. I would let you know if I was going to do this.

Only I will be able to listen to the recording of our conversation. I will type up this recording, but I will do this without including your name or anyone else's, so that you cannot be identified and neither can anyone else you might mention. This means that things you say might be used as examples of young people's views on smart-inhalers when I write my research up but nobody would be able to tell that it was you who had said it.

The recording of our conversation and the typed up copy will be kept safe in a secure place that only I can access.

Any information that includes your name, date of birth or contact details will also be kept in this secure place and will not be seen by anyone else.

The recording of our conversation will be destroyed as soon as the research is finished.

I will keep copies of our typed up conversation for three years but this will still be kept anonymously so that you cannot be identified from it. This is in case I want to do more with the research.

Location

I will meet with you at the Royal Brompton Hospital when you bring the smart-inhaler back. We will meet for around 30-40 minutes in a private room in the hospital.

Disclaimer

You do no have to take part in my research and should not feel pressured by anyone to. If you change your mind about talking to me after saying yes then that is okay and you can decide not to meet me without having to give a reason. This will not affect your care at the hospital.

If you would like to ask me any questions please contact me through the email address at the start of this letter.

If you would like to meet with me to tell me what you think about the smart-inhaler then please fill in your details on the assent form. (I will give you a copy of this).

Thank you

Amy Stewart

Appendix 4 – Caregiver Information Sheet on Behalf of the Young Person

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator
Amy Stewart
u1235007@uel.ac.uk

My name is Amy and I am carrying out some research about young people's views of smart-inhalers for my university studies. I have put together this letter to tell you more about this research and to help you think about whether you would like to be part of it.

Research Title

Experiences of Adherence Assessment in Asthma

Research Description

I am interested in what young people think about smart-inhalers.

I would like to ask you what you think about the smart-inhaler you were given at one of your appointments at the Royal Brompton Hospital.

I'd like to hear what you think is good about the smart-inhaler and what you think is not so good about it. I'd like to know why you think you have it and how you were told about it. I'd also like to hear about your experiences of using it over the last few months.

There are no right or wrong answers. I just want to hear what you think.

If you would be happy to talk to me about the smart-inhaler then I will meet with you at the Royal Brompton Hospital when you bring the smart-inhaler back. We will meet for around 30-40 minutes in a private room in the hospital.

As I will be interviewing a lot of young people about the smart-inhaler I would like to be able to record our conversation on a voice recorder. This will help me think about all the young people's views in more detail and will help me when I write up the research for my studies.

Confidentiality of the Data

Everything we talk about when we meet will be treated confidentially. This means that our conversation is private. The only time I will tell anyone what we have talked about is if I am worried about your safety or someone else's. I would let you know if I was going to do this.

Only I will be able to listen to the recording of our conversation. I will type up this recording, but I will do this without including your name or anyone else's, so that you cannot be identified and neither can anyone else you might mention. This means that things you say might be used as examples of young people's views on smart-inhalers when I write my research up but nobody would be able to tell that it was you who had said it.

The recording of our conversation and the typed up copy will be kept safe in a secure place that only I can access.

Any information that includes your name, date of birth or contact details will also be kept in this secure place and will not be seen by anyone else.

The recording of our conversation will be destroyed as soon as the research is finished.

I will keep copies of our typed up conversation for three years but this will still be kept anonymously so that you cannot be identified from it. This is in case I want to do more with the research.

Location

I will meet with you at the Royal Brompton Hospital when you bring the smart-inhaler back. We will meet for around 30-40 minutes in a private room in the hospital.

Disclaimer

You do no have to take part in my research and should not feel pressured by anyone to. If you change your mind about talking to me after saying yes then that is okay and you can decide not to meet me without having to give a reason. This will not affect your care at the hospital.

If you would like to ask me any questions please contact me through the email address at the start of this letter.

If you would like to meet with me to tell me what you think about the smart-inhaler then please fill in your details on the assent form. (I will give you a copy of this).

Thank you

Amy Stewart

Appendix 5 – Caregiver Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator
Amy Stewart
u1235007@uel.ac.uk

Consent to Participate in a Research Study
The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in my research study. The study is being conducted as part of my Doctorate in Clinical Psychology at the University of East London.

Project Title
Experiences of Adherence Assessment in Asthma

Project Description

- This research project aims to understand different experiences of adherence assessment. I am interested **in your thoughts and experiences of the smart-inhaler** that a healthcare professional within the Asthma team at The Royal Brompton Hospital has **issued your son/daughter/young person in your care.**
- If you decide to participate, you will be invited to share your experiences through an interview with myself. This interview will last for approximately 20 minutes and you will be asked to talk about how your son/daughter/young person you care for was introduced to the smart-inhaler, your thoughts about the smart-inhaler and how you and your son/daughter /young person you care for are finding the smart-inhaler. Interviews will be audio-recorded and transcribed for analysis.

Confidentiality of the Data

- Any information you choose to share with me will be will be treated confidentially and all names and identifying references (e.g. a name of a place) will be removed/anonymised from the transcriptions of interviews (that may be read by my supervisor or examiners) and for write up/dissemination purposes.
- All information collected will be kept in a safe and secure place that only the researcher has access to. Personal information will not be shared with anyone else.
- All audio recordings will be destroyed at the end of the study, however electronic copies of anonymised transcripts will be kept for 3 years for possible further development of the research project.

Location

- Interviews will be carried out face to face at The Royal Brompton Hospital.
- This interview will take place in a private setting during one of your regular clinic appointments and will last approximately 20 minutes.

Disclaimer

- You are not obliged to take part in this study and should not feel coerced.

- You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason.
- Should you withdraw from the research after you have completed your interview, the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr Ken Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4576 K.N.Gannon@uel.ac.uk]

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Amy Stewart
Trainee Clinical Psychologist

Appendix 6 – Young Person Assent Form
UNIVERSITY OF EAST LONDON

Experiences of Adherence Assessment in Asthma

I have read the information letter about the research and have been given a copy to keep.

The research has been explained to me, and I have had the chance to talk about the research and ask any questions I may have.

I understand what I will be doing.

I understand that my information and the conversations I have with Amy are confidential.

It has been explained to me what will happen once the research has finished.

I know I can change my mind about meeting Amy at any time without having a reason. I understand this wont affect my care at the hospital.

I would like to take part in Amy's research project.

Assent to participate in a research study

Name

……

Signature

……..

Researcher's Name

……..

Researcher's Signature

……

Date: ……..……..

Appendix 7 – Caregiver Consent Form on Behalf of Young Person

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Experiences of Adherence Assessment in Asthma

- I have the read the information sheet relating to the above research study and have been given a copy to keep.
- The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which my son/daughter will be involved have been explained to me.
- I understand my son/daughter's/young person in my care's involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.
- I understand that relevant data collected during the study, may be looked at by individuals from the University of East London, from regulatory authorities or from NHS Trusts, where it is relevant to my taking part this research. I give permission for these individuals to have access to my son/daughter's/young person in my care's data.
- I understand that you will contact the GP of my son/daughter/young person I care for to inform them of their participation in the research.
- I hereby freely and fully consent to my son/daughter/young person in my care participating in the study, which has been fully explained to me and them.
- Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself or my son/daughter/young person in my care and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher].

Participant's Name (BLOCK CAPITALS)
……..

Participant's Signature
……..

Researcher's Name (BLOCK CAPITALS)
……..

Researcher's Signature
……
Date: ……..

Appendix 8 – Caregiver Consent Form
UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Experiences of Adherence Assessment in Asthma

- I have the read the information sheet relating to the above research study and have been given a copy to keep.

- The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

- I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

- I understand that relevant data collected during the study, may be looked at by individuals from the University of East London, from regulatory authorities or from NHS Trusts, where it is relevant to my taking part this research. I give permission for these individuals to have access to my data.

- I hereby freely and fully consent to participate in the study, which has been fully explained to me.

- Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher].

Participant's Name (BLOCK CAPITALS)

……

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……..

Researcher's Signature

……

Date: ……..…

Appendix 9 – Healthcare Professional Information Sheet

UNIVERSITY OF EAST LONDON
School of Psychology
Stratford Campus
Water Lane
London E15 4LZ

The Principal Investigator
Amy Stewart
u1235007@uel.ac.uk

Consent to Participate in a Research Study
The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in my research study. The study is being conducted as part of my Doctorate in Clinical Psychology at the University of East London.

Project Title
Experiences of Adherence Assessment in Asthma

Project Description

- This research project aims to understand different experiences of adherence assessment. I am interested in your experiences of using the smart-inhaler in your clinical practice within the Asthma team at The Royal Brompton Hospital.
- If you decide to participate, you will be invited to share your experiences through a focus group facilitated by myself, where your other colleagues who use the smart-inhaler will also be present (and sharing their views). This focus group will last for approximately 30 minutes and you will be asked to share your thoughts regarding the smart-inhaler.

Confidentiality of the Data

- Any information you choose to share with me will be will be treated confidentially and all names and identifying references (e.g. a name of a place) will be removed/anonymised from the transcriptions of the focus group (that may be read by my university supervisor or examiners) and for write up/dissemination purposes.
- All information collected will be kept in a safe and secure place that only the researcher has access to. Personal information will not be shared with anyone else.
- Anonymised notes made during the focus group will be kept for 3 years for possible further development of the research project.

Location

- The focus group will be carried out face to face at The Royal Brompton Hospital.

Disclaimer

- You are not obliged to take part in this study and should not feel coerced.
- You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason.
- Should you withdraw from the research after you have completed your interview, the researcher reserves the right to use your anonymised data in the write-up of the study and any further analysis that may be conducted by the researcher.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact the study's supervisor Dr Ken Gannon, School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4576 K.N.Gannon@uel.ac.uk]

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Tel: 020 8223 4493. Email: m.finn@uel.ac.uk)

Thank you in anticipation.

Yours sincerely,

Amy Stewart

Trainee Clinical Psychologist

Appendix 10 – Healthcare Professional Consent Form
UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Experiences of Adherence Assessment in Asthma

- I have the read the information sheet relating to the above research study and have been given a copy to keep.
- The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.
- I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.
- I understand that relevant data collected during the study, may be looked at by individuals from the University of East London, from regulatory authorities or from NHS Trusts, where it is relevant to my taking part this research. I give permission for these individuals to have access to my data.
- I hereby freely and fully consent to participate in the study, which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.
- I also understand that should I withdraw after the focus group is complete, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher].

Participant's Name (BLOCK CAPITALS)

……..

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……..

Researcher's Signature

……

Date: ……..……

Appendix 11 – Young Person Interview Schedule

Gender: M/F Age:

History of asthma, medical treatments, management/self care

1. Can you tell me about your asthma?

PROMPTS: How long have you had asthma? Who told you about it? What did they say? How does it affect you? What do you think about it (asthma)?

2. How have the RBH asthma team/ other doctors/nurses treated your asthma?

PROMPTS: what treatments/medicines/ care have they given you up to now? How do they explain things to you?
FOLLOW UP: What do you think about that/them? PROMPTS: helpful/unhelpful, useful/not useful etc.

3. How do you look after your asthma? / What sort of things do you have to do to look after yourself with your asthma?

PROMPTS: Do you have to take your inhaler at certain times? If so, when? How do you remember to? Do you have to avoid certain things?

4. Does anyone in your family help you with your asthma, if so who and how?

PROMPTS: what do they do to help, is that always helpful or not, how does it make you feel? What do you think about that?

Smart Inhaler

5. You were given a smart-inhaler at your last visit; can you tell me about how you got it?

PROMPTS: How did you get it? Did someone explain what it was for? Who? What did they say?

6. Why do you think the doctor/nurse gave it you?

PROMPTS: did they say it would remind you to take it, did they say it would help them see how you use it?
FOLLOW UP: What do you think about that?

7. What do you think the smart-inhaler is for?

PROMPTS: How is the smart-inhaler different to your other inhalers?

8. What do you think your parent/s/caregiver thinks the smart-inhaler is for?

PROMPTS: Have you spoken with them about it, what did they say?

9. You've had the smart-inhaler for about 2 months now, how did you find that? How did you use it?
FOLLOW UP: Ask for examples of when, where and if not why. How was this different to before?

10. Who was in charge of the smart-inhaler while you had it?
FOLLOW UP: Why? How? Examples?

11. Has the smart-inhaler helped with the control of your asthma? How/Why?

12. Can you tell me about any ways the smart-inhaler helps you/or parent take care/responsibility for your asthma? Or any ways it makes this harder?

13. What do you think about your doctor/nurse being able to use the smart-inhaler to see when you are taking your medication?
FOLLOW UP: Has this changed what you think about your doctor/nurse? Why?

Appendix 12 – Caregiver Interview Schedule
Gender: M/F Relation to young person:

Smart Inhaler

1. Your son/daughter was given a smart-inhaler at their last visit; can you tell me about how this came about?
PROMPTS: How did they get it? Did someone explain what it was for? Who? What did they say?

2. Why do you think the doctor/nurse gave it to them?
PROMPTS: did they say it would remind your son/daughter to take their inhaler, did they say it would help them see how your son/daughter uses it?
FOLLOW UP: What do you think about that?

3. What do you think the smart-inhaler is for?
PROMPTS: How is the smart-inhaler different to other inhalers?

4. What do you think your son/daughter thinks the smart-inhaler is for?
PROMPTS: Have you spoken with them about it, what did they say?

5. Your son/daughter has had the smart-inhaler for about 2 months now, how has that been? How did they use it?
FOLLOW UP: Ask for examples of when, where and if not why. How was this different to before?

6. Who was in charge of the smart-inhaler during this time?
FOLLOW UP: Why? How? Examples?

7. Has the smart-inhaler helped with the control of your son/daughter's asthma? How/Why?

8. Can you tell me about any ways the smart-inhaler helps your son/ daughter/or yourself take care/responsibility for the asthma? Or any ways it makes this harder?

9. What do you think about your doctor/nurse being able to use the smart-inhaler to see when your son/daughter is taking their medication?
FOLLOW UP: Has this changed what you think about your doctor/nurse? Why?

Appendix 13 – Healthcare Professional Focus Group Schedule

1. How is the smart-inhaler used in your service/ in your clinical practice?

2. How do you explain/introduce the smart-inhaler to patients/families?

3. What do you think are the benefits to your patients of using the smart-inhaler?

4. What do you think are the benefits to the staff/service of using the smart-inhaler?

5. What do you think are the disadvantages to your patients of using the smart-inhaler?

6. What do you think are the disadvantages to the staff/service of using the smart-inhaler?

7. How do you discuss the data collected from the smart-inhaler with patients?

8. Does the smart-inhaler help patients/families take responsibility for their healthcare or not? Why/How?

9. What impact (if any) has the smart-inhaler had on your relationships with patients/families? Examples?

Appendix 14 – School of Psychology Ethical Approval

SCHOOL OF PSYCHOLOGY
Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of East London
www.uel.ac.uk

School of Psychology

Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology

Appendix 15 – University of East London Ethical Approval
5 August 2014

Dear Amy,

Project Title:	**Experiences of Adherence Assessment in Asthma**
Researcher(s):	**Amy Stewart**
Principal Investigator:	**Amy Stewart**

I am writing to confirm that the application for the aforementioned NHS research study reference **14/LO/0732** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **05 August 2018**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NRES ethical approval and provide a reason why UREC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS ethical approval.

Please ensure you retain this ethics letter, as you may be required to provide evidence of ethical approval.

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

Yours sincerely,

Catherine Fieulleteau
Ethics Integrity Manager
For and on behalf of
Professor Neville Punchard
University Research Ethics Committee (UREC)
Research Ethics Office
Email: researchethics@uel.ac.uk

Appendix 16 – NHS Ethical Approval Documents

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Fulham
HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7816
Facsimile: 0161 625 7299

29 May 2014

Mrs Amy Stewart
Trainee Clinical Psychologist
Camden and Islington NHS FT Trust
4th Floor East Wing
St Pancras Hospital
St Pancras Way
NW1 0PE

Dear Mrs Stewart

Study title:	**Experiences of Adherence Assessment in Asthma**
REC reference:	**14/LO/0732**
IRAS project ID:	**151486**

The Research Ethics Committee reviewed the above application at the meeting held on 19 May 2014. Thank you for attending to discuss the application with Ms Louise Flemming.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Shehnaz Ishaq.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

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

1. The consent forms should be revised as follows:
   a. Insert the following mandatory statement 'I understand that relevant data collected during the study, may be looked at by individuals from (company name) from regulatory authorities or from NHS Trusts, where it is relevant

to my taking part this research. I give permission for these individuals to have access to my data.

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

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

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

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

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

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

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

Registration of Clinical Trials

All clinical trials (defined as the first four categories on question 2 of the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

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

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

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

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

Ethical review of research sites

NHS Sites

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

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study

The Committee asked you to describe the smart inhaler.

The Committee were informed that the smart inhaler was devised by a company called Nexus and is an attachment that fits onto the smart inhaler, which records when the dosage is taken by the patient.

The Committee noted the sample size was relatively small and questioned how the figure of 12 was decided upon.

It was explained that training had been conducted on qualitative research and within that training it was recommended that data saturation can be reached by that number, after 12 the amount of new information received can significantly drop off.

Recruitment arrangements and access to health information, and fair participant selection

The Committee asked you to talk through the recruitment procedure, and explain how participants would be identified.

It was confirmed participants who attend the clinic will already be under the care of the clinical team. When the smart inhaler is given to the patient the child and/or parent/carer will be advised that someone not from the clinical care team may wish to contact them about taking part in the study. If the child and/or parent/carer shows interest then the clinical nurse specialist will pass on those details to you and you will then contact the participant by telephone and introduce yourself and explain the study in more detail. If the participant is interested, you would arrange to meet them in 6-8 weeks when they are due to bring back the inhaler.

Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)

The Committee queried the severity of the asthma and whether the children could have other drugs or devices that may affect the outcome of the study.

You informed the Committee that the children are selected for the severity of the asthma, but one of the questions you were going to ask at the beginning of the study was about the asthma journey and how it had affected their lives/treatment etc.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee asked whether the children could have other co-morbidities apart of asthma.

It was confirmed they could have other co-morbidities but that you have very good clinical data collection on all the patients.

Informed consent process and the adequacy and completeness of participant information

The Committee questioned the consent process.

You confirmed the information sheet and consent form would be sent to participants in advance and participants are advised to bring it with them on the day of the clinic appointment, if they are happy to take part then consent would be taken at that point, you would be happy to give participants more time if they choose not to consent at that time point.

Suitability of supporting information

The Committee noted the feedback letter requested the interview schedule be piloted and it was queried whether this pilot had taken place.

It was confirmed that the schedule will be piloted and revised dependent on the responses given, but confirmed no further questions would be added just removed to make shorter in length.

Other general comments

The Committee asked who would be funding the study.

It was confirmed the study would be funded by the University of East London.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering letter on headed paper		16 April 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	1	03 April 2014
GP/consultant information sheets or letters	1	03 April 2014
Interview schedules or topic guides for participants	1 Draft Interview Schedule	03 April 2014
Other [Young Person Assent Form]	1	03 April 2014
Other [Final version of research proposal]	1	03 April 2014
Other [Feedback from University on original proposal]	1	03 April 2014
Participant information sheet (PIS) [Caregiver Information Sheet on Behalf of Young Person]	1	03 April 2014
Participant information sheet (PIS) [Caregiver Information Sheet]	1	03 April 2014
Participant information sheet (PIS) [Young Person Information Sheet]	1	03 April 2014
Participant information sheet (PIS) [Healthcare Provider Information Sheet]	1	03 April 2014
REC Application Form	3.5	03 April 2014
Participant consent form [Healthcare Provider Consent Form]	1	03 April 2014
Participant consent form [Caregiver Consent Form]	1	03 April 2014
Participant consent form [Caregiver Consent Form on Behalf of Young Person]	1	03 April 2014
Research protocol or project proposal	1	03 April 2014
Summary CV for Chief Investigator (CI)	Kenneth Gannon	16 April 2014
Summary CV for Chief Investigator (CI)	1 Amy Stewart	03 April 2014

Membership of the Committee

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

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

14/LO/0732	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

Yours sincerely

pp

Signed on behalf of:
Dr Charles Mackworth-Young
Chairman

E-mail: nrescommittee.london-fulham@nhs.net

Enclosures:	List of names and professions of members who were present at the meeting and those who submitted written comments
	"After ethical review – guidance for researchers"
Copy to:	Professor N A Punchard
	Mr Patrik Pettersson, Royal Brompton & Harefield NHS Foundation Trust

A Research Ethics Committee established by the Health Research Authority

NRES Committee London - Fulham

Attendance at Committee meeting on 19 May 2014

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Kanagasabai Ganeshaguru	Retired Scientist	Yes	
Dr Shaun Griffin	Director of Communications and Public Affairs	Yes	
The Rev'd Nigel Griffin	Parish Priest	Yes	
Dr Akil Jackson	Physician	Yes	
Mr David Leonard	Pharmacist	Yes	
Dr Charles Mackworth-Young	Physician (Chairman)	Yes	
Dr Colin Michie	Paediatrician	Yes	
Dr Frank Miskelly	Physician (Vice-Chairman)	Yes	
Dr Shirlony Morgan	Psychiatrist	No	
Lady Alexandra Roche	Lay Member	Yes	
Mrs Gillian Sichau	Occupational Therapist	Yes	
Mrs Katie Wilkinson	Clinical Trials Centre Manager	Yes	
Mrs Marney Williams	Lay Member	No	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Diane Catterall	REC Assistant

Written comments received from:

Name	*Position*
Mrs Marney Williams	Lay Member

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Fulham
HRA NRES Centre Manchester
Barlow House
3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7816
Facsimile: 0161 625 7299

03 June 2014

Mrs Amy Stewart
Trainee Clinical Psychologist
Camden and Islington NHS FT Trust
4th Floor East Wing
St Pancras Hospital
St Pancras Way
NW1 0PE

Dear Mrs Stewart

Study title: **Experiences of Adherence Assessment in Asthma**
REC reference: **14/LO/0732**
IRAS project ID: **151486**

Thank you for your letter of 30 May 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 29 May 2014

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant consent form [Caregiver Consent Form]	2	29 May 2014
Participant consent form [Caregiver Consent Form on Behalf of Young Person]	2	29 May 2014
Participant consent form [Healthcare Provider Consent Form]	2	29 May 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Covering letter on headed paper		16 April 2014
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	1	03 April 2014
GP/consultant information sheets or letters	1	03 April 2014
Interview schedules or topic guides for participants	1 Draft Interview	03 April 2014

	Schedule	
Other [Feedback from University on original proposal]	1	03 April 2014
Other [Young Person Assent Form]	1	03 April 2014
Other [Final version of research proposal]	1	03 April 2014
Participant consent form [Caregiver Consent Form on Behalf of Young Person]	2	29 May 2014
Participant consent form [Healthcare Provider Consent Form]	2	29 May 2014
Participant consent form [Caregiver Consent Form]	2	29 May 2014
Participant information sheet (PIS) [Young Person Information Sheet]	1	03 April 2014
Participant information sheet (PIS) [Caregiver Information Sheet]	1	03 April 2014
Participant information sheet (PIS) [Healthcare Provider Information Sheet]	1	03 April 2014
Participant information sheet (PIS) [Caregiver Information Sheet on Behalf of Young Person]	1	03 April 2014
REC Application Form	3.5	03 April 2014
Research protocol or project proposal	1	03 April 2014
Summary CV for Chief Investigator (CI)	1 Amy Stewart	03 April 2014
Summary CV for Chief Investigator (CI)	Kenneth Gannon	16 April 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/LO/0732 **Please quote this number on all correspondence**

Yours sincerely

Miss Diane Catterall
REC Assistant

E-mail: nrescommittee.london-fulham@nhs.net

Copy to: Professor N A Punchard

Mr Patrik Pettersson, Royal Brompton & Harefield NHS Foundation Trust

Appendix 17 – The Royal Brompton R & D Approval

Royal Brompton & Harefield NHS
NHS Foundation Trust

Royal Brompton & Harefield NHS Foundation Trust
Research Office
Chelsea Wing
Sydney Street
SW3 6NP
www.rbht.nhs.uk

Direct Line: 020 7 351 8121 ext. 2610
Email: a.cooper@rbht.nhs.uk

11th July 2014

Dr Louise Fleming
Honorary Consultant in Respiratory Paediatrics
Royal Brompton & Harefield NHS Trust
Sydney Street
London SW3 6NP

Dear Dr Fleming,

Project Title: Experiences of Adherence Assessment in Asthma
R&D Ref: 2014AT009B
REC Ref: 14/LO/0732
CSP Ref: N/A
Study Sponsor: The University of East London

Notification of RB&HFT NHS Management Permission for Research

Thank you for registering the above study with the Research Office. I am pleased to inform you that your study now has NHS Management Permission (previously know as R&D approval) and can commence at Royal Brompton & Harefield NHS Foundation Trust (RB&HFT).

NHS management permission for the above research study is granted on the basis that the study will be conducted as described in the protocol and in accordance with the supporting documentation submitted (listed below), and on the understanding that the study is conducted in accordance with the principles set out in the Research Governance Framework for Health and Social Care (April 2005, 2nd Edition, Department of Health (DoH)) and RB&HFT Policies and procedures.

Documents Reviewed	Version number	Date
Protocol	1.0	03/04/2014
Patient Information Sheet (PIS); young person information sheet	1.0	03/04/2014
Patient Information Sheet (PIS);caregiver information sheet	1.0	03/04/2014
Patient Information Sheet (PIS); healthcare provider information sheet	1.0	03/04/2014
Patient Information Sheet (PIS); caregiver information sheet on behalf of the young	1.0	03/04/2014

person		
Informed Consent Form (ICF); caregiver consent form	2.0	29/05/2014
Informed Consent Form (ICF); caregiver consent form on behalf of the young person	2.0	29/05/2014
Informed Consent Form (ICF); healthcare provider consent form	2.0	29/05/2014
GP Letter	1.0	03/04/2014

Study Amendments

It is the responsibility of the Principal Investigator (PI) to notify the Research Office of **all** study amendments or changes to the status of the projects including study suspension or premature termination.

Safety Reporting

The research Sponsor, or the Chief Investigator (CI) or the local Principal Investigator (PI) at a research site, may take appropriate Urgent Safety Measures in order to protect research participants against any immediate hazard to their health or safety. The Research Office should be notified of such measures within the same time frame of notifying the REC. The notification should include reasons why the measures were taken and the plan for further action.

All **patient related incidents**, including study-related Adverse Events/Reactions (AE/Rs), must be reported internally by the study team in line with the Trust's Adverse Incident Management and Reporting Policy *via* the Quality and Safety Department database **Datix** and marked **"research-related".**

In addition, **all** SAE/Rs must be reported to the study Sponsor and the main REC in line with the approved research protocol.

Audit

Please note the Trust is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This responsibility is delegated to the Research Office and will be achieved by random audit of research projects ongoing in the Trust in accordance with RB&HFT Audit SOP.

Yours sincerely

PP Rabia Pebbie

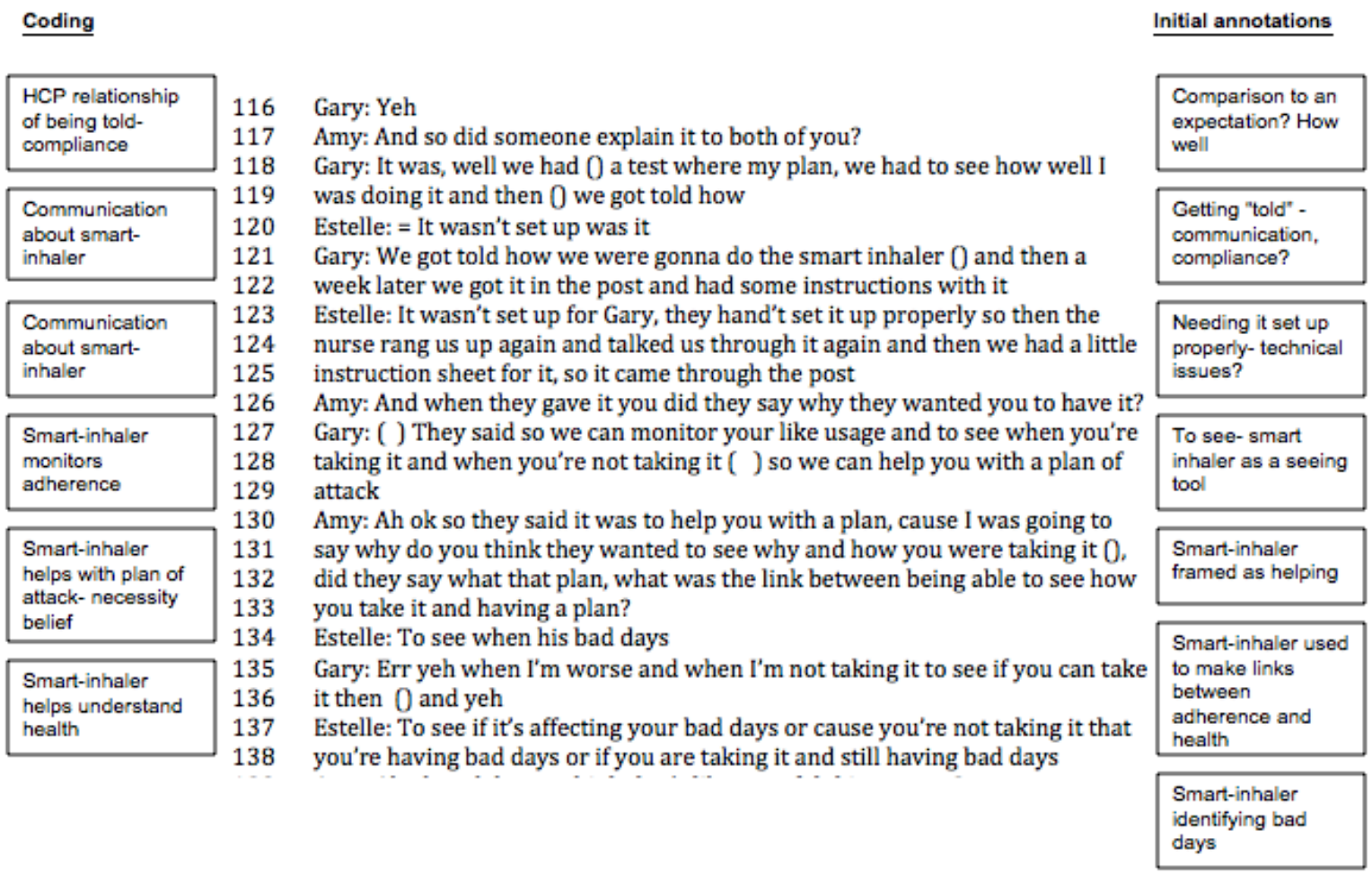
Dr Angela Cooper
Associate Director of Research

Appendix 18 – Transcription Conventions

[unclear]	Indicates that the person transcribing was not sure about what was said
=	Indicates where someone has finished another's sentence
[ ]	Indicates when the author wants to add comment e.g. [someone enters room]
[interruption]	Brief interruptions shown by inserting interruption in square brackets e.g. Claire: They said that they were gonna erm record me to see if I was taking it cause I weren't really taking it before [Amy: Ok] and they said that err they were trying like to help me get better
(unclear 'insert word')	When the transcribe was uncertain what was said but able to make a reasonable guess
,	Person speaking changes their sentence e.g Focus group discussion: One patient has refused, possibly for fear of being found out
-	Unfinished word e.g. Amy: And is that different to before did it not fe-, did you now feel so pressured before cause they didn't- they weren't able to look at it like is it any different or was there still that argument about

Adapted from Parker (2005)

Appendix 19 – Worked Extract Example



Appendix 20 – Initial Coding

No.	Initial Coding
1	acceptance of hcps recommendation
2	acceptance of hcps recommendation/ being told
3	adherence checked in other ways
4	adherence decreases escalation in healthcare needed
5	Adherence is not simple
6	adherence model of healthcare
7	adherence questioned
8	adjusting to hospital routine
9	age influences acceptance of results
10	ambivalence about si
11	assessment process overwhelming
12	asthma affects physically and psychologically
13	asthma as annoying
14	asthma as life long
15	asthma as long term
16	asthma as serious
17	asthma as something can ignore
18	asthma as something you just have
19	asthma as unpredictable
20	asthma can affect people differently
21	asthma feels like dying
22	asthma gets in the way of things
23	asthma impact
24	asthma is annoying
25	asthma is frightening
26	asthma is life threatening
27	asthma is scary
28	asthma is severe
29	asthma is unpredictable
30	asthma like being non existent
31	asthma makes unwell
32	asthma makes you ill
33	asthma makes you poorly
34	asthma makes you poorly at times (asthma varies?)
35	asthma means hospital
36	asthma non adherence as dangerous
37	asthma stops you doing stuff
38	asthma will affect life in the future
39	avoiding extreme weather
40	awareness of hcp monitoring
41	awareness of hcps workload

42	barriers to adherence- limited time
43	being monitored means adherence matters
44	being monitored means it matters
45	being proved wrong
46	being told
47	benefits to smart inhaler but not the monitoring
48	checking up good
49	children like praise
50	communication about non adherence
51	communication about responsibility
52	communication about si
53	communication with wider family system about monitoring
54	compliance model of healthcare
55	concealing asthma impact
56	confusion about how si works
57	confusion in hcp interaction
58	confusion over how si works
59	dependency on si
60	disagreement in parent child relationship
61	discrepancy in responsibility
62	discrepancy in responsibility talk
63	doctor was worried
64	doctors are suspicious of adherence
65	doctors asking parent's view
66	doing for their own good, good intentions
67	doing to him
68	dr as expert
69	drs need to know whether young people using inhalers properly
70	excuses for not using si
71	expectations of inhaler use
72	experiencing poor healthcare
73	explaining non-adherence a challenge
74	family excuses for not using si
75	family planning
76	fear of being found out
77	fear of breaking si
78	fear of hcp
79	fear of losing raised through Communication
80	fear of losing si
81	fear of wasting doctors time
82	forgetting
83	forgetting to take inhalers
84	get better
85	get used to smart inhaler
86	getting used to si if there long term
87	going through results together

88	good intentions
89	good intentions of si
90	good si explanation encourages use
91	good things about si
92	grow out of asthma
93	harder for parents to be responsible for teenagers inhaler use
94	having own asthma routine and knowledge
95	hcp gives me medicine
96	hcp is wrong
97	hcp mistrust
98	hcp monitoring
99	hcp not listening to yp views
100	hcp power
101	hcp questioning adherence
102	hcp trying to catch you out
103	hcp uncertainty about how ts use the si
104	hcps can see what he's done
105	hcps checking medicine is working
106	hcps don’t believe you
107	hcps encourage inhaler use
108	hcps listen to parental views
109	hcps moan
110	hcps responsible for my asthma
111	hcps talks to me
112	hcps trusting si but not yp
113	hcps want me to take inhaler
114	hcr partnership
115	health benefits to si
116	history of adherence monitoring
117	hospital school different
118	hospitalisation
119	hcp sees yp away from asthma
120	I don't like the si
121	I don’t need the si
122	I just leave it
123	I told them my view
124	I'll prove it
125	if forget inhalers asthma will be worse
126	increasing age increasing responsibility
127	increasing age: increasing understanding of asthma
128	increasing responsibility at secondary school
129	inhaler knowledge
130	inhaler necessity belief
131	inhaler representing asthma (symbol of asthma)
132	inhaler use during sport
133	inhaler: necessity beliefs

134	inhalers important to mum/nan
135	instructions with si helpful
136	insulting/ infantilising
137	intentional & un-intentional non adherence
138	intentional non adherence
139	intentional non use of si
140	interest in new technology
141	intrusive
142	it's hard to go against doctor's wishes
143	keep inhalers by side
144	keeping inhalers in same place helps remember
145	knowledge of asthma management/adherence expectations
146	knowledge of healthcare treatment
147	learning from results
148	less responsibility at primary school
149	limited interest
150	limited knowledge of what happens next
151	limited understanding of si monitoring process
152	make you take it
153	medical testing to check heart
154	medication beliefs
155	medication in different places
156	medication supervision necessary to get better
157	medicines help me get better
158	minimal concern for si
159	minimising of non-adherence
160	misrepresenting adherence
161	mistrust
162	mixed views about si
163	monitoring changes behaviour artificially
164	need responsibility for asthma
165	need si for a while for impact, or for it to show any changes, influence behaviour
166	needing parental reassurance
167	neg feedback affects hcp relationship negatively
168	negative feedback
169	new information on inhaler use
170	no necessity
171	non adherence dangerous
172	normalising non adherence
173	normalising non adherence
174	not being believed
175	not believing results
176	not bothered by si process
177	not happy about si
178	not keen on hospital
179	observed the benefits of si

180	older children don't like being checked up on
181	older yp should have more responsibility
182	other adherence measures used: GP prescription pick up
183	overprotective parents experienced as unhelpful
184	parent reminders
185	parent gets on with hcps
186	parent giving different inhaler for when parent not there
187	parent not happy si
188	parent wanting to check but aware yp doesn’t like
189	parent's can't control inhaler use
190	parental checking
191	parental checking helpful
192	parental checking/questioning
193	parental checking/questioning annoying
194	parental monitoring
195	parental positivity towards si
196	parental power
197	parental power to force
198	parental reminders
199	parental responsibility
200	parental responsibility means Si doesn’t influence adherence
201	parental responsibility to check child inhaler use
202	parental role
203	parental supervision
204	parental threatening
205	parental ways of checking adherence
206	parents getting questions about adherence because of si
207	parents nervous about si monitoring
208	parents not believing results
209	parents see as positive thing
210	parents should be supervising their kids
211	physical symptoms
212	physical symptoms indicate non adherence
213	poor planning in introducing smart inhaler
214	portability issues with si
215	positive feedback helpful
216	power
217	power of si
218	power of si: HC interactions informed by si data
219	practicalities talk
220	practicalities talk (si not practical)
221	practicalities talk: inhaler hard to remember
222	practicalities talk: in-practicalities promote non adherence (un-intentional non adherence)
223	practicalities talk: keeping inhaler nearby
224	practicalities talk: many medications lead to forgetting

225	practicalities: lost the smart inhaler
226	pressure
227	psychological features of asthma
228	pt refusal to use si
229	qus asked by families about how monitoring works
230	reasons for non adherence
231	regular healthcare reducing hospital admissions
232	regular hospital visits
233	reminders help adherence
234	reminders on si helpful
235	responsibility sharing
236	responsibility shifting
237	results not fed back
238	routine helps adherence
239	scared about using si right
240	self care
241	self care as adherence to medicines and inhaler
242	self care as taking medicine when really ill
243	severity of asthma warrants si
244	shared responsibility
245	si influences adherence
246	si a new thing
247	si a waste of time
248	si acts as reminder
249	si aids medical understanding
250	si allows parents to supervise adherence better
251	si an eye opener for parents
252	si as allowing hcps to disregard verbal info in favour info recorded
253	si as becoming the focus of the hc interaction
254	si as being watched
255	si as lie detector
256	si as objective way of measuring adherence
257	si as portable healthcare
258	si as specificity tool
259	si as tracker of adherence
260	si avoids escalations in treatment
261	si avoids hcps doing more invasive treatments
262	si belongs to hospital
263	si broke
264	si can be used to maintain good health
265	si can get you in trouble
266	si changes (parents?) priorities
267	si checks not forgetting
268	si checks up
269	si checks up on parents

270	si confusing
271	si data can look like but be wrong
272	si data kept in medical records
273	si doesn't affect relationship with hcp
274	si doesn't change/improve adherence
275	si doesn't change/improve adherence (not an intervention in itself)
276	si doesn't reflect reality
277	si encourages routine inhaler use
278	si for bad asthma
279	si for difficult asthma
280	si gets you into trouble
281	si given as part of practice
282	si gives evidence
283	si gives hcps power
284	si gives information on asthma control and DA
285	si gives opportunity to take responsibility
286	si gives parents power
287	si gives proof
288	si good for severe asthma
289	si helps doctors decide if need to increase meds
290	si helps hcps get the basics right
291	si helps hcps monitor adherence
292	si helps hcps problem solve other ways to promote adherence
293	si helps hcps see if remembering
294	si helps hcps understand link between health and adherence
295	si helps parental monitoring
296	si helps parents take responsibility for supervising yp's adherence/inhaler use
297	si helps pts avoids more invasive treatments
298	si helps with plan of attack
299	si helps with shifting responsibility to yp
300	si helps yp take inhaler regularly
301	si helps yp use inhaler
302	si helps hands off parental monitoring
303	si identifies poor parental supervision
304	si importance
305	si improves hcis vs shifts power to device
306	si improves health
307	si increases parental awareness of child's adherence/inhaler use
308	si influences adherence but only in the short term
309	si influences hcp actions
310	si influences parent behaviour
311	si introduced as helping hcps see how the inhaler is used and DA linked

312	si introduced in routine assessment procedure
313	si introduced to parent
314	si introduced when concerns about asthma control
315	si is insulting
316	si kept on one inhaler
317	si lets hcps see how taking inhaler
318	si like big brother watching you
319	si limited to short term
320	si makes hc relationships easier
321	si makes non-adherence a big deal
322	si makes question own inhaler use
323	si makes question self
324	si means adherence on the mind
325	si means hcps watching you
326	si means yp not responsible?
327	si monitoring improves health
328	si monitoring influences adherence
329	si monitoring scary
330	si monitors
331	si monitors adherence
332	si monitors self care
333	si negatively affects hcp relationship
334	si not appropriate for adults
335	si not changing parental checking
336	si not explained
337	si not explained well
338	si not needed if parental monitoring
339	si not relevant?
340	si ok
341	si okay if adherent
342	si opens up communication about inhaler use
343	si optional
344	si part of assessment protocol
345	si part of hcps job
346	si power over word of mouth
347	si process as generalised
348	si process frightening
349	si process infantilising
350	si process scary
351	si records inhaler use
352	si records me/ my inhaler use
353	si reduces excuses
354	si reduces family stroppiness
355	si reminds you
356	si removes arguments about adherence in hci
357	si removes confrontation in hcr

358	si reverses parental involvement, mum more involved
359	si reverses yp responsibility
360	si scary
361	si shows room for improvement
362	si spys on you
363	si timer made it hard
364	si too big
365	si used as proof
366	si used to understand poor health
367	si used when concerns about adherence
368	si used when non-adherence
369	si used when parental supervision of child a concern
370	si useful for older yp
371	si watches you
372	si when hcps think you're not adhering
373	side effects to using inhalers
374	similar experiences at different hospitals
375	staff changes
376	surveillance
377	taking inhalers and meds looks after asthma
378	taking medicine properly
379	technical difficulties
380	technical difficulties, unable to go through results with pts in clinic
381	technology but not at its best
382	teenagers forget to take inhaler
383	teens are stubborn
384	teens need to be monitored
385	tension in holding responsibility vs needing support
386	the inhaler hurts my leg as its bulging out
387	they [hcps] tell me what to do
388	they won't believe me
389	thought asthma would go away
390	time implications of using si in hc practice
391	transparency in communication
392	trust
393	uncertainty about long term impact/effect of si once taken off
394	understanding of si technology
395	ups and downs of asthma control
396	using inhaler as normal
397	using inhalers reduces unpredictability
398	using visual information to feedback results
399	we got told
400	wider family role in checking/questioning
401	working together in hcp relationship
402	worry

403	yp independence in managing asthma
404	yp responsibility
405	yp responsible for asthma
406	yp responsible for inhaler use
407	yp should be responsible for asthma
408	yp taking responsibility for si
409	yp wanting their individuality recognised, si as dismissing individuality

Appendix 21 – Higher-Level Coding

No	Higher-Level Codes
1	adherence aids
2	adherence is not simple
3	asthma beliefs
4	communication
5	dependency on si
6	excuses
7	fear of losing si
8	hcp monitoring
9	hcp relationship
10	hcp relationship- adherence
11	hcp relationship- compliance
12	history of adherence monitoring
13	intentional & un-intentional non adherence
14	minimising of non-adherence
15	mistrust
16	negative feedback
17	non adherence common
18	other ways of monitoring adherence
19	parental monitoring
20	parental responsibility
21	power
22	responsibility
23	responsibility discrepancy
24	self care

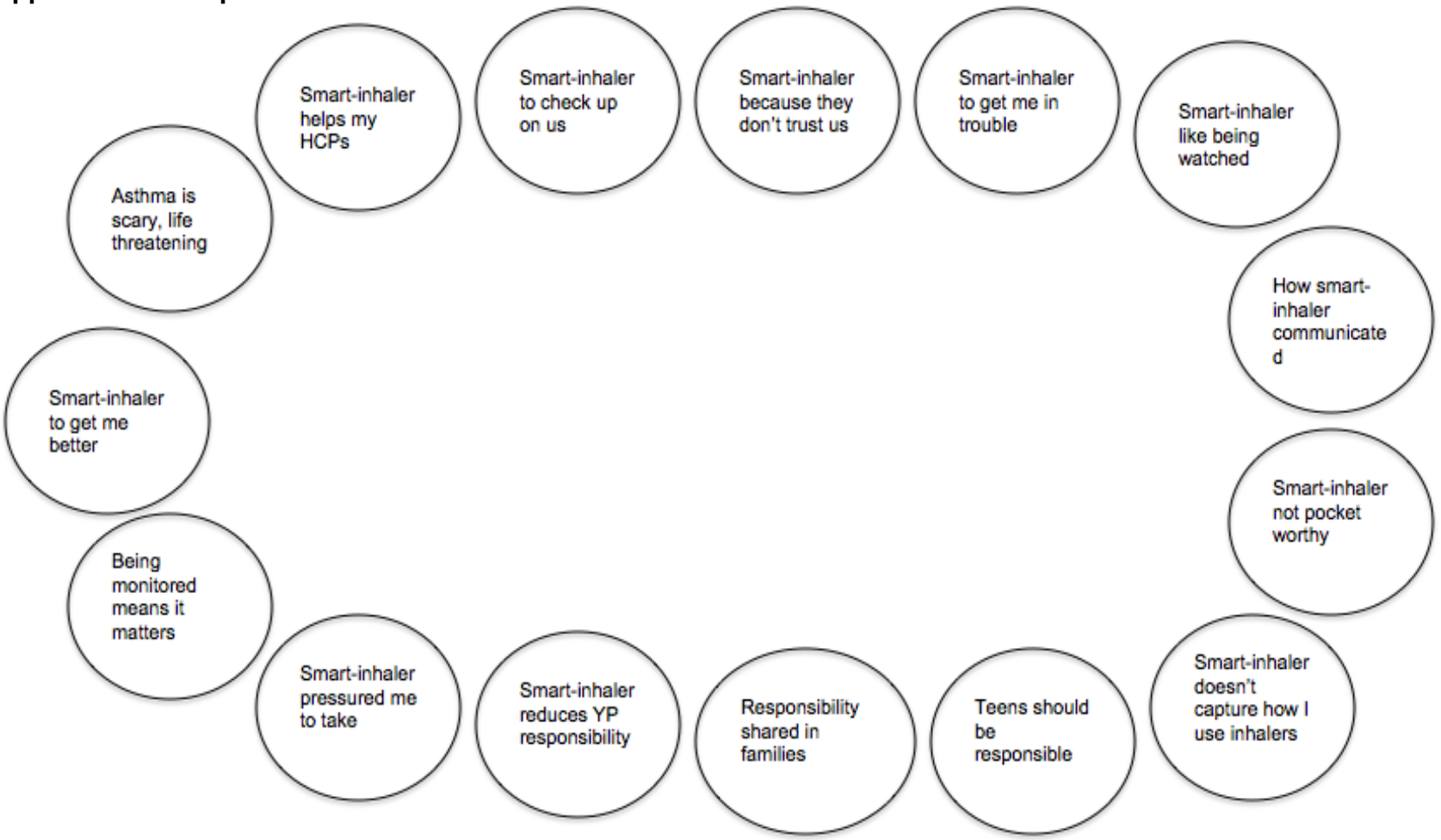
25	short term effect of si
26	si as part of standard assessment
27	si beliefs
28	si concern beliefs
29	si gives proof
30	si improves unintentional non-adherence
31	si influences parent behaviour
32	si makes non-adherence a big deal
33	si monitoring didn't influence adherence
34	si monitoring influences adherence
35	si necessity beliefs
36	si not needed if parental monitoring
37	si used when concerns about adherence
38	surveillance
39	treatment beliefs
40	treatment concern belief
41	treatment necessity beliefs
42	trust
43	unintentional non adherence
44	what helps adherence
45	wider family monitoring

Appendix 22 – Coded Extract Example

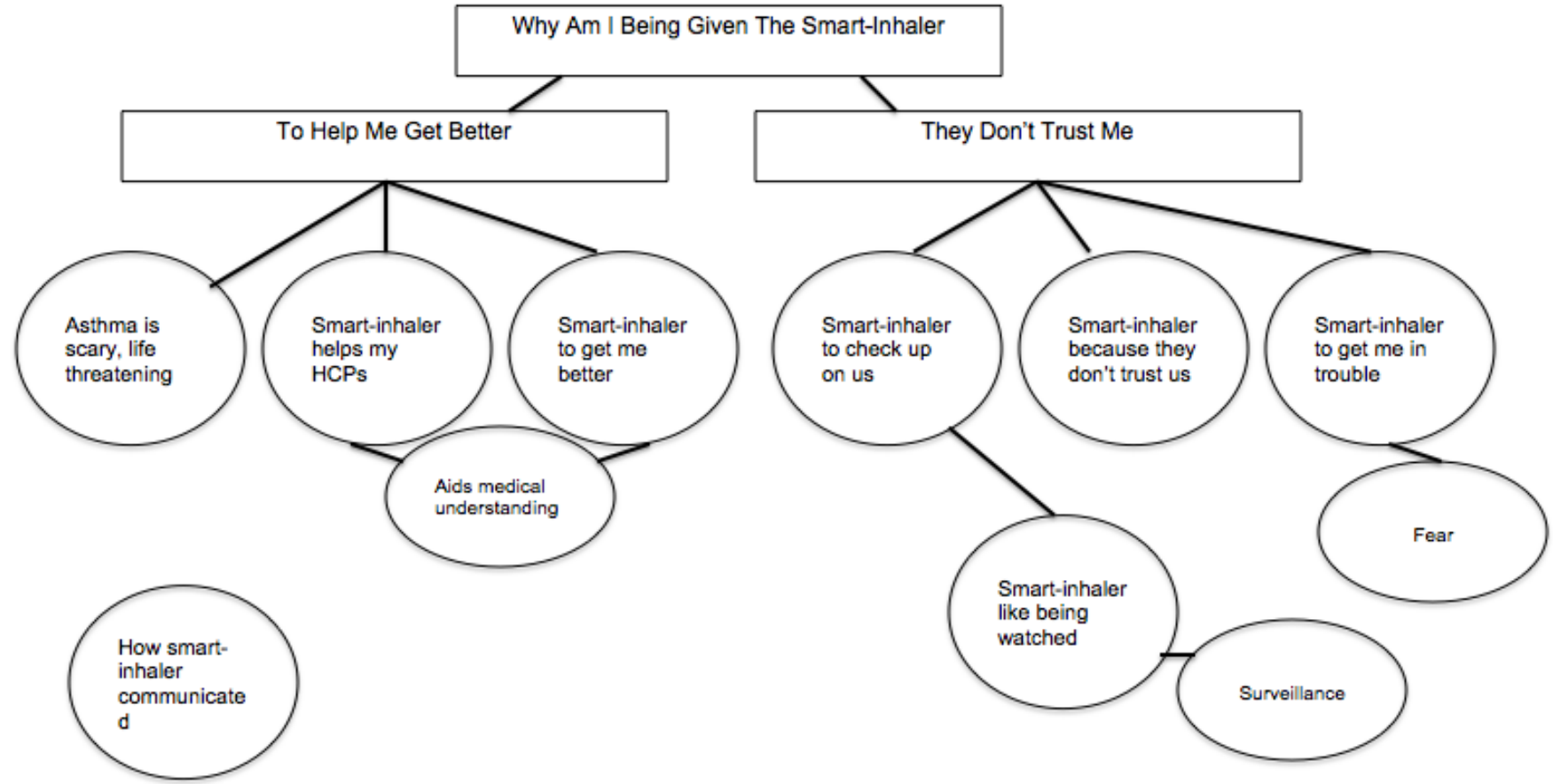
Interview	Line no	Higher-Level Code	Initial Code	Extract
YP 2 Sam	95-102	mistrust	mistrust	Amy: And the way [nurse] explained it can you remember how Sam: = She said that she said that it would record how many times I take it and that they can see you and whether whether I've been taking it or not Amy: An so you said like it felt a little bit spyee do you think anything else about it and why you were given it? Sam: Maybe she thought I wasn't taking it Amy: And what do you think about that? Sam: That she was wrong
YP 6 Isla	108-113	mistrust	mistrust	Amy: Yeh yeh and like you say I guess if you'd given it in and you knew they were gonna look at it and obviously like you say you've not been able to use it all the time [Isla: Yeh] do you think that would have been like quite hard to explain or how do you think you would have managed that? Isla: I would have explained it but I don't think like they would believe me sort of thing [Amy: Yeh ok] but I have been [laughs] I have [Amy: Yeh]

YP 6 Isla	174-182	mistrust	mistrust	Amy: And do you think you would fe-, if you knew that you were coming to an appointment where they were gonna look at the results and you'd had the chance to use if for say a period of time and where you had it and you knew how to use it er would you be feeling alright with that or do you think you would be a bit worried about what they were gonna see or what? Isla: Well if I took it all properly I'd still be worried but there's no reason really to be if I've took it properly but it's just I dunno Amy: What do you think that worry is about do you think it's cause it's just Isla: =They don't trust me yeh
YP & CG 5 Gary and Estelle	148-153	mistrust	si as lie detector	Estelle:= Yeh just seen them judging by his erm his the breathing he's done today they can tell that he hasn't been using it properly they said it's really obvious and then when we come back in a couple of weeks time they are going to plug it in an they are going to see if what they've seen today is gonna be so they can see if Gary has been telling them lies or not [pitch of voice goes higher]
YP & CG 5 Gary and Estelle	154-160	mistrust	they won't believe me	Amy: And how does it feel for you Gary, kind of knowing that they are going to look at them in that way? Gary: It feels scary cause whenever I don't, whenever I think of taking it but I haven't it's like oh, whenever your found or someone says you haven't done this and you plead innocence they are always gonna say that they won't believe you cause it's the results but you thi-, you say ok I'd thought I'd tooken it but I didn't know if I had and yeh

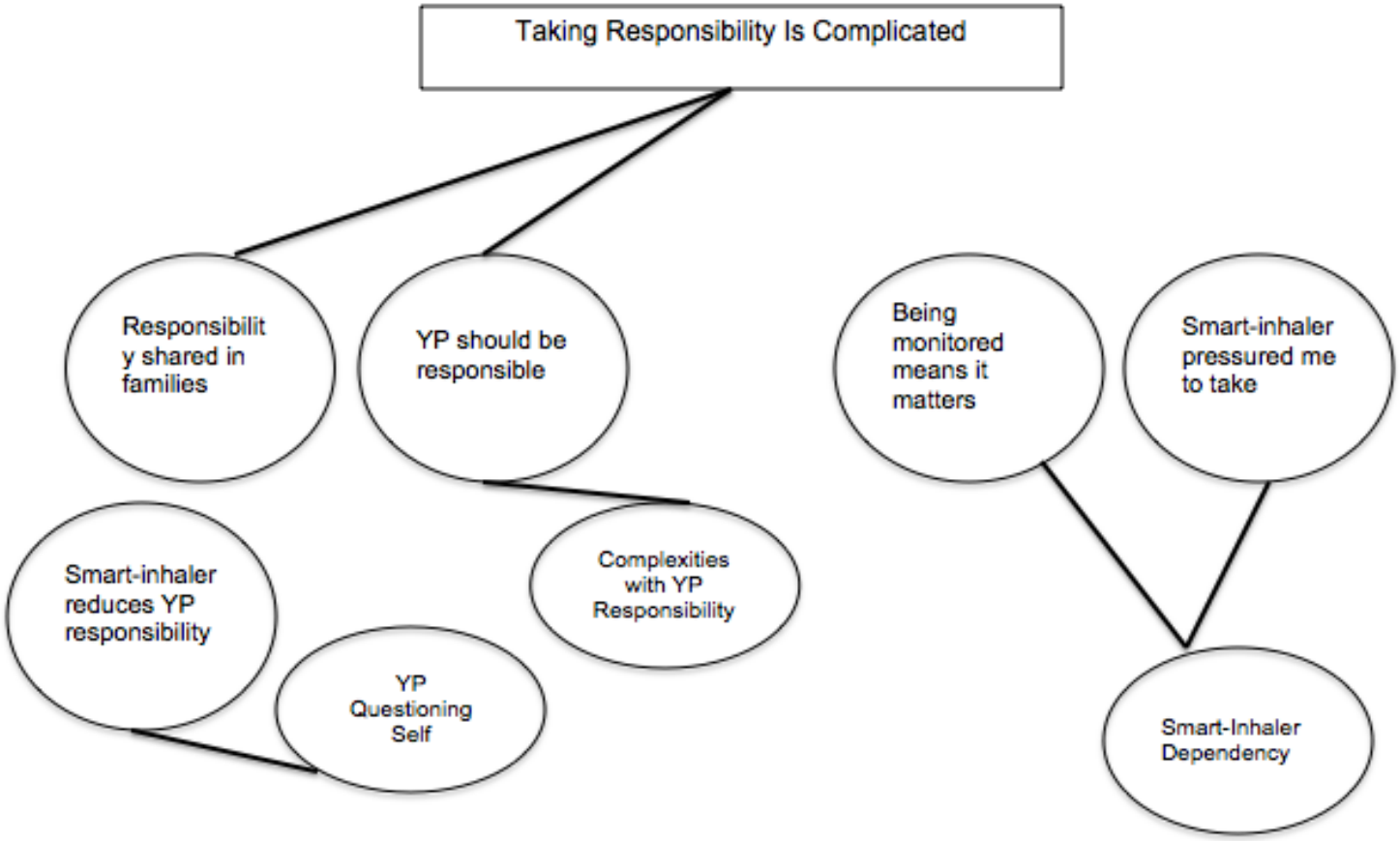
Appendix 23 – Map of Provisional Themes



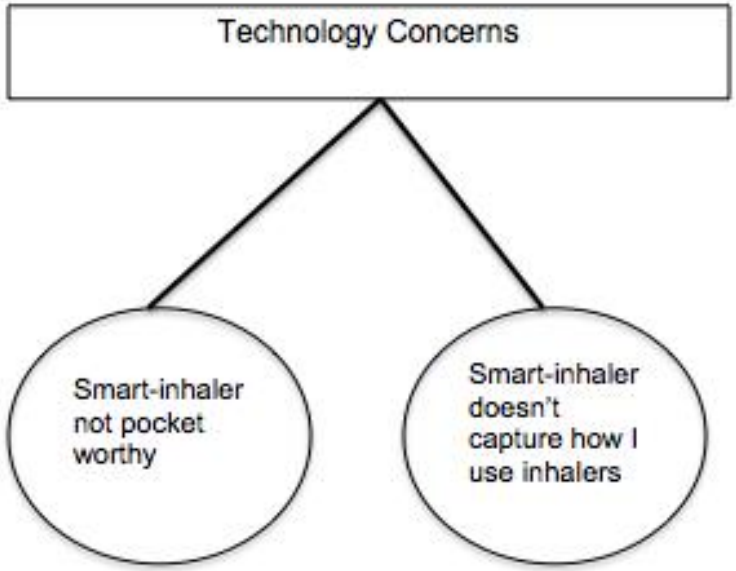
Provisional Thematic Map 1



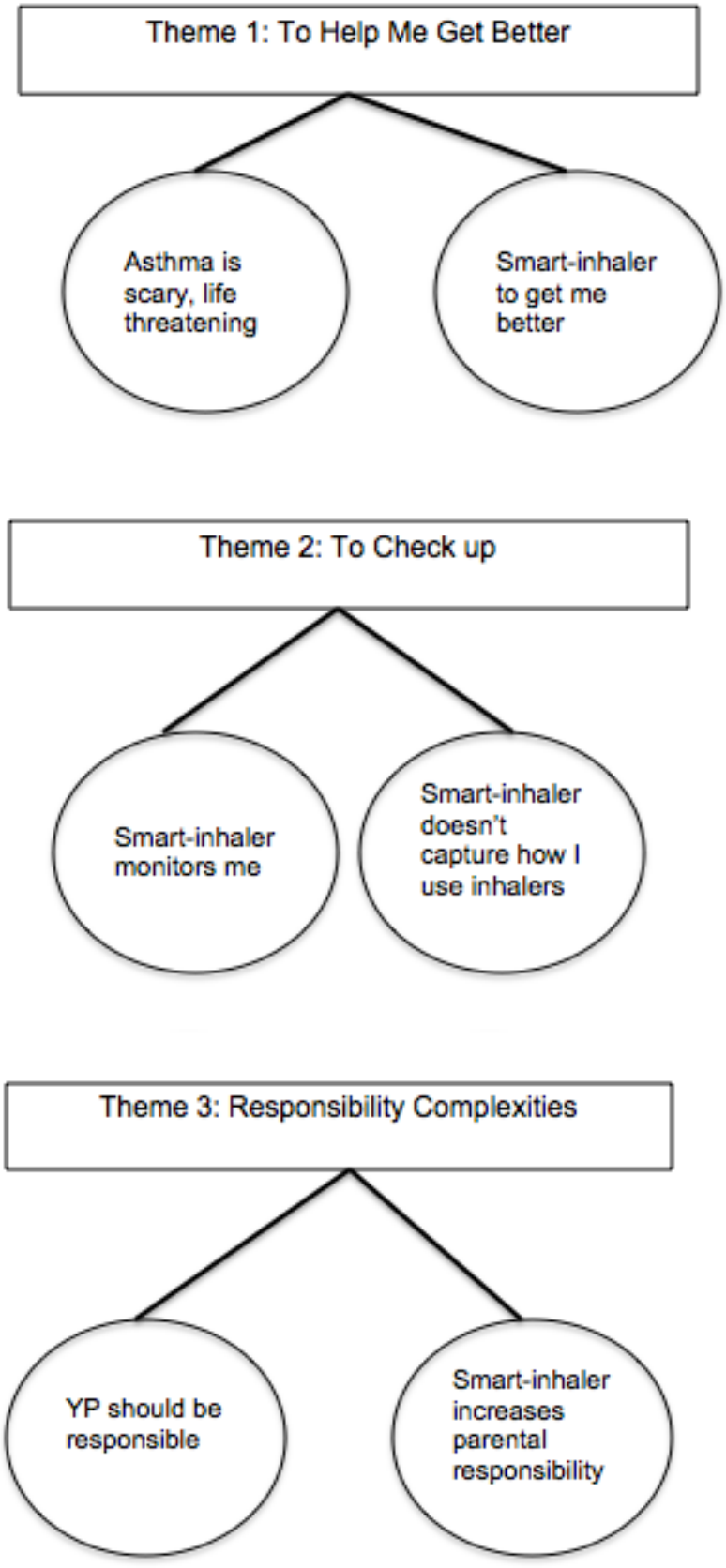
Provisional Thematic Map 2



Provisional Thematic Map 3



Appendix 24 – Thematic Map of Revised Themes



Appendix 25 – Defining & Naming Themes

Name Of Theme	Definition	What Was Of Interest/Relevance To Research Question
Theme 1: "They Were Trying To Help Me Get Better"	Illustrates how participants' beliefs/understandings of asthma influenced their expectations of the healthcare relationship and their experience of being given the smart-inhaler	Highlights participants' perceived need for the smart-inhaler & how this interacts with the healthcare relationship
Sub-ordinate theme: "It Feels Like I'm Kind Of Dying"	Outlines some of the beliefs participants held about asthma and the need for medical treatment	Highlights participants' perceived need for the smart-inhaler
Sub-ordinate theme: "It Helps Us To Get The Basics Right"	Describes participants' views of the smart-inhaler as helping healthcare professionals to improve patient's health	Describes how process of being given the smart-inhaler interacts with the healthcare relationship
Theme 2: "It's Clearly Just To Check Up"	Illustrates how participants experienced the introduction of the smart-inhaler as being to monitor their inhaler use and how this influenced their inhaler use	Describes participants' concerns with the introduction of the smart-inhaler and the issues it raises in the healthcare relationship
Sub-ordinate theme: "It Was A Little Bit Spyee"	Outlines how the introduction of the smart-inhaler raised issues of mistrust, fear of getting into trouble & promoted a sense of surveillance of young people, both in the healthcare relationship and from caregivers	Describes participants' experiences of the smart-inhaler raising issues of surveillance & mistrust & blame in the healthcare relationship

Sub-ordinate theme: "They Should Put The Tracker In Your Throat"	Illustrates the ways some participants viewed the smart-inhaler as inadequate at recording real life inhaler use	Highlights participants' concerns about the smart-inhaler's inability to capture inhaler use accurately & the need for improved technology
Theme 3: Who Is Responsible?	Focuses on participants' accounts of taking responsibility and ownership for their asthma and some of the complexities with this process	Describes participants' experiences of YP taking responsibility/ caring for their asthma & how the smart-inhaler influenced this process
Sub-ordinate theme: "As I'm Older Now She Tells Me It's My Responsibility"	Describes some of the developmental expectations that exist around taking responsibility for asthma during the period of adolescence	Highlights participants' beliefs that YP should be taking responsibility for their asthma self-care
Sub-ordinate theme: "It Reversed Back To Being Us"	Describes how the introduction of the smart-inhaler reduced the level of responsibility young people possessed for their asthma in most cases, & when inhaler use was promoted, this was short term	Describes how the process of being given the smart-inhaler reduced YPs responsibility. Highlights that the smart-inhaler promotes adherence but only in the short-term, raising concerns about where responsibility lies; with the YP, or the HCP & the smart-inhaler