

# **Living with a long-term condition: a grounded theory**

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## Abstract

This study explores and explains how people make sense of their long-term, potentially life-threatening, health condition. Thrombophilia offers an example of a little-researched condition which may not affect people significantly on a day-to-day basis, but can lead to acute illness. The second condition under consideration, asthma, was selected due to its similarity in this regard. The literature indicates that information about long-term conditions is acquired from various sources and influenced by experience. Such conditions are frequently perceived as being problematic. However, some are accepted, and affected individuals can achieve wellbeing. The literature does not offer insights into how knowledge may support this process of achieving wellbeing.

A constructivist grounded theory approach was adopted, and interviews used to collect data from ten individuals affected by thrombophilia. Constant comparison of the data was carried out. Theoretical sampling suggested the inclusion of six people with a second long-term condition, and the process continued until saturation was reached.

Findings indicated a two stage process. *Gaining knowledge* comprises of phases occurring pre-diagnosis and during diagnosis, and this assists participants in making sense of their condition. *Living with a long-term condition* consists of the phases making informed decisions, accepting the condition, and living with it. Previous research has not elucidated this entire process or the importance of the pre-diagnosis phase.

Based on these findings, a theory is offered. This proposes that individuals diagnosed with a long-term condition create constructs about it based on information and experiences, which are used as the foundation for decision-making. Some people are able to accept their condition and its nuances. Those who understand their condition, make informed decisions and accept it are able to live with it. Those who are unable to do so will live alongside their condition and do not integrate it into their lives.

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## Chapter 1: Introduction

This thesis arose from an interest in how individuals with a long-term condition perceive it, and particularly how information may influence their perceptions. Chapter one will outline the background to the study, considering the impact of long-term conditions in the UK, detailing the exemplars chosen for study and the rationale for the research. It will also provide an overview of the structure of the thesis.

Long-term conditions affect a large proportion of the UK population, involve a range of healthcare services and, in many instances, are at least partly self-managed. Some long-term conditions, including thrombophilia, asthma, epilepsy, Addison's disease, hyperthyroidism, and hypothyroidism, can be asymptomatic or have little influence on individuals' lives for much of the time, but may on occasion cause acute incidents which may be life-threatening. For clarity, this type of condition will be designated as long-term, potentially life-threatening, throughout this document. Effective self-management of such conditions, including using available information, taking medications and amending lifestyle activities, could reduce the risk of experiencing a serious event. These are the type of conditions selected for consideration in this study, as previous research tends to focus on those life-changing conditions which have a significant impact on the day-to-day life of those affected. Although the study focuses on a particular type of long-term condition, it is possible that the findings could be transferable to others.

The conditions specifically chosen as exemplars are thrombophilia and asthma ('the study conditions'). Thrombophilia was originally chosen, and asthma added when it became clear that the theoretical concepts arising required further exploration with a different condition. The aim of this study is to explore and explain how people make sense of their long-term, potentially life-threatening, health condition.

## **Background**

### ***Long term conditions in the UK***

Approximately 20 million people in England have at least a single long-term condition (LTC), and 70% of healthcare spend is used to treat and care for these people (Parliament 2013). A long-term condition has been defined by the Department of Health as “one that cannot currently be cured but can be controlled with the use of medication and/or other therapies” (Department of Health 2010, p.4); this definition can be applied to the study conditions. Long-term conditions are managed through various services and healthcare professionals in the NHS, including general practices, nurse-led services, secondary care, emergency medicine, social care and mental health services. They have a significant impact on the health services: according to a report from the Royal College of General Practitioners based on Department of Health data,

“people with LTCs account for more than 50% of all general practice appointments, 65% of all outpatient appointments and over 70% of all inpatient bed days” (2011, p.4).

Policy in England relating to long-term conditions emphasises the importance of self-management, and information as a fundamental aspect of this. The National Service Framework (NSF) for Long Term Conditions, though focused on neurological conditions, is explicitly expected to be applied to other conditions, stating

“Although the NSF focuses on people with longterm neurological conditions, much of the guidance it offers can apply to anyone living with a longterm condition.” (Department of Health 2005, p.3).

Quality requirement 1 of this NSF is to provide a person-centred service, saying that people

“are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.” (ibid, p.19).

In order to promote self-management, the UK has an Expert Patient Programme. Although originally housed within the NHS, this programme is now delivered by the not-for-profit social enterprise, self management uk (self management uk 2013), who offer a range of self-management programmes and advice, including some delivered by individuals who themselves have experience of living with a long-term condition. A significant aspect of this programme, according to the website, is the provision of information and education about LTCs and about tools which can be used to help manage them.

Despite this focus from the NHS on long-term conditions, The King's Fund (2010) has found that

“care quality is currently suboptimal and highly variable, and could be significantly improved through a better understanding of long-term conditions among primary care professionals and a more proactive approach to care management.” (p.71).

Thus there is a strong policy focus on improving care and access to self-management strategies, including information, for those with long-term conditions. In addition, a review of the literature (see chapter two) indicates that much of the research carried out to date concerns conditions which could be said to be problematic. These are LTCs which have a significant impact on the lives of those affected, affecting their ability to work, altering their physical appearance and changing their identity. However, there is a small body of research which shows that not all conditions are problematic for those affected. The conditions chosen for study herein are ones which may not present a problem, and have a limited effect on people's lives for much of the time.

Thus, this study will explore the views of those affected by a long-term condition, including how information can help them to make sense of it and other factors which contribute to how they deal with their condition on a day-to-day basis.

### ***Study exemplars: thrombophilia and asthma***

Thrombophilia is a disorder of blood coagulation which results in an increased likelihood of inappropriate clotting, or thrombosis. Thrombophilia may be inherited or acquired over an individual's lifetime. Hereditary thrombophilia results from a change (mutation) in one of the genes involved in the blood coagulation cascade, of which several forms exist in the Caucasian population (Lim et al. 2007). It is estimated that the most common type of inherited thrombophilia, Factor V Leiden, affects between 5% and 8% of the European population, and the second most common variant, prothrombin 20210, up to 4%, with greater prevalence in the south of Europe (Khan and Dickerman 2006). Acquired types of thrombophilia result from a range of circumstances, the most common cause of which is antiphospholipid syndrome (Simioni 2012; Comarmond and Cacoub 2013), related conditions characterised by positive results for antiphospholipid antibodies such as Sneddon's Syndrome (Dutra et al. 2012), cancer (Prandoni et al. 2005), thalassaemia (Cappellini et al. 2010), Cushing's Syndrome (Van Zaane et al. 2009) and inflammatory diseases such as irritable bowel disease and nephrotic syndrome (Cenni et al. 2011). An increased risk of thrombosis is also linked with immobility, oestrogen therapy, pregnancy, obesity and major surgery or trauma (Walker, Greaves and Preston 2001; Anderson and Spencer 2003; Watson and Baglin 2010).

Thrombophilia increases the risk that a venous thromboembolism (blood clot in the veins) will form. The majority of venous thrombi form in the leg veins and are designated deep vein thromboses (DVT). A thrombus may fragment and block blood vessels downstream of its origin, potentially leading to pulmonary embolism (blockage in the blood vessels in the lungs), which can be fatal. In women, thrombophilia may also lead to recurrent miscarriage (De Santis et al. 2006; Helgadottir et al. 2012).

Following a thrombotic event or other symptoms indicative of the condition, testing for thrombophilia may be carried out to determine whether a deep vein thrombosis or pulmonary embolism is linked to a form of thrombophilia. Alternatively, family history may indicate that, due to the occurrence of

thromboses in other family members, an individual could be at risk of a hereditary form of thrombophilia, in which case genetic testing may be carried out. Identification of a high risk gene variant can then be used to determine which individuals are at risk of thrombosis, with the aim of preventing clots in those who are currently asymptomatic and preventing further thromboses in those who have experienced them previously.

Treatment varies according to the clotting and risk status of an individual. Those who have recently experienced a clot will be prescribed heparin to disperse the thrombus. Those who have had clots in the past and remain at high risk of further thrombi will be prescribed anticoagulants such as warfarin. Aspirin may be recommended for others at increased risk of a clot, and heparin may again be prescribed for high-risk situations such as long haul flights. For pregnant women, there are few high quality, comparable studies, but current recommendations advise heparin and aspirin are used in combination to reduce the risk of miscarriage (McNamee et al. 2012; Kovac et al. 2014).

Those who have had clots may experience long-term effects known as post-thrombotic syndrome (PTS). This is characterised by lower limb pain, redness and swelling, varicose veins, abnormal feeling in the leg, and ulcers (Vazquez and Kahn 2012). PTS can be reduced through the use of compression stockings (ibid).

Asthma is a common condition which affects individuals worldwide; it is estimated that 300 million people have the condition (Global Initiative for Asthma 2012). It is characterised by inflammation of the airways, obstructed airflow and bronchial hyperresponsiveness (easily triggered spasms in the small airways) (O’Laughlen and Rance 2012). These cause the symptoms of coughing, wheezing, shortness of breath and tightening of the chest, and may be triggered by allergens, temperature changes, infection, hormones, exercise or emotional factors, or air pollution (Ritz et al. 2010; Abelsohn and Stieb 2011; Papadopoulos et al. 2011; O’Laughlen and Rance 2012; Ritz et al. 2012; Ostrom et al. 2013). Women may find that their symptoms increase in the days before and during menstruation (Tan 2001; Murphy and Gibson

2008). Causes of asthma include a family history (over 100 genes have been linked with asthma according to Zhang et al. (2008)), allergies, exposure to tobacco smoke, particularly before birth, premature birth and low birth weight, and experiencing bronchiolitis as a child (NHS Choices 2012a). Children born after infertility treatment are at higher risk of being affected (Carson et al. 2012) and adults may develop asthma following recent respiratory infections (Rantala et al. 2011). There has been an indication that, at least in some populations, obesity may be linked to asthma (Mathew et al. 2009) and can result in increased symptoms (Raviv et al. 2011). Those with asthma are at higher risk of lower respiratory tract infections (Corne et al. 2002), and most patients who die from the disease “had chronically severe asthma” (British Thoracic Society and Scottish Intercollegiate Guidelines Network 2012, p.57).

Diagnosis of asthma in adults is achieved through consideration of the symptoms experienced, where cough (particularly at night), wheezing, breathlessness and chest tightness are considered to be indicative of the condition, confirmed through spirometry or peak flow measurement; variation in airflow indicates the presence of asthma (Kaufman 2012). Bronchodilators – both short- and long-acting – may be used to control the condition, including inhaled beta-agonists and corticosteroids, in most people, whilst those with poorly controlled asthma may be prescribed oral corticosteroids, leukotrine receptor antagonists or methylxanthine theophylline (ibid). Short-acting beta-agonists can also be prescribed to treat exacerbations of the condition, though more serious illness will be treated with an increased dose of inhaled or oral steroids (ibid). Diagnosis in children (asthma is one of the most common childhood illnesses) requires the same symptoms to be experienced, though these may be explicated by parents or carers rather than the patient themselves, and in under-5s is assumed where no other cause for the symptoms can be identified, and the symptoms respond to asthma treatments (Redwood and Neill 2013). Both the NHS (NHS Choices 2012a) and the national asthma charity in the UK - Asthma UK - indicate that asthma symptoms may be well managed through treatment such that the condition has little impact on daily life.



Thrombophilia and asthma are thus both examples of long-term conditions which may be perceived to be asymptomatic or to have little effect on individuals' lives for at least some of the time and may be managed through self-management techniques, but may on occasion lead to severe, potentially fatal, illness. The two conditions therefore offer an opportunity to explore with affected individuals how information contributes to how they make sense of a condition which could be described as being mostly existential and non-problematic – as it exists in the background of one's life, rather than always being a priority, for much of the time.

## **Research problem and study rationale**

In this study, I wished to explore how people make sense of their long-term condition, and specifically what contribution to this is made by information and knowledge about it. As will be seen in the next chapter, extensive literature exists regarding LTCs, much of it describing single conditions. I was interested in identifying theoretical concepts which may apply not only to a single condition, but to conditions which exhibit similar disease patterns, particularly those which may have little effect on an individual's life on a day-to-day basis. I wished to explore individuals' views of having a condition not only in the context of how, in their view, they had been advised to manage the condition by healthcare professionals or through other information sources, but also how this influenced the choices and decisions they had made to manage it.

Thrombophilia is a little-studied condition, and so was selected as an exemplar for study. A number of concepts arose from the research with people affected by thrombophilia, and theoretical sampling indicated that further exploration of these in relation to other long-term conditions would be appropriate. I therefore expanded the sample population to include people with asthma. Further detail about the reasons for this is provided in chapter three.

This study is timely as long-term conditions are increasingly affecting the global population and, although policy and previous research has identified

many of the problems associated with having such conditions, there is a need to consider the process of having a long-term condition in a holistic manner, including the possibility that this may not always be problematic for the individual concerned. The House of Commons Health Committee (House of Commons Health Committee 2014) has recently reported on managing the care of those with long-term conditions, indicating a range of problems with the current system, including the need for an urgent strategic response from Government and the National Health Service to the anticipated increase in such conditions, and corresponding lack of funding. One of their recommendations includes the following:

“The objective of the health and care system in treating people with long-term conditions should be to improve the quality of life of the person.” (ibid, p.78).

This holistic approach can be supported by understanding what knowledge and information individuals have about a condition, and how this affects their perspectives of it.

There are several reasons for choosing this topic, in addition to its timeliness. It is not known how information and knowledge of a condition may affect individuals' lives. Thrombophilia is a little explored topic, and the existing literature describes specific aspects of living with it, rather than the holistic experience of an individual. Regarding asthma, although this condition has been investigated frequently, I particularly wished to explore the relevance of specific concepts which arose during the consideration of thrombophilia, and thus this viewpoint of asthma is also novel. I am not employed by nor have I received training from the health services and so am not influenced by my employment status – and, importantly, neither are the participants in this study, to whom I have made it clear that I am a university employee. This could offer a different perspective than that of the healthcare professional, to whom participants with LTCs could feel obliged to tell a particular story.

Research into long term-conditions has mainly focused upon the management of these, and of the people living with them, as problematic. The NHS promotes self-management of LTCs, and information is considered

to be a significant aspect of this. Both thrombophilia and asthma are conditions which, though not curable, may not have a significant daily impact on the lives of those affected, and may thus not always be seen as problematic by affected individuals. Personal interest and the existing literature have thus contributed to the development of the aim for this study: to explore and explain how people make sense of their long-term, potentially life-threatening, health condition.

It is important at this point to comment on the terminology adopted throughout this thesis. I have chosen not to use the words disease or illness to represent the conditions under study, as none of the participants did so. I have instead used condition or long-term condition (LTC). Illness is used specifically for those occasions when the conditions caused people to become ill, either with a blood clot or an asthma exacerbation, or when it has been used in the literature. The word disease is often associated with infections, and is not used herein as neither condition is infectious.

## **Structure of this dissertation**

This chapter has provided a brief background to and rationale for this research. Chapter two will explore the existing literature in relation to this study. The initial review was undertaken by searching for literature relating to perspectives on, understanding and experience of and life with a long-term condition, together with that relating specifically to asthma and thrombophilia. Search terms included 'long term condition' 'asthma' and 'thrombophilia' (a full list of search terms can be found in appendix 1). I also adopted the berrypicking method (Bates 1989) of identifying relevant literature. I did this by identifying particular journals which I regularly checked as they contain many of the relevant papers, by searching for articles by authors known to undertake research in the field and by selecting relevant literature from the reference lists of chosen articles. The literature demonstrates that extensive research has investigated information sources and self-management for those with a long-term condition, frequently considering having a LTC to be problematic. Some literature demonstrates that not all conditions are

perceived to be problematic from the perspective of those affected. However, no known existing research has considered in total the process of learning about and living with long-term conditions which are seen to be non-problematic. This study will address this gap.

Chapter three describes the methodological approach adopted in this study. The project is qualitative, and specifically uses a constructivist grounded theory methodology. This enables an explanatory theory to be developed, grounded in the data collected, which is located in a specific time, place and culture. The use of the literature is described, and an explanation given of the data collection methods and sampling approach used. Interviews were used to collect data from individuals affected by thrombophilia and asthma; three different access routes were adopted to invite people to participate in the study. Ethical matters and quality criteria for grounded theory are considered.

The findings of the study are presented in chapters four and five. These chapters detail how individuals gain knowledge about their condition, beginning for some before their diagnosis, confirming it at the point of diagnosis and gaining an understanding of their LTC in an ongoing manner. They also provide evidence that people make decisions based on this knowledge and understanding, and in some instances accept their condition. For some people, the findings demonstrate that it is possible to live with a long-term condition. **The findings and discussion are presented separately** in the interests of clarity, though it is recognised that this may result in some repetition.

Chapter six discusses the findings of the study, including theoretical considerations and dialogue with the literature. Several theories are considered for their contribution to the findings, and I offer some suggestions for how existing theories could be amended in the light of this research.

Chapter seven offers my reflections on the study, considering my personal interest in the study and consequent preconceptions, and thoughts regarding the methodological approach taken to the research. I discuss the conflict I

experienced when a family member was diagnosed with thrombophilia and my thoughts about becoming a qualitative researcher. Limitations of this research are examined. I conclude with some considerations about participants as experts and how their views have changed my thoughts about life with a long-term condition.

Chapter eight details the theory developed from the findings of this study, together with some considerations of its potential use. Implications for both further research and practice are discussed. Finally, the contribution to knowledge of this project is also reflected upon.

## Chapter 2: The Literature

An initial literature review was undertaken in order to determine the existing state of knowledge and to identify a gap which may be filled by this study; this has subsequently been updated to ensure that the review maintains currency throughout the duration of the study. It was carried out by searching databases for literature relating to having a long-term condition and the use of information in connection to this. I also searched for literature linked to the two specific conditions identified as exemplars in this study, these being thrombophilia and asthma. The databases searched and search terms used can be seen in Appendix 1. In order to ensure that literature was identified even where it was not found in these specific databases, or selected using these search terms, I also adopted the berrypicking approach (Bates 1989). This involved identifying and selecting useful information and references, and using each of these to direct the search to the next relevant item. In this instance, the strategies adopted included a journal run of several journals (Sociology of Health and Illness, Social Science and Medicine, Journal of Clinical Nursing), author searching, citation searching and footnote chasing to identify other articles.

A grounded theory approach was adopted for this study, requiring that identification of further relevant literature be guided by the data collected and the emerging codes and categories. As a result, the literature review was completed later in the project. Dunne (2011) discusses the benefits of undertaking a literature review in grounded theory, including the opportunity it offers to identify knowledge gaps, contextualising the study and enabling the researcher to gain access to concepts which may support the study. As suggested by Dunne (2011), I have approached this project from the perspective that a literature review is a practical necessity; as a Doctoral study, it was required in order to undertake the project. In doing so, I have approached the study with a “mind that is sufficiently open” (ibid, p.117), allowing the findings to dictate the concepts arising and subsequently exploring or re-considering the literature for relevant connections. Literature

identified during the course of the project has also been used in dialogue with the research findings (this is presented in chapter six).

Data collection indicated other topics of interest. For example, I investigated the literature relating to decision-making, and that concerning asthma was explored specifically when theoretical sampling suggested the addition of a second condition.

Thrombophilia offers an example of a long-term condition which has been little-studied, particularly when considering both the acquired and inherited forms, and individuals who have and have not experienced clots.

Undertaking this research using thrombophilia as an exemplar thus offers an opportunity to answer the aims of this study, whilst also offering novel research into the experiences of individuals with the condition. It will explore and explain how people make sense of their long-term, potentially life-threatening, health condition, using thrombophilia as one example. In doing so, it will consider the entire process of being diagnosed and living with the condition.

Analysis of data collected from individuals affected by thrombophilia suggested that a second long-term condition ought to be considered (see chapter three for full discussion of the reasons for this). As with thrombophilia, the condition chosen, asthma, may be latent for long periods of time but may lead to serious or life-threatening episodes, which may be influenced by self-management strategies. It is however recognised that in other ways the two conditions differ; the impact of these on the study findings are considered in chapters four to six.

This literature review is ordered according to concepts arising in the literature, some of which are similar to those identified in the findings of this study. It begins by considering the literature relating to information and LTCs, followed by how this information is used to make decisions and how individuals self-manage their condition. Practical issues relating to having a long-term condition are considered. It then moves on to review the literature detailing what it may be like to contend with a long-term condition. This is

contrasted with that considering how individuals may accept and experience well-being whilst living with a LTC. The study conditions are then explored individually.

## **Acquiring information about long-term conditions**

Patients acquire information about long-term conditions from a number of sources. They will receive information from the healthcare professionals dealing with them (including GPs, nurses, hospital consultants and/or specialists running condition-specific services) and they may also acquire information from friends, family members, others with the same or similar conditions, support groups and via the media or texts. Patients may also inadvertently come across information in the course of their daily lives. Longo (2005) states that

“health information is not always intentionally sought, yet it may be used and have profound consequences” (p.189).

This unsought information is important as it can reach everyone, and may be subconsciously assimilated into individuals’ understanding. It can be the cause of misconceptions if it is inaccurately presented or misunderstood.

### ***Acquiring information from health professionals***

Information is acquired from a variety of health professionals, potentially prior to, at the time of, and subsequent to diagnosis.

The final wave of a survey for the Department of Health (Ipsos MORI 2011) indicates that individuals with long-term conditions tend to approach healthcare professionals when seeking self-care advice or information in connection with their condition and would prefer to use this source in future. They also used the internet, books or magazines, and family and friends. Most people indicated that they were very satisfied with the advice received. This publication does not detail how the study was undertaken, and it offers interesting findings in comparison with much other research, which suggests that individuals often have unmet information needs. It is possible that this resulted from the survey only asking about the information provided, not



about whether patients were satisfied that their information needs had been met.

Patients affected by bleeding disorders (all of whom were members of the UK Haemophilia Society) reported a preference for receiving information from healthcare professionals or Society leaflets (Barlow et al. 2007). Desired information included that relating to current research, the effects of and managing the condition, lifestyle management and the psychological and social effects.

Individuals who had experienced a stroke rated different information important than healthcare professionals (Choi-Kwon et al. 2005). Patients perceived the following to be important: information about drugs including dosage, the drugs used, duration of administration, and the possibility of cure; medical knowledge about stroke (ibid). In contrast, health professionals perceived risk factor management (excluding stress), reasons for regular administration of drugs, and information about surgical treatment to be most important (ibid). Given these different perspectives, it would not be surprising if patients were left feeling that they had not received sufficient information, though this was not explored as part of the study. Healthcare professionals do not always wish to provide detailed information, as it may lead to anxiety, repeat visits from patients and could undermine their judgement in prescribing medication (Hamrosi et al. 2013).

Similarly, Lewis et al. (2010) systematically reviewed the literature investigating provision of information to children affected by epilepsy and their parents, and found that parents perceived that healthcare professionals' focus was on medication and number of seizures, and that they felt they lacked information about side effects, children's behaviour, managing school and prognosis. Patients with unexplained chest pain also experienced unmet information needs; this was the main theme found in a study undertaken in Norway (Røysland et al. 2013). Multiple sclerosis patients in Australia also had unmet information needs; healthcare professionals provided less than adequate information, and patients would like to receive more from this source (Matti et al. 2010).

Patients using internet discussion boards considered themselves to be responsible for the management of their diabetes, but valued doctors working in partnership with them, with patients and doctors learning together and respecting one another (Hewitt-Taylor and Bond 2012). Contributors discussed managing healthcare professionals, but power issues could result from the gatekeeping role of professionals (for example, where they did not agree that particular medication changes were necessary). This study offers an interesting contribution as data was collected from internet message boards, with posts which were relevant to the research question collected and analysed (ibid). As a result, contributors are likely to have been open in their thoughts about healthcare professionals, in a way they may not be in an interview or similar setting.

Parents of children in Finland were found to use a range of information sources to find out about their children's medication (Holappa et al. 2012). Data collected through questionnaires demonstrated that information was sourced from healthcare professionals and patient information leaflets, and the presence of a long-term condition increased the use of healthcare professionals for information. Other sources, such as the internet, medical books, the media, family and friends, helplines and natural food stores were used less frequently.

A review of the literature considering strategies for improving chronic care, found that knowledge could be improved by the provision of materials accessible to patients, however, the mode through which information should be provided is unclear (Singh and the Surrey and Sussex Primary Care Trust Alliance 2005). Written information may improve knowledge, but does not impact upon behaviours or quality of life. Though a large study considering 560 reviews and randomised trials, the authors do not offer reasons for this. However, it may relate to the analysis by Dixon-Woods (2001), which indicates that patient information leaflets follow one of two discourses: these being patient education and patient empowerment. The former contain information derived from the biomedical agenda, potentially to reduce the need for expensive time with a healthcare professional, or to reinforce

information provided in a consultation. The patient empowerment discourse, which is smaller in volume, offers information written for patients, reflecting their needs and priorities and acknowledging that difficulties in understanding and remembering information may exist, but aiming to empower patients rather than correcting them.

The literature indicates that information acquired from healthcare professionals may result in unmet information needs, potentially as a result of the differing views between professionals and their patients regarding what information ought to be provided. Written information which aims to empower patients may better reflect their needs than that written with the intention of educating them. As a result of their unmet information needs, patients tend to also gain information through other routes, which will be considered next.

### ***Acquiring information from others***

The literature indicates that individuals with long-term conditions also gained information from other people, either through support groups, or from family members. The latter occurred particularly where children were learning about their condition from their parents. Lewis et al. (2010) undertook a high quality, mixed methods systematic review of studies investigating the sharing of information about epilepsy with affected children and their parents. This study found that information obtained from parents could result in misconceptions and misunderstandings.

The information which is communicated may differ between settings and individuals. For example, contrasts were identified in information communicated about haemophilia in a healthcare setting when compared with that conveyed within a family (Gregory et al. 2007). Information was conveyed within the family at an appropriate time and in a relevant context, often over a longer period of time (ibid). Close relatives were informed of a diagnosis of inherited high cholesterol more frequently than more distant relatives (Van den Nieuwenhoff et al. 2007).

Family members' health and medical histories formed complex narratives in discussions of common illnesses (Lindenmeyer et al. 2011). Although decisions were made not to speak to some family members about particular topics, mainly to reduce the risk of them worrying, stories about how an individual was feeling and their general health were frequently shared, particularly between sisters. Stories about the health of the family as a whole were also created and shared. It is unclear how this data was analysed; the authors state that they developed a coding scheme based on their first interviews, but no detail is given about the analysis of their final interviews. However, the themes identified are supported by other research (for example, Van den Nieuwenhoff et al. 2007).

A focus group study of individuals attending cancer support groups (Docherty 2004) indicated that group members used one another's experiences as sources of both information and support, and the group offered a sense of belonging which could not be found within the health services. Online support group members with a range of long-term conditions were also found to share information and experiences, enabling other members to become better informed, enhancing self-esteem and improving acceptance of the illness (Bartlett and Coulson 2011). Most participants discussed the information they had gained from support group members with their healthcare professionals, and the majority of these were happy with the response they received (ibid).

Information from others focuses on experiences rather than on factual information. The literature shows that families may play an important role in disseminating information about health and illness, although information about specific conditions shared between family members may not always be medically accurate. They will however reflect the perceived experiences of the family. In contrast, online support groups have been shown to offer information, which increases the knowledge of and empowers individuals to discuss their condition more confidently with their healthcare professionals.

### ***Information in the media***

Many people search the internet for information (Childs 2004; Kivits 2004; Sillence et al. 2007). This may be of particular use, especially where patients feel they are not receiving enough information from health professionals (Kivits 2004), but may be inaccurate (Childs 2004), confusing or written in technical language (Brashers et al. 2002; Wyatt et al. 2005; Sillence et al. 2007).

Childs (2004) indicates that, although many people use the internet to find information on a health topic, “most websites, even those produced by health professionals and organizations, contain incorrect information” (p.15). It is important to note that specialised terminology and recent advances can cause problems for members of the public. Personal experience information may contain inaccuracies which can then lead to confusion as it contradicts other information available. This questionnaire study found that individuals preferred to use professional organisation and support group sites, and that privacy was an important factor. This is supported by Brashers et al. (2002) and Nettleton et al. (2005), who state that “The internet is a significant source of health information for lay people.” (p.972). Reflecting this, a survey conducted in the US found that 72% of people living with chronic conditions had access to the internet, and most had looked online for health information (Pew Research Center 2013). An earlier study, also in the US, found that almost a quarter of individuals with a long-term condition had sought out peers online (Fox 2011). Kivits (2004) explored the concept of the ‘informed patient’ and the use of the internet. Participants were asked why they access the internet and

“relentlessly stated that they do not have enough information from medical professionals” (ibid, p.515).

They also indicated that doctors were not providing answers to patients’ questions regarding their health. All types of information on the internet were used by participants – general and lay information in addition to medical or professional information.

Studies looking at internet use by cancer patients found conflicting results. Powell et al. (2005), whose participants had a mean age of 69 years, found that most participants with colorectal cancer did not use the internet to access information about their condition. This may however have been attributable to the average age of participants. In contrast, several authors have identified perceived benefits in accessing information through the internet, including Ziebland et al. (2004), Gray et al. (2005), Alexander and Ziebland (2006) and Antheunis et al. (2013). Benefits included that the internet could be accessed at all hours, without even needing to leave home; did not require face-to-face interaction; enabled access to information of different levels and types as and when appropriate; allowed individuals to check information from healthcare professionals; offered information which was current and portrayed a range of perspectives; enabled individuals to gain support from others and exchange advice. Potential problems with using the internet were also recognised, including quality of the materials, the lack of specificity when using search engines and the potential to find irrelevant sites, privacy concerns, and the risk of trusting others' experiences or of unwarranted worry caused by misdiagnosis.

The media, therefore, can be seen to have a significant impact on patients' understanding of health issues. Patients may access the internet in their search for information, particularly if they feel they have not received sufficient information from their health professional. Some individuals are aware of the potential problems associated with using the internet, but issues with information quality and the lack of opportunity to question information still exist.

In summary, information is acquired from a number of sources, and is of varying degrees of use to different people. Healthcare professionals have been shown to be the preferred source of information in a number of studies. However, they may have different opinions to patients of what information is necessary or desirable, and this can result in patients being left with unmet information needs, which often leads them to seek information from other sources. Written information may not be provided, in instances where

healthcare professionals act as gatekeepers, or can be inaccessible to some individuals. Other sources may include the internet, which is convenient with regard to time and place, allows individuals to gain information, and may support decision-making. However, there are a number of recognised problems with use of the internet, including the potential for information to be incorrect or written in technical language, privacy concerns, and the potential for unwarranted worry resulting from self-diagnosis. Information and experiences are also shared between individuals accessing support groups and family members; some of this may be incorrect and perpetuate inaccuracies, whilst stories allow individuals to access family information which would otherwise be unavailable. As can be seen, much of the research to date focuses on those information sources which are used most by patients, or considers them in isolation. This study will consider all of the information sources used by individuals, by asking them to consider where they obtained information, and will also consider how this information is used in day-to-day life with a long-term condition.

## **Making decisions about long-term conditions**

The information individuals acquire regarding their long-term conditions may be used for a range of purposes, and the literature demonstrates that in particular it can be used to guide decisions made by those with such conditions.

Stewart et al. (2010) used interviews with schizophrenia patients to explore patients' views and experiences of medicine management. The authors indicate that they used a modified grounded theory approach although they state that it is not clear whether saturation was reached (see the methodology chapter on saturation). Decision making regarding choice of medication, dose and format was frequently left to healthcare professionals, but participants did acknowledge that at some time they may need to take responsibility for their medication, with agreement that adherence was necessary. Staring et al. (2009) provide evidence that those who adhere to antipsychotic medication may experience not only reduced psychotic

symptoms but also increased side effects and reduced quality of life. The authors of this study state that there are therefore often other reasons for patients to comply with recommended treatment regimens than quality of life alone.

A range of tools were used to investigate the links between patient autonomy preferences (decision making and obtaining information), perceived support from healthcare professionals in being autonomous, trust in and satisfaction with physicians and health outcomes for patients with type 2 diabetes in Taiwan (Lee and Lin 2010). Those who received greater support had higher levels of trust in and satisfaction with healthcare professionals, particularly for those who preferred to make decisions, and higher levels of mental health related quality of life. However, greater support to act autonomously was not linked to objective health outcomes (glycaemic control), or to physical health related quality of life, except in those who wished to obtain comprehensive information regarding the condition. The findings suggest that supporting autonomy may, for those who wish to make decisions and to obtain comprehensive information, lead to both improved satisfaction in dealing with healthcare professionals but also to improved health outcomes.

According to a further review of the literature, individuals affected by long-term conditions decide to seek urgent care only when their condition becomes exacerbated (Langer et al. 2013). Patients generally sought to self-care where possible, offering a range of reasons as to why they preferred not to seek urgent care unnecessarily, but perceived that urgent care was an anticipated, integral and on occasion essential aspect of having a long-term condition.

Decision-making for those with LTCs may be aided by information gained about such conditions. Such information includes knowledge of circumstances in which urgent care may be needed. Decision-making does not solely relate to self-management, though this is one important aspect. With conditions requiring anti-psychotic medication, patients may rely on healthcare professionals to make decisions, and often follow these despite an adverse impact on quality of life. This study will consider the effect of



information on decision-making, as one aspect of the influence information has on those affected by a LTC.

## **Self-Management**

There is a range of literature relating to self-management of long-term conditions. This considers whether, how and under what circumstances individuals take responsibility for managing and, where possible improving, their health and the conditions affecting them. Higher levels of self-management have been linked to greater physical health and to having fewer depressive symptoms (Cramm and Nieboer 2012). According to a review of self-management approaches by Barlow et al. (2002), delivery takes place in a range of locations, most frequently clinical settings or the home, using a variety of formats through a group-based or individual route. The majority of tutors were healthcare professionals rather than lay people affected by chronic conditions, and the target population tended to be adults. Content of self-management interventions ranged from information, to drug or symptom management, dealing with psychosocial consequences, lifestyle, social support, communication, and other self-management strategies, such as coping, accessing support services and spirituality.

Audulv et al. (2010) explored through interviews the attribution of responsibility by individuals living with a range of long-term conditions. Two forms of responsibility attribution were identified, internal and external, and these applied to different aspects of responsibility, these being for causing good or poor health, making self-management decisions and whether to perform self-management behaviours. Participants who attributed responsibility to internal factors took responsibility for their actions, made decisions about the impact they would allow the condition to have and decided which behaviours to adopt accordingly. They also recognised the burden that came with being responsible for making choices, though over time some of these became routine. Other individuals attributed responsibility to external factors, believing they had limited control over their condition and expected instruction regarding self-management, including medication and

lifestyle adaptations, to be provided by healthcare professionals; these people tended to be vulnerable in situations where they did not receive necessary support. Many participants described a combination of internal and external responsibility.

Patients with chronic low back pain who had been discharged following physiotherapy reported a range of strategies which they used to self-manage their condition (Cooper et al. 2009). In particular, many wished to be able to self-refer back to a physiotherapist and most did some exercises, though not all were those recommended by the physiotherapist or at the frequency recommended by the healthcare professionals. Other self-management behaviours included being careful when lifting or bending, using heat, keeping mobile, lying down, taking painkillers and losing weight; most of these were self-taught by patients. The authors suggest that the participants may have insufficient knowledge to make decisions about when to self-manage or seek help, though it would appear that they were sufficiently knowledgeable to identify behaviours which could help them with their back pain, so I would question this proposition.

The experience of self-management amongst individuals affected by knee osteo-arthritis was explored by Ong et al. (2011). Individuals learned how to control and manage their pain through experimentation, and the findings demonstrate that hard work was required in order to manage their pain.

Individuals with mild-moderate psoriasis may find self-management problematic (Ersser et al. 2010), potentially due to a lack of information. They frequently had low expectations of health services and many developed their own self-management regimes. Most participants' use of topical creams could be erratic, focusing on treating particular symptoms, as they were unaware of the benefits of consistent use. Confirming this, Nelson et al. (2013) found that patients with psoriasis often perceive healthcare professionals to lack knowledge of the condition, to not recognise the condition as a stressor for those affected, that they do not manage the condition effectively or view it as a long-term condition, and as a result, patients often find alternative ways of coping with it.

In contrast to the findings of Ersser et al., boys with haemophilia (aged 4-16) were found to use personal experience and education from healthcare professionals, parents and other affected family members to develop self-management skills (Khair et al. 2013). Lack of adherence to prescribed treatment for haemophilia has a more immediate effect, as boys are likely to suffer painful and debilitating bleeds if they do not maintain their prophylactic regimen, which may not be the case with some LTCs.

A cross-cultural study undertaken in the United States and Denmark to explore the extent and reasons for self-care for those with multiple sclerosis found that both groups undertook self-care behaviours, particularly regarding fatigue, depression and limb weakness (McLaughlin and Zeeberg 1993). Knowledge of self-care skills and techniques was obtained from a range of sources, including experience (own and that of others), health and social care services, the media, support groups, and family and friends, and tactics included altering medication doses as well as altering the environment in which they lived and worked. Individuals stated that self-care gave them a feeling of independence as well as enabling them to help themselves and potentially reduce the symptoms they experienced.

A more recent review of qualitative studies concerning self-care for those with diabetes found that a number of factors acted as facilitators or barriers to the process (Wilkinson et al. 2014). Communication with healthcare professionals and provider issues, such as access to healthcare providers and quality of care, could promote or reduce the ability to self-care, as could a range of personal factors. Education which was appropriate, understandable and specific was necessary to support self-care, as was support from others. The authors summarise that

“Self-care ability is a dynamic, evolutionary process that varies from person to person and involves moving from a disease focused existence to maximising life.” (Wilkinson et al. 2014, p.111).

In the UK, the Expert Patients Programme has been promoted as a route to helping patients self-manage their long-term conditions (Department of Health 2005). The programme has been found to perpetuate the medical

model, though it also legitimised patients' experiences and provided support, with some participants meeting up on an informal basis outside of the Programme structure (Wilson et al. 2007). Barlow et al. (2009) found that patients with multiple sclerosis who attended the Expert Patients Programme showed a trend towards improvement in self-efficacy and depression; these results were however not statistically significant. Research reviewed by Vadiee (2012) offers further insights into the Programme. This indicated that the Programme does not have long-term positive effects on individuals' ability to self-manage and thus does not reduce their need to access healthcare services. It has also had a limited reach, and many patients who may utilise the Programme have experienced barriers to its uptake.

Barlow et al. (2002), undertaking a review of literature relating to self-management approaches, determine that self-management may offer benefits to patients, including knowledge and self-efficacy. However, this is contrasted by a Cochrane Review (Foster et al. 2009) of self-management programmes, including the Expert Patients Programme, which concluded that little evidence exists of the benefits of self-management programmes. Patients interviewed by Gatley et al. (2007) confirm that, according to the self-report of most individuals, taking part in an Expert Patient Programme does not reduce their level of service use; statistical data demonstrates similar findings (Kennedy et al. 2013). There is thus contrasting evidence regarding the benefits or otherwise of self-management programmes; it appears that individuals may gain personal benefits in the form of support and improved self-efficacy and having their experiences acknowledged, but at a healthcare systems level, implementing the Programme does not reduce reliance on and the need to access healthcare services. Conflicting results may also arise from the purpose of and approach used in the study; the Cochrane review included only randomised controlled trials (Foster et al. 2009), whilst the review by Barlow et al. (2002) included reports of non-randomised controlled trials.

Research into healthcare professionals' opinions of self-management for patients resulted in interesting findings; not only were they concerned that

patients may not follow their prescribed medication regimes (as can be seen in the other literature detailed herein, this is a factor in self-care), they also believed that some individuals would have limited capacity to self-care (Lake and Staiger 2010). Barriers cited included: cognitive impairment; complex conditions; dysfunctional family situations; and cultural context. The majority of participants had not received training in supporting patients with self-management and I would suggest that this could have been a factor in their opinions of the barriers to self-management. Interestingly, they list having cognitive impairment and complex conditions as barriers; this may result in them not promoting self-management to affected individuals who could have benefited from such an approach.

Self-management is often promoted as a way for individuals to manage their long-term conditions which requires less input from healthcare professionals. Training and education in self-management may take place at a range of locations, involve different actors, both lay and professional, and may consist of different formats and content. In addition, some self-management techniques are self-taught, as individuals learn through experimentation what may help with their condition. Self-management has the potential to lead to greater health and less depression, and may be more likely to be successful if one has an internal attribution of responsibility. Despite their intentions, self-management programmes do not always result in reduced reliance on healthcare services, but they can lead to benefits for individuals in the form of knowledge and behaviours.

Of course, many of the conditions discussed differ from those in the current study. However they need to be considered as they show similar experiences, problems and solutions. My research will not specifically consider the self-management experiences of participants, but it is expected that this will arise as part of the conversations held.

## **Practical issues associated with long-term conditions**

Some previous research has focused upon the practical challenges offered by having a long-term condition. Though limited, this offers important insights into some of the day-to-day effects of having such a condition.

Various 'hassles' were identified by individuals affected by diabetes or respiratory or neurological conditions in an interview study by Wilson et al. (2013). Such hassles included the need to carry equipment and, most frequently, the need to order and collect repeat prescriptions. This latter issue was compounded for those individuals who were affected by multiple conditions and taking a range of medications, due to the significant hassle represented by needing to collect a range of prescriptions at different times. Those with thrombophilia and asthma may be taking medication for their condition, and could thus also experience the need to collect multiple prescriptions.

In contrast, a questionnaire study by Anandan et al. (2006) investigated the difficulties experienced by individuals living with HIV, a once fatal condition which is now considered to be chronic due to medical advances. The most frequently reported occupational competences were managing finances and doing what the individual set out to do. The authors note that there may be a range of reasons for these, including medications, the lifestyle those with HIV may live, and the uncertain course of the illness. As a questionnaire study utilising specific instruments, there was no opportunity to further explore individuals' experiences of these issues, and how they may specifically affect their lives. Similarly, the course of both asthma and thrombophilia may be uncertain, as neither condition is fully controlled by medication and limiting risk.

The literature demonstrates that having a long-term condition may result in day-to-day problems which need to be met by individuals, such as obtaining repeat prescriptions, potentially for a number of different medications which need to be collected at different times, and arranging financial matters. I will

now turn to consider more existential issues which those with LTCs may experience.

## **Contending with long-term conditions**

A range of literature has explored the experience of living with a long-term condition, and frequently treats such experiences as problematic. However, the research is sometimes construed in such a way as to explore the negative aspects of having a long-term condition, rather than the experience as a whole. This section will consider what it is like to contend with a long-term condition, before I move on to consider how it may be possible to accept such a condition and achieve well-being in spite of it.

Charmaz (1999) describes the concept of suffering in connection with chronic illness, as a physical sensation, which can eventually lead to a changed self, elevating or reducing one's moral status, and how suffering may lead one to reflect differently on one's own story of the self. This can be contrasted with Wilson et al. (2013), who describe the practical effects of having a long-term condition.

Having chronic obstructive pulmonary disease (COPD), was also perceived by patients as a negative experience (Clancy et al. 2009). This qualitative study considered existential experiences, and the findings indicated themes such as struggling, fear (also seen with HIV), experience of ill health, blame, fatalism and hidden disability. The authors state that

“None of the participants appeared to have found ways to embrace their condition or make positive changes to their lifestyle in an attempt to master and cope with their illness.” (Clancy et al. 2009, p.84).

This is confirmed by Kurpas et al. (2013), who found that levels of illness acceptance for individuals with a variety of chronic respiratory illnesses was low, and that low acceptance correlated with increased age, being divorced, lower education levels and increased use of the health services. These authors also report that quality of life is reduced amongst individuals of older age with a range of conditions, and reduced quality of life also correlates with

increased number of long term conditions, lower levels of education and increased use of health services. Higher levels of acceptance of the illness resulted in higher quality of life scores. Although the study focuses specifically on the relationship between age, illness acceptance and quality of life, it is possible that this statement holds true for individuals across the lifespan. The current study does not intend to explore healthcare economics, but may find evidence which contributes to the concept of illness acceptance and wellbeing.

Another study identified similar findings: having more long-term conditions negatively impacted on quality of life, and lower levels of education negatively impacted on Health Related Quality of Life scores (Heyworth et al. 2009).

The above may be contrasted with evidence from Chittleborough et al. (2011) who explored the links between chronic conditions and psychological distress amongst different age groups. The findings indicated that those of a younger age were more inclined to experience psychological distress, and those with a chronic condition were more likely to be distressed than those without. The study also demonstrates that different chronic conditions are associated with varying levels of psychological distress, with arthritis and mental health conditions being linked to distress for all age groups, and cardiovascular disease, asthma and osteoporosis being linked to distress for specific age groups. With regard to older people, anxiety disorders have been linked to chronic conditions including arthritis, back pain, migraine, allergies, cataracts, gastrointestinal, lung and heart disease (El-Gabalaway et al. 2011). Anxiety disorders under consideration were panic disorder, agoraphobia, social phobia and post-traumatic stress disorder. In addition, the more long-term conditions affecting an individual, the more likely they were to also have an anxiety disorder.

Fiest et al. (2011) undertook a study in Canada to estimate the rates of long-term conditions and comorbid depression and to estimate the associations between these in two adult populations: those over 50 years of age, and those aged 65 and over. The findings demonstrate that more than three



quarters of those aged over 50 years (82.4%) are affected by at least one long-term condition, of whom 3.7% also had recently experienced a major depressive episode. However, the study is unable to evidence a causal relationship between long-term conditions and depression, due to the nature of the data collected. Moussavi et al. (2007) used data collected through the WHO World Health Survey to identify prevalence rates for depression, angina, arthritis, asthma and diabetes. They concluded that rates of comorbid depression were significantly higher than depression rates in the absence of one of these diseases, and that several measures of health used in the survey were worse for individuals with both depression and one of these conditions. The survey is however limited in its consideration of long-term conditions, and it would be interesting to explore the rates of depression in individuals with conditions other than angina, arthritis, asthma and diabetes.

Patients' illness perceptions of systemic lupus erythematosus (SLE) and proliferative lupus nephritis (inflammation of the kidney, which may lead to kidney failure, common in those with SLE) were explored by Daleboudt et al. (2011). These were more negative in patients with SLE than those of patients with asthma (though there was no matching of age and gender for the comparison), however, patients who had lived with the condition for a longer period of time and those who had experienced more episodes of proliferative lupus nephritis tended to experience less anxiety.

Illness perceptions were found to be important in explaining anxiety, depression and fatigue in individuals with chronic fatigue syndrome (CFS) (Edwards et al. 2001). Those who were anxious or depressed experienced increased symptoms, perceived themselves to have little control over the illness, and believed that the consequences of CFS would be severe.

Price (1996) reviewed with patients what it means to have a chronic illness, through case studies of individuals with rheumatoid arthritis and asthma. The resulting personal constructs indicate that life with a long-term condition for these people is problematic. The body does not function as it should, though they hoped that treatment changes could improve this functioning, and the

participants focused upon the disability caused by the illness, rather than on other aspects of their selves. Participants' perceptions of their social (in)adequacy also arose as a construct. The author suggests that there are implications for healthcare, which may wish to take account of individuals' constructs of their illness and its impact upon their lives. This paper does not describe what forms of analysis took place of the information offered by the participants, though the constructs offered are not all the participants' own words and so some form of analysis clearly did occur. It does, however, offer interesting insights into how those with long-term conditions may perceive the illness as problematic, at least at some point in their illness journey, and offer some reasons for why this may be so.

A review undertaken by Kingsley et al. (2011) of outcome measures used in relation to rheumatoid arthritis (RA) indicates that those with active disease score lower in quality of life measures, as do those with RA compared to those without. Indeed, some patients completing the EuroQoL tool obtain scores which indicate they are in "states worse than death" (Kingsley et al. 2011, p.597).

Individuals with some conditions may experience biomedicalization of what may be considered normal processes, particularly if they are 'diagnosed' with a high risk of becoming ill, rather than a condition specifically. Salter et al. (2011) explored with older women the experience of being diagnosed as being at higher than normal risk of having a broken bone. Individuals who had taken part in a trial to determine whether a community based screening programme for osteoporosis could be successful in reducing the risk of fracture in older women were interviewed about their experiences. The findings suggest that the diagnosis of being at higher than normal risk of having a broken bone could be confusing, frightening, shocking and unexpected, though some participants anticipated the outcome as a normal part of ageing or based on previous history. Some participants described changes they had made to their lifestyles as a result of the 'diagnosis'. Biomedicalization also occurs with other conditions; indeed, thrombophilia, discussed later in this chapter, could be described as the biomedicalization

of an increased risk of having a blood clot, particularly in the inherited form when individuals have never experienced a previous thrombosis.

According to these research findings, those with a long-term condition could be described as contending with their illness; the illness is perceived as problematic, altering the self, creating biographical disruption, affecting quality of life and potentially leading to anxiety and depression. The condition may be disabling, through mental or physical means which may lead to social isolation, impact upon employment and restrict general activities. Some studies suggest that illness perceptions may correlate with the emotional and mental impact of a long-term condition, and this will be considered again in the next section.

### **Long-term conditions: acceptance and well-being**

In addition to the range of literature which indicates that having a long-term condition may be problematic for individuals concerned, research has also demonstrated that it may be possible to accept and achieve well-being, even when living with such a condition. This research tends to focus on meaning and the qualitative experience of having a LTC, and offers alternative perspectives, often of the same or similar conditions.

In contrast to the findings of Kingsley et al. (2011), who identified through a quantitative study that those with arthritis may obtain particularly low quality of life scores, Sanderson et al. (2010), using a grounded theory approach to the analysis of interviews with individuals affected by rheumatoid arthritis (RA), developed a theory designated *feeling well with RA*. Four major themes were identified which contributed to this: living in the body, being in the mind, adapting to illness and being in the world. Feeling well was a multifaceted experience for participants, and did not solely relate to the impact of having rheumatoid arthritis; indeed, some participants who reported feeling well were disabled by and experiencing symptoms of rheumatoid arthritis at the time of the study. The qualitative findings of Sanderson et al. (2010) are thus interesting as they indicate that not all long-term conditions, even when causing illness, are viewed as problematic by

those experiencing them. They also demonstrate that measuring quality of life through established and validated tools may result in different findings than qualitative research which explores with affected individuals what it is really like to live with a condition. Thus a qualitative approach will be adopted for the current study, and the research will assume that having a long-term condition is not necessarily problematic for those affected, with interview guides constructed accordingly.

Similarly, a study considering illness perceptions of rheumatoid arthritis (Graves et al. 2009) found that disease activity (the extent of the symptoms of the condition) did not relate to disease identity. The authors state that

“This suggests that patients' perceptions of their illness may not be a function of disease severity. When the illness is worse, we may expect corresponding beliefs, but the absence of a relationship suggests this is not the case; there is wide variation among individuals, and illness beliefs cannot be explained by disease status. Patients with very active disease do not necessarily view their illness as worse than others.” (ibid, p.422).

This can be contrasted with the findings presented in the previous section, which suggested that perceptions of systemic lupus erythematosus and chronic fatigue syndrome were negative and may lead to anxiety and depression. Thus it appears that illness perceptions differ according to an individual's experience of illness, and may depend upon the illness in question. In at least some instances, severity of the illness at a particular time-point does not necessarily correlate to how an individual perceives their condition.

In a study to illuminate the meaning for women of living with urinary incontinence, Hägglund and Ahlström (2007) found that acceptance of living with the condition contributed to the theme of striving for adjustment, where the overall meaning of living with the condition is powerlessness. Striving for adjustment was an attempt to regain power over the condition and be able to live a normal life.

The personal impact of having type 2 diabetes decreased over time, and individuals were more likely to have accepted the condition and both knew

more about it, and wished to gain increased knowledge according to the findings of Kenealy et al. (2008). This was despite an increase in co-morbidities and complications associated with the diabetes, together with taking medications for these. A study by Wilson et al. (2011), exploring how individuals experienced chronic fatigue due to a range of health conditions, found that acceptance was a prominent theme, allowing people to recognise that they had changed and to come to terms with this.

Cooper et al. (2010) explored with individuals affected by inflammatory bowel disease (IBD) their beliefs regarding self-control and personal management, and found that a single main theme emerged, this being reconciliation of the self in IBD. This was comprised of three sub-themes, including living with uncertainties and contradictions and I've got it or it's got me. Self-management involved not only managing their lifestyle but also accepting that at times the condition could be inconsistent in its effects. For some individuals, good quality of life could be found despite the condition. The authors make several brief references to the contribution of information to the reconciliation of the self in IBD, but do not bring these together as a concept and it is difficult to draw conclusions from these. The current study will explore the contribution of information to life with a long-term condition more explicitly.

Listening to the body was found to be an important contributor to behaviours and the meaning of particular experiences for both healthy individuals and those with long-term conditions (asthma and multiple sclerosis) (Price 1993). Those with a long-term condition were more likely to speak of vigilance and control – both having control and being out of control. The group of participants with multiple sclerosis described the uncertainty that came with the condition. The findings suggest that individuals listen to their bodies both consciously and unconsciously and have an explanation of 'what is me' (the body paradigm). Those with chronic conditions adapt to a new body paradigm as the effects of the condition become apparent and who they physically are changes.

Nurses affected by musculoskeletal disorders (Wiitavaara et al. 2007) also were more aware of their bodies, when they experienced pain and discomfort. Despite this, participants found ways of attaining wellness, and came to accept the illness, though it was handled not only as an experience, but also as a threat. This grounded theory study, though small and focused solely on women, offers a useful theory which explains how people with particular types of disorder strive for a balance in order to feel 'well enough'.

Despite hypertension being considered to be a non-symptomatic condition, individuals interviewed by Sångren et al. (2009) reported experiencing signs when their blood pressure was higher, which made participants aware of their behaviour. These signs were used to test the body, with participants adapting their behaviours according to their impact on their perceived or actual blood pressure. Individuals experienced an altered approach to life; they did not however consider themselves to be ill. Overall a diagnosis of hypertension is conceived as a "biographical disruption" (a concept developed by Bury, 1982), which has an impact on everyday life for those affected. They did however adapt to their diagnosis. Little consideration is given to the criteria required for this adaptation, and whether all participants achieved it.

Well-being was experienced by adolescents with a range of long-term conditions or disabilities according to the findings of Berntsson et al. (2007). An important aspect of well-being was acceptance of the illness as part of everyday life; knowledge was a significant contributor to this. Feeling supported was also necessary for well-being to occur, as was a feeling of personal growth. The participants took responsibility for making decisions about their conditions and were self-reliant.

Acceptance was also a core theme arising from a study to explore well-being among older recipients of home-help (Hammarström and Torres 2012). Predictability – how predictable their situation was – and how much control they had over their situation also affected whether individuals experienced well-being, well-being despite it all, well-being so far or a lack of well-being.

The literature offers indications that, as an alternative to perceiving a long-term condition as disabling, having a long-term condition may be accepted by some individuals and they may be able to experience well-being in spite of it. This does not necessarily correlate with active symptoms: even when feeling ill, some people were able to feel well. Acceptance appears to be a significant component of being well, and information may also hold relevance. Recognising one's body – rather than merely living in it – may help individuals to realise what is possible whilst living with a long-term condition.

Interestingly, qualitative and quantitative studies involving consideration of the same condition may lead to conflicting results regarding individuals' perceptions and experiences of their condition. This study adopted a qualitative approach, as one more likely to be able to explore concepts with participants in greater depth and discover how they really feel about their condition.

I will now consider the literature specifically concerning the study conditions.

## **Thrombophilia**

A limited amount of research has considered the effects of a thrombophilia diagnosis on individuals affected by the condition. The majority of the identified literature relating to thrombophilia was biological, scientific or medical and is therefore not considered herein. The literature which does exist indicates that most of those with thrombophilia are aware that it confers an increased risk of blood clots. They may or may not have received sufficient information from health professionals, and some sought information from other sources. Information considered necessary includes risk factors, knowledge of which could lead to the adoption of different health behaviours in order to mitigate the risk of clots. However, some individuals did not give informed consent to be tested for thrombophilia and some were unaware of their positive test result. Having a clot or post thrombotic syndrome may impact on quality of life, and individuals may be scared by the experience. It should be noted that much of the literature detailed herein relates to inherited

forms of thrombophilia, but it is anticipated that the findings are relevant to acquired forms due to the similarity in disease mechanism in leading to an increased risk of clot for those affected.

In a pilot study relating to the management of asymptomatic individuals with thrombophilia, Wells et al. (2009) found that

“Patients with VTE and thrombophilia and their FDRs (*first degree relatives*) are often not interested in thrombophilia testing.” (p.475)

Several studies have found that individuals are not always aware that they have been tested for thrombophilia or of the results of the test (Hellmann et al. 2003; Saukko et al. 2007; Etchegary et al. 2008; Vegni et al. 2013), and those who are aware of the test and its result may have little understanding of their meaning (Vegni et al. 2013). For some, the receipt of a positive thrombophilia test result may lead to considerable distress (Van Korlaar et al. 2005), though this is in conflict with the findings of Legnani et al. (2006), who found in a questionnaire study that those receiving thrombophilia test results did not experience significant worsening of various wellbeing and anxiety scores even if they were diagnosed as having the condition.

Factor V Leiden test results were shared with family members, according to the findings of Bank et al. (2004), and individuals claimed that the condition did not impact upon their lives. This was however contradicted by their comments: one individual had experienced discrimination from his insurers, another had changed her lifestyle and others were worried about their thrombophilia status. However, only individuals who had not previously experienced clots were interviewed; the findings may have been different for those with experience of deep vein thrombosis.

For individuals with a personal history of DVTs, the test for hereditary thrombophilia was not considered to be exceptional and it was perceived as being less serious than some other medical tests (Saukko et al. 2006). Participants compared the condition with other illnesses of which they had experience, and placed thrombophilia testing within this context. However, a small group of individuals were particularly distressed, reflecting the findings



of Van Korlaar et al. (2005). This group tended to be less certain about whether the lifestyle changes they had made were effective. Despite this, the authors indicate that participants used the test results to inform their decisions about hormone treatments and flights.

Heshka et al. (2008) undertook a questionnaire study to compare those with thrombophilia to those without with regard to perceived causes of clots, perceived control, health behaviour changes and the use of healthcare services in Canada. The findings demonstrated that some individuals did not fully believe their test result, whether positive or negative for the condition. Individuals were aware of risk factors for clots, though they overestimated the risks associated with anxiety, negative attitudes and over-exertion. Most individuals had changed their behaviours since the test result, including limiting their exposure to chemicals, avoiding infections, adopting a more positive attitude, decreasing stress levels, losing weight, improving their diet, exercising more and reducing their risk of injury. Fewer people had also avoided long trips and were not working as hard. Few wore compression stockings, even at times of increased risk. Most of those surveyed indicated that they were satisfied with the information provided by health professionals regarding the condition.

A range of studies have demonstrated that those who have experienced a thrombotic event may experience reduced quality of life (van Korlaar et al. 2004; Klok et al 2010), particularly those who develop post-thrombotic syndrome (Kahn et al. 2002; Kahn et al. 2008; Wik et al. 2012). One patient's experience of having a blood clot following an ankle fracture (Harvey and Runner 2011) describes how she felt severe pain in her calf, followed several days later by difficulty in breathing together with chest pain. Despite having several risk factors for thrombosis, and having complained of pain, she felt that the healthcare professionals were unsupportive and had not listened to her. The authors state that "Patients are fearful and angry" (ibid, p. 190).

An interpretative phenomenological analysis of interviews carried out with individuals with hereditary thrombophilia was undertaken by Moore et al. (2008). They identified three major themes relating to individuals'

experiences of repeated blood clots and having thrombophilia: the impact of thrombophilia on causal models of clots, primary control and secondary control. Before receiving their diagnosis of thrombophilia, individuals had identified a cause for their (repeated) DVTs, and, following diagnosis, anxiety about further DVTs tended to be reduced. All those interviewed had changed their behaviour in order to decrease their risk of clots (primary control) despite the disadvantages of, for example, taking warfarin. Individuals also accepted their risk of clots, including the uncertainty associated with the condition, and

“described the importance of re-prioritizing aspects of their lives and expressed a deep appreciation for life and the need to focus on important relationships” (ibid, p.781)

Confirming these findings, Lindqvist and Dahlback (2003) also found that those affected by hereditary thrombophilia may change their behaviours, in this instance their oral contraceptive taking, though not all those in the study chose to do so. In addition, they found that some of the women who responded to the questionnaire were worried about becoming pregnant again following their diagnosis, though there was no corresponding increase in the rate of abortions compared with a group whose thrombophilia test was negative.

The experiences of women coping with thrombophilia during pregnancy were explored by Martens and Emed (2007). Treatment to reduce the risk of miscarriage or other complications involves injections of either unfractionated or low molecular weight heparin, self-administered by the woman. Four themes were identified, these being

“the impact of diagnosis and treatment on the pregnancy experience, the need for professional support, a perceived sense of uncertainty, and successful coping strategies” (ibid, p. 57).

Participants felt that they did not receive sufficient information regarding the condition or the practicalities of injecting themselves with heparin. They took control by requesting testing or treatment from their doctor, and by seeking

information from a range of sources, including the internet, books, and stories shared with other women.

A number of studies have confirmed that people with thrombophilia do not feel they have been provided with sufficient information, including those with Factor V Leiden, some of whom used other information sources (Hellmann et al. 2003) and individuals who had been tested for hereditary thrombophilia in the UK (Saukko et al. 2007) and Italy (Vegni et al. 2013). In the latter instance, the authors state that

“The test does not seem to have an emotional impact, but rather a cognitive one: the test is perceived as a tool for knowledge.” (Vegni et al. 2013, p.90).

This does not seem to be true of all the studies considered, but may be a reflection of the timing or location of the study.

Themes differed in online discussions compared with offline interviews carried out with people who had been tested for or had thrombophilia (Saukko 2009). Those participating in online groups were more likely to be taking medication or to have had a recent clot. The most common theme for the online group was the use of anticoagulant medication, whilst the most common topic among interviewees was that participants did not consider thrombophilia or testing for the condition as particularly important. The author suggests that internet groups may create a group culture which focuses upon a particular topic, such as medication.

Etchegary et al. (2008) explored psychosocial aspects of having clots, collecting data through interviews and using constant comparison to analyse the data. They describe zones of relevance relating to the experience of thrombosis. The first of these occurs during and immediately following a thrombosis, when individuals may be particularly anxious and experience difficulties in complying with the requirements of its management such as frequent blood tests. Another occurs in relation to travel, with individuals curtailing or changing their approach to travelling. They tended to seek a cause for the clot they had experienced and to comply with recommended

behaviours such as wearing compression stockings. All participants had been tested for thrombophilia, though not all remembered this, and most had warned family members of their potential risk. It is possible that the use of a “detailed question guide” (ibid, p.491) may have resulted in the omission of some topics of relevance; there is no mention of the risk to pregnancy despite some participants being under the age of 40 and female.

The literature relating to information sources, the use of this information and the experiences of individuals living with thrombophilia is limited and none considers the process and links between these factors in its entirety. Not all individuals received sufficient information from healthcare professionals, and some sought information from alternative sources. There is contrasting evidence regarding the impact of the condition on people’s lives. Some people made lifestyle changes as a result of their diagnosis, and certain groups of people are at a higher risk of experiencing anxiety after their diagnosis. Online groups may be accessed by those affected by thrombophilia, but these can acquire a group culture focused around a particular topic, which could lead to the exclusion of some individuals or discussion topics.

## **Asthma**

The literature relating to asthma is extensive and includes not only literature considering studies on self-management and information seeking, but also a range of other research undertaken with regard to this condition. Some of this literature focuses on the experiences and perceptions of children with asthma. The current study will not consider the experiences of those under the age of 18 years, so this literature has been considered only minimally in this review.

Unlike the literature relating to thrombophilia, which is limited, this aspect of the review is separated into different aspects of the experience of those with asthma, in order to aid the reader in making sense of the extensive reading available. Despite the extent of the literature available in relation to asthma, this is considered to be an appropriate second exemplar in this study due to

the similarity to thrombophilia in the nature of the condition, and because no previous literature has explicitly considered how individuals make sense of their condition, as this study will.

### ***Information and asthma***

Information about asthma is obtained from a range of sources: Abadoğlu et al. (2010) found that the majority of patients in a Turkish setting preferred to obtain information from a healthcare professional, but other sources included family and friends, the media, and medical journals. Half of those involved in the study felt well informed about their condition. Participants in an American setting (Zahradnik 2011) also preferred to obtain information from healthcare professionals, though other sources also included family and friends, the internet, herbalists or traditional healers, leaflets or books, or spiritual leaders. Many of those who completed a survey were found to be knowledgeable about their condition, though misconceptions occurred in relation to triggers, treatments and the possibility of cure.

Different studies have identified key information needs of asthma patients, including medications, their side effects and the possibility of new therapies, asthma attack triggers, avoidance measures and prevention, substances, environment and allergy, allergic asthma, lifestyle issues, cause and effects of asthma, the long term outlook and control of symptoms (Caress et al. 2002; Bush et al. 2006). Confirming the findings of Abadoğlu et al. (2010), participants perceived that some of these information needs were unmet.

In a study considering why patients with asthma choose complementary and alternative medicines rather than prescribed medications, Kopnina and Haafkens (2010) found that all individuals read the instructions for their prescribed medicines. However, most also read further information such as online information and articles about the prescribed drugs. Some consulted printed sources. Although some described being overwhelmed by the information and finding that it was written using jargon, most indicated that the information they found enabled them to make informed choices. Family and friends provided an addition information source, as did fellow asthmatics.

The authors argue that participants were using the medical model of evidence-based medicine themselves, to make informed choices which led to their rejection of conventional medications and to their acceptance of complementary and alternative medicines.

Asthma is the most common long-term condition affecting children, as a result of which the parents of affected children become involved in learning about asthma and how to care for their children. Information needs may be unmet and misconceptions may arise (Anwar et al. 2008; Orrell-Valente et al. 2011; Archibald and Scott 2012).

Information leaflets mandatorily provided with asthma medications elicited a mixed response from patients with asthma in the UK (Raynor et al. 2004), with some considering them to be useful and informative, whilst others perceived them to be confusing, unclear or missing important information. Information on side effects was not considered to be freely provided. In a US study, the information provided alongside asthma inhalation devices was found to be at an inappropriately high reading level, and instructions were offered in an out-of-order sequence compared to the order in which actions were to be taken (Wallace et al. 2006). With regard specifically to oral steroids, taken when asthma symptoms are severe, interview participants perceived the need to take the medication, but felt that the information provided by GPs, particularly about their side effects, was insufficient (Stevenson et al. 1999). This occurred even when participants requested further information, and on occasion they felt that their concerns about taking steroids were ignored.

Information about asthma found on the Korean internet in early 2003 was frequently unreliable (Park et al. 2004). The readability of websites may also be an issue for patients; less than a third of websites considered in a US study had an appropriate reading level (Oermann et al. 2003). The findings of a more recent study (Nagappa et al. 2009) also suggest that many websites offering information about asthma are not of excellent quality; using criteria for website evaluation offered by the Health Summit Working Group, just over a quarter of websites considered (26.19%) were graded as

excellent. Of 68 websites evaluated by Meadows-Oliver and Banasiak (2010), only 6 were considered to contain accurate information. Although it is to be expected that sponsored websites may maintain a bias towards the sponsor, unsponsored websites may be assumed to be more accurate; however, of 36 unsponsored websites considered, only 4 contained accurate information.

Information about asthma is acquired from a range of sources, including the preferred source of healthcare professionals; this is similar to findings for other long-term conditions. However, many people, including parents of affected children, describe unmet needs and they are often aware of specifically unmet information needs. Information about asthma medications may be useful, but is often inaccessible. The same findings were identified when using the internet, where individuals preferred to access the experiences of others rather than sites containing only factual information.

### ***Self-management and education***

According to Demoly et al. (2012), 53.5% of those with asthma across five European countries (UK, France, Germany, Italy and Spain) do not have their condition under control. Many of these report frequent breathlessness, use of reliever medication and waking with symptoms in the night. Individuals with asthma are willing to spend time on and pay for asthma self-management programmes (Barner et al. 1999). Despite this, a recent review found that the uptake of self-management strategies is low, although research suggests that they can reduce the impact of asthma on individuals' health (Andrews et al. 2014). This could be at least partly due to a lack of engagement between patients and healthcare professionals; a personalised service may be necessary to support health literacy, self-efficacy and hence self-management practices. It may also result from the desires of patients; according to Gibson et al. (1995), patients who had a strong desire to gain information about their condition nevertheless did not wish to make decisions during an asthma exacerbation. According to a review undertaken by Ring et al. (2011), medically focused action plans may not make sense to those with

asthma, as their explanatory models of the condition and its management differ from clinicians. This is likely to result in their under-use.

Education aimed at improving patients' knowledge of asthma may be conducted through a range of formats. Studies have considered the use of group or individual education programmes, using a range of formats and some have also included self-management such as monitoring (Thoonen et al. 2002; Meszaros et al. 2003; Berg et al. 2004; Demiralay 2004; Sundberg et al. 2005; Urek et al. 2005; McPherson et al. 2006; Joshi et al. 2007; de Vries et al. 2008; Petkova 2008; Nokela et al. 2010). Some have specifically considered education and self-management programmes targeted at children (Burns et al. 2008; Razi et al. 2011). Bauman (1997) reviewed literature relating to asthma education materials and found that the readability of these materials is often inappropriate. They are frequently written to target high reading ages (assuming higher levels of education), and are unlikely to be comprehensible to much of the population. Print and video-based education materials were shown to both improve recall of information regarding inhaler use and asthma triggers, and those patients who later reviewed the print materials (they were not given the opportunity to take the video away for review) recalled information at a later date better than those who did not. Education was frequently found to have a positive impact on individuals:

- parental coping was improved through the use of a home-based intervention (Dolinar et al. 2000),
- information need was reduced and patient satisfaction increased through the use of a tailored education programme (Thoonen et al. 2002),
- one year after an educational programme, knowledge and correct inhaler use increased, but not compliance with treatment or hospital admissions (Demiralay 2004), and



- asthma-related knowledge, improved symptoms and reduced reliance on reliever inhalers resulted from the use of three different education programmes (Urek et al. 2005).

However, Urek et al. (2005) also demonstrate that different programmes have a different impact on quality of life (integrated asthma classes and individual verbal instructions had a greater impact than an asthma booklet) and peak flow readings (again, the booklet had least effect).

A Cochrane Review (Powell and Gibson 2002) recommends that self-management of asthma incorporates self-monitoring of either peak flow readings or symptoms, resulting in self-adjustment of medications according to a written action plan. Alternatively, regular medical review may result in medication adjustment.

Some self-management strategies have been shown to be effective in resulting in improved asthma control (Janson et al. 2003; Janson et al. 2009) or not (Kuijer et al. 2007). According to other studies, there may be reasons for these: information about asthma and how to manage it could be perceived as irrelevant or provided in complex language, and individuals balanced the 'good' (being able to undertake daily activities) with the 'bad' (asthma symptoms and recommended treatments or lifestyle restrictions) (Ross et al. 2010). A plethora of different terms may be used, not all of which hold a clear meaning for the patient (Ring et al. 2011). According to Laignon et al. (2009) who undertook a study in the US, different self-care strategies are adopted by individuals; some opt to control symptoms, taking medication as prescribed and seeking medical advice if they experienced an acute attack despite this. Others manage their condition by preventing symptoms, though through avoidance of triggers rather than through the use of medication. Reliever inhalers were used only when alternatives were ineffective. This group rarely required emergency treatment for an acute attack. The final group of people tolerated asthma symptoms, in part because they were unable to afford the treatments. Some participants switched between strategies at different points in their biographical journey with asthma.

According to daily diaries kept by participants, adherence to asthma self-management plans varies and is more likely to occur when asthma is more severe (Wraight et al. 2002). Both symptoms and peak flow readings were used by participants to monitor their asthma, though management plans tend to focus on the latter. The authors do note the potential that diary recordings may be unreliable.

Information provision and monitoring through a diary record of treatment and its outcome resulted in increased control of asthma and quality of life, together with a higher number of individuals who altered their medications (Nokela et al. 2010). In contrast to the above, a computer programme designed to provide information about asthma, medication and inhaler use and triggers was found to have no effect on hospital admission, symptoms, knowledge and quality of life (Sundberg et al. 2005). Indeed, there was a significant reduction in the number of participants offering a positive response to the question 'Do you know what asthma is?' in the intervention group.

The latter is confirmed in a Cochrane systematic review (Gibson et al. 2003), which found that limited education programmes targeted at providing information only do not reduce use of the health services or change medication use. It is possible that they may reduce symptoms, but the authors indicate that this may also be a reduction in perceived symptoms due to bias. Self-management interventions, which provide not only information but also regular medical review, a written action plan and the opportunity for self-monitoring, reduce health services utilisation, episodes of night-time asthma, time taken off work and improve quality of life. This offers an interesting contrast to the Cochrane Review undertaken by Foster et al. (2009, detailed above) of self-management programmes which concluded that self-management programmes do not affect healthcare use and have a limited impact on health.

Participants used their own experiences to determine whether their asthma was getting worse; when asked in a questionnaire, they indicated that they relied on symptoms rather than peak flow meter readings to assess their

asthma (Harver et al. 2009). This occurred in both adults and children and did not depend on asthma severity. The authors indicate that they believe that this may be due to the increased demand placed on the individual to undertake peak flow monitoring when compared with symptom monitoring. Participants also indicated that they wished to know more about asthma. As this study was survey-based, participants were not offered the opportunity to discuss in detail the reasons that they used symptom monitoring, or what kinds of information they felt they needed. This is one of the reasons the current study will adopt a qualitative approach; it will ensure that participants can discuss their experiences and reasons in more detail. A review of the literature indicates that individuals with asthma frequently under- or over-perceive their symptoms when compared with pulmonary function measures (Janssens et al. 2009). It is possible that objective measures do not always match individuals' perceptions of their symptoms; however, this does not necessarily mean that individuals' perceptions are inaccurate.

Individuals in Australia reported that they would like greater involvement from their pharmacist in managing their asthma, including providing information, monitoring their asthma, checking lung function and inhaler technique (Panvelkar et al. 2010).

Asthma may not be adequately controlled in many individuals. The uptake of self-management may be limited, and interventions may be successful or otherwise. Research has investigated the use of education and monitoring for patients with asthma, with a range of formats considered. In some instances, the accessibility of the materials limited their usefulness. Information-only interventions were found to be of the least use, and the most useful were those that included written action plans for patients. As with other long-term conditions, self-management of asthma could lead to individual benefits, including control of asthma, increased quality of life and ability to alter medications as necessary, but did not always lead to reduced use of the healthcare services. Self-management for those with asthma did not always mean complete elimination of symptoms or total adherence to medication. Individuals used their own experiences, particularly their

symptoms, to determine their asthma status and preferred this to reliance on peak flow measurements.

### ***Perceptions of and life with asthma***

Asthma has been shown to have an impact on individuals, including having a negative effect on wellbeing and quality of life (Meszaros et al. 2003; Nishimura et al. 2004; Ampon et al. 2005; Opolski and Wilson 2005; Leander et al. 2009; Partridge et al. 2011; Syk et al. 2012), being linked to depression (Ampon et al. 2005; Opolski and Wilson 2005; Wainwright et al. 2007; Furgal et al. 2011; Lu et al. 2013), anxiety (Fernandes et al. 2010; Furgal et al. 2011; Cano-Vindel et al. 2012; Zhukava and Shot 2012; Lu et al. 2013), distress (Panicker et al. 2008), anger (Cano-Vindel et al. 2012), and non-respiratory symptoms (Small and Lamb 1999; Leander et al. 2009). Women with asthma tended to experience lower quality of life than men affected by the condition (Larsson et al. 2007; Sundberg et al. 2009; Sundell et al. 2011). Fernandes et al. (2010) undertook a cross-sectional study of asthma patients to investigate any links between anxiety, outcomes and clinical variables, and found that most patients exhibited anxiety. Those who were anxious were also found to have lower quality of life scores, lower asthma control and increased need for treatment with oral corticosteroids. Bonala et al. (2003) suggest that there may be a link between dose of inhaled corticosteroids and depression and anxiety, potentially explaining some of the findings of other studies. A link between asthma and non-respiratory symptoms was found by Leander et al. (2009), including headache, dizziness, eye problems, exhaustion and fatigue, depression, restlessness and difficulty relaxing, pain in the joints, back and legs, and feeling cold. Though useful in identifying these symptoms, and indicating that quality of life is decreased in individuals with asthma, this study used surveys and so did not explore in depth the effect of these symptoms on life with asthma. Hyperventilation, one of the symptoms of asthma reported during exacerbations, results in lower perceptions of health together with lower perceived control over the condition (Ritz et al. 2008). Asthma had a social impact on both children and adults affected by the condition, with children missing school and adults taking time off from or giving up work due to their condition and activities such as

walking, carrying shopping, gardening and decorating being restricted (Nocon and Booth 1990). Arrangements regarding holidays and household tasks involved consideration of their condition, and in some instances changes were made as a result.

A study by Baptist et al. (2010) considering asthma in older people found that participants described both typical asthma symptoms (shortness of breath, cough, wheezing, chest tightness and congestion) and also non-typical symptoms such as fatigue and lethargy, feeling like they were being smothered, had been punched in the stomach or had an elephant sat on their chest, yawning and having aching sides. Those affected by other conditions such as cardiac disease and hypertension were unsure which condition was causing their symptoms, and the side effects of medication were of concern, with participants feeling that their medications could have led to other conditions such as cataracts, osteoporosis and glaucoma. Some participants expressed a desire to self-manage their condition independently, and this included the use of alternative therapies and home remedies, none of which were discussed with their healthcare professional. As an American study, the cost of medication was raised as an issue.

As with a number of the studies described herein, asthma patients in Sweden reported frequently experiencing symptoms (Ställberg et al. 2003). They also reported avoiding particular activities, specifically sports, going outdoors, exposure to pets and smoke or strong smelling scents, on days when they experienced symptoms. Participants mostly followed prescribed medication regimes, though few did so every day of the year.

Some studies have shown that adolescents and older people may accept asthma as part of their lives (Snadden and Brown 1992; Knight 2005; Goeman et al. 2007; Kintner 2007; Oncel et al. 2012). A small number of adults who exhibited pessimism or stigma in relation to their asthma in a survey were selected for interview by Snadden and Brown (1992). Most, though not all, participants appeared to have accepted that they had asthma, a process which required adjustment including accepting limitations, resolving anger, acquiring knowledge and understanding of the condition,

and gaining control over the condition. Mentorship, through discussions with and support from others (those with asthma and healthcare professionals) supported participants to gain the necessary knowledge of their condition. Interestingly, participants were selected on the basis of the stigma and pessimism they felt, and yet the findings do not demonstrate a strong sense of pessimism according to this article. Adolescents who accepted asthma exhibited a desire to take possession of the condition, by learning about it and thus taking better care of it (Kintner 2007). They shared their illness with family and friends, were watchful and ready to take action if necessary, and in contrast with participants in some studies, took their medication as prescribed as part of their routine. In direct contrast, people living with asthma were described as feeling despondent and resigned by Haughney et al. (2004). I would however question whether participants were describing resignation or acceptance of their condition. Many of the participants did not take their inhalers as prescribed, and lived with persistent symptoms. They experienced reviews with their healthcare professionals as functional experiences, which did little to help improve their asthma. Many participants had not been given tailored advice regarding their medication, despite being willing to manage their inhaler doses without healthcare professional intervention.

As with Baptist et al. (2010), another American study confirmed cost to be an issue, in addition to identifying other concerns for older people with asthma (Cortes et al. 2004). These included the negative impact of asthma on quality of life and non-adherence to their prescribed medications. Participants described the condition as affecting their quality of life in several ways, including being unable to sleep, go outside if the weather is hot, undertake social activities or household chores, or physical activities such as walking and forcing them into taking early retirement. This list seems to be quite restricted, which may result from the study focus, of using themes arising from focus groups to produce patient care and education materials.

Quality of life for those with asthma was shown to be influenced by coping styles according to Van de Ven et al. (2007). A positive quality of life was

linked to the coping strategies of not hiding asthma from others, and the positive reappraisal of the condition (for example, trying to learn about it). These were the most commonly reported strategies. Leading a restricted lifestyle was linked to a poorer quality of life, as was worrying about asthma.

Individuals with asthma who experienced fewer symptoms were found to have a higher quality of life score according to Ehlers et al. (2001) and Oh (2008). When asked in interviews to speak about asthma and quality of life, participants in a study by Drummond (2000) offered accounts of an existential quality of life, where asthma only affected quality of life when severe or when individuals encountered severe exacerbations. Other aspects of their lives were perceived as being of more value and decisions were made based on what the individual felt (this being an emotional rather than rational decision-making process) was best for them, rather than what was best for their asthma. Social relationships, not illness, were the major influence on happiness.

Not disclosing the use of complementary and alternative or over-the-counter medication to healthcare professionals was identified in mothers (Sidora-Arcoleo et al. 2008) and in patients in Malaysia who perceived complementary and alternative medicines as being good for their health (Alshagga et al. 2011). Systematic reviews undertaken to determine the usefulness of acupuncture and homeopathy found that neither could be recommended based on the available evidence (McCarney et al. 2004).

One study exploring perceptions of asthma identified a condition viewed as something specific to the individual but manageable through knowing one's own triggers and the medications available to relieve symptoms (Andrews et al. 2013). However, some participants acknowledged that they were in denial about their condition, or were not prepared to act until symptoms were life-threatening.

Other studies have demonstrated that some individuals believe that they do not have asthma unless they are exhibiting symptoms (Halm et al. 2006; van Dellen et al. 2008; Heidarnazhad and Tavasoli 2009). The belief that having

no symptoms meant not having asthma – designated by the authors the ‘no symptoms, no asthma’ belief – was found to be prevalent in a study investigating whether individuals hospitalised for the condition felt that asthma was a chronic or acute disease (Halm et al. 2006). The participants of this American study were predominantly Hispanic or African-American women, who had low incomes and a history of admission for asthma. Most indicated that they only had asthma when experiencing symptoms, and this group tended to have poorer medication adherence, particularly when asymptomatic, and to believe that their asthma could be cured.

This perception of asthma as an acute rather than chronic condition was also found in a study by van Dellen et al. (2008) undertaken in the Netherlands. Focus groups were undertaken with children who had asthma and their mothers. None of the participants knew what caused asthma, though the mothers offered their thoughts about why their child could be affected. They frequently perceived the condition as acute, existing only when symptoms were present, and some believed that the condition would improve or be cured. As with Halm et al. (2006), lack of recognition that asthma is a chronic condition meant that mothers felt their children did not need preventer medication when not experiencing symptoms. The expectation of a cure was also identified in a study undertaken of adults with asthma in the US (Mancuso et al. 2003).

Cultural differences can be seen in individuals’ perceptions of asthma (Hazir et al. 2002; Hussein and Partridge 2002; Zhao et al. 2002; Koinis-Mitchell et al. 2008). Parents of children with asthma in China had poor knowledge and non-compliance with their children’s medication, mainly due to concern over side effects and forgetfulness (Zhao et al. 2002). Knowledge was limited with regard to asthma symptoms and triggers, medication (including as with several other studies listed here the belief that asthma can be cured) and management. Parents in Pakistan also had limited knowledge about the condition, including believing that certain foods could trigger the condition (including rice and oil-rich foods) and that the condition can be passed between people (Hazir et al. 2002).



Symptom perception has been shown to vary between individuals; according to a review by Rietveld and Brosschot (1999), both biomedical and psychological factors have an impact on the accuracy of symptoms perceived. Individuals who experienced low fear of symptoms were found to experience respiratory symptoms as less unpleasant than those who had greater fear of symptoms (Janssens et al. 2011). Thus an increase in perceived control can result in milder symptoms.

Adams et al. (1997) found that the majority of asthma patients can be described as either deniers/distancers or acceptors. Deniers/distancers were those who rejected the diagnosis of asthma and claimed that the condition had little effect on their lives; they did not take prophylactic medication, but instead relied on reliever medication when experiencing symptoms. Conversely, acceptors accepted the condition into their lives and self-image, and took prophylactic medication. These people considered that they were not ill with asthma, so long as they controlled their symptoms. Acceptors have higher levels of knowledge of both the condition and its treatment.

Vincent et al. (2006) undertook a qualitative study to identify which words were used by asthma patients to describe their experiences of asthma becoming worse. Although healthcare professionals would describe this as an 'exacerbation', many participants had not heard of this term, and those who had tended not to use it. Participants generally used the term 'asthma attack' to describe particularly bad symptoms, which required medical intervention, though some also used it where they experienced milder symptoms with rapid onset. Instead, participants used descriptions of their symptoms to describe their asthma. The study suggests that participants do not use medical jargon, but instead name their asthma symptoms in ways which are understandable to both themselves and to others, and the authors state that the reflection of patients' own terms by healthcare professionals may aid successful communication between the two groups.

Asthma affected individuals of all ages in a variety of ways; they may experience reduced quality of life, depression, anxiety or distress, and they described other symptoms in addition to typical respiratory symptoms.

Asthma could be described as a condition which can be disabling, as it limits individuals' abilities to join in day-to-day activities, potentially leading to social isolation. It may also restrict their ability to undertake employment and attend school. Individuals with a higher quality of life tended to be those who were less restricted by their asthma and who were able to maintain social relationships. Some individuals chose to take complementary and alternative medications, though they were reluctant to inform healthcare professionals of this and evidence for these treatments is lacking. Some people, particularly in the US, also found that the cost of medications was restrictive.

Asthma is frequently perceived by those affected, or the parents of affected children, as a curable and acute condition, which only exists when symptoms are apparent. This may have an impact upon the medication use of these people. Others may deny the existence of the condition or of symptoms. Symptoms may be perceived and described differently by individuals, and differences in how they are described can lead to miscommunication between patients and healthcare professionals. Perceptions of asthma differ between cultures, with some having limited scientifically-accurate knowledge, though it is possible that their perceptions are based on perceived experiences. Acceptance of asthma is possible, and appears to require knowledge and a feeling of control over the condition. For this group, the condition may not be considered to be problematic or to have a significant impact on day-to-day life.

## **Summary**

The initial literature review undertaken for this study has been updated to ensure currency throughout the project. Literature reviewed includes that relating to long-term conditions and experiences of living with and self-management of such conditions. The literature concerning how and where people acquire information about long-term conditions was also reviewed.

The literature regarding LTCs demonstrates that information is acquired from a range of sources, including healthcare professionals, other people and the media. This information may be used to inform the decisions made by

individuals regarding their condition, though previous research suggests that some people prefer to rely on healthcare professionals making decisions on their behalf, particularly with regard to medications. Autonomy may be connected with greater quality of life and better health outcomes, though the decisions made may conversely reduce one's quality of life.

Self-management is promoted in the UK as the preferred method of managing long-term conditions. However, self-management requires that individuals are fully informed of their condition. Some individuals identified personal self-management strategies which did not comply with those recommended by healthcare professionals, often through experimentation of what was possible and helped them to manage their condition. Thus experiences become important for those with long-term conditions, as these enable them to learn about what may be possible with their condition. Evidence concerning the Expert Patients Programme in the UK is conflicting, but overall seems to indicate that few long-term benefits result from participation, particularly regarding access to health services. This may in part result from participants in such studies becoming more aware of the need to consult a healthcare professional at pertinent times, rather than an inability to self-manage one's condition.

Individuals affected by a long-term condition may perceive this to be a challenge, as something which causes them to become anxious or depressed, which alters their concept of self in a negative way, leads to reduced quality of life or day-to-day hassles. This can be influenced by age and by the number of conditions affecting an individual. Conversely, other people could be described as being well, even where the symptoms of their long-term condition are disabling. Being well did not relate to periods when symptoms were reduced, but to an acceptance and perception of the illness which differed from those who contended with illness. Some people were able to listen to their body and use the information gained to determine not only the current state of their illness but also to adapt to an altered body paradigm resulting from their condition.

Despite the extensive research previously undertaken, there exists a gap in the literature which explores in total the information collected by individuals with a long-term condition and how this contributes to their perspectives of and how they make sense of the condition. Studies tend to focus on either information and where this is collected from, or on experiences, but do not consider how the two may contribute to one another, and to individuals' overall views of a long-term condition. The current study will address this gap in knowledge.

Research also indicates that some long-term conditions may cause the individual to contend with illness, whilst others can permit the individual to accept their condition and be well in spite of it. Some of the literature reviewed indicates that some conditions exist on both sides of this dichotomy. Many of the LTCs under study have been those which may lead to disablement or have a significant effect on one's day-to-day life. In contrast, few studies have considered whether long-term conditions which do not necessarily have a significant, life-changing effect on a day-to-day basis are perceived as problematic for those affected.

Both thrombophilia and asthma are long-term conditions which can lead to life-threatening illness, in the form of a blood clot or an asthma exacerbation. The risks of these may be reduced, through medication and lifestyle choices, but not entirely eliminated. However, the conditions may be described as having a limited effect on a day-to-day basis at least for some of those affected; the conditions do not lead to disfigurement and therefore social isolation, those affected are generally able to work and neither results necessarily in a limited lifespan. Research into thrombophilia focuses upon the inherited nature of some forms of the condition, with little research other than the biomedical literature exploring acquired forms. Extensive literature exists relating to the experiences of those with asthma, but no studies yet exist which have considered how information about the condition is collated, and the effect of this upon the perspectives of those with the condition. This study will therefore address a gap in the literature, how individuals collate different forms of information about a long-term condition and how this

impacts upon how they make sense of their condition, using the examples of asthma and thrombophilia.

Having considered the literature, the next chapter will focus on the methodological framework for this study, detailing the grounded theory approach adopted and the methods of data collection used. I will first revisit the aim of this research, and detail the objectives achieved in meeting this aim.

## Chapter 3: Methodological Framework

This project aimed to explore and explain how people make sense of their long-term, potentially life-threatening, health condition, specifically thrombophilia or asthma. As is usual in grounded theory studies, I intended that this would result in a theory based in the data, which would explain how people make sense of their condition and how this affects their lives with it. The two conditions have been selected as they may have little impact on one's life on a day-to-day basis, but can potentially lead to life-threatening illness on occasion. The project aim was achieved by:

- a) investigating where and how individuals obtain information and exploring its contribution to and usefulness for their understanding of the condition;
- b) illuminating beliefs and understanding of information about the condition; and
- c) examining other factors which may affect the process experienced by individuals living with these conditions.

In this chapter, I will describe the methodological approach I adopted in the study, and the methods of data collection and analysis. I will also consider the ethics of undertaking this project and offer an overview of criteria which can be used to judge the quality of the theory developed. I begin by offering a list of definitions of concepts used in this chapter, followed by a review of the qualitative approach taken to this research.

### Definitions

There are a number of phrases to which I shall return several times in this section, and it would appear useful at this point to define them.

**Ontology** considers the nature of existence, studying what is (Crotty 2003). In this research, the ontological perspective adopted is that the world exists independently of consciousness (Crotty 2003).

**Epistemology** is concerned with the nature of knowledge (Crotty 2003). This includes, for example, objectivism, where truth and meaning exist in an object irrespective of consciousness. The positivist viewpoint states that the scientific method is able to attain this truth and meaning. The epistemological stance taken in this study is that of constructionism, which argues that there is not an objective meaning available for discovery, but that meaning is constructed through human interaction between each other and the world (Crotty 2003).

**Purposive sampling** occurs where the sample population is identified and selected based on their relevance to the study. For example, purposive sampling was initially used in the current study, selecting individuals on the basis that they were affected by the long-term condition thrombophilia.

**Theoretical sampling**, in contrast, occurs when the researcher selects individuals on the basis of their potential contribution to the theoretical concepts emerging from the study. Sampling theoretically should enable the further development and explication of categories, and is a fundamental aspect of grounded theory studies (Charmaz 2006). In this research, theoretical sampling was used to determine other groups who ought to be interviewed, including those with a different long-term condition, and to revisit existing data in order to identify relevant concepts which may have been missed earlier in the analysis.

**Saturation** is an important but complex concept in grounded theory studies. In its simplest form it means that data should be collected until no new concepts can be found and the categories and their properties are accounted for in the theory (O'Reilly and Parker 2012). In order for saturation to be reached, categories should be developed and relationships between concepts should be defined (Corbin and Strauss 2008). It is important to note, as do Corbin and Strauss (2008), that it would be possible to continue sampling in perpetuity in order to ensure saturation had been achieved; the researcher must instead determine the point at which the explanatory detail of concepts and categories is sufficient for the research purpose.

## **A qualitative paradigm**

The study is situated within the qualitative paradigm. This section will provide a brief overview of how qualitative research is defined and the reasons for choosing this approach in the current study. Many authors have written about the use and history of qualitative research, and the frequent questions about its ability to produce quality research (for example, Denzin and Lincoln 2011; Erickson 2011; Mills and Birks 2014). This thesis will not reiterate these arguments, but will instead start from the assumption that qualitative research is now an accepted paradigm throughout the healthcare and social sciences (Denzin and Lincoln 2011; Erickson 2011). Considerations of how the quality of qualitative research could be assessed are offered later in this chapter.

Qualitative research may be defined in a number of different ways; frequently it is defined by comparison with quantitative studies. This could be considered inappropriate, given the widespread acceptance of qualitative methods for gaining understanding of phenomena. A useful definition for the purposes of this study is offered by Holloway (2005a), who states that

"the main purpose of qualitative research (is) the understanding of social behaviour and thought through people's own accounts and observations of their interaction with others, and stresses the researcher's own involvement with the participants" (p.2).

This prioritises the viewpoint of the insider, the individual experiencing the phenomenon under study. Creswell offers a similar definition, stating that qualitative research is

"an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem ... Those who engage in this form of inquiry support a way of looking at research that honors an inductive style, a focus on individual meaning, and the importance of rendering the complexity of the situation." (Creswell, 2014, p.4).

Qualitative research thus enables the researcher to gain an understanding of emotions, meanings, reasons for actions and relationships relating to the phenomenon under study, whilst considering the individual as a holistic being



(Holloway 2005a). According to Sogunro (2001), it enables rich description of the phenomenon under study, and the researcher to understand not only the events but also the wider context in which they occur. As a result, qualitative research is particularly useful when little previous work exists (Stern and Porr 2011; Creswell 2014). In addition, as indicated by Denzin and Lincoln (2005) and Holloway (2008), this type of study allows exploration of meaning and enables participants' comments to direct the study. Specific qualitative approaches, including the grounded theory approach adopted herein, allow the researcher to develop theory (Mills et al. 2014). In doing so, the participants are given a voice which may allow unspoken assumptions to be made apparent (Holloway 2005b). It is not possible for the researcher to reconstruct an exact picture of the participants' worlds, and so their voices are interpreted by the researcher, meaning that the findings and theory as described herein are constructed in part by the researcher.

There are thus several reasons for having adopted a qualitative approach to this study. As evidenced by the literature review in the preceding chapter, little information is available regarding experiences of living with a type of long-term condition which could be defined as being non-problematic. Non-problematic conditions are those which appear not to represent a problem for those affected. However, they may be more complex than this definition may suggest, and this study has explored this. A qualitative approach has enabled me to gain an in-depth insight into people's perspectives and meanings of their long-term condition and their reasons for particular behaviours. Participants have been given a voice; the use of a grounded theory methodology has ensured that the findings and theory developed are grounded in the data collected, including the use of codes and concepts based on participants' own words. This allowed unknown concepts, concepts which have not been seen before within this topic area, and those which have not been defined in relation to this topic, to be identified, developed and understood.

The complex nature of life with a long-term condition was unlikely to be elucidated through a quantitative study, where the concepts under

consideration are limited to those identified by the researcher. Quantitative studies tend to test hypotheses, which are based on previous knowledge, thus a quantitative approach may have meant that information which was important or gave meaning to the participants' experiences remained hidden.

## **Grounded theory**

A grounded theory approach (Glaser and Strauss 1967; Strauss and Corbin 1998; Charmaz 2006; Corbin and Strauss 2008) was chosen for this study as it produces an explanatory theory rather than a description of the data (Glaser and Strauss 1967; Charmaz 2006; Holloway and Todres 2006). This enabled the production of a theory regarding how people make sense of their long-term conditions. Grounded theory is rooted in symbolic interactionism, an approach which is based in the writings of the sociologist George Herbert Mead (1863-1931). This perspective advocates that individuals' actions are based on their interpretation and meanings of symbols (i.e. others' behaviours), and that these meanings result from social interaction and are shared within a culture (Blumer 1969; Flick 2009). As a result, humans construct their social worlds and act and react according to these.

Grounded theory was first described by Glaser and Strauss in their text *The Discovery of Grounded Theory* (1967). This introduced for the first time a systematic approach to collecting and analysing qualitative research data which enabled the researcher to produce theory.

Since then, Glaser and Strauss have gone separate ways ideologically and have offered very different versions of what constitutes grounded theory, though both have described approaches which can be described as objectivist (Strauss and Corbin 1998; Glaser 2002; Charmaz 2006; Corbin and Strauss 2008). These approach grounded theory from the viewpoint that theory is discovered in the data, and the researcher maintains an objective stance. However, their original text was more open and flexible than some of their later works. Further to this, Charmaz (2006) has described a

constructivist version of grounded theory<sup>1</sup>, followed by Corbin (Corbin and Strauss 2008) who indicates that she adopts a constructivist approach. Thus, the approach I have taken to grounded theory is based on Charmaz' interpretation (2006), with some principles adopted from Corbin and Strauss (2008). I will consider my reasons for this in the next section.

### ***Constructivist grounded theory***

Glaser and Strauss, particularly Glaser, believed that a researcher records facts relating to an external reality and that a theory can be discovered from the data (Strauss and Corbin 1998; Glaser 2002; Charmaz 2006; Corbin and Strauss 2008). In contrast, the theory of social construction advocates that knowledge is not discovered, but instead constructed and reconstructed by individuals and/or society<sup>2</sup>. Knowledge of and meaning in the world is not a constant reality waiting to be discovered but is interpreted and constructed. Charmaz describes a constructivist approach to grounded theory, in which data and analysis are socially constructed and the analysis produces a theory located

“in time, place, culture and context (and) also reflects the researcher's thinking. Thus the sense that the researcher makes of the data does not inhere entirely within those data” (Charmaz 2003, p.313).

The approach contends that it is not possible to see the world completely from another's point of view, but that it is only possible to try to discover what it may be like and to interpret this. Thus, I did not attempt to see the world from the perspective of my participants, but instead interpreted their words in order to create constructs of what this may look like. In doing so, I acknowledged my influence on the findings and discuss this in the reflections chapter.

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<sup>1</sup> Charmaz has published a new edition of her book in 2014 which came out after the completion of my research.

<sup>2</sup> Social constructionism is also designated constructivism by many authors, though Crotty (2003) has indicated a useful distinction which is adopted here.

Constructivist grounded theory also promotes the investigation of meaning, process and interaction and how people define and construct their social reality within the social context. This aids the researcher's ability to construct and interpret participants' worlds (Charmaz 2006).

I chose to adopt a constructivist epistemological approach to this study. This is in part because I have a strong interest in chronic illness, having friends with asthma and having the condition myself, knowing someone with thrombophilia, and also having grown up in a family where several people are affected by long-term conditions. These experiences inevitably had an impact on my views of the conditions and I would have found it difficult to completely suspend all of my assumptions in relation to this project. I have also read around the subject and cannot 'put aside' the literature reviewed. A constructivist grounded theory approach allowed me to use and acknowledge each of these factors, whereas objectivist grounded theory would have required me to set them aside (Glaser and Holton 2004; Charmaz 2008). Throughout the research, I have tried not to let my assumptions influence me but use them as 'sensitising' devices and stayed open to ideas coming from the participants.

This study is located in a particular time and place, this being the UK in the early 21<sup>st</sup> Century, when medical science is advanced, long-term illnesses are common with treatments available to reduce their risks in many instances, and people are living longer lives. In the UK, the NHS offers care which is free at the point of access. This context provides a set of circumstances which may lead to specific findings, which may not be seen in other times, places or cultures. A constructivist approach allows acknowledgement of these circumstances. I later consider the implications of the external situation on the findings and theory developed (see chapter eight).

During this study, I explored how participants constructed their ideas and worlds. As the researcher, I also constructed codes and categories in order to produce a grounded theory. The language used was, where possible, derived directly from the data through the use of in vivo codes, but I also

needed to construct codes and categories which were interpretations of the data. Also, the researcher inevitably provides a different layer to these ideas and is necessarily more abstract and theoretical. Thus, both the participants, myself and the reader co-construct the study and its findings.

## **The literature and grounded theory**

Both Glaser and Strauss (1967) and Charmaz (2006) profess that it is impossible to not have previous knowledge of a substantive field to be worked in and that this knowledge can be used to offer illuminating insights which can contribute to development of a grounded theory. Charmaz in particular advocates the use of background knowledge as “points of departure” (2006, p.17) on which the initial interview questions can be based. Thus, the literature was used to identify areas for exploration in the initial interview guide.

Following the collection of some data, Blumer (1954) describes the use of sensitizing concepts as giving “the user a general sense of reference and guidance in approaching empirical instances” (p.7), and Bowen (2006) argues that these “provide starting points for building analysis to produce a grounded theory” (p.7). It is however important to be aware that over-use of or reliance on these concepts “may lead to an exclusion of other theoretical perspectives” (Kelle 2005, p.11). An example of a sensitizing concept in this study was information and the acquisition of information from a range of sources; this was evident from the literature, and was used to develop the initial interview questions. However, it became clear during interviews that experiential knowledge was often of equal or greater importance than information acquired from other sources – thus the concept provided a starting point rather than being relied upon to develop the theory in this study.

I undertook an initial literature review, focused on information provision and thrombophilia in order to scope the current knowledge base and clarify gaps in the literature which this study could address. This was expanded to encompass research undertaken in relation to living with a range of long-

term conditions. As I followed up the concepts in my theoretical sampling, I decided to add people's perspectives on another LTC, asthma, and so looked at the literature about perspectives on this condition. Asthma was chosen as it offers another condition which may appear to be non-problematic for much of the time, and yet cause life-threatening acute events, similarly to thrombophilia. Identification of further relevant literature was guided by the data. Such literature is used in dialogue with the data and has become integrated in the study as described by Strauss and Corbin (1998). In my later discussions, the literature specifically relates to those themes which emerged from the data, and formed an additional source of data; consideration of the literature in light of the study findings can be found in chapter six.

The literature review I undertook in order to identify a gap in the knowledge base suitable for exploration in this project exposed me to many of the recent writings in the field. It is neither possible nor desirable to ignore this information, as it offers the basis for the initial interview guide and provides the researcher with a known gap from which to begin their research. However, care was taken throughout the project to ensure that existing concepts did not direct my research. For example, although the concept of uncertainty is widely known in the literature relating to illness, in this study it was identified initially in the data collected and then, once known, compared with this concept in the literature.

## **Recruitment to the study**

Recruitment was undertaken through three different routes. Initially, individuals were recruited through their prior contact with a consultant haematologist regarding their thrombophilia. Due to insufficient numbers being accessed through this route (only 5 were interviewed), I also accessed people through a UK charity which works to increase awareness of thrombosis among healthcare professionals and the public. They offer information, advice and support to those who have experienced clots and so offered an excellent route to access participants with thrombophilia. A final

recruitment phase was introduced, targeted at individuals with either thrombophilia and asthma, through local networks.

Recruitment criteria for this study included:

- Over 18 years of age
- Ability to speak English (no funds were available for translations)
- Had either thrombophilia or asthma.

Those under the age of 18 were excluded as the study focuses on the experiences of adults.

Having thrombophilia or asthma was an essential criterion for participants as these are the long-term conditions being considered. It is appreciated that other conditions could have been chosen, however, access to those with thrombophilia and the prevalence of asthma were important factors in identifying these as the two conditions to be studied.

All potential participants were provided with copies of the participant information. The consultant haematologists (based at two hospitals in a large conurbation on England's South Coast) identified patients with thrombophilia to be invited to take part in this study, and posted copies of participant information and an accompanying letter introducing the study. Patients who felt they may be interested in taking part were asked to send a reply slip directly to me (see Appendix 2).

Subsequently, a UK charity working with those who have had clots was approached with regard to the possibility of them placing an advertisement on their website for the study. They also offered to place a notice on their open and closed group pages on Facebook. Approval was granted by their Medical Director and Trustees. The Facebook notices attracted several interested participants. Individuals contacted the charity's executive officer in the first instance, who obtained the contact details of potential participants

and passed them to me (see Appendix 3 for participant information and consent form).

Further participants were identified by sending out an invitation to take part in the study through local networks by email (details of the documentation can be seen in Appendix 4). This resulted in several people contacting me directly.

All those who made contact were offered the opportunity to request further information (those recruited through the latter two routes were also provided with participant information), discuss the study in more detail, and consider whether or not they wished to participate before signing a consent form.

## **Ethical considerations**

Following a number of ethically unprincipled instances of research being undertaken on people without their knowledge (see Flick 2007 for a brief summary), ethical codes of practice are now offered by a range of bodies, including the institution at which this research was undertaken. The principles to be considered include: the need to gain informed consent; the avoidance of deception; safeguarding privacy and confidentiality; maintaining accuracy; respect for the person; beneficence; and justice (Christians 2011). I have adopted these ethical principles, and detail below how these have been applied to the study.

Ethical approval for this study was obtained through two different routes. Approval was acquired from the NHS National Research Ethics Service to undertake the study and access patients through two hospitals. Bournemouth University School of Health and Social Care ethics committee approved the addition of access to participants through a relevant charity. Both approved the inclusion of participants with asthma.

As detailed above, potential participants were identified specifically through three routes; ethical implications arose from each of these:



- For those who were identified by colleagues at two hospitals, I did not need to access patient records and I only found out that individuals were affected by thrombophilia if they contacted me.
- I did not gain access to the closed group Facebook page of the UK charity on which the study was advertised as I felt that this would have been unethical as I myself do not have thrombophilia and have not had a clot. As a researcher I would have felt it necessary to ask permission from all the group members to access the page, and this was neither feasible nor necessary for this study.
- Participants with thrombophilia and asthma were identified by advertising the study through local networks, and asking those who were interested in taking part to contact the researcher. I only became aware of individuals who were affected by one of the conditions if they contacted me directly about taking part in the study.

All potential participants were sent the participant information, and offered the opportunity to gain further information or ask questions about the study. When individuals confirmed their interest, they were sent a consent form. Anyone who did not respond after being contacted twice was not contacted again, as I felt that this could be viewed as coercing them to take part which would have been unethical.

All potential participants were encouraged to consider whether or not they wished to take part, before informing me of their decision. Participants were informed both in the information sheet and when I spoke with or emailed them that they may withdraw their consent at any time; this would not have affected the grounded theory as ideas and concepts were based on the comments of a number of participants. They were also informed that, whether or not they decided to take part, their treatment and access to healthcare would not be affected. Informed consent was gained, either at a meeting with participants, by mail or email, and then the first interview arranged, by telephone where possible, for a later date. This allowed participants some time to change their mind about participating if they wished. At the request of the research ethics committee, I asked those who

had been identified through the NHS for permission to inform their GP that they were involved in the study.

Participants were provided with contact details for myself and my supervisors before or at the start of the interview. NHS participants were also provided with a list of charities which provide support for thrombophilia patients, and informed that, if they required support, I would be happy to contact these charities on their behalf. Those who had been recruited through the national charity working with those who have had clots were already clearly aware of such charities.

In addition to providing written consent in advance, participants were asked at the beginning of each interview to confirm that they consented to taking part in the interview.

All participants were referred to throughout using a unique reference number rather than their name in order to ensure confidentiality. I transcribed interviews myself, so no-one else had access to the data until it was in the form of a transcript without any identifying features. Where names were mentioned in the interview, these were replaced with details (so for example, if someone mentioned their daughter's name, this was replaced in the transcript with [eldest daughter]).

Although participants were not placed at risk of physical harm during the study, there was a possibility that participants may have become distressed as they discussed their own or others' long-term condition. In order to minimise risk of upset or distress, I undertook interviews sensitively and would have stopped if it seemed that a participant was becoming upset. I would not have continued to follow lines of enquiry which caused upset to a participant unless they expressly wished to continue. In case of upset following the interview, participants were encouraged to contact their GP, relevant charities, consultant haematologist, myself or one of my supervisors if they felt in need of support. The following procedure was designed to reduce any distress which might occur, it was not used at any point during the interviews, as no participants appeared to become upset.

- I would offer to pause the interview or, if the participant was too upset to answer, would stop the interview
- The participant would be given time to recover. I would discuss something positive with them in order to not end the interview negatively.
- I would ask whether or not the participant would like to continue with the interview or stop for today, and would proceed according to their response.
- In the case of participants becoming upset following the end of the interview, they would be informed that they may contact either myself or my supervisors.

It was unlikely that criminal or other disclosures which required action would take place; this did not happen during the study. However, if such disclosures had been made, I would have discussed any such issues with my supervisors, in order to agree on the appropriate action to be taken.

With regard to health and safety issues, there was potential for risk as: face-to-face interviews may have been undertaken in private rooms to ensure privacy for the participant; face-to-face interviews may have been undertaken in participants' homes; interviews may have disclosed information which distressed or upset the researcher. Procedures were established in order to limit these risks (see risk assessment in Appendix 5) and access to counselling was available through the University if it was deemed necessary.

As my sample is not large, I believed it to be unethical to include a sample interview within the appendices, and thus have not done so.

## **Sampling**

A number of different sampling strategies were adopted for the project. Initially purposive sampling was used and potential participants were individuals affected by thrombophilia and had consulted a haematologist

regarding this. Theoretical sampling was used to follow up emergent concepts, and was undertaken by both accessing people through a national charity working with those who have had clots, and subsequently exploring the perspectives of people with another long-term condition, this being asthma. Sampling theoretically in this way enabled the exploration of concepts with a different group of individuals, affected by a condition which exhibits some similar properties, with the intention of further elaborating the concepts and categories identified through data analysis. It is recognised that there are differences between the two conditions under study, and it was intended that these would support theoretical sampling by potentially offering further explanatory detail to the concepts. An initial sample size of ten interviewees with thrombophilia was achieved. In addition I interviewed six people with asthma. Achieving full saturation is difficult in any study, but by interviewing through several modes, and adopting theoretical sampling by interviewing individuals with two different long-term conditions which exhibit some similar characteristics and through the further analysis of interview data already collected, I have attempted to achieve saturation. I have reached the point where no specific ideas important for the emerging theory arose in the data, and the concepts and categories relevant to the research aim have been fully explained.

Members of either gender can undergo the process identified in this study. Neither of the conditions under consideration are sex-specific, and gender did not appear to significantly impact on the different stages of the process nor on participants' perceptions. Appendix 6 summarises the demographic information collected from interviewees. Four men and six women with thrombophilia were interviewed and age at the time of interview ranged from 25 to 60. Some individuals had been experiencing symptoms of their condition for up to forty years, whilst others had never had symptoms of the condition. Of those with asthma who were interviewed, half were men and half women (total of six), and ages at the time of interview ranged from 32 to 51. All but one participant had access to the internet at the time of the interview.

## **Pilot interview**

Although pilot studies are not necessary when undertaking grounded theory research as the process of grounded theory is developmental, Gillham (2000) recommends that pilot interviews are undertaken with representatives of the group under study in order to refine the structure and content of the interview. A single pilot interview was carried out for this project in order to ensure that the proposed interview questions were collecting the appropriate data, to check whether the questions were understandable, and to allow me to gain experience of undertaking a research interview. This was done with a colleague whose family are affected by a chronic condition, and in addition to the proposed interview questions, I also asked the participant to provide me with feedback on the questions. The recording was transcribed and analysed (as advised by Sampson 2004). As a result, the structure of some of the questions was amended; this mainly related to questions which were over-long and could be asked differently with more clarity. I also added to the aide memoire as a result of the pilot interview to ensure that I was collecting as much relevant data as possible.

## **Data collection methods**

In this section, I will describe the methods I used to collect data, and explain why I made these choices. I will also outline the disadvantages of using these methods.

According to Johnson (2002), data collection methods should be appropriate to the research. In this case, the study aimed to elucidate how participants make sense of their condition. The interview has been described by Kvale and Brinkman (2009, p.2) as “a professional conversation” and by Seidman (2013, p.8) as “a basic mode of inquiry” which enables the researcher to hear another’s story. By undertaking interviews, the researcher can attempt to understand people’s perspectives of their experiences and the meaning they make of them (Seidman 2013). Interviews can be used to gain an understanding of knowledge which is often taken for granted and not readily articulated (Johnson 2002), and allow the elicitation of in-depth, detailed

responses from participants which may be further explored and expanded upon when they are questioned. These 'conversations with a purpose' also enable the discussion of sensitive issues in depth.

Interviews are of particular use in grounded theory research as they are of a flexible and emergent nature, allowing the researcher to guide the conversation around their topic of interest, whilst responding to the participants' answers. Charmaz (2002) and Seidman (2013) suggest that undertaking several interviews with an individual rather than a single interview might be of benefit to grounded theory studies, for a number of reasons. It is not possible to know in the earlier interviews with an individual what data may emerge at a later date, what concepts might arise, and thus what questions should be asked. If a participant is interviewed more than once, it is possible to re-visit this data and gain another perspective. It is also necessary to build up a relationship of trust with a participant, which takes time - thus, data may emerge which the participant may not entrust to the researcher at a first interview - and also their perspectives may change over time.

I planned to undertake a maximum of three interviews with each participant – though any participant who indicated that they were unwilling to take part in a further interview was not to be re-contacted. However, due to a variety of reasons (being uncontactable on repeated occasions, being clearly resistant to further interviews when re-contacted) only a small number of participants (n=3) were formally interviewed a second or third time. Despite this, I had spoken to almost all participants prior to the interview, in order to arrange the interview time and date and begin to build a relationship with them, and most people had started to provide me with information about their experiences at this point. I therefore did not feel that anyone had been resistant to providing me with information during the interviews.

Different modes of interview were used during this study. Face-to-face interviews were undertaken with participants based in the local area. However, some participants lived further afield and a decision was taken that, in order to achieve saturation of the data and taking account of the

limited resources and researcher time, a variety of modes would be offered: face-to-face, telephone, email or Voice over Internet Protocol (VoIP, in this instance Skype).

The literature indicates that telephone and email interviews may be used to gain data of equivalent quality and depth to face-to-face interviews (Carr and Worth 2001; Sturges and Hanrahan 2004; Meho 2006). VoIP has the potential to be used effectively for research interviews (Hay-Gibson 2009) but those who have attempted to use the technology warn of associated risks, including individuals not having the technology installed, the technology failing, the location chosen by the participant creating a distraction and participants not 'turning up' (Hanna 2012; Weinmann et al. 2012; Deakin and Wakefield 2014). When conducting telephone and email interviews, the literature warns of the need to be aware of the reduced social cues available; this was recognised throughout data collection (Carr and Worth 2001; Sturges and Hanrahan 2004; Meho 2006; Opdenakker 2006). For both face-to-face and Skype interviews, verbal cues can be used during the interview; for Skype, this involves utilising fewer resources and therefore incurring reduced costs (Bertrand and Bourdeau 2010; Hanna 2012). Both face-to-face and telephone interviews were undertaken; participants were offered the opportunity of being interviewed by email and Skype and only one participant used the former for a follow-up interview. Several participants indicated that they did not have access to Skype.

In practice, a number of minor differences were noted between the two interview modes, though I do not believe that any had a significant impact upon the study findings. Face-to-face interviews had enabled me to build up a rapport with interviewees more easily, and so I chose whenever possible to arrange telephone interview appointments by telephone rather than by email, in order to begin forming a relationship before the interview itself. During the first two telephone interviews, I found it more difficult to read people's cues and so interrupted them more than I would have done had I been interviewing them face-to-face; however, I became accustomed to this, and in the later telephone interviews interrupted less frequently. Those interviews

conducted face-to-face tended to move away from the topic more often than those undertaken by telephone, which tended to be more focused. There did not seem to be a difference in interview length between the two modes; some interviews were shorter than others when participants had less to say and this seemed to have more of an influence on interview duration than the mode through which they were conducted.

The negative aspects of undertaking interviews are outweighed by the increased potential for obtaining rich data which enabled me to explore how people make sense of their health condition. Two individuals interviewed indicated that they had appreciated having someone to speak to about their condition, as they rarely got the opportunity to discuss their experiences. Others were looking for information either about their condition, or about research into it. Consequently, rather than being exploited, some participants felt that they benefited from the interview experience.

The interview questions were initially based upon an amended version of the pilot questions, and then further amended in an ongoing manner, depending on the incoming data and the analysis. This led to more focused interviews towards the end of the study, as the data already collected had indicated areas for exploration ('progressive focusing'), including the idea of living with or alongside one's condition, decision-making and acceptance. Examples of the interview guide can be found in Appendix 7. Although the interview guide contained a list of questions, these were used as prompts where the topic had not already been covered by the participant; I frequently asked only a small number of the questions listed in the guide as participants had already offered much of the information.

In all types of interview, I ensured that I actively listened to participants, both so that I knew where further prompting may be needed, but also so that I could return to the train of thought if the participant got 'lost' (as advised by Morse 2001). Participants were left to tell their story at their own pace, and I recognised that I was learning not only interview technique, but also that I was learning from the participant in order to achieve the aims of the project (Morse 2001). I was also aware of the potential for participants to view me as



an 'expert' who could answer their questions about their condition, or confirm and explain queries they may have. This occurred in several interviews, and I provided information to the limit of my ability. I took care to ensure that this did not constitute advice – which I am not trained or qualified to give – but only information that could be found easily on the internet. I do however believe that throughout the study, the experts were the participants; although I was able to draw on my own experiences towards the end of the study, it was their knowledge, expertise and experience which allowed the development of the findings and theory produced in this research.

### **Grounded theory: data collection and analysis**

All grounded theory approaches comprise a systematic and structured method of analysis involving an interaction between the data collection and analysis (constant comparison). This involves going back and forth between new and already analysed data and constantly comparing it. Although the process of analysis is iterative, I have explained below the process as a linear one so that it can be described. However, each of these stages was repeated, and they may at times be undertaken simultaneously. During this process, it is possible that overarching themes may become evident in the data, and such themes can be useful to inform further data collection (Corbin, personal communication, 30 June 2012).

Data analysis for this project progressed in the manner described by Charmaz (2006) using aspects of Corbin and Strauss (2008). Interview data was transcribed as soon as possible by the researcher. Notes taken immediately after the interview also formed part of the data.

Initial coding (Charmaz 2006; a similar process is designated open coding by Corbin and Strauss 2008) of the data took place; questions were asked of the data in order to identify ideas mentioned by the participants. At this stage, in vivo codes were used wherever possible, and any other codes remained as close to the data as possible. In vivo codes are those which use participants' own words to describe a concept – they "help us to preserve participants' meanings of their views and actions in the coding itself"

(Charmaz 2006, p.55). Corbin and Strauss (2008) also advocate the use of in vivo codes. Comparisons were made between data from the same interview, across interviews, and across different types of data. Similar ideas were assigned the same or similar codes and codes were renamed as the concepts developed. For example, the concept now designated *the diagnosis: confirming the condition* started out as *being diagnosed*. Corbin and Strauss (2008) include within open coding the grouping of concepts within higher order explanatory categories and this was also carried out. The properties of these categories were also identified, enabling their parameters to be determined and categories to be differentiated.

Finally, the links between categories were identified and described (axial coding according to Corbin and Strauss 2008), before provisional hypotheses based on these were produced. With regard to axial coding, I did not adopt Strauss and Corbin's (1998) formal procedures, but, as indicated by Charmaz (2006, p.61), identified links between categories and subcategories and described these. I chose to do so because the formal framework offered by Strauss and Corbin in their 1998 text seemed to act as a barrier to the identification of links between categories by creating a distance from the data. However, I found that asking the questions offered by the authors provided a useful structure for the novice researcher to ensure that all dimensions were identified.

The whole process was repeated with each new set of data, and codes, categories and working propositions amended as appropriate until no new ideas were emerging from the data and properties had been fully elucidated, ensuring that the theory was fully informed before data collection was stopped. As ideas began to emerge, selection of further participants was directed by the emerging concepts, and participants were then interviewed based on these ideas (theoretical sampling). I maintained a reflective approach throughout the study; this involved keeping a diary and memos (defined by Strauss and Corbin (1998) as "the researcher's record of analysis, thoughts, interpretations, questions and direction for further data collection" p.110) to aid the development of the grounded theory. Memos

were written as soon as possible following data collection and also whilst coding in order to draw out points for further reflection and issues to be explored further in future interviews, and to indicate areas where codes needed further consideration. Memos were also written to indicate possible areas which may later become categories; for instance, by the end of the analysis of the first interview, I had identified a small number of areas which might later have become categories. Ideas emerging from the analysis were refined (by reviewing for internal consistency) and validated (by comparing the grounded theory with the raw data).

Codes which were identified during early interviews included *experiencing symptoms, involving others in the diagnosis, consulting the doctor, speaking with non-experts, receiving the diagnosis, what is thrombophilia, acting to reduce the risk of thrombosis, lacking knowledge and acting on symptoms/warning signs*. Further data collection confirmed the existence and name of these, some metamorphosed into different codes or categories (*consulting the doctor* became *information from healthcare professionals*), whilst others changed slightly (for example, *experiencing symptoms* became *experiential knowledge: symptoms*). This is consistent with the grounded theory process, where further data collection and analysis and constant comparison enable the re-naming and changing of codes and categories in order that they describe the data as accurately as possible (Corbin and Strauss 2008).

### ***Conceptualisation of the codes and categories and the resulting core category***

Conceptualisation of the codes into categories occurred through constant comparison, and led to the identification of a number of concepts which were grouped into discrete stages of the process. Categories included *pre-diagnosis: tentative learning, the diagnosis: confirming the condition, understanding the condition, making informed decisions, and accepting the condition*. The core category – that which represents the main concept of the research (Corbin and Strauss 2008) – is identified as *living with a long-term condition*. Further conceptualisation resulted in the identification of a theory

which denotes a process undergone by all interviewees and offers a hypothesis suitable for further testing outside of this study and with potential applicability for practice.

### ***In vivo codes and the language used by participants***

Whilst considering the findings, writing about them and identifying the core category, I made an effort to use those words used by participants at least initially. Fleischman (1999), a linguist who developed a serious medical condition which led to her reflecting on the use of language in connection with illness, explains how different terms can indicate different meanings; the phrases 'I am', 'I have' and 'I suffer from' offer different degrees of ownership and acceptance of a condition. None of those interviewed used the term 'I suffer' and so I have consciously not used this throughout the study; this phrase would, if used, be an imposition upon their experiences which inaccurately reflects their perspectives. Instead, participants described themselves as having a long-term condition, whether asthma or thrombophilia. Neither group described themselves as 'being an asthmatic' or 'being a thrombophiliac'.

It is also important when considering language to note that the words used to construct the codes and categories (except in the case of in vivo codes) were chosen by me. They were based upon my interpretation of the data received from the people interviewed. As a result, as explained in chapter one (p.20), I have chosen not to use disease or illness but instead condition or long-term condition to denote thrombophilia and asthma, as participants did not use disease or illness themselves.

### **Quality criteria in grounded theory research**

Criteria for quality in qualitative research are less clearly defined than those for quantitative research, and a significant volume of literature is available discussing both the terminology to be adopted and the criteria which may be used. Herein I consider the criteria often adopted for use with grounded

theory studies, and also detail some other principles which may be of use for contemplating quality in qualitative research.

Glaser and Strauss (1967) indicate that a grounded theory ought to

*“fit the substantive area in which it will be used, ... be readily understandable by laymen concerned with this area, ... be sufficiently general to be applicable to a multitude of diverse daily situations within the substantive area ... allow the user partial control over the structure and process of daily situations as they change through time”* (p.237).

Glaser (1978) later revised these to fit, work, relevance and modifiability, and Charmaz (2006) indicates that these

*“are particularly useful for thinking about how your constructed theory renders the data”* (p.182).

Fit means that “the categories of the theory must fit the data” (Glaser 1978, p.4); the theory is constantly updated as more data are analysed, and all existing categories used must earn their way into the data, rather than the data being forced to fit the category. I have throughout the study constantly gone back to the data in order to ensure that the categories identified fit the interviewees’ comments. I have also tried to ensure that the names given to the categories fit as well as possible, in order that the reader is not led away from the data by a misnomer.

For a theory to work, it must

*“be able to explain what happened, predict what will happen and interpret what is happening in an area of substantive ... inquiry”* (Glaser 1978, p. 4).

I trust that this theory, being based in the data, explains what happened and is happening for those interviewed and can predict what may happen in further instances of individuals being diagnosed with a long-term condition such as thrombophilia or asthma. The theory, being based upon the concerns and processes described by participants, is relevant to those affected by these long-term conditions. It is also modifiable, and may be amended if new data are identified which do not fully comply with its current form.

In addition, Cash (2009) suggests the following criteria for use in assessing qualitative research findings:

“Substantive contribution – does the piece of writing contribute to our understanding of social life?

Aesthetic merit – is the writing artistically shaped, satisfying, complex and not boring, inviting interpretive responses in the reader?

Reflexivity – has the author held themselves accountable to the standards of knowing and telling about the people they have studied?

Impact – does the writing resonate emotionally and intellectually?

Expression of reality – does the text embody a fleshed out sense of lived experience, does it provide a credible account of a cultural, social, individual or communal sense of the ‘real’?” (ibid, pp.81-82).

I have attempted whilst writing this thesis to ensure that it is written in such a way as to involve the reader and, particularly during the findings section (chapters four and five), to offer an insight into the worlds of those interviewed. Where I have recognised that conceptualising and writing about codes and categories has created a distance between the reader and the people I interviewed, I have re-written the sections in order to create a closeness which allows the reader to both conceptualise the categories and also to feel the impact of participants’ words. I hope that this gives a sense of realness to the findings. I have also adopted a reflexive approach, and my considerations in this regard can be found in chapter seven.

## **Potential transferability**

Although the data in this study was collected from people affected by thrombophilia and asthma, it is possible that the theory may also be applicable to other long-term conditions which follow a similar disease pattern (i.e. long periods when the condition is stable or invisible, interspersed by acute phases). In particular, the theory may be applicable to other conditions which are not considered by those affected as being problematic on a daily basis. The literature indicates that a variety of illnesses and conditions, including arthritis, allergy, heart disease, renal transplant, cystic fibrosis and diabetes mellitus may be perceived by those

living with the condition to be non-problematic (Berntsson et al. 2007; Sanderson et al. 2010).

As a constructivist grounded theory approach was used in this study, the theory developed is located in a time, place and culture (Charmaz 2003). This is specifically the UK, with a national health system which is free at the point of access and enables access to a range of tests and treatments, at a time when diagnosis of thrombophilia and asthma is medically possible. It is possible that the resulting theory would not be exactly the same if, for example, the study had been conducted in a country with a different type of healthcare system. For example, research undertaken in the United States often finds that financial considerations are prominent, and these were not mentioned by most participants in this study in connection with day-to-day healthcare (Cortes et al. 2004; Baptist et al. 2010). One participant in this study had experienced several healthcare systems, having lived in various parts of the world, and it is clear from her experiences that financial factors were prominent in her healthcare decisions. The theory may thus require some amendment in order to be used in other types of health-care system, where access to tests and treatments may be limited practically or financially. It may also require amendment over time; it is not possible to say with certainty that it will remain applicable indefinitely, particularly with regard to information sources and the medical knowledge of the lay public.

## **Summary**

This project adopted a constructivist grounded theory approach and used interviews to explore how people make sense of their long-term, potentially life-threatening, health condition. Three different sampling routes were used to access potential participants. Quality criteria for grounded theory specifically and qualitative research more widely offer a way of considering the findings of this project, their presentation and the theory derived from this study. It is likely that the theory developed may have some transferability to life with other chronic conditions.

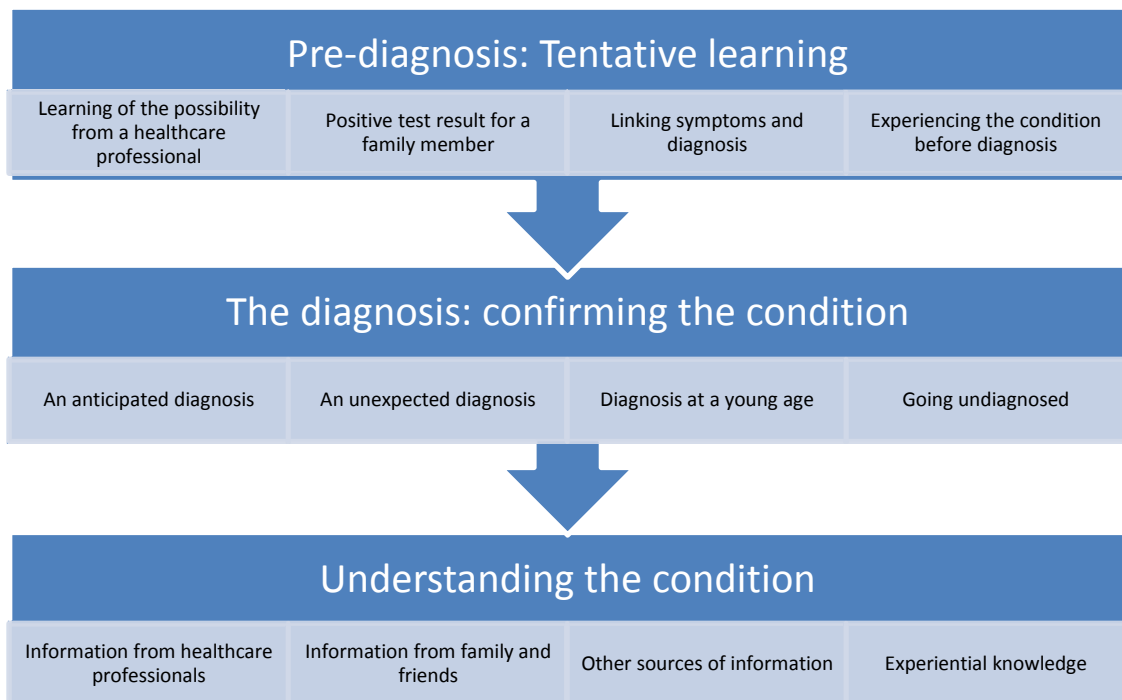
The next section will consider the findings of this study, beginning with the stage of *gaining knowledge*, during which individuals learn about and gain understanding of their long-term condition.



## Chapter 4: Gaining knowledge

This chapter, together with the following one, will detail what it is like to be diagnosed and live with a long-term condition, incorporating how people learn about and understand thrombophilia and, following further theoretical sampling, asthma. Following identification of the process of making sense of these conditions, dialogue between the findings and the literature was undertaken and this can be found in chapter six. The theory resulting from this study will be detailed in the final chapter.

This chapter will describe in detail the stage of *gaining knowledge*, considering three phases, designated *pre-diagnosis: tentative learning*, *the diagnosis: confirming the condition*, and *understanding the condition*. In line with theoretical sampling, the concepts arising from interviews with individuals affected by thrombophilia will be discussed first. These will then be compared with those resulting from interviews with people affected by asthma, and the similarities and differences identified. Figure 1 offers a diagrammatic representation of these phases.



**Figure 1: Diagrammatic representation of the stage gaining knowledge, comprising of the phases pre-diagnosis: tentative learning, the diagnosis: confirming the condition and understanding the condition.**

## **Pre-diagnosis: tentative learning**

Some individuals start to learn about their condition before diagnosis. They become aware that they might be affected by some sort of illness and will begin to gain knowledge about it. They learn that they could be affected from healthcare professionals, family members, or by linking their symptoms to a possible cause. Some people will gain experience of their condition before being diagnosed, particularly those who struggle to obtain a diagnosis.

### ***Learning of the possibility from a healthcare professional***

For some people in my research, the possibility that they may have thrombophilia was raised by a healthcare professional before they were tested for the condition. Those who found out about the condition through this route were unlikely to have a known family history of thrombosis, and so this was their first contact with thrombophilia.

One person, for instance, had been warned before having tests for thrombophilia that he may have the condition, and that it was hereditary. He was the first person in his family – as far as he was aware – to have experienced thrombosis. Although he had been warned that he might have hereditary thrombophilia, he was not expecting other members of his family to have a positive result as he thought that it would have caused others to have been hospitalised – as he had been - as a result.

*I didn't really expect anybody else in the family to have had it because I think naturally I was thinking, well you know I've just spent 10 days in hospital getting this looked at. If anybody else has had it surely they would have gone through the same sort of thing as well (Unique Reference Number P093)*

Another man was the first in his family to be diagnosed with thrombophilia and was informed before testing that this may have been the cause of a deep vein thrombosis he had experienced.

*I'd never heard of it. I'd never heard of Factor V ... suggested that I go back to see somebody with an expertise in that sort of thing who then took various blood tests and he'd explained what he was gonna do with them yes (P113)*

Awareness for these individuals came from an external source, in the form of healthcare professionals. These people were likely to have experienced symptoms which led to healthcare professionals' suspicions of the condition.

Similarly, some individuals affected by asthma learned that they may have the condition when they consulted a healthcare professional. One individual's words are an example of this:

*It was getting quite sort of keeping me awake at night and I was really struggling sometimes, so that's when I went to the doctor's erm and they sort of listened to my chest and they said I think it's more, you know, it's not just a a a cold, it's possibly asthma here. It sounds your, you know, chest sounds very tight and wheezy (P142)*

Thus individuals can learn that they could have a LTC through consulting a healthcare professional about symptoms, which may lead the professional to suspect a particular condition.

### ***Positive test result for a family member***

For some individuals with hereditary forms of thrombophilia, the first knowledge that the condition exists in their family is the positive test result of a relative. This occurred for several of the participants in this study. One was unaware of the condition and had never experienced thrombosis; her sister's diagnosis made her realise that she might also have thrombophilia.

*It started with my sister, erm she had a problem with her eye and they found out that she had a blood clot behind her eye erm and they did tests for several months because they couldn't work out what it was and then found out that she has the factor V ... her doctor at the hospital had told her to tell us to get checked (P091)*

One woman had become aware of thrombophilia in her family at the age of 10 when her father experienced a deep vein thrombosis and was diagnosed with the condition.

*It all started with my dad I guess ... he, when he was 38, had pretty much three DVTs at once 'cause he refused to go to the hospital ... and they worked out that he had thrombophilia (P112)*

At the time of learning that they might be at risk from thrombophilia, these participants could not be sure that they were also affected, only that the condition existed in their family and that there was a possibility that they too might have it. Awareness came from an external source, and was based on others' experiences.

In contrast, those with asthma did not mention the possibility of a family link to the condition. There is still a lack of clarity regarding genetic links to asthma (see for example Zhang et al. 2008) and participants may not have been aware that having a family member with asthma could increase their likelihood of being affected.

### ***Linking symptoms and diagnosis***

Some people made links between symptoms and the possibility of having a blood-related condition. Those with inherited thrombophilia frequently linked their own symptoms to those of members of their family. Symptoms perceived as being linked to thrombophilia included clots (deep vein thrombosis or pulmonary embolism), non-thrombotic symptoms such as painful legs and varicose veins, or other blood-related issues, particularly stroke. Some of the participants who identified a connection between symptoms and a condition sought medical advice about this, and received a variety of responses.

One individual, for example, had made links between her painful legs and the varicose veins she suffered and her mother's strokes and emboli. These connections were prompted by a friend's experience of DVT, and led to the participant contacting her GP.

*I've always had very, very erm achy legs and varicose legs and I said erm, you know, I was worried because I was talking to somebody and they said ooh you know I've, I've got a clot in my leg and I thought, oh gosh, I don't like the sound of that. So it got me worried, concerned about you know my mother, what she had, went to the doctor (P081)*

Another woman had experienced two clots personally and had two family members who had also had thromboses. The participant had been tested for thrombophilia after a second clot, but the test was incorrectly negative (the implications of this are discussed in the next section). Several years later, her sister had a positive test result for thrombophilia, which prompted re-testing of the participant, which confirmed that she also had the condition.

*She started spontaneously having clots in her arms and then she had a clot in her leg and then of course she mentioned to her doctor, oh my sister's, my mum died of one, my sister's had them and they went, ooh now that's interesting, so they tested her and she had Factor V ... they tested me and I've got it too (P111)*

During the time between the initial negative test and her sister's positive diagnosis of thrombophilia, this individual was aware that something was causing blood clots in several family members, and so she spent some time tentatively learning about this 'thing'.

Those with asthma sometimes link their symptoms to those experienced by others in order to identify the possibility that they may have the condition. The wife of one interviewee had asthma, and he had compared his own symptoms to those of his wife.

*My wife has asthma and she has the puffers and I have symptoms that she recognises and when I use her puffer the symptoms go away (P147)*

Those who make links between symptoms in order to determine whether they might be affected by a type of condition do so based on personal belief

rather than information from others. Thus the source of their knowledge is internal. This may occur over a longer or shorter time period, and, as evidenced in the words of those with hereditary thrombophilia, it can be based on the perceived collective experiences of a family rather than solely on a single person's experience. As a result, their information sources were likely to include family members and experiences in addition to information from healthcare professionals.

### ***Experiencing the condition before diagnosis***

A number of individuals in this study had been affected by their condition, albeit undiagnosed, for a period of time before they were able to achieve a diagnosis. During this time, they learned about their condition, experienced symptoms, consulted healthcare professionals and made lifestyle changes. However, they were not able to give a label to the condition and did not realise that they had it. Some had experienced illness prior to their diagnosis, and as a result had learned something of the condition.

Subsequent to diagnosis, they reflected on their experiences and recognised not only symptoms, but also the responses of healthcare professionals and changes they had made as a result of having their condition. For example, two individuals with thrombophilia reflected on their experiences of having a clot (diagnosed and undiagnosed as such) and the impact this had had on their life.

One individual, for instance, had experienced symptoms of blood clots which had gone undiagnosed for 20 years.

*It's taken like 39 years for them to decide that that's what I've got, having had problems for 20 years of that time (P121)*

Another indicated that she had been offered several reasons that she might have had a clot before receiving confirmation that she had thrombophilia, saying:

*At that time, because they were trying to think, oh it's a freak incident, you know. Oh, they tried saying I was overweight which is ironic as I wasn't because I was 100lbs less than I am today... They were trying to say oh, you must have an unhealthy lifestyle. I don't smoke. Oh, you must be on birth control. I'm not on birth control. (P143)*

During the time they went undiagnosed, individuals with thrombophilia experienced symptoms and gained knowledge about how the condition affected them. They discussed the insights they had gained into the attitudes of healthcare professionals towards their illness, including instances where they dismissed clots as one-off incidents or blamed the individual's lifestyle, or where they dismissed symptoms altogether and did not diagnose thromboses. Learning acquired through the experiences of their undiagnosed condition remained with individuals, and they discussed this during interviews even where it had taken place a number of years previously. These experiences thus contributed to individuals' knowledge of their condition, despite often occurring before their condition had been given a name.

Although both those with thrombophilia and those with asthma discussed their experiences during the time before diagnosis took place, those with thrombophilia tended to talk of long periods during which they had blood clots, experienced symptoms and the reactions of healthcare professionals and learned about the condition. In contrast, those with asthma looked back following diagnosis, and suggested that they may have had a mild form for some time. For instance, two participants mentioned that they seemed to have had something which affected their breathing, with one saying:

*When I went in it all sort of clicked that I should probably have been on inhalers before that 'cause there's a few times I'd been wheezing and er seem a bit strange to, you know, myself and family and so on and so forth (P145)*

For this group, the feeling that there is something different about their breathing may be dismissed until they are diagnosed with asthma, when it

becomes apparent that they were not merely unfit. Tentative learning thus occurs by individuals reflecting on their pre-diagnosis symptoms and making meaning of these at a later date.

As shown by the findings, individuals learn of the possibility that they may have a long-term condition through several routes, these being:

- Having consulted healthcare professionals about symptoms, and been advised that particular conditions are suspected to be the cause. Some limited information is likely to be provided at this point.
- Learning of the condition through a family relationship, for example when family members receive a positive test result confirming that a particular condition is in the family. However, they cannot, prior to being tested, be sure that they individually are also affected. Information will be gained from both family members and healthcare professionals.
- Others have a feeling that they might have some sort of illness. For those with thrombophilia, for instance, this could be a feeling that something relating to blood or blood clotting is happening, either personally or within their family. Individuals who experience an impression or feeling about something happening may not be able to name the condition, or may even have wrongly been informed that no such condition is affecting them. Alternatively, they may discover that someone they know is affected by a particular condition and recognise their symptoms as being similar, and so be able to give them a label.

Learning of the possibility that one could be affected by a LTC may be an immediate recognition, for example when informed by a healthcare professional who believes that the individual is affected by the condition, or it may be the consequence of a gradual realisation that there may be a link between repeated occurrences of particular events. This type of realisation may result from thrombosis occurring in blood relatives or personally, and those who gradually realise that events may be linked are likely to have experienced illness themselves.



The source of the knowledge can be external to the individual – a healthcare professional or family member – or internal. It may be based on personal experiences only (for example, where awareness results from an individual's symptoms) or on collective experiences (where a family history of clots or the diagnosis of another family member leads to awareness).

The knowledge gained at this point will be limited; for example they might learn about some of the characteristics of the condition, and it may not all be medically accurate. The characteristics and symptoms differ between conditions, as do treatment options. The information gained at this time is likely to be tentative as the cause has not yet been confirmed. Those individuals who are affected by a condition for some time before being diagnosed are likely to reflect on their experience post-diagnosis and begin to make meaning of it. This can happen when people go undiagnosed for a time.

Many of those diagnosed with thrombophilia were adults, and only one had been diagnosed as a teenager. Some of those with asthma were also diagnosed as teenagers, whilst others were diagnosed at a very young age. For this group, the time before their diagnosis was unknown to them due to their age, and so they were unable to tentatively learn about their condition. There are other reasons for people not to tentatively learn about their condition; some people were diagnosed who had no previous awareness or experience of their condition. This occurred when there was no reason to believe the condition could affect them, or when other illnesses had led to the premature death of members of previous generations. This group will not be considered further in this section, but will be discussed later in the chapter.

Knowledge may be based on beliefs which have arisen through the individuals' experiences of the condition. Those who have lived with a condition for some time before diagnosis have learnt about it through their experiences. This may occur for others also, but those who were diagnosed a relatively short time after experiencing symptoms are likely to have fewer experiences from which to learn. In all instances, the knowledge gained at

this stage may or may not turn out to be accurate. However, it will contribute to the knowledge acquired in relation to the condition.

Those who go through the phase of tentative learning are conscious of something which causes their symptoms. They might not be able to name this, and they might not at this stage have received confirmation of the possibility from a health professional. However, almost all participants in this study who became aware of a potential illness or condition were later diagnosed medically. Tentative learning leads individuals to develop constructs about their condition which may or may not be medically accurate.

Learning that one may have a health condition frequently leads to a diagnostic test, in order to confirm the condition. From this point onwards, tentative learning is no longer an appropriate description and individuals will have confirmation regarding their status. Those who were only aware of a possible condition will now be able to label it. The next section will consider the phase of confirmation, this being the point at which individuals receive the diagnosis of their long-term condition.

### **The diagnosis: confirming the condition**

Participants in this study had all been diagnosed with a long-term condition, most frequently by a healthcare professional. This enabled them to label their condition and symptoms and to start learning about the LTC which directly affects them and so is personally meaningful. For some, this occurred subsequent to their initial awareness and built upon the constructs which had previously formed. Others had received no indication that they were at risk and so they entered the process of learning at the point of diagnosis. This particularly included those who were unaware that they could be affected by a particular condition, or those who had been diagnosed at an early age. Thus, some people were anticipating their diagnosis, in contrast with others for whom it was unexpected.

Most people had undergone some form of testing before a healthcare professional confirmed their diagnosis. In this study, all of those affected by

thrombophilia had been diagnosed by healthcare professionals, usually through various blood tests. Some of those with asthma were also diagnosed by a healthcare professional, who took peak flow readings and confirmed the condition. In contrast, two individuals with asthma self-diagnosed. These do not offer deviant cases, as the process gone through by these individuals fits with the theory identified, but their route to diagnosis differed as they themselves decided that they had a long-term condition. A number of individuals were diagnosed at a young age, and did not remember a life without their condition. Others talked of going undiagnosed, as a result of healthcare professionals missing the diagnosis or of them not seeking medical advice despite experiencing symptoms.

### ***An anticipated diagnosis***

Some individuals expected to receive their diagnosis and were prepared for it. In these instances, the diagnosis offered confirmation of what they suspected, and allowed them to substantiate what they had started to learn about the condition. This occurred in some instances where healthcare professionals suspected a particular LTC and had advised the participant of this, and where people linked their own symptoms to those of others known to have the condition.

For instance, one woman, whose father was known to have thrombophilia, had a blood clot at the age of 14. She had subsequently been tested for thrombophilia and, although she had not been warned that thrombophilia would be one of the tests carried out, she was nonetheless expecting a positive test result.

*I guess 'cause the diagnosis the the actual genetic diagnosis came after the DVT it was like, well yeah, obviously (P112)*

This is confirmed by another individual who had temporarily been treated for asthma as a child, before being diagnosed as an older teenager after experiencing increased symptoms. He did not express any surprise at the

diagnosis, and indicated that in between these events he had experienced mild ongoing symptoms of the condition.

*I was first diagnosed with asthma when I was a child but I wasn't given any er inhalers... I had symptoms all that time, but they were very mild...at the age of 16 I was getting the same symptoms but they increased and then I was fully given the the standard inhalers (P145)*

As seen in the previous section, a range of information is already known to many individuals diagnosed with a long-term condition, based on experience, advice from others or assumed links between symptoms and a known condition. In those instances where individuals anticipated their diagnosis, this information is confirmed as being of personal relevance and they can begin to make sense of their condition. This contrasts with those who receive an unexpected diagnosis, where they may need to ascertain which information is relevant and to adjust their perceptions about a condition which was previously unknown to them or had been wrongly diagnosed.

### ***An unexpected diagnosis***

In contrast, some participants had not expected the diagnosis they received, despite being warned by healthcare professionals that they might have the condition and in some instances experiencing symptoms for a number of years.

Diagnosis of thrombophilia was described by one participant as 'a bit of a shock' (P081), by another as 'a big bombshell' (P111), and another said:

*it was a shock in that you know they when you sit down after you've sort of got that you you go home and you start piecing everything together in your head and you think my god you know actually maybe I actually am quite lucky here (P121)*

Those who had had symptoms for some time and could now label these as being due to a particular condition were often pleased to receive the diagnosis:

*I'm glad I know because I will obviously try and sort of take account of it now in decisions (P121)*

Others were unsure how they ought to feel about the diagnosis:

*Is it better to know you've got it or better not to know you've got it? It's a difficult position really (P081)*

Conversely, those participants affected by asthma did not describe their diagnosis as unexpected or surprising. This might be linked in part to the timing of their diagnosis, as some were determined to have the condition whilst still children. It may also be linked to the greater general knowledge within the UK population of the condition; those who had been diagnosed at an older age were all aware of other people with the same disorder. Several of those diagnosed with thrombophilia had never heard of it prior to their diagnosis.

For those people in this study who received an unanticipated diagnosis, the information they had collected was independent of the condition itself. Only after the diagnosis did they start to make sense of the condition as a named entity; prior to this they had an unnamed or incorrectly diagnosed set of symptoms which they had not linked. From the point of diagnosis, they were able to label the condition and begin to make meaning of it within the context of the information they had previously collected.

### ***Diagnosis at a young age***

All of those with thrombophilia had been diagnosed as teenagers or adults. In contrast, some of those with asthma had been diagnosed at a young age and had lived with knowledge of it for most of their lives. As a result, their knowledge began when their parents were informed of both diagnosis and ways to manage the condition. For example, one individual stated:

*I think they diagnosed it pretty early and I think, it didn't get too drastic, sort of erm, a really bad point and they did diagnose it and to*

*be honest with you I do remember having it from, from ever, I always remember having it (P141)*

These individuals were too young when diagnosed to see this as surprising. It led them to know asthma from a young age, to be aware of the need for treatment, of the possible symptoms which they might experience and of the risk of serious illness as a result of the condition. As will be discussed later in this chapter, those who were diagnosed at a young age gained much of their information from sources other than healthcare professionals.

### ***Going undiagnosed***

Diagnosis is not always a simple process for those with a long-term condition. This was particularly relevant to those with thrombophilia in this study. Delayed diagnosis may result from illness occurring prior to the development of appropriate tests, results not being communicated to individuals, or when healthcare professionals do not recognise the cause of symptoms. This happened to some individuals in this study. Those who went undiagnosed experienced further illness before a diagnosis was received and they were provided with appropriate information and advice about the condition.

For example, one woman had experienced two clots and received a negative test result.

*At the time the thrombophilia tests then were really, I mean this is 30 years ago, they were really not very good at all and they at the time it came back and they just looked for things like lupus and stuff like that and it all came back negative so they said no it can't be anything wrong, it's just bad luck (P111)*

As a result, a family link to blood clotting had been dismissed until her sister was later diagnosed with thrombophilia.

Similarly, another individual had only received a diagnosis of thrombophilia when he experienced a second DVT and had a repeat test – he indicated that the results of the initial tests had been lost.

One person had some symptoms of thrombosis as a teenager, but, despite consulting health professionals repeatedly over a period of time, had not been diagnosed for two decades. Another woman, who experienced a DVT at the age of 14, indicated that she wished she had been tested sooner for thrombophilia, following her father's diagnosis.

*I guess I was annoyed at my dad somehow because he hadn't got us tested sooner (P112)*

Going undiagnosed for this individual differed from the other cases as this woman wished that she had been tested before having symptoms of thrombophilia. However, she revealed that, had she been tested before the DVT occurred, *'it wouldn't (have) come as such a surprise'*.

In contrast to the delays which could be attributed to healthcare professionals, several of those with asthma who were diagnosed as teens or adults suggested that they had experienced symptoms for a time prior to seeking medical advice, but had dismissed these as a result of being unfit. They therefore went undiagnosed as they had not sought medical advice for a time.

Some individuals went undiagnosed for a period of time after first experiencing symptoms. Healthcare professionals might act as a barrier to being diagnosed; conversely, individuals may not recognise that their symptoms result from a health condition. Most of those who encountered a delay in receiving a diagnosis of their condition had experienced the condition before diagnosis. They were aware of symptoms of the condition, had been ill and as a result had gained extensive tentative information before receiving a diagnosis.

All participants in this study knew the label for their condition. Most of those with thrombophilia had been diagnosed with Factor V Leiden and were aware of this, though some were unsure of the precise terminology. For example, one participant said that *'I never knew I had this leiden 5'* (P094) and another said *'I can't remember van veiden, leiden or something'* (P081).

Some participants with inherited thrombophilia had also been diagnosed with possible Protein C and/or Protein S deficiency; diagnosis of these forms of thrombophilia is uncertain and participants were aware of this<sup>3</sup>. In both cases, the individuals concerned recognised that this was another facet of their condition; one individual described how:

*luckily I'm one of these people who thinks well if I've got a double whammy anyway, even if I've got a single whammy, I have a whammy, so you know what's one whammy or less whammies between friends* (P111)

Those with asthma were all able to name the condition, though they did not describe it, as a health professional might, as being mild, moderate or severe. Thus all participants in this study were able to give a name to their condition. No participants denied their condition, or indicated any doubts about their diagnosis of thrombophilia or asthma.

Individuals were diagnosed with a condition at a range of different ages; the nature of the condition tended to result in an earlier or later diagnosis. For example, there was a tendency for those with thrombophilia to be diagnosed at an older age than those with asthma. One individual with thrombophilia had received the diagnosis in her 60s, whilst most had been diagnosed in

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<sup>3</sup> *Protein C and Protein S deficiencies are diagnosed through assay tests to determine the amounts of the protein present in the blood. There is uncertainty regarding levels of Protein C and Protein S and the determination of levels which indicate a deficiency (Baglin 2000; Greaves and Baglin 2000; Favaloro 2005). Baglin (2000) and Favaloro (2005) indicate that levels of Protein C activity in those with thrombophilia may be comparable with those of unaffected family members.*



their 30s and 40s, though some had experienced symptoms prior to this. In contrast, asthma is known to be the most common childhood illness. Several interviewees had been diagnosed with asthma as a child and their memories of the condition started from an early age. Others were diagnosed as teenagers and, looking back, they recognised that they had probably been experiencing symptoms for some time. The diagnosis made sense of their struggles with breathing.

The age at which an individual is diagnosed with a condition will affect the information they receive and gain about it. Diagnosis as a child will mean that their parents are informed of the implications of having the condition, rather than the individual themselves, and the child will learn from their parents and from experience. Those who are diagnosed as a teenager or adult will learn about the diagnosis from the healthcare professional managing their diagnosis and treatment.

In addition, those who participated in my research had been diagnosed at different times over the past 50 years. This led to different levels of information. For example, one woman who had been diagnosed with thrombophilia before the advent of the internet had restricted access to information as a result. One man with asthma who was in his 50s at the time of interview remembered as a child sleeping with a tar lamp in his bedroom (though a common remedy for breathing problems at the time, this is now known to exacerbate asthma).

In learning of their diagnosis, participants began to confirm the information they held about their condition. This could be confirmation that they are affected by a LTC, that they might need medication, to make lifestyle changes, or to amend their activities. It could also confirm or deny their experiences, allowing them to determine which were meaningful in the context of the condition with which they had been diagnosed, and enabling them to dismiss those which were peripheral and irrelevant. Some of their perceived knowledge, for example that thrombosis is linked to strokes, may be incorrectly maintained in the absence of proof to the contrary. Those who were diagnosed at a young age did so with little personal experience of their

condition, and so their knowledge was acquired mainly from family members, in contrast with those who were diagnosed as adults who were able to learn from both experience and information offered by healthcare professionals. Information at this point starts to become personally meaningful and allows individuals to start to become knowledgeable about their condition.

Development of constructs relating to the condition will continue, now within the context of having a known and named long-term condition.

The next section will discuss the phase of understanding one's condition, this taking place within the context of confirmation. This forms a substantial part of the current chapter, in order to consider in full the range of information and knowledge sources used by the study participants.

## **Understanding the condition**

As discussed in previous sections, some people acquire tentative knowledge prior to receiving a diagnosis. This is likely to be limited, and may lack meaning until they are able to name their condition. During this time, individuals may begin to learn about their LTC from their experiences. All will have their condition confirmed through diagnosis, enabling them to identify which information is personally relevant. This section will consider the final phase of *gaining knowledge*, that of *understanding the condition*. This begins at the time of diagnosis; indeed, Willig (2011) states that "Diagnosis...tends to give rise to a desire for information" (p.898) and this is confirmed by my study. Subsequent to diagnosis, individuals will begin to use their knowledge to determine how to deal with and manage their condition on a day-to-day basis. They will also amalgamate existing, relevant information with this ongoing knowledge.

Information and understanding will be gained from a variety of sources, including healthcare professionals, family and friends, the internet, books and other media and, most significantly, experience.

### ***Information from healthcare professionals***

Most participants had been given information about their condition by healthcare professionals before or at the point of diagnosis, or during a follow-up appointment. The latter could occur at any time after diagnosis. For those with thrombophilia, later appointments tended to result from a suspected further occurrence of thrombosis, or a change in circumstances which led individuals to seek out further information. Most of those who had regular appointments at the blood clinic to check their international normalised ratio (INR)<sup>4</sup> levels did not gain much information from these particular appointments, beyond determining their clotting levels and the need to maintain or amend their medication.

Information was provided by GPs, nurses, nutritionists, pharmacists, and hospital consultants. For example, one participant was aware that his body didn't break down clots as easily as other people.

*They tell you that my body doesn't break down when you injure yourself and ... 'cause if you injure yourself your body like normally clots but my body can't break down that clot as efficiency as efficiently as what it should do (P083)*

One woman had moved around the world due to her job, and found that she had received very little information when first diagnosed as having a clot. When she was transferred to Italy the healthcare professionals would work with her to assess appropriate diet and activity levels and determine the level of warfarin to be taken in order to reduce her risk of having a clot. Another had received useful information from healthcare professionals when she was eventually diagnosed with thrombophilia. She indicated that they had given her information about the condition, about groups she might like to consider contacting, and provided her with information from relevant journals.

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<sup>4</sup> International normalised ratio is a measure of how rapidly the blood clots, and is used to determine the correct dose of warfarin or other anticoagulants for the individual.

*They told me about erm a couple of groups that I could sort of look up on the internet and that as well ... I felt as though I'd got some answers and I felt if I had more questions, I could get somebody to answer them for me ... I'm quite a curious person and and I like to know the detail you know and I'm I'm pleased with the the information that the doctor (GP) gave me, that it is quite erm it's from the British Journal of Haematology so it's quite you know it's quite medically written you know but I don't mind wading through that 'cause I feel that I can you know get enough out of it, that I've learnt stuff from it (P121)*

Two people with thrombophilia indicated that they had not been provided with the most useful information, how dangerous a clot could be, with one saying:

*I think I should've been told when I had the first one that there was the possibility that a bit would break off and hit my lungs and kill me (P111)*

A majority of participants with thrombophilia had been given written information which reflected that provided by healthcare professionals and generally participants did not find this to be useful. One said for instance:

*He gave me a leaflet that sort of explained it slightly but of course being medical terms it's very difficult (P081)*

One individual who worked with others affected by her condition indicated that many of the leaflets provided are not particularly useful, and this was mostly confirmed by other participants' recollections. However, one participant had received several items of written information, including some leaflets from charities working in the field, which she found useful, though not as detailed as she would have liked. She said:

*They gave me a couple of leaflets I think and they also made it very clear to me that if I wanted to go back and speak to them at any point I*

*could do ... It it it was useful. I I think I'd prefer it to have been a bit more in depth erm, I don't, I still don't feel like there's an awful lot of in depth information around (P121)*

In contrast to those with thrombophilia, follow-up appointments for participants with asthma tended to be regular events during which medication was considered, peak flow measures taken and information about medication and how to manage exacerbations offered as necessary. Information provided could change over time, particularly that relating to medication. Individuals who had previously been advised to take their Ventolin inhaler before their steroid inhaler to enhance its effects were then advised to stop this when new research indicated that this could reduce the effects of the Ventolin (the blue inhaler). For instance, one participant stated:

*I know last time I went, I used to also take my blue inhaler at night as well whether I needed it or not ... but she said there had been some new sort of research or some new thinking that you should only take that when necessary (P142)*

Thus information was acquired from healthcare professionals in both written and verbal form, and was considered useful by some but insufficient or not understandable by others. It is possible that unmet information needs result when information is not retained or is not offered. Where people were provided with what they perceived to be insufficient information, they sought it from other sources, or used an experimental approach to managing the condition; I shall now move on to consider these.

### ***Information from family and friends***

Several participants indicated that they had gained information from family and friends. This ranged from being aware that acquaintances had their condition, to gaining most of their information from family members. Those who were affected by inherited forms of thrombophilia clearly had a reason to discuss this with family members, but other participants also spoke of conversations about their condition with relatives.

With specific regard to inherited thrombophilia, one individual indicated '*this is not the sort of thing that comes up at the dinner table*' (P111), and so discussion amongst family members tended to be at pertinent times, such as when a relative was diagnosed or when making decisions about treatment. One individual said that '*I've never really sort of spoke to my mum and my brother about it*', although he also indicated that he had discussed treatment options with his mother:

*My mum's sort of like she had her two penn'orth to add when I was thinking about taking the heparin injection and it's probably the first time she's really said about it to me, apart from the fact she's oh I I don't take 'em and I've gone through my whole life not knowing you know that I've had it (P093)*

Another woman had discussed the condition with several family members. She found that it was easier to discuss the condition with some family members than with others, for a number of reasons.

*My gran, who was sort of in between my great-granddad and my dad, just because she's managed to get away without having it somehow, but she's not very bright so having a conversation with her is difficult, erm and my mum as well because we wanted to know where the other bit of mine's come from, the protein C deficiency or the protein whatever it is they don't know ... and my brother as well... I can talk to him about it (P112)*

One woman who had acquired thrombophilia had discussed with her father the possibility of the condition being inherited and determined that this was unlikely.

*I remember calling my dad, saying dad, do we have you know this problem? He said, no, never had a problem you know. And all my siblings have never had this. My father, you know, never this problem you know (P143)*

Some individuals indicated that they had recognised their condition in others, including not only family, but also friends and acquaintances. For example, one participant believed that a family member had thrombophilia, despite negative test results, as she had had several DVTs, matching his own experience. He had also met a woman in hospital, whilst undergoing treatment for his second DVT, who was similarly being treated for a clot. Both had been eating healthy foods as a result of an advertising campaign, which the individual believed was the cause of clots for both himself and the woman.

*My sister, although they said that she has not got Factor V, has had three erm embolisms ... When I was in hospital, I was talking to this woman down there and she'd done the same, she'd gone into healthy eating 'cause it was on the TV and she'd been into all this same stuff and she had one she said (P083)*

Varicose veins were linked in participants' minds to thrombophilia, as indicated by one woman:

*I suspect I probably have inherited it from my mother 'cause she has loads of problems with erm sort of varicose veins and things (P121)*

There appears to be a difference between those individuals with inherited forms of thrombophilia, and those with asthma in terms of who they approach for information. Those whose family are affected by the condition not only inform them of their risk, but also discuss the condition at pertinent times, including obtaining advice about particular situations. There is a tendency to focus on linear family (parents, grandparents, children and siblings). In contrast, those with asthma gained information from their parents if they were diagnosed at a young age, but those who were diagnosed when older tended to acquire information from their peers. This could be accidental – through knowing people with asthma, and being aware of what this might mean - or through the purposeful pursuit of information.

For instance, one woman, who had been diagnosed with the condition as a child, had gained much of her knowledge about the condition from her mother. Another who was diagnosed as a teenager was aware of friends at school having the condition.

*I had a friend with asthma when I was at school so I suppose I always had an awareness of, you know, or actually I had two, one of them had it quite badly and I think she got taken to hospital on one occasion when she'd had an attack and didn't have her inhaler, so I think I was aware of it but probably not more than, oh, you know, people can't catch their breath (P142)*

In contrast, another participant with asthma had obtained much of his information from his peers, saying:

*There was people at school and stuff that had the asthma, asthma inhalers and, you know, it was, you, you know, I knew quite a lot about it ... speaking to some peers and so on (P145)*

Although asthma is not known to be directly inherited, some participants mentioned their parents having the condition. One mentioned that her mother seemed to experience similar symptoms to those she knew to be caused by the condition.

*I'm pretty sure my mum has always had asthma but it's never really been diagnosed 'cause I see her with the same symptoms as me and like, she's, she's exactly the same. Like if she goes, not, not as bad with, like her house, but if we go into a room and it's very damp, very mouldy, she will feel all tight-chested and doesn't wanna be in there (P141)*

Interestingly, individuals who had acquired information from family or friends did not question whether this was correct, even though it was frequently based upon perceived experiences. This can be contrasted with the comments made by those who had found information on the internet in the



next section. This information contributed to the knowledge individuals acquired and used in their understanding and management of their long-term condition.

### ***Other sources of information***

Information about LTCs was acquired from a variety of other sources, including the internet and books. This information was in some instances not offered, but had to be sought by participants. Alternatively, it could be a news story or similar which caught their attention due to its subject matter. Several of those participants affected by thrombophilia had sought out information from alternative sources, particularly the internet. It should be noted that some information sources, such as the internet, were unavailable to participants for a time due to their diagnosis occurring before its advent.

Some participants, for example, had looked up the condition in a medical book, as exemplified by the comments of one:

*We've got one of those medical books as well at home, we looked it up on there but er I think a lot of the information really was what the doctor said to me which was mostly, it was sort of all there (P094)*

Several people had looked up the condition on the internet and struggled to understand the terminology, including a woman who had not experienced thrombosis and said:

*I've looked on the internet erm about things, erm my sister had something printed off which I read but trouble is the way they speak, it's hard to understand, I just want it in layman's terms of do you know what I mean, easy, sort of understandable ... you try and read it and you've got all these big words and it doesn't make sense to me. It kind of do you know what I mean. I can't absorb it, I need it to be made quite simple really (P091)*

In contrast, other participants had found the internet to be a useful source of information, and were aware of the potential pitfalls. One said:

*You can search about on the internet but obviously you've gotta be sort of careful about what it is you're reading, and how good quality it is, and whether it's actually in this country or a lot of it's from America as well so erm, but I think that's probably because I'm I'm quite a curious person and and I like to know the detail (P121)*

Although most participants in this study had accessed the internet to seek out information, this individual is the only one whose purpose reflected the findings of Hewitt-Taylor and Bond (2012), who found that individuals using the internet valued doctors working in partnership with them, with patients and doctors learning together and respecting one another. This was particularly important for this individual, as she had gone undiagnosed with clots for a long period of time, and had finally found a healthcare professional with whom she felt she could work. Another had accessed journal articles and reports through her aunt (a medical editor) as well as searching for information on the internet.

Some individuals did not search for further information as they felt it was unnecessary, despite recognising that they were capable of doing so. One said:

*I probably ought to find out more but like I say, I I suppose personally I could have gone out and looked at more (P093).*

In contrast, those with asthma tended to receive information from family, friends and healthcare professionals, though some did state that they had looked up the condition in books or seen articles in the popular press. For example, one man had adopted some deep breathing techniques as a result of books he had read. He had also rejected one form of treatment he had seen mentioned in the press as he had been unable to find any evidence supporting its use.

*I think the first erm thing that I saw was a book on er asthma and hayfever which was a sort of a health, erm one of those self-help books ... Some Russian er treatment, er in relation to asthma that,*

*that was again, it was breathing... I could never find the number of studies that had been done to back it up alright but there were a lot of claims for it, erm. But I tend to distrust the media er in the broadest term until I've looked underneath it (P131)*

Others had identified information of relevance whilst reading materials for other purposes or whilst listening to the radio, with one individual saying:

*I always do find it interesting when I hear something, erm, to do with asthma. I heard something on Radio 4 the other day and I can't remember what it was but there, yeah I do, if, if I hear something I pay attention and I might then listen or deliberately tune in or whatever for that but I wouldn't say I go out of my way to look for it (P141)*

Although individuals received information from healthcare professionals, they also sought out information, sometimes to help them to understand what they had been told. Several participants indicated they had looked on the internet for information; some found this to be too complicated, whilst others indicated that it was their main information source. Others had looked in books to gain information, or had used alternative sources such as journal articles. There appears to be a clear difference between those with the more common condition, asthma, almost all of whom had identified news items relevant to their condition and those with the rarer thrombophilia, who had infrequently seen or heard such news items.

Information gained from these sources is amalgamated with the information acquired from healthcare professionals and family and friends, and informs the constructs created by individuals of what their condition is and how it affects them. It will be tested against their experiences, in order to determine what is useful and relevant, and what may be discarded. Constructs based solely on external information hold some meaning, as they hold direct relevance to individuals known to have the condition, but may lack the personal meaning and knowledge which result from experiences of the condition.

### ***Experiential knowledge: symptoms***

A wide range of experiential knowledge contributes to what people know of their condition, beginning for many with its symptoms. It was often these which caused individuals to consult healthcare professionals and receive their diagnosis. Only two of the individuals interviewed, both of whom had inherited thrombophilia, had not experienced illness in the form of a clot as a result of their condition, but one had experienced other symptoms.

Those with thrombophilia found that a clot could produce symptoms, or may be asymptomatic. All participants in this study who had had thrombosis had experienced symptoms of either deep vein thrombosis (DVT) or pulmonary embolism (PE) which led them to consult their GP and/or hospital. However, some had only experienced symptoms of pulmonary embolism and not DVT symptoms, and some were aware of other people who had not had any identifiable symptoms. The specific symptoms differed between individuals, the site of the blood clot when it became symptomatic, and even between occurrences for the same individual. Symptoms can be classified as those which are recognised as being indicative of DVT or PE, herein referred to as classical symptoms, or atypical symptoms which are less commonly associated with thrombosis (NHS Choices 2011; NHS Choices 2012b). Those who had not had thrombosis previously, had not been diagnosed at the time of experiencing a clot, or who experienced new symptoms, often did not recognise that they had a clot.

Some participants had other symptoms of thrombophilia, in addition to clots. For example, one woman was led to consult her GP as a result of aches and varicose veins in her legs. Another experienced a miscarriage, which, after years of having blood clots in her legs and being dismissed by healthcare professionals, she was aware could have been caused by thrombophilia.

For one participant who had experienced two deep vein thromboses in his leg, the symptoms he encountered had been those generally associated with DVT (NHS Choices 2012b).

*three weeks after the hernia op I had a dead leg ... after about three or four days of it slowly getting worse ... I goes off to the doctors with a erm a phlebitis, well like a kind of sort of a bad vein in my leg ... my calf muscle's tight (P083)*

When he experienced similar symptoms the second time, he was aware that it could be a clot. Another participant had experienced chest pains, a recognised symptom of pulmonary embolism as a result of a blood clot moving around the body (NHS Choices 2011).

The symptoms experienced by another participant were a mixture of those which are classically recognised as being caused by thrombosis, and those which could less easily be linked:

*I felt that I was getting erm the flu ... flu symptoms like feeling tired and weak you know, a bit heavy but it was my leg that was was, I could feel my leg swelling (P094)*

Another individual indicated that, although her first two deep vein thromboses had shown classical symptoms, the third she experienced later had shown atypical symptoms.

*My third DVT didn't hurt at all and it didn't swell at all but I just had loads of really weird lines on my legs like I don't know what it was but yeah that was my third DVT and it was just so very different (P112)*

Those who had experienced atypical symptoms encountered a variety of responses from health professionals; the first individual described above was misdiagnosed in the first instance, whereas the second individual, who at this time was known to have thrombophilia, was accurately diagnosed as having a deep vein thrombosis.

One individual had a pulmonary embolism which caused chest pains as a result of a broken finger; he did not identify any symptoms associated with the clot in his finger and indicated that the chest pains were '*completely out of the blue*' (P093). Another participant's mother had suffered a pulmonary

embolism, resulting from an asymptomatic DVT in her leg. Those who have experienced previous clots will be alert to symptoms and use this knowledge to determine whether a clot may be present, and thus whether medical advice ought to be sought. However, this is not always possible when clots are asymptomatic.

In comparison, the symptoms, and diagnosis, of asthma and related illness in the form of asthma exacerbations are far easier to recognise; indeed, they may be recognised by the lay individual in the case of those who self-diagnosed. As a result, those with asthma were more easily able to identify occasions where they needed treatment, either in the form of self-medication using short-acting bronchodilators, or by requesting more intensive forms of treatment such as corticosteroid tablets from their healthcare professional.

For example, one individual described how pine trees caused her chest to become tight, how dry heat such as that in a sauna doesn't cause an asthma attack but feels 'bad', taking away her breath, and that emotional upset could cause her to feel like clingfilm had been placed over her face, restricting her access to oxygen.

*It's like you've got clingfilm over your face but there's just a little hole in there and you can, you know, you can get like oxygen, but not, you have to really try hard to get that oxygen through that tiny hole (P141)*

Thus, a single individual could describe their experience of asthma symptoms in different ways depending on the circumstances and severity. Even on occasions where she did not become ill, she could still become aware of her breathing where the combination of her condition and environmental conditions caused her to feel different.

The description of feeling as though clingfilm had been placed over one's face was reiterated by another individual. He stated that he would seek additional treatment if he reached a point where

*I'll be gasping, yeah, which is horrible, it feels like clingfilm wrapped round your head (P145)*

He also described other symptoms, such as wheezing, shortness of breath, struggling to breathe and coughing as a result. He experienced dizziness with more severe attacks, due to either lack of or too much oxygen (after taking his reliever inhaler). Another man also described being unable to breathe, wheezing and feeling his chest tightening, and indicated that, in addition, exacerbations caused him to feel lightheaded and his muscles to ache, due to oxygen depletion.

Although many of the symptoms described by participants were similar and predictable, individuals also described additional symptoms linked to exacerbations, such as feeling lightheaded or dizzy, and aching. They were also able to identify circumstances which felt 'bad', although these did not necessary lead to an asthma attack.

Experience of symptoms contributes to people's knowledge of their long-term condition, and enables individuals to recognise when their condition is causing them to become ill. Individuals indicated that they would look for similar symptoms in future. It may lead them to seek or administer treatment or medical advice, and, for those with thrombophilia, could lead to long-term implications where illness had caused permanent damage. Knowing and understanding the symptoms of their condition, particularly how these manifest individually, enables people to make informed decisions about their condition.

### ***Experiential knowledge: treatment***

All participants in this study had either been prescribed medication for their condition (though not all continued to take it) or had acquired medication through an alternative route. Some individuals had received both ongoing treatment and emergency, acute treatment, whilst others had received preventative treatment only in the absence of any illness. Their experiences of taking the medication and its side effects led to constructs being formed

about the drugs and these contributed to the overall experiential knowledge each individual held about their condition.

All participants who had had thrombosis had received anticoagulation treatment to dissolve the blood clot; some individuals mentioned that this was heparin. This was the case whether or not they had experienced clots prior to this event, and whether or not they had received a thrombophilia diagnosis. They had also been given warfarin or a similar drug to reduce their chances of having a further thrombosis. Some individuals, particularly those who had not experienced blood clots, were prescribed aspirin to reduce their risk of becoming ill. All those taking medication had experienced unwelcome side effects either of the medication itself or of the routines required to maintain the correct level of blood coagulation.

One participant was prescribed anticoagulant injections and then warfarin. Another man had been placed on a heparin drip when admitted to hospital. He had then experienced a reaction to excessive levels of warfarin which had led to him being re-hospitalised and made him cautious of preventative treatment for thrombosis; this links with the decisions he then made as he did not wish to take treatment again in case he experienced similar side effects.

*Obviously with the warfarin tablets it was a scary moment at work and I was, I went to the toilet and suddenly realised there was blood where there shouldn't be blood and I was like ah that's not good, so again I was back in hospital again (P093)*

One woman had experienced seven confirmed blood clots, including a pulmonary embolism, as a consequence of her acquired thrombophilia. She had encountered a range of side effects whilst taking medication, including raised cholesterol levels, repeated broken ankles and cravings for dairy products which she attributed to

*the vitamin K and vitamin D being sapped out of my bones from the Coumadin (P143)*



She also found that, in the US, the treatment was prohibitively expensive and, whilst it would be paid for by the US Department of Veteran's Affairs, she would be chased and so would need to repeatedly remind them to make the payment.

Individuals who had not had a clot were advised to take aspirin as a preventative measure. One individual considered this to be less serious than the alternative of warfarin, and so had adopted the medication.

Treatment for a clot relies upon an accurate diagnosis: those people who had not at the time been correctly diagnosed as having a clot were not prescribed appropriate medication. Those people who had a single clot were treated solely for that clot, though once diagnosed with thrombophilia they may be advised to take medication at appropriate times or as a preventative. Others who had had multiple clots were prescribed medication to take in an ongoing manner. An individual's reaction to medication could impact upon future treatment decisions, as an adverse reaction may make them wary of future treatment or create a need to take an alternative anticoagulant. These are discussed further in *making informed decisions*. The impact of taking treatment to dissolve clots, and to prevent their recurrence, could create challenges for participants. One individual indicated that attending the clinic interfered with his life too much and another had to repeatedly remind the government department responsible for her prescription charges that they needed to be paid.

In addition to medication, most participants with thrombophilia had been advised to wear compression stockings. All indicated that they wore these, at least much of the time, and most seemed to consider them to be less intrusive than the medication they had been prescribed, though, as indicated in the comments of several participants, they were disliked. For example, one said:

*How much good it would do to wear the compression stockings because erm they are sort of helping basically to keep the the the skin healthy as well as you know sort of keep the the circulation going ...*

*well they're blooming awful aren't they god, they're uncomfortable, they're not attractive and honestly by the time you've put 'em on in the morning, you feel exhausted. Just horrible ... the guy at the hospital said look you know the state of your skin, because like the skin on my legs is very very thin and and flaky and sort of horrible, he said you know it is the unfortunate thing, it is highly likely that you'll get leg ulcers in the future, and I just think you know if there's anything I can do to stop me from ending up like my grandmother I will do it (P121)*

The woman who had experienced seven clots and so been advised to wear compression stockings and take warfarin, wore her stockings, but not as prescribed.

*I wear these for comfort. I no, I have a large stockpile of compression er hose that I'll put on but er it's gotten to a point where I've been wearing the er compression socks just because they're comfortable and warm ... I'm not wearing them for, you know, they were down, they were not up, which is not how they're supposed to be worn (P143)*

In contrast with those participants affected by thrombophilia, those with asthma were more likely to maintain their treatment regime, if not always exactly as prescribed, and less likely to question whether they ought to take medication. One individual took medication which he had identified as being necessary, in the absence of a GP's diagnosis of the condition, to which he gained access through his wife, who also has asthma. During times when they were experiencing exacerbations, individuals were often able to identify themselves that they required additional or different treatment, and were able to request these from a healthcare professional, either their GP or through emergency care. This can be contrasted with those affected by thrombophilia, who mostly experienced illness prior to receiving a diagnosis, and so were unaware of the need for treatment.

For example, when one man experienced asthma symptoms, he would contact his GP and inform the GP of how he planned to manage this:

*In the mild cases er that happens, well, I consult with the doctor and er say, look, I'm increasing my reliever at the moment, using the preventer er as well, to to up that, erm and I'll come and see you if needs be. Er, do you have a nebuliser in the clinic. Erm, you know, it's usually a bit of give and take you know, they know I'm dealing with things my own way and quite happy with that (P131)*

One woman had been prescribed a blue inhaler (short-acting bronchodilator, to relieve symptoms) and a brown inhaler (preventer inhaler). The latter she was aware should be taken twice each day, and the former she knew she ought to carry with her at all times, in case of symptoms occurring. However, she mentioned repeated occasions where she had found herself without her blue inhaler, and she had been advised by her GP that she needed to take her brown one as prescribed.

*I don't use my brown inhaler enough because when I'm not ill, say for example over Christmas I had a bit of a cough and a bit of a cold about me so I used my brown inhaler regularly and I was very conscious to take it, but then when I'm feeling fine, I don't really you know, I'll go weeks without taking my blue inhaler and forgetting to take my brown inhaler. And then you know it's only when something triggers it then I'm, oh, quick, have I got the blue inhaler. But then it's silly 'cause I know that taking the brown inhaler regularly really helps, but I do find when I first take it it feels worse... I feel quite tight chested at first (P141)*

As can be seen, although some participants with asthma did not take their medication always as prescribed, they did maintain their medication regimes at least to some extent. This is in contrast with some of those affected by thrombophilia, who did not take their prescribed medication, or did not choose to take medication in high risk circumstances. Those with asthma were able to identify circumstances when they required more intensive medical care; it was clear to individuals when they were experiencing difficulty breathing. None of those with asthma mentioned that they experienced unpleasant side-effects from taking their medication. Thus, it is

likely that individuals with asthma both perceived the importance of taking their inhaler – as otherwise they experienced distressing symptoms – and were less deterred by side-effects when compared with those who had thrombophilia, who were more likely to have experienced side-effects and to not have become ill as a result of not taking medication.

Gaining knowledge and understanding through experience of taking and not taking medication for their long-term condition enabled individuals to make decisions regarding treatments. This will be considered in further detail in the next chapter.

### ***Experiential knowledge: illness***

Most of the participants interviewed in this study had experienced illness as a result of their long-term condition. Those with thrombophilia had experienced blood clots, either deep vein thrombosis or pulmonary embolism, and one individual had also experienced a miscarriage which she believed could have resulted from the condition. Not everyone will experience illness as a result of thrombophilia, as the condition confers only an increased risk, and so not everyone will go through this phase. Both men and women may experience illness, and there did not appear to be a gender difference in the seeking of medical care when ill. Being ill may occur before, after or alongside diagnosis and it offered a range of experiences from which individuals gained insights and which they applied to the decisions they later made. These experiences included not only those relating to symptoms and treatments, as previously discussed, but also:

- Interpersonal dealings with healthcare professionals
- The specific trigger which led to their becoming ill
- The longer term effects of illness

Dealings with healthcare professionals: Most of the participants had consulted healthcare professionals due to illness, offering an insight into how healthcare professionals would deal with them and manage their concerns. Several individuals had lost their trust in their GP as a result of how their concerns had been dealt with.

For instance, when one man had a second DVT with similar symptoms to the first, his GP treated him for phlebitis with anti-inflammatory drugs. This was eventually diagnosed correctly as a DVT, but the experience led to him later distrusting his GP when he developed sciatica; he experienced numbness in his leg with sciatica as he had done when he first had a DVT. Other participants consulted their GP as a result of feeling unwell, having experienced a variety of symptoms. One individual was misdiagnosed when she experienced a pulmonary embolism which caused her to become breathless to the extent that she couldn't climb even a few stairs without needing to stop; again, this is a classic symptom of a clot. This was repeatedly misdiagnosed by her GP, first as a chest infection, then as asthma and as panic attacks. The PE was diagnosed when she collapsed at work, following which she spent three days unconscious.

One woman repeatedly consulted health professionals when experiencing pain, swelling and redness in her leg, but continued to go undiagnosed for a number of years. This was despite presenting with typical symptoms of DVT and PE; she eventually lost trust in the doctors she was seeing and expressed her disbelief that they had not diagnosed her over such a long period of time.

*It's all just a mystery to me how it can happen ... you get to the point where you you you sort of you realise that you've kind of lost your faith in the medical profession you know 'cause you just don't know whether they actually are looking at you and thinking you know this isn't quite what we would expect or whatever (P121)*

She came to feel that she was a bother to her doctors, after they repeatedly failed to diagnose clots in her legs.

*I always just felt like such a bother you know, it's like they didn't think there was anything wrong with me and they clearly thought that I was just a bit of a hypochondriac (P121)*

A different type of loss of trust can be seen with the individual who acquired thrombophilia through being given vaccinations by the military. She experienced the first clot of seven after her eighth dose of anthrax vaccine, combined with several other vaccinations. As a result, she stated

*That has made me a lot more paranoid er than previously and I think that it will actually prevent me from getting certain medical treatments in the long run ... I have a huge distrust you know of the medical community (P143)*

In contrast, those with asthma who consulted a healthcare professional when they first felt ill were mostly diagnosed appropriately and prescribed medication, though this might be changed at a later date. The issues with trust which resulted from a missed diagnosis of thrombosis did not occur for those with asthma. Only one individual with asthma described a misdiagnosis. This person now had a good working relationship with his GP, and felt able to work with them. However, a consistent theme arising from the stories of those with asthma was the difficulty in being able to obtain an appointment with an appropriate healthcare professional, with one individual stating:

*They've done a new thing at our doctors, you used to be able to ring and book a normal appointment. Now they've gone onto the thing that others, where you have to ring on the morning you know, and they don't seem to understand if you're at work and, takes me 45 minutes to get to work, I can't just nip back and forth during the day. You probably do go less than you perhaps should sometimes (P142)*

Although those with asthma did not come to distrust their healthcare professionals, they still experienced difficulties, particularly in gaining an appointment at an appropriate time.

Misdiagnosis, missed diagnosis or lack of appropriate advice may result in a lack of trust as individuals feel that they cannot trust their GP to diagnose them correctly, affecting how they sought treatment at later dates. Some

individuals whose illness was not diagnosed felt that they were being labelled, and that the judgements made in doing so contributed to their lack of accurate diagnosis. Some individuals indicated that, although they were advised to make appointments in relation to their condition, they were not always able to do so at a convenient time, causing them to delay seeking advice.

Perceived trigger: Illness in both of the conditions under study may be triggered by a particular event. These may include, in the case of thrombophilia, long-haul flights, immobility, pregnancy, taking hormone treatments such as the contraceptive pill and hormone replacement treatment or being dehydrated; the causes identified in this study included these. People may wish to identify a specific cause of illness in order to feel more in control of their later risk, and may avoid triggers in future. It may not always be possible to identify a cause, other than thrombophilia, for spontaneous DVTs.

Participants with thrombophilia had often worked out the cause of the clot they had experienced; in some cases, it appeared this was a process aided by healthcare professionals, and in others they did so independently. The latter occurred particularly when an obvious cause could not be identified. When individuals had been offered no explanation by a health professional, they could acquire beliefs about the cause of clots which altered their behaviour subsequently. For one participant, the second thrombosis he experienced could not be linked to an obvious trigger (the first happened due to immobility resulting from a hernia operation), and he associated it with an increase in his consumption of vegetables, particularly those containing Vitamin K<sup>5</sup>. The doctors had informed him that this could not be the case; he did however choose to ignore them and was sure that the high levels of

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<sup>5</sup> Vitamin K is involved in blood coagulation. Warfarin acts to reduce the availability of Vitamin K, thus reducing the clotting mechanism. Another participant had also found that eating a lot of broccoli had caused changes to her INR, though she stopped eating high amounts when she found this out.

Vitamin K in his diet at this time had caused thrombosis, and as a result avoided vegetables in future.

*I bought myself one of these steamers and I was cooking spinach, broccoli, duck, cabbage, everything you can possibly think of high in vitamin K and feeding it to my kids and me and then after about three week of eating all these vegetables, that's when I got phlebitis and the doctor ... I did overdose on vitamin K 'cause I was eating spinach, I was eating cabbage and putting a sprinkling of spinach on it as well, and it's all vitamin K (P083)*

Several individuals had experienced spontaneous DVTs, which could not be attributed to any identifiable cause beyond thrombophilia. For one of these people, members of her family had also had spontaneous DVTs. Another individual had experienced clots over a period of time and was unable to suggest reasons for these other than thrombophilia.

In contrast to this group, individuals affected by asthma were able to identify triggers for exacerbations they experienced. One individual found that she had several triggers which caused her breathing to worsen. One man found that drinking alcohol and undertaking exercise triggered his asthma:

*I hardly drink anymore. I used to, I used to drink I wouldn't say heavily, but I used to drink you know your sort of your average, I would say, drinking at weekends and stuff. I I rarely drink now, the occasional drink, but er alcohol definitely set it off er quite, quite bad, specially the day after. The hangover would also include er bad asthma ... I can't do any long distance activities (P145)*

Others found that damp living conditions would exacerbate their condition, with one person mentioning that this had been the cause of one of his worst asthma experiences, whilst another also struggled in cold or windy conditions.



*I was living in quite er some insalubrious surroundings er with a lot of damp and it er was over a cold winter and er gradually the asthma got worse and worse and worse ... yeah I found it very, very hard to breathe (P131)*

*The times when it's worse is if it's very cold erm and I go out you know, sort of you're out and about, it's cold, I can't catch my breath erm, or if I get a cold erm, I seem to be more susceptible to it sort of getting, getting onto my chest ... I've also noticed in this wind as well, where sometimes it's windy and you can't catch your breath 'cause it's windy, erm, when I come out of the wind it doesn't you know, it sort of, I'm struggling slightly to breathe and I'd have to take my inhaler whereas I guess for other people they'd come out of the wind and they're ok again (P142)*

There were some activities which individuals avoided where possible, however, not all triggers were avoidable, including for example external conditions such as cold and wind, and living conditions such as damp and mould. Other triggers, such as alcohol, could be avoided and sometimes were as they were known to make one's breathing difficult. Similarly to thrombophilia, risk factors were not always avoided, particularly where avoiding triggers caused disruption to people's day-to-day lives.

The implications of knowing the triggers which caused clots or asthma exacerbations are returned to later in this chapter, when I shall consider experiential knowledge based on lifestyle activities. They will also be considered in the next chapter, as they inform the decisions people make.

The longer term effects: Becoming ill as a result of a long-term condition may result in longer term effects. Those with thrombophilia interviewed for the current study indicated that they experienced ongoing effects of having been ill, some of which impacted upon their daily lives. Experiences described included feeling that clots have had some effect on the body, post-thrombotic syndrome, ulcers and an impact upon the ability to exercise. These could be temporary, intermittent or permanent.

For example, one participant indicated that he experienced 'twinges' which he thought were the result of thrombosis, but could not be sure.

*I sometimes, how I can I put it, I sometimes get a twinge but whether that's do you know in funny places I don't know if that makes any sense, you know like erm I'll go oh what was that and it it'll just be something like a split second or a second or what do you know, on the odd occasion (P094)*

Another man felt that the DVTs he had experienced had caused some damage to the veins in his legs and that this affected his ability to carry out some activities.

*it has wrecked my legs, the DVTs ... I used to jump down the stairs and stuff. I found that I cannot take the full weight 'cause you can actually feel the pressure inside your legs ... now it's messed up both of them (following second thrombosis) and the other thing I find hard is when you're sitting on the floor kneeling down that's uncomfortable 'cause you can actually feel the veins the pressure on your veins ... It's not painful it just feels uncomfortable (P083)*

Another individual indicated that she had post-thrombotic syndrome (PTS) – most people did not use this term – which caused pain in her leg. She had also suffered permanent lung damage, and temporary pulmonary hypertension, as a result of a pulmonary embolism. She found at times that her leg was so painful that she would worry that she had another clot; none had been identified to date, but she was aware that it could be small clots causing the pain, or the PTS.

*I've got post-thrombotic syndrome in my leg so my leg does give me gyp from time to time but sometimes it really gives me gyp and it gives me an awful lot of pain but I'm very lucky in that I can you know I can go and have I'll go and have it scanned if I need to, they've never found anything so they say you know we don't know whether you're throwing tiny little clots that are causing pain but they're dispersing or*

*whether it's just you know your PTS flaring up a bit and causing you a lot more pain than it normally does (P111)*

As can be seen, some of the side effects of experiencing clots were similar to the symptoms of a new clot, and individuals used their experiences to determine whether they ought to seek medical advice regarding such symptoms.

A variety of longer term effects were mentioned by participants affected by thrombophilia. It is possible that not all of those who experience thrombosis are provided with information regarding the potential long-term effects; one participant certainly indicated that she only found this out later. Not all longer term effects will be temporary, and it may not be possible for some of the effects to be mitigated, meaning that they have the potential to impact on an individual's lifestyle. Other people did not experience any lasting effects of their clots. Individuals with asthma did not indicate any side effects resulting from exacerbations.

### ***Experiential knowledge: having and managing a long-term condition***

Individuals gained extensive knowledge of their condition through simply having and managing it on a day-to-day basis. This included identifying occasions when they were experiencing similar symptoms which were unrelated to their condition and managing day-to-day activities which could affect their condition. They also identified ways of managing exercise regimes so that they had as little impact as possible. These experiences are an important aspect of managing a long-term condition, as they occur on an individual level and frequently, but are not necessarily ones about which they will receive advice from healthcare professionals. Individuals may thus adopt an experimental approach to managing their condition.

For example, several participants with thrombophilia recognised that symptoms which could be indicative of DVT did not always mean that they had a thrombosis:

*There were times when I was driving and I would think you know my legs are starting to ache a little bit and, but then again, I I don't know whether it's a blinkered view, it's kind of are they hurting because I've just been sat in the car a while (P093)*

*Measures my calf and all that, like when I was at the nurse last week she it was about 3cm bigger on upper and lower, that's how big it is at the minute. But of course it gets like tonight and tomorrow it'll be bigger because I'm it's like the stress when we're busy (P094)*

*Not every pain in my leg is is a clot and I've learnt to live with that. Not every pain in my chest is a clot, not every time I have a cough or I feel a bit breathless am I about to die from a pulmonary embolism (P111)*

One person had been unable to gain information about exercising and so used an experimental approach to work out how much he could cycle. He found that he could not undertake hill walking as this caused the skin on his ankles to become sore; he also found that he needed to wear compression stockings when cycling as otherwise his legs would become swollen. Two others found, by experience, that eating large amounts of green vegetables could be dangerous. This can be contrasted with the woman who had been advised of foods which reduced her risk of clotting, which would increase her risk and the combinations of food and medication she ought to adopt in order to remain at reduced risk of clotting.

Those with asthma also described experiences from which they learned, which enabled them to determine what was possible and appropriate. One man had experimented to identify what types of exercise he was able to manage, having tried several, and found that losing weight had also helped his asthma.

*I can't do running. Er what else? I can only do short burst exercise. I got better recently er, when was it, last, only last year really, I started doing more cardio and I sort of forced myself through a few barriers.*

*At first I'd be coughing and spluttering and so on, but it actually really helped, really strengthened (P145)*

This individual had swapped his bedding to anti-allergy bedding, and made sure that clothes were dried with the windows open to prevent the air from becoming damp.

Another individual was aware of factors which could exacerbate her condition.

*I'm probably in some ways my own worst enemy. I know sometimes, you know, like a spray air freshener or something like that. If somebody sprays that near me, that can set me off, and spray deodorants as well (P142)*

One man had found a solution to his asthma being aggravated by stress.

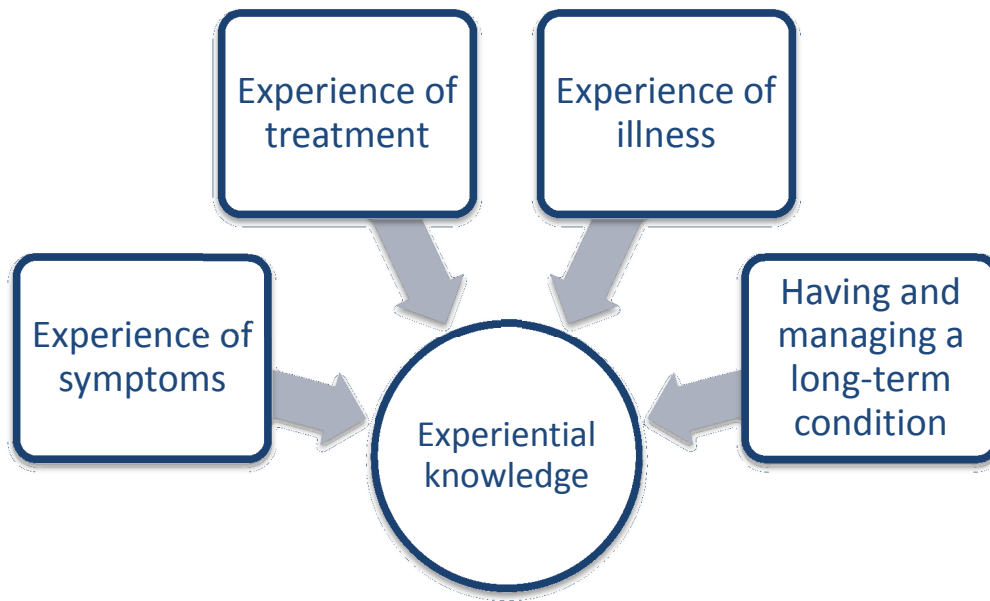
*I suppose the only er, lifestyle change, but it's related to a lot of other things, is, er you know, involved in er a lot of deep breathing, deep breathing exercises and er, yeah, sort of pseudo-meditation really in a way (P131)*

Similarly to those with thrombophilia, individuals with asthma managed their condition through the adoption of some activities and the rejection of others. Experiences were important to those interviewed, and contributed significantly to how they made sense of their long-term condition. They incorporated experiential knowledge alongside theoretical knowledge acquired through other routes. These experiences were not necessarily medically accurate and may not have been advised by healthcare professionals as an appropriate course of action. However, they contributed to the constructs developed by an individual about their condition. These were used as the basis for the decisions made by individuals, to be discussed in the next chapter.

Understanding the condition comprises several elements. As discussed, information was provided by healthcare professionals at the point of

diagnosis. With regard to thrombophilia, healthcare professionals were often consulted subsequent to diagnosis if individuals believed, rightly or wrongly, that they might be experiencing a (further) thrombosis. Information was provided in verbal or written format, and these different types can be considered more or less useful by patients.

Information was also accessed through the internet and medical books. Family members and friends offered information. Knowledge of the condition may also be derived from personal experience, or the perceived experiences of others thought to have the same condition. This experiential knowledge, based on experience of illness, perceived causes of illness, observed symptoms, treatments and their effects (see Figure 2), appears to be significant in terms of its impact on the way people manage and the decisions they make about their long-term condition. Experiential information also allowed individuals to move from gaining information about their condition to becoming knowledgeable. Information alone was external and did not necessarily hold personal meaning, allowing the individual to merely know **of** the condition. Knowledge in comparison enabled the individual to know their condition in a **personally meaningful** way, and they were able to predict its likely response to their different circumstances and activities. Knowledge was gained through the experience of acquiring information from a range of sources, amalgamating this and comparing it with personal experiences to produce a construct of the condition as it affects the individual.



**Figure 2: Diagrammatic representation of the different kinds of experiential knowledge and their contribution to such knowledge as a whole**

It was clear from interviews that becoming knowledgeable did not necessarily equate to learning everything one possibly could about the condition. Few of those I interviewed stated that they felt they knew everything there was to know, and most indicated that they could have found out more if they wished. However, they were sufficiently knowledgeable for their needs at this point in time, and were aware of sources of further information if it was required at a later date. In contrast, some individuals had gathered a range of information, but felt that they did not know enough despite being able to tell me far more than other people I had interviewed.

Thus, a variety of information sources were used to obtain knowledge about and understand long-term conditions. Some people did not seek out any further information beyond that provided by health professionals. However, everyone interviewed had used their experiences together with other information to reach an understanding of their condition.

## **Summary**

People with a long-term condition often tentatively learn about it prior to diagnosis. This can result from a healthcare professional's advice that a particular condition is suspected, when individuals link their symptoms to a

particular diagnosis, or through the positive diagnosis of a family member. Some individuals encounter symptoms before being diagnosed.

The condition is confirmed through diagnosis, usually by a healthcare professional. Some individuals anticipate their diagnosis, whilst for others it is unexpected. Some participants with asthma were diagnosed at a young age and were unable to remember life without the condition. Others, particularly those with thrombophilia, went undiagnosed, some for long periods of time. This usually resulted from a missed diagnosis by healthcare professionals, though on occasion occurred because participants did not seek medical advice. There was no indication that study participants denied having their condition or doubted the accuracy of their diagnosis.

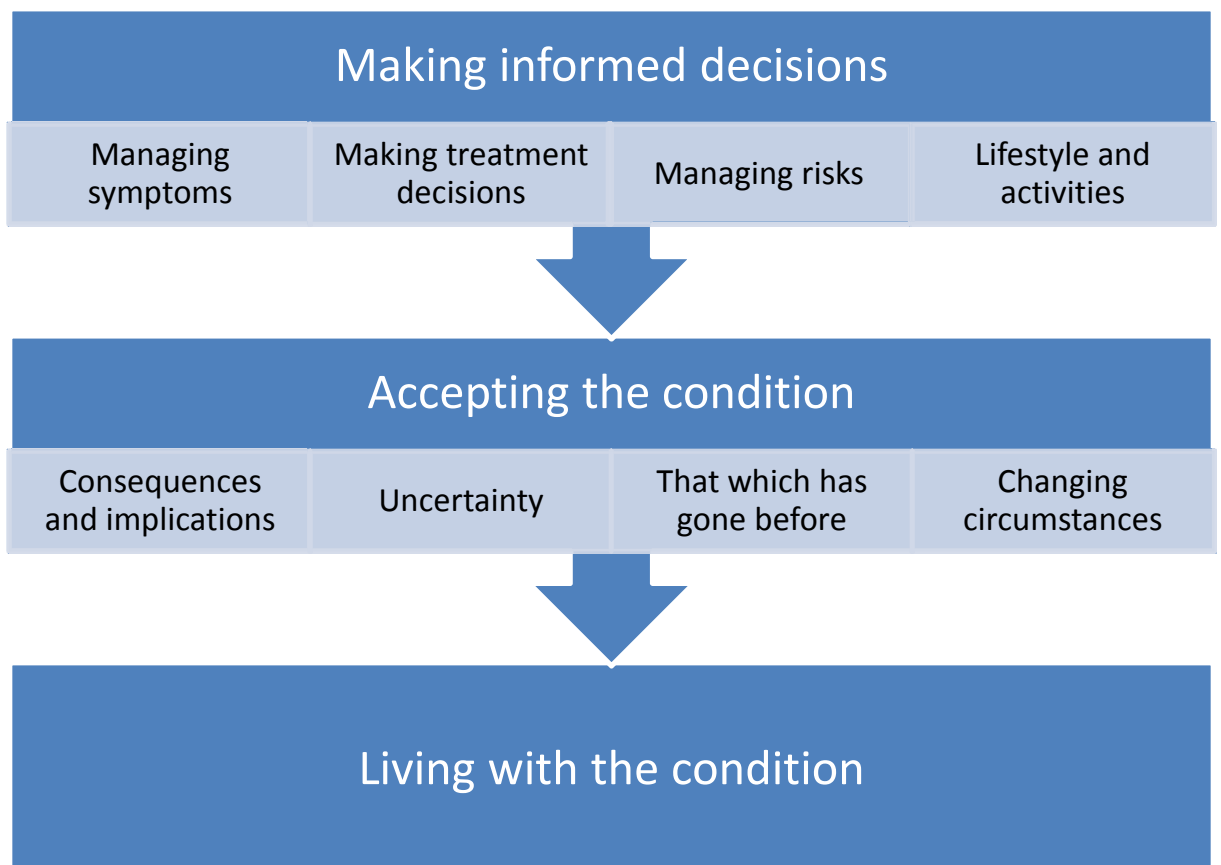
Individuals with a long-term condition gain information and understanding from a variety of sources. The experiences of others and those of the individuals themselves may allow people to reach an understanding about life with the condition on a day-to-day basis. This knowledge may confirm the information gained before diagnosis, especially for those who had had their condition for some time before being diagnosed. Each individual acquired different types of knowledge and understanding, and created constructs relating to their condition, based on this. These form a representation of the condition as it exists for that individual. This aspect of the process may continue indefinitely.

Knowledge of a condition is used to make informed decisions. Sufficient knowledge is also necessary for individuals to accept their condition. These will be discussed in the next chapter, which considers the stage of *living with a long-term condition*.



## Chapter 5: Living with a long-term condition

As can be seen from the previous chapter, individuals with a long-term condition gain knowledge through amalgamating information from a range of sources, leading to the development of constructs about the condition and enabling them to make meaning of it. This chapter will move on to consider the consequences of being knowledgeable about one's long-term condition, when individuals are able to make decisions, may accept their condition and can learn to live **with** it. These phases are shown diagrammatically in Figure 3.



**Figure 3: Diagrammatic representation of the stage living with a long-term condition, comprising of the phases making informed decisions, accepting the condition and living with the condition**

### **Making informed decisions**

Individuals affected by a long-term condition make decisions, often on a daily basis, in relation to it. Once a condition is confirmed, knowledge gained prior

to diagnosis will become meaningful and begin to inform decision-making. The knowledge held by individuals can be limited or extensive, and is likely to change over time, leading to different decisions. Decisions made are important as they will affect one's risk of illness and its outcomes. They will be made in connection with new symptoms and about treatments, risks and lifestyle activities.

### ***Managing symptoms***

All participants had made decisions regarding the management of potential symptoms of their condition. All were aware of these and some were able to describe symptoms they knew to be serious in contrast to symptoms they could safely ignore. However, this meant that, each time they encountered symptoms, they needed to make a decision about how these ought to be managed. Information about symptoms was acquired from a number of sources, as demonstrated in the previous section, including past experiences. Consideration of whether symptoms may indicate potential illness relies on this knowledge.

Those with thrombophilia who had had DVTs or PEs tended to look for the symptoms they had experienced when they had thrombosis previously. For example, one individual who had had both a DVT and a PE looked for the symptoms she had experienced before, leg pain and breathlessness.

*I do sometimes as I said get pains in my legs, but there's only been a couple of times where I've sort of convinced myself that I might have another clot ... yeah and I I've never ever since been breathless like I, if I had another PE, boy would I know about it (P111)*

However, this participant also said that she had leg pain on occasion which she believed to be caused by post-thrombotic syndrome, and so did not seek medical treatment for this. Thus, she made informed decisions regarding when her symptoms were significant enough to seek medical help and when she felt that her symptoms were more likely to be due to post thrombotic syndrome than a new DVT.

Another individual sought medical help when he had the same symptoms as he had experienced when he had a DVT, although he was found on this occasion to have sciatica rather than a clot. This man was not initially convinced by his GP's argument that the symptoms could be the same, but the condition different.

*I had er a slipped disc and my leg went dead and it felt exactly the same as a DVT, so I was back off down the doctor's saying look I said I've got a dead leg and he says but yes it's not a DVT and I said but you told me that last time. He says this is a back problem and I said but I haven't got any backache ... it was in my back but it was a dead leg as well and my big toe was numb. He says but it's not a DVT. I actually rang up the DVT clinic 'cause I didn't believe the doctor (P083)*

Another man found that his leg swelled up in response to stress or being busy at work, but did not seek any medical help until he started to get ulcers as a result. This person had also experienced flu-like symptoms and his leg swelling up when he first had a DVT; he had however accepted that his leg swelling up in response to stress was now normal, and so he did not need to seek medical treatment when it happened.

Another individual was aware of the symptoms, and that she may on occasion experience symptoms which could be indicative of thrombosis. She did however say that if she believed she had a clot forming, she would seek immediate medical treatment.

*I suppose pain you know, if I got pain in my calf particularly erm and I think you know for I if I got any sort of pain or swelling I would be straight you know in pain I I would be straight off to see somebody about it now. I mean the thing is though you do find yourself getting a bit like well it my calf is actually hurting today, now do I need to worry about that or don't, and that's that's a bit of a thing you know you think god am I just having a paranoid day and or do I actually need to worry about that. How much pain is significant pain do you know what I*

*mean. It's it's hard and my my right leg's always a little bit more swollen than my left as well (P121)*

Thus individuals made decisions based on their previous experience and knowledge of symptoms to determine an appropriate response. In some instances, they decided that the symptoms were unlikely to represent illness and so they would not seek medical help. On other occasions, symptoms indicated that they could be ill and that medical help ought to be sought. Some decisions could, with hindsight, be deemed to be inappropriate, for example, some people would seek medical advice for a clot when they did not have one, or would delay seeking advice when they needed to consult their GP. However, the appropriateness of a decision can only be determined by evaluating its outcome after the event, and individuals learned from these experiences, thus contributing to their knowledge and informing future decisions.

Those with asthma also made informed decisions about their symptoms; however, they were more likely to be able to self-medicate their condition as it is standard for those with the condition to be prescribed a reliever inhaler. Decisions included whether to take the reliever inhaler, seek urgent medical advice, or request further medication. For example, some individuals were aware of their asthma symptoms when exercising but chose to continue their activities until their symptoms eased. They may however decide to take their reliever inhaler in advance of undertaking exercise, in order to reduce symptoms. One individual differentiated between those occasions where he experienced symptoms and was able to relieve them, and those where he needed to seek urgent medical care.

*Some of them were, were scary and some of the others were like I was on the brink and felt I needed to see someone (P145)*

Another man chose not to seek urgent medical care on one occasion when he was particularly ill, although he reflected during the interview that he maybe should have done. He found that eventually the symptoms went away.

Thus, participants in this study were aware of the symptoms of illness and compared these with previously experienced symptoms. Although there is a contrast between those with conditions who are able to self-medicate to relieve their symptoms and those who need to consult a healthcare professional when faced with illness, all individuals made decisions based on their previous experience and knowledge of symptoms in order to determine an appropriate response.

### ***Making treatment decisions***

Occasionally, medical emergencies happen that render the patient unable to participate in decision-making and require doctors to act quickly and independently. In all other circumstances, individuals have a range of treatment options about which decisions are made. For those with thrombophilia, these include taking heparin immediately after a clot or whilst pregnant, taking warfarin or equivalent medications on an ongoing basis, taking aspirin, and using compression stockings. It should be noted that decisions were made solely on the basis of the options known to the individual: some people had not been offered and were not aware of alternative medications, and so were unable to make the decision to adopt these. There was a consistent approach to those decisions which were made. Individuals made these based on their experiences, and, where appropriate, information and the experiences of others. They also determined how acceptable each choice was to them personally.

For instance, several of those with thrombophilia chose to take the treatments recommended by healthcare professionals. One man had been advised to take low-dose aspirin, which he did as prescribed.

*Now I do take half you know the small low dose aspirin as a precaution (P113)*

A woman, having experienced three deep vein thromboses at a young age, took warfarin as advised even though she disliked the side effects, and

despite the risks of the medication causing her employers to instigate additional safety measures for her.

*All the side effects of warfarin like tummy problems and stuff, I'd just I'd rather not and it did cause problems at work and things as well... so now I have my own lone working procedure where I ring in every hour or something, say I'm still alive don't worry (P112)*

She did however indicate that she would no longer consider stop taking warfarin without medical advice, though she had done so as a teenager. She explained that doing so when she had both Factor V Leiden and Protein C and/or Protein S deficiency would *'be asking for trouble'* (P112).

Some people had worked with their healthcare professionals to make informed treatment decisions, particularly where the medication was having significant side effects. One individual had, following his second DVT, been told that he should take phenindione for the rest of his life (he was allergic to warfarin). He was however experiencing quite severe side effects of the medication, and so was asked by his consultant if he would like to stop taking it. This was offered with the proviso that another form of treatment – compression stockings – was continued with.

*It just makes you feel old. That's all I can say, it sort of like it ages you, it makes you feel old, and when you stop taking it you sort of feel ten years younger. And you put on a bit of weight, I put on a bit of weight as well ... So anyway I goes after about two years on this stuff and the consultant saying look he says erm you're supposed to be on it lifelong and I said oh. He says how do you feel about coming off it 'cause it don't suit you too well anyway, so I says well what do you think and he says well provided you wear the surgical stocking he says and you have had warnings in the past he said and you're quite erm active so just keep just keep moving about and that and see how you go and if you have any problems just ring (NHS) direct and erm that's how it's been left (P083)*

One person described how, whilst taking warfarin, she started to bleed very easily. She was offered the option of stopping taking the drug, whilst being made aware of the risks whichever decision she made.

*P111: after about 4 months I suppose I started to get really bad bleeding episodes and in the end the risk of me having a DVT actually outweighed the risk of me bleeding to death if I fell. I had I had I had a fall down a flight of stairs, only about 3 or 4 steps, it wasn't you know it wasn't a sort of fall down 'em and break your neck jobby and I landed very hard on my backside and a few hours later I started getting really bad pains in my stomach and they got gradually worse and worse and worse and then my stomach started to swell up so I went up to the hospital - didn't even bother with the GP 'cause by then I had absolutely no faith in him whatsoever - so I went up to the hospital and they did an ultrasound and they said you're bleeding into your abdominal cavity, what have you done, and this fall had actually ruptured an artery which was slowly seeping out into my abdominal cavity, and they did surgery and fixed it all but they talked to me afterwards and said you know by then I was getting really bad bleeding gums, very bad spontaneous bleeding. I had some bleeding in my eyes, some bleeding in my ears, so I was starting to get bleeding problems before this huge problem and then this huge one came along and and they talked to me in the warfarin clinic a couple of weeks later and said you know we really need to weigh up now or you need to weigh up, we need to give you all the options but you need to weigh up whether you wanna carry on taking it or whether you wanna carry on having this risk of a of a clot and you're not taking anything for it*

*Interviewer: so kind of was that your decision to say actually no more warfarin*

*P111: yeah that was my decision. I mean they didn't say you've gotta come off it but they said you know they did, they were actually really good with me 'cause I was very young and and you know but they*

*were very good and they sat down and they talked to me like an adult and they said well these are the consequences if you stay on it and these are the consequences if you stop taking it*

*Interviewer: right that's good*

*P111: but I think really the erm the thing that really brought it home is that you know the guy said to me you could fall and hit your head and die of a brain haemorrhage*

She said that she had considered stopping taking warfarin as a result of bleeding excessively, and described the choice in the following way:

*P111: I was toying with the idea anyway. To be honest I think they sort of gave me a way out of something that I was thinking very long and hard about doing anyway*

*Interviewer: yeah yeah it was just convenient timing that they kind of said you could do it*

*P111: yeah ok you've just given me permission to make this crazy decision or what I thought at the time was a crazy decision but actually it wasn't, not at all*

Another individual described how he was encouraged to take medication when encountering high-risk situations, such as long journeys or long-haul flights. He had considered the possibility of doing so, but discounted it; he disliked the thought of giving himself a heparin injection, and also, having experienced the side effects of the blood thinning too much, was worried about this happening again.

*They did say you've just got to be careful of erm times you know when clotting could occur which was the usual you know long haul flights ... But obviously they did sort of say if you're going on any long journeys you know you've got aspirin you can take them you know, one aspirin or something like that ... 'cause the other thing that was suggested*



*apart from the er aspirin was you know potentially to give yourself a heparin injection erm which kind of just sort of freaked me out a little bit. I was like hmmm you know I'd rather not if I don't have to ... I think it was at the back of my mind I had the thought of the second trip to hospital where there was blood in the urine (P093)*

In contrast, another individual was advised that heparin should be considered if she was considering a long haul flight. She had recently been invited to visit a friend in the Falkland Islands, and was happy to accept this advice.

For those who had not had thrombosis, medication is solely preventative and for both interviewees in this position, involved taking aspirin. For one individual, this was an indication that the condition was not serious at this point, and she was happy to take the drug.

*Well the way I looked at it when the doctor put me on aspirin, I thought oh well I'm not on warfarin so it can't be that serious. I mean I know it's serious but it's not that serious do you know what I mean. I thought the day I go on warfarin I'll think oh gosh it's a bit more you know but at the moment (P081)*

The other individual had been prescribed aspirin but had stopped taking it without her doctor's advice as she found that it caused her to bruise easily. She also expressed concern that taking aspirin could cause any clots she had to travel further; she particularly mentioned this in connection with her mother's death as a result of stroke as her mother had also been taking aspirin. Thus the decision she made to stop taking aspirin was based on her understanding of the condition and medication.

Reflecting the experiences of this individual, another woman had made the decision to stop taking warfarin after many years of taking the drug and having experienced seven clots. She had experienced severe side effects and was concerned about the effects of taking too much warfarin whilst unable to access medical care. She thus chose to stop taking the

medication. She was fully aware of the risks of this, but decided that these were outweighed by the benefits at that time.

*I went off the Coumadin. I haven't had swelling erm, since then, I've increased my running, I haven't broken any bones ... it's almost as if right now I'm going back to what I like ... it bothers me because I know I'm playing with fire ... do I need the prescription, is it something that I feel I have to have? Do I have a false sense of security because I have been off for six months and this is the longest I've gone without an incident ... I had pneumonia several times while I was on Coumadin. I've never been sick as often as I have on the Coumadin (P143)*

In addition to taking various medications in order to reduce the risk of clots, some individuals with thrombophilia – particularly those who had had clots – had also been advised to wear compression stockings. As demonstrated in the previous chapter, almost all made the decision to wear these.

For those with asthma, decisions included taking preventative medication (usually a corticosteroid inhaler), taking reliever medication (Ventolin), taking steroid tablets and/or using a nebuliser when experiencing severe symptoms, which may result from asthma exacerbations. In contrast to those with thrombophilia who chose not to take medication, participants with asthma indicated that they took their prescribed inhalers, though they did not always take them consistently and exactly as prescribed. One individual had chosen not to question the healthcare professionals' advice about her inhalers.

*I've never really looked into the, you know, alternatives, or should you take it or shouldn't you take it. I've just thought that's, well, what they've told me, you know, I'll just do as I'm told (P142)*

Another had considered not taking his medication, but chose to continue with it:

*There's been times when I'd like to not use it but ... I'm quite happy er to continue using it because it it er maintains the life that I've got (P131)*

When making decisions about recommended treatments, either medication or non-medication, individuals use their knowledge and understanding of their condition and past experiences to determine the most appropriate option at the present time. They may at a later point make a different decision – the individual who chose to stop taking Coumadin had been taking it for much of the past ten years and had otherwise been taking heparin. These decisions will also be informed by their understanding. The advice of healthcare professionals may contribute to these decisions, but may not be the most important factor.

### ***Managing risks***

Individuals interviewed were aware of risks which could increase the chance of them becoming ill. Individuals had been warned to consider whether or not these activities should be undertaken, and potentially take action to reduce their risk. The risks involved are specific to the condition, and there appear to be differences in the advice offered to some individuals; it is not clear whether this was the perceived advice, or whether there really are differences in the advice offered, even with regard to the same condition and risk.

For example, for those with thrombophilia, long-haul flights are deemed to present a high risk. Several of those interviewed indicated that they had thought about their condition in connection with long-haul flights. As discussed previously, some considered taking medication. Others chose to manage their risks without medication, but by adopting other measures. One said that she was prepared to take considered risks, such as long haul flights, but she ensured that she was informed in order to make the decision:

*Somebody asked me the other day if I wanted to go erm to visit them in the Falklands you know. I was like that's a flipping long flight you*

*know, so I did go and make an appointment to see the doctor and say look is this actually a sensible thing for me to think about and is it something that you know can you give me some treatment for it or whatever, and the doctor she said oh I'm not actually sure I'm gonna find out for you ... I can't say I'm 100% happy about it but er it's like you were saying about finding a balance, I don't want it to sort of rule my life and put me off doing things you know, but erm I'm I'm I don't mind taking a calculated risk if I think I can do a reasonable amount to to keep the risk as low as possible (P121)*

One individual who had not experienced thrombosis had been advised not to take long haul flights; she indicated that she would not be doing so. Another indicated that she always tried to keep mobile when on flights, and had done so even before her diagnosis.

One individual with thrombophilia had been advised to eat sensibly; she had immediately eaten far more healthily and lost weight, but then went back to eating the foods she usually did. Another individual indicated that she had been advised to keep hydrated and found this difficult. Both found that changing their daily routine to eat healthier foods or drink more water was difficult in the longer term.

Other participants who had experienced thrombosis found that they could easily reduce their risk by making small changes to their daily lives; one made sure that he kept mobile even when ill with flu, another kept his leg raised in order to reduce the risk of further thrombosis. Other measures to reduce the risk were found to be more difficult. One participant indicated that he sat cross-legged and drove long distances without stopping to move around, though he did try to force himself to do the latter. In both cases, it appears that these were things he was used to doing from habit, and so they were difficult to change.

*I might have a pain in my leg or something like that from just sort of sitting funny or something like that. Now I'm I'm sat cross-legged I mean that one thing the doctor told me not to do. I'm I'm it's almost*

*like he told me not to do it and I start doing it, such a rebel erm, but again it's things like I'll be sat at my desk and I I sit cross-legged all the time and I'll be thinking oh my leg's gone dead (P093)*

Another indicated that, despite being told that he should not be on his feet too much, he spent all day at work doing exactly that.

Individuals with asthma had also been advised of several actions which they ought to undertake in order to reduce their risk. Several mentioned the influenza vaccine, which is recommended to those with the condition as catching 'flu can lead to a severe asthma exacerbation. Whilst some of those interviewed were prepared to have the vaccine on their GP's recommendation, specifically to reduce their risk of becoming ill with asthma, another was not prepared to do so. Having had the injection once, which had made her feel ill, and having become worried about the side effects, she decided to take a risk.

*I didn't feel particularly well after I'd had it ... then they had that swine flu one didn't they and I was really worried about that because I thought they, they can't have tested it in the short amount of time they've had to do it, I didn't feel that it was possibly a safe thing to do ... it doesn't stop you getting flu, there's different strains, it's only you know they're guessing which are gonna be most prevalent so I'm not gonna do it but erm you know I think I'd rather risk getting normal flu and having a bit, my asthma getting bad than the side effects of you know potential issues around getting the jabs (P142)*

As can be seen, there are a range of risks which need to be managed by those with long-term conditions, particularly those which are known to be linked to specific risk factors. Some habits may not be easy to break, despite individuals being advised to change them by healthcare professionals. Those with LTCs on occasion make informed decisions to undertake an activity known to increase their risk of illness. Conversely, at other times they will decide that a risk is too great and they will avoid it. As with medication

decisions, the knowledge held and therefore decisions made may differ between individuals and over time.

### ***Lifestyle and activities***

Participants had identified a range of lifestyle activities which they perceived to influence their condition, and they indicated that they may take action to either avoid or reduce the risks associated with these. These were infrequently activities which had been deemed to be risky by a healthcare professional, but were those which the individuals themselves had identified as affecting their condition. There are direct links between these activities and people's experiential knowledge, as it was experience which caused them to identify these circumstances and activities as ones which could increase their risk of illness.

For instance, several individuals with thrombophilia spoke of the impact of food and alcohol on their condition. One person with thrombophilia indicated that drinking alcohol had impacted upon her warfarin treatment, and as a result she had made the decision to limit her consumption. As a teenager, she had drunk more alcohol and this had meant that she had to have frequent blood tests to check her blood coagulation levels. Having reduced her alcohol intake, she did not need to have her INR levels tested so frequently and viewed this as a lifestyle choice she had adopted.

*I don't really drink at all now. I do have the odd occasion where I do but last time I did that I drank five snowballs and was really ill the next day so I don't generally drink which I think I probably would do otherwise. But when I was I don't know 17, 18, 19 I did drink, I just lived the life of a 17, 18 year old and I had to go for a lot more blood tests and now I don't have to go for a blood test, like I only have to go about every eight weeks, I'd rather it was like that and just stayed steady (P112)*

She had also gone through a phase of eating broccoli and stilton soup, which also had a significant impact on her INR levels. Another individual had

identified that eating too many green vegetables such as spinach, broccoli and cabbage had caused his second DVT, and so avoided eating these. One woman had worked with several healthcare professionals in Italy to identify the food and drinks she was consuming which were affecting her blood coagulation levels, and had spent some time managing these very closely, until she decided to stop taking warfarin.

*I was able to see their equivalency of a nutritionist to say, this is what actually interacts and this is why your INR numbers are going up and down. Because I love spinach, I was a recovering vegetarian, no-one told me not to eat you know cherries, how was I supposed to know they have an aspirin-like effect? ... I couldn't drink tea ... I'm drinking tea, I'm not controlling my er spinach intake ... I'd much rather eat a clove of garlic or two a day, have an excuse to have a glass of wine than to know I'm deliberately putting a poison in my body that I use to kill the dormice in my house (P143)*

This individual was one of the few who had worked with healthcare professionals to identify which foods could be problematic and how she could manage this, and she preferred to manage her coagulation levels through the food she consumed rather than through taking warfarin. Once she stopped taking the medication however, she stopped controlling her intake of these foods.

Similarly, those with asthma had identified that alcohol aggravated their condition, with one man also saying that any kind of 'overindulgence' led to symptoms. Another woman also found that wine aggravated her condition, which she would manage by using her reliever inhaler.

*As I've got older, I've found drinking alcohol brings on my asthma. Erm, I don't know why that is, just, and it's only sometimes, only some kinds of alcohol – white wine weirdly seems to bring it on which is odd (P141)*

Other lifestyle activities had also been identified by participants as potentially increasing their risk of becoming ill. For one woman with thrombophilia, her professional role was affected by her need to take warfarin. She worked alone away from her office for some of the time, this was identified as a potential health and safety risk and so procedures had been implemented to ensure she was safe.

*Sometimes I have to go out on site and as soon as they discovered I was on warfarin it was like, oh, massive health and safety thing, what if you cut yourself when you're alone on site or something? So now I have my own lone working procedure where I ring in every hour or something, say I'm still alive, don't worry ... I did cut myself once on site, it wasn't until I did that that they got really heavy handed with me (P112)*

A man with asthma indicated that it was possible that the condition had been one of the reasons he had gone into an office-based profession; he had not enjoyed more physical activities as a child because of the condition.

*It may be that's why I'm in the work I'm in ... it's a sedentary occupation, it's not er, I'm not dealing with er particularly noxious substances ... it doesn't affect my work but it may be that er I have come into this line of work because other things may not have been er things that I enjoyed as a youngster because of my asthma (P131)*

Two women with asthma had identified that feathers could trigger their condition, with one having particular difficulty when she travelled as she found that pillows in hotel rooms often contained them. She said:

*It's so uncomfortable, I have to get away from them ... We check ahead erm when [husband] or I book a hotel, we always have to say no feather pillows and we get in there and there are feather pillows, so I have to go out of the room and [husband] has to phone down reception and and very carefully take them out and put them outside the door. Mostly it's fine 'cause even new feathers it's a little bit bad*



*but old feathers, for some reason it's, feather dust, it's like poison to my body (P146)*

Exercise was considered to be an activity which could trigger asthma exacerbations, though conversely it was also perceived as beneficial. One individual who undertook frequent light exercise classes found these to be manageable, but found that undertaking high intensity exercise caused her to have an asthma attack and she was forced to leave the class to recover. Not only had the experience made her ill, but she was also embarrassed by the possibility that others attending thought she may be unfit.

*She was doing this like high impact dance aerobics or something, erm, and that nearly killed you know, I actually had to leave the room and go and sit outside and take my inhaler quite a few times so I think it was just too much and once I got that out of breath I just was sort of wheezing and I couldn't, you know, by myself even just sitting down and relaxing, it it wasn't stopping you know, I had to take my inhaler a few times (P142)*

Another man found that exercise did not trigger the condition unless particularly strenuous, and in these instances he was able to get through this. He also used meditation and deep breathing techniques to help the condition.

Some of those with asthma found that the condition was affected by their environment, with one individual identifying damp forests, pine trees and dry heat (such as desert) as being problematic. In contrast, she indicated that being near the sea was of benefit, and had actively sought to buy a property in such an area, despite the increased costs she incurred. Another individual confirmed that being near the sea was beneficial, and contrasted this with being inland.

*I do notice different environments. I lived in I lived in Sheffield for two years and lived, 'cause I'm from the coast ... when we moved to Sheffield for a couple of years I don't know if it was the altitude or the*

*fact I was inland but I'd feel it and I can remember always doing the train journey and getting off at Sheffield and I'd feel tight ... sea air just feels better to me (P145)*

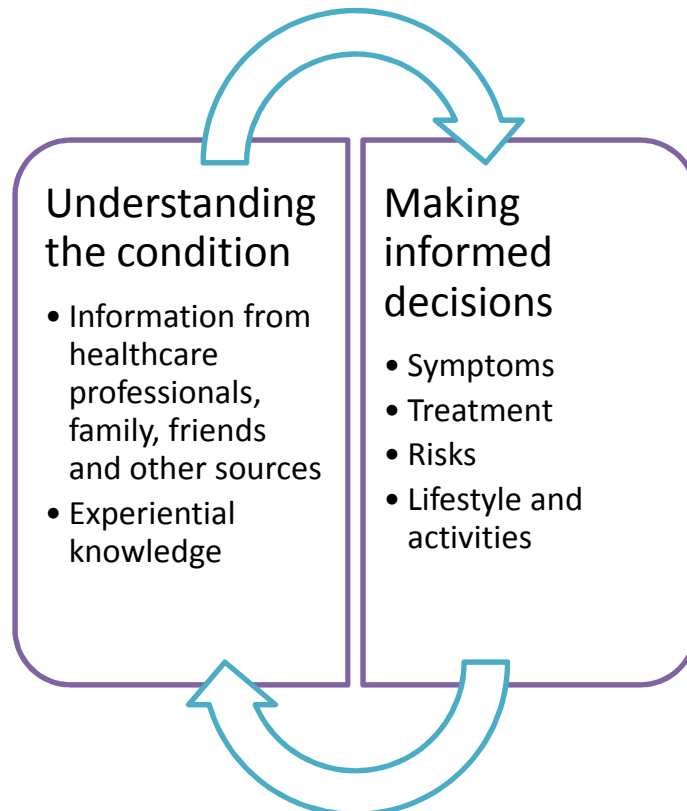
As can be seen, people with long-term conditions make a variety of decisions in connection with their condition, including:

- Symptoms, whether to act on these by taking medication, seeking medical advice or self-managing them
- Treatments, in the form of medication (preventative, acute treatment, medications for other, linked conditions) or non-drug treatments such as compression stockings
- Risks, whether to take them and which are considered to be acceptable or otherwise to the individual
- Other lifestyle factors which affect the course of the condition.

These are deemed to be informed if they are known to have a particular condition and are learning or have learned through information or experience of the possible outcome of these decisions. Decisions are made at different times and with varying frequency. Some individuals make decisions on a daily basis, re-affirming these each time, for example, taking medication daily. Other decisions are made only at pertinent times, for example, those with thrombophilia considering taking a long haul flight. Individuals also make decisions which, though reversible, are intended to be permanent (for example, to start or stop taking medication). Most people will make each of the different types of decisions, depending on their circumstances at any specific time.

Different people will, in apparently similar circumstances, choose to make different decisions. These will not necessarily be those deemed to be most appropriate by a healthcare professional but will be the ones considered to be most appropriate by that individual at that point. By making decisions, individuals take responsibility for managing and a degree of ownership for their condition. However, as will be seen later in this chapter, this does not equate to acceptance of, or living with, the condition in all instances.

There are clear connections between this phase and that of *acquiring knowledge* discussed in the previous chapter. Knowledge gained about one's condition informs the decisions to be made. In addition, a feedback loop exists such that decisions made, and the outcomes of these, contribute to an individual's knowledge, and will influence further decisions made. This is represented diagrammatically in Figure 4.



**Figure 4: Diagrammatic representation of feedback loop existing between understanding and informed decisions made by those with a long-term condition**

Making informed decisions about a variety of factors is a core aspect of living with a long-term condition. Informed decisions are enabled by the knowledge and constructs an individual holds about their condition and its effect on their life.

### **Accepting the Condition**

Many of those with a long-term condition enter a phase of accepting the condition. This may occur immediately, or after a period of time. Acceptance comprises of a range of factors, these being the diagnosis, the implications

and consequences of the condition, any uncertainty associated with it, and, where relevant, past events. The latter includes acceptance of missed diagnoses and the cause of the condition. Some people will not accept at least one aspect of their condition. Others may on occasion move between acceptance and non-acceptance as a result of changing circumstances.

All participants in this study accepted that they had a long-term condition, and the label for this. The phase explained herein assumes diagnosis of a long-term condition and acceptance of this. It is acknowledged that acceptance of a diagnosis may not occur with all long-term conditions, together with the possibility that individuals may struggle to obtain a diagnosis, although all those interviewed for this study had a diagnosis and accepted this.

Individuals who believe that they are uninformed or have insufficient information and knowledge about their condition will be unable to accept it, as they will continue to seek information. Thus another fundamental requirement for acceptance to occur is that the individual must feel sufficiently knowledgeable for their own needs at a given point in time.

### ***Consequences and implications of the condition***

Having a long-term condition may have consequences and implications for individuals, some of which have been discussed previously with regard to knowledge and making informed decisions. Individuals may accept what it means to have their condition, including medication and its potential side effects, the physical effects of having the condition, and its effect on their lifestyle.

Some individuals were prepared to accept that they had been advised to take medication to reduce their risk of having a clot, and did so in the knowledge that this was a long-term recommendation and that their medication may have side effects. For example, one individual mentioned that she would prefer not to have to take warfarin.

*I'm just waiting for them to invent something else, yeah anything please that won't eat me away inside (P112)*

Others were aware of the physical effects that could result from thrombophilia, with one mentioning that his leg would swell up and be obviously larger than the other when he was busy at work. Some individuals recognised that having a long-term condition meant that they may need to take some responsibility for their actions in connection with it. They indicated that they had been given notice of their condition and some advice about what they ought to do, but could not expect full responsibility to rest with healthcare professionals.

*They've both given me a warning and I think, you know, it's really down to me isn't it now ... they've done as much as they can (P081)*

*I have come to the conclusion there is not a lot that can be done to improve things, it's down to me to try and manage the condition well (P113)*

Another man indicated that thrombophilia was something that needed to be managed at appropriate times, but did not require him to actively manage it frequently, and he accepted responsibility for doing so. Others indicated by their actions that they had accepted that they needed to undertake certain actions in order to stay healthy.

*Last year I had flu and I was in bed for four days, I was just, literally couldn't get out, and I made sure I wiggled my toes, moved me feet (P083)*

Thus some of those with thrombophilia can be seen to accept the consequences and implications of their condition. However, not all of those interviewed did so, and these people expressed their worries and concerns. For instance, one woman was unhappy with the advice she had received to not take any medication. This individual had stopped taking aspirin, which she had been recommended to reduce her risk of clots, and said:

*When they say, you know, there's no need to take medication until something happens, it's kind of like saying, well you can eat fatty foods until you have a heart attack and then after you've had the heart attack you'd better stop, do you know what I mean? (P091)*

Several of those with asthma also indicated that they had accepted the consequences and implications of having their condition. They described instances where they accepted that certain activities were difficult or not possible, whilst also mentioning others which were possible despite their effects on the individual's breathing. For example, one woman smoked and was aware that this may not be good for her lungs.

*I do from time to time have a cigarette which I I know I shouldn't and I know it's bad for my asthma (P141)*

However, she described the lengths to which she had gone to ensure that her living conditions were appropriate, and although she recognised the implications of this, she had clearly accepted it.

*One of the big triggers for me is damp and mould so erm, for example, all through my student years looking for accommodation and things, I had to be very careful where I was living, erm, and also now recently, earlier in the year I bought a flat and trying to find somewhere that wasn't old, that wasn't a risk that it could get damp, mouldy, you know. It was quite a long process and eventually sort of managed ... it's difficult though because I ended up having to buy a flat that was a lot more expensive than I would necessarily, you know, been able to afford or sort of would've wanted to pay (P141)*

A range of consequences and implications result from having a long-term condition. Some people will recognise these as facets of this and accept them, including the responsibility for managing it. Others may question these consequences and so not reach a point of acceptance.

## ***Uncertainty***

Having a long-term condition such as thrombophilia confers a potential risk of illness. Both the condition itself and the risk of illness – the circumstances in which it might occur, the potential cause, the timing, whether or not one will become ill – can lead to uncertainty. Some people are able to accept this uncertainty, recognising that these unknowns are a part of their condition and cannot be fully controlled.

For example, one individual was aware that she might experience blood clots due to thrombophilia, but had accepted this rather than letting it take over her life.

*About the clotting, he said it shouldn't happen well but then what do I do, do I just you know curl up in a corner and think I'm gonna get you know a clot or do I just carry on (P081)*

Another individual, who had experienced a number of clots both personally and of family members, recognised the uncertainty linked to thrombophilia and accepted that it was an inherent part of the condition. She had taken some time to reach a point at which she was able to accept the uncertainty inherent in having thrombophilia.

*Statistically speaking the chances of my having another clot are only even now about 12% more than the general population ... just because you have it doesn't mean to say you're gonna get a clot. It's just one of those horrible things that happens (P111)*

In direct contrast, some participants did not accept the uncertainty that results from having a condition such as thrombophilia. One woman posed questions repeatedly during the interview which demonstrated how unsure and worried she was. Comments she made included:

*Obviously I don't want to find that I've got a blood clot somewhere that's gonna do some damage ... if there's anything that, you know, I should be doing ... I would like to know whether there are tests that I*

*could have done to find out if I have got blood clots ... how do I know that I haven't got a blood clot now that's just sitting there waiting to travel somewhere? Do you know what I mean? I do worry ... Is there any particular thing that could make, cause a blood clot ... but what is it that makes it happen? Do you know what I mean? (P091)*

She confirmed that the uncertainty associated with the condition was of concern to her.

*I think that's what's worrying actually, is not knowing fully (P091)*

Another individual discussed how uncertain she was about the effects of the treatment she had been advised to take (this being warfarin), together with her uncertainty about why she kept getting clots. She had been diagnosed with acquired thrombophilia, and had had a number of clots despite having been on warfarin. She was also unsure about what she should do going forward; she had stopped taking warfarin due to restricted access to medical care and was aware that this was a risk.

*There's no explanation erm about why it continues happening, you know, because it's, I don't know, that I don't understand ... I don't know what the long-term effects of Coumadin were, erm, I, it's never been explained. If you're on Coumadin for this long, yes, I know that it kills the insides of rats, it causes internal haemorrhaging but no-one's ever told me by you taking this medication, this is what it's doing to your insides ... so it's kind of a, that the way forward is not clear (P143)*

Thus acceptance of the uncertainty associated with a long-term condition which may cause acute illness does not occur in all instances. Some people may find that the uncertainty is too much to accept, and are unable to answer all of the questions invoked by their condition. This may result in them becoming concerned about the uncertain nature of the condition.



That it is possible to accept the uncertainty and risk of having a long-term condition is confirmed by participants with asthma. One individual was aware that his condition could cause illness in certain circumstances, but was aware of the risks and uncertainty.

*I knew, I've always known the dangers associated with a severe asthma attack (P131)*

Another would be concerned if she did not have access to her reliever inhaler; this gave her a feeling of control and having access to it meant that, even if she experienced an exacerbation, she would be able to manage it.

*When I was younger and I'd go out to a club say with friends, I would never not go but I had been known to arrive somewhere, realise I didn't have my inhaler and then spend a fortune getting a taxi back home to get my inhaler and then coming back because I would panic massively if I didn't have my inhaler in that kind of environment (P141)*

There is a difference between the experiences of uncertainty for those with the two conditions. Those with thrombophilia lived with a very uncertain condition; spontaneous clots can arise which offer no warning, cannot be controlled by the affected individual and may be fatal. The most common treatment for the condition (warfarin) is widely used, but individuals had not all been advised of its effects. There is also no clear pathway for those affected to follow if they chose not to take the advice of healthcare professionals. In contrast, those with asthma were usually aware of triggers, although they could not always control these. They were able to self-medicate in an attempt to reduce the illness, this was not possible for those with thrombophilia. They were also able to directly and fully experience symptoms of illness. Thus those with thrombophilia accepted uncertainty and were unable to try to control this. Those with asthma, conversely, were aware of the uncertain nature of their condition, but were able to control this by reacting appropriately to symptoms and ensuring they had the means to control illness, by keeping their reliever inhaler accessible. This difference

results from the various features of the two conditions, and the way in which self-management of asthma is promoted in the UK.

### ***That which has gone before***

Some of those interviewed in this study indicated their acceptance of their past experiences. This included a missed or delayed diagnosis, either of a clot or of thrombophilia, or the cause of their condition. Those who accepted the past turned their attention to managing their condition.

For example, several individuals had experienced a missed or delayed diagnosis. They did not express anxiety, concern or resentment towards this, and accepted that it was a part of having the condition; some even accepted a degree of responsibility for the delay. An example shows this:

*Then when it (thrombosis) happened the second time, they did all the tests on me again ... 'cause I never heard the results and denial, I didn't bother asking (P083)*

Several of those with thrombophilia had inherited the condition, and all accepted this as an aspect of having thrombophilia; none expressed feeling any blame towards their parents and one individual indicated that it helped her to understand that she was not responsible for having it.

*At least then I know it's not my fault and anything I've done, it's just the hand I've been dealt I guess (P112)*

This was echoed in the comments of another woman:

*You've just got to accept that nobody deserves it, or very few people deserve it, most people don't deserve what life throws at them and you've just gotta get on with it, it's not personal (P111)*

In contrast, others with thrombophilia had not accepted previous events. One woman had experienced repeated missed diagnoses over a period of decades, and was aware that she may have miscarried as a result of the untreated condition. She struggled to understand how the condition had been

missed for so long despite her frequent symptoms and consultations with healthcare professionals.

*It's just such a frustrating feeling, you know, and it's not about sort of blame or I'm gonna sue them and all the rest of it, but you just think, god you know, all those flipping opportunities ... I think it's the pregnancy thing that's really upset me I suppose because I feel as though I'll never know whether that's the reason why I had that miscarriage. It could've been a million and one other reasons, I realise that ... you put your trust in a doctor don't you and you assume that, you know, they've got the knowledge that you haven't sort of thing, and it's, you do feel quite let down I think when when they haven't (P121)*

Another had acquired the condition as a result of a military vaccination programme, and she expressed her feelings towards vaccines vehemently. She had a young daughter and was clear about her views on whether or not she ought to have vaccinations.

*I'm very resentful er towards vaccinations. I'm now paranoid. I don't want my child being vaccinated against things that I do not accept as standard ... I no longer trust vaccination programmes ... I don't trust the medical community er, I certainly don't trust the army for their vaccinations systems because of all the problems that I've had (P143)*

In contrast, few of those with asthma had an extended history of the condition, and so they rarely talked of an unacceptable past. However, one individual had been diagnosed with a lung condition as a child and been treated, as was usual back then, with a tar lamp being lit in his bedroom. He had also experienced a severe asthma exacerbation as a child, which he indicated would, with current knowledge, have initiated an emergency response. He discussed each of these experiences in the acceptance that the former could have made his condition worse and the latter could have been fatal, but without any resentment or accusation.

*Some of the first memories that I've got of er, you know, night lights with erm, you know, coal tar in them burning away ... probably the worst experience that I've had ... looking back, I felt very very unwell ... I would've assumed nowadays that probably er I'd have done something quite a lot different, er I've have done something quite a lot different you know. I was er very short of breath and er you know if I saw the same in someone I'd be concerned about them (P131)*

As can be seen, although some individuals accepted that which had gone before, whether this related to the cause of their condition or missed diagnoses, not all did so. It is possible that this may relate to the circumstances; where individuals did not accept the past, this may result from ongoing questioning about why events happened or were not prevented. However, this is not a necessary consequence of avoidable situations, as several of those who accepted previous events had experienced unnecessary missed diagnoses.

### ***Changing circumstances***

Those with a long-term condition are likely to experience it over an extended period, during which time one's circumstances may change. This can alter individuals' perceptions towards their condition, leading to a change in their acceptance status.

For instance, two women with thrombophilia discussed the possibility that they may one day wish to have children. The condition is known to cause an increased risk of miscarriage, together with an increased risk of clots both during pregnancy and after giving birth. Recommended treatment may include heparin injections for the woman. They were aware that this change in circumstances may lead them to seek further information, or could create new uncertainties.

*It'll be a bit different if I ever try to have a baby or anything, 'cause there's a lot of things to think about, but it's manageable (P112)*

*If I was actively trying to start a family again at the moment, I would want to know more, more about that, erm, and I guess specifically I'd wanna know more about the, the whole process of injections and any associated risks with that (P121)*

Others mentioned that if they experienced another clot they may wish to find out more at that point.

*That's enough (information) for me ... whether or not I'd think that was the right angle to take if I have another problem again (P093)*

Others had experienced changes in their circumstances, including one woman for whom this allowed her to accept having thrombophilia. She had experienced a pulmonary embolism soon after her mother died of a blood clot, and she associated her negative feelings with both the diagnosis and with her mother's death. Having grieved, she was able to reach a point where she accepted the condition.

*Life's not fair, why did it happen to me, it's not fair ... yeah I did have the self-pity phase ... I think a lot of it was probably grief for her ... and then it became self-pity for me and I'd spend all day every day sitting there saying it's not fair, why did it happen to me (P111)*

Another woman had recently left the military, which had forced her to follow rules for an extended period of time, and this had led her to question her approach to managing thrombophilia. This represented a significant change in her life, which altered her perception of the condition, from something she had accepted to something she now did not accept. She stopped taking warfarin and re-started activities such as running which she had been advised to stop.

*I accepted it for the last 10 years and now that I erm I left the military service to come to do my PhD so it almost feels as if that was part of the yoke around my neck during my service ... I think that because of the break with the military that's the the Coumadin almost mentally*

*locked in with that, erm so it's like ok, I'm gonna break it, I can accept it you know, different stage of life. Even though I know that is that most irrational thought I could probably have, I'm trying at that stage, ok, fine, yeah, I've had this problem. If I mentally think that I won't have this problem, well I don't have this problem (P143)*

As a long-term condition necessarily is something which continues indefinitely, individuals are likely to experience a change in their circumstances. Minimal changes, such as the need to consider taking medication due to a long-haul flight, are insignificant. However, major changes such as planning for a child, change of career or country of residence, or a family death, can lead to an altered perception of one's condition and a change in whether or not one accepts the condition.

Thus, acceptance of the condition, including its implications and consequences, responsibility for managing it, any uncertainty inherent in it, and any adverse events which may have happened, forms a pivotal point for individuals with a long-term condition. Those who are able to accept their condition, in all its guises, will be enabled to live with it. However, those who do not accept it will live alongside their condition. Despite their lack of acceptance, these individuals had taken some ownership of their condition; they accepted their diagnosis and were making decisions about the condition. Acceptance may continue in spite of changing circumstances, where the individual is able to manage these. For example, for those with thrombophilia, medication may be recommended prior to a long-haul flight, and they are able to maintain their acceptance whilst making a decision about whether to take this. However, significant changes in circumstances may result in a change of acceptance status.

## **Living with the condition**

Most of those interviewed in this study reached a point where they lived **with** the condition. For these people, their condition is part of who they are and it exists in the background of their daily life for much of the time. They are knowledgeable about it, able to make informed decisions, and accept both

the diagnosis and its implications, consequences, any uncertainty it may cause and any related past occurrences. It may attract their attention on occasion, but, once this is over, it will return to the background until something new happens to cause them to consider it in a conscious manner.

Individuals offered a variety of descriptions of what their condition meant to them and its effect on their life, with many saying that they do not think about it very often. Some also indicated that it had changed their outlook on life, due to the threat it had posed at one time. Others compared the condition to other illnesses, emphasising that thrombophilia was less serious than other conditions of which they were aware.

For example, one individual indicated that he didn't often think about thrombophilia.

*As I say I don't really think about it (P083)*

He also described how having a clot and then an ongoing risk of further clots due to thrombophilia had offered him a different outlook on life.

*It does give you a different outlook on life 'cause before it happened I was sort of like worrying about everything and my whole attitude to life has changed 'cause I don't worry about anything 'cause as long as you've got your health nothing else matters (P083)*

Someone else explained how she thought that having thrombophilia had had a liberating effect on her life.

*I'm very que sera now you know if it's gonna happen, if it's written in the stars or whatever you wanna call it, then there's nothing I can do about it ... I live my life for today and I think it does give you, if you can get past that sort of paranoia about when am I gonna die, I think it actually liberates you to live ... 'cause you you don't just know when the sword of damacles is gonna come and whack you on the head (P111)*

Several people indicated that the condition was just part of their life, including a woman who had other health conditions in her family which she believed may one day affect her, and considered thrombophilia to be less serious. She said

*I suppose everyone's got to have something so I'm glad it's only thrombophilia in a way ... well it's not sort of cancer or anything, you can get on with life ... you sort of don't think about it otherwise, it's just like breathing or something (P112)*

This can be contrasted with those people who lived **alongside** their condition. For this group of people, the condition frequently draws their attention, causing them to seek information, knowledge, certainty or solutions. These individuals have taken a degree of ownership over their condition, by accepting their diagnosis and making decisions, and so cannot be deemed to be in denial or at a distance from their condition. However, it has not become part of their identity and their everyday life, but is an unwelcome burden which disrupts their day-to-day life by causing concern and restriction. Thus it exists alongside them, not distant but also not part of one's being. These people did not accept at least one facet of their condition, and their comments can be seen in the previous section *accepting the condition*.

Those with asthma also confirm that it is possible to live with one's condition.

*It's part of me, I don't define myself as an asthmatic erm but when I do look at myself I am someone who had asthma and so it's always there, there's always that knowledge that's experiential as well as factual knowledge erm and er, what does it mean for me? It doesn't mean limitation, it just means that's who I am (P131)*

*I feel so used to it and it's so part of my life that I don't really know any different, so I, it's just part of life. I don't I don't really feel it's a particular burden or otherwise, it's just just part of the day-to-day for me (P141)*



*It's something that's in the background that if you thought about it you'd probably think, yeah I wish I didn't have it, but that you don't really kind of dwell on too much (P142)*

Those who live with their long-term condition absorb it as part of their identity. They make informed decisions about it, and accept its implications and uncertainty together with past events where relevant. Some acquire a new outlook on life which leads to them worrying less than they did previously. They also may compare the condition to others of which they are aware. These people have discovered a life with their condition which holds meaning for them as individuals. The condition has become part of their self, rather than existing as a separate entity which draws their attention. Conversely, others live alongside their condition, which they find burdensome. It draws their attention, asks questions of them and causes concern as well as restricting their activities. In such cases, acceptance is also unlikely; both acceptance and knowledge are necessary for one to live with one's long-term condition.

## **Summary**

Living with a long-term condition comprises several stages, which include informed decision-making and acceptance. Decisions made by those with such a condition are based on the knowledge and understanding they have acquired, and they will further inform later decisions through a feedback loop with *understanding the condition*. These relate to a range of activities, such as managing symptoms and what to do about treatments, risks and other lifestyles activities.

Some individuals will accept their condition, including its implications, the uncertainty it creates and any past events of concern. However, changing circumstances can lead one to revise their (non-)acceptance. Others in contrast may not accept their condition, there may be too much uncertainty about it or the memory of past events may feature too strongly for this to be possible.

Living with the condition occurs only when individuals feel themselves to be knowledgeable, are able to make informed decisions as a result, and accept their condition. This enables the condition to become part of the self, drawing attention only occasionally and existing in the background for much of the time. Again, this can be contrasted with those who live alongside their condition. For this group, the long-term condition draws their attention, restricts their activities, and is perceived to be a burden.

These findings have been presented as a sequential series of stages which occur when individuals have a long-term condition. However, understanding the condition and informed decision-making will take place simultaneously. Acceptance is likely to occur alongside these, enabling one to live with a long-term condition.

In the next section, I will discuss the findings of this study, considering them in dialogue with the literature. I will then offer a theory, grounded in the findings of this study, in the final chapter.

## Chapter 6: Discussion

### Introduction

The findings of this study demonstrate that individuals with a long-term condition create constructs about it based on the knowledge they acquire before, at the point of and after diagnosis. These are used as the basis on which they make decisions. People may accept their condition and its nuances, or struggle to do so; they can move from acceptance to non-acceptance and vice versa. Those who are informed, making decisions and accept the condition are able to live **with** it as part of their identity. Others are unable to integrate it into their lives and live **alongside** the condition. This discussion chapter will consider these findings in dialogue with the wider literature, exploring relevant concepts in detail.

In a constructivist study, it is important to consider the wider healthcare and scientific context in which a diagnosis occurs. Advances in healthcare and medical science have enabled diagnosis to take place. The research took place in England, and all of those interviewed had been accessing healthcare in this country. The healthcare system in England allows tests at limited direct cost to the individual, and so there are few immediate financial implications of having a test. There are also limited financial implications of any ongoing treatment decisions, due to the country's approach in charging a small fee for prescriptions, no matter how much the treatment costs. This style of healthcare system means that individuals are not discouraged from being tested for financial reasons. Free care at the point of need in a national healthcare system, together with limited costs for prescriptions, offers different circumstances for those diagnosed with long-term conditions in the UK compared with other countries.<sup>6</sup>

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<sup>6</sup> One participant had lived in several countries, she was a US citizen and she discussed the financial implications of having thrombophilia together with the practical issues she faced. She was studying in the UK at the time of the interview, and found that it was difficult to access healthcare when she travelled back to the US as she needed to register with a healthcare professional – but was already

All participants lived in a country where access to healthcare professionals is not limited, either for ongoing care and treatment or when emergency treatment is needed. This would not necessarily be possible in a developing country with limited access to healthcare. However, some participants highlighted perceived difficulties in obtaining a convenient appointment with their GP. These affected people's ability to seek care and contributed to their constructs of their condition, as one which may not be problematic in itself, but can lead to logistical issues for those affected.

The study also took place within a social context which enables the conditions under study to be named and defined. In this study, there were examples of individuals with either study condition being incorrectly diagnosed and treated due to the lack of appropriate diagnostic tests at the time they first experienced symptoms. Thus the specific timing of the study is important; it took place at a point when both conditions have been defined by the medical profession, and tests are available to determine their existence. This forms another layer of constructs; the labels denote particular biological or medical happenings (for example, the term 'thrombophilia' denotes a condition of increased tendency for blood clotting). Although asthma is not particularly contentious, it is possible to argue that thrombophilia is determined to be a medical condition, when it may instead be merely a biological characteristic which means that some people are more at risk of blood clots than others. However, this was not questioned by individuals in the study, and so the label of thrombophilia with its associated meaning of an increased tendency for clots is maintained for this study.

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registered in England. She offered an interesting alternative perspective on paying for healthcare, particularly as she herself had been a member of the US armed forces, which limited her financial commitment to healthcare, before leaving the forces and being required to purchase health insurance and pay for treatment.

## **Becoming knowledgeable**

Becoming knowledgeable is the first major category identified in this study. Individuals may enter this stage of the process at one of two points, either at the pre-diagnosis phase or at the point of diagnosis. This will depend on their circumstances, and whether they have been alerted to the possibility of a long-term condition through one of the routes identified. Those who did not know that they might have a long-term condition will only begin to learn about it from the point of diagnosis. All those in the current study had a diagnosis, and moved into the phase of understanding the condition.

There is a difference between the two conditions with regard to how long people will spend in the different phases. Those with asthma tend to go through the pre-diagnosis and diagnosis phases more quickly than those with thrombophilia, due to the nature of their condition. People affected by asthma and their healthcare professionals can clearly identify that they have some difficulty with their breathing. In contrast, those with thrombophilia are unlikely to identify it themselves, and diagnosis by healthcare professionals can be delayed due to a range of factors, as demonstrated by the findings. Whilst the first two phases have a defined endpoint, this being the diagnosis itself, understanding the condition will be a longer process, sometimes continuing indefinitely.

The findings of this study reflect some aspects of the 'distributed health literacy' concept developed by Edwards et al. (2013). This occurs where individuals draw upon the health literacy skills of others in order to seek, understand and utilise health information. Specifically, individuals in the current study shared knowledge and understanding with others and used their social networks to access and evaluate information in a distributed manner. This included using the knowledge and skills of others to help them to manage their condition. Those interviewed in this study mostly felt that they were able to access information, but often discussed it with others in order to evaluate it and compare it with others' experiences. This allowed

them to determine how useful and relevant the information was to their own circumstances.

Lipowski (1983) offers a schema and taxonomy of psychosocial reactions to illness. The first of these, meaning of illness, describes

“the subjective significance for the patient of all the illness-related information that impinges on him or her. Patients appraise the information in the light of their personal experience, knowledge, values, beliefs and needs.” (p.1070).

This can clearly be seen to hold relevance to the findings of the current study, which similarly demonstrates that individuals amalgamate knowledge and information from a variety of sources. Lipowski indicates that there are four major categories of meaning, these being *challenge or threat*, *loss*, *gain or relief* and *punishment*. I would argue that my findings show there are many more nuances to the meaning a long-term condition may hold for the individual, and these may be clear only to that person. For example, one individual stated that having thrombophilia allowed her to ‘live life’ because she never knew what might happen, whilst others considered their condition to not be serious (despite its life-threatening nature). However, as Lipowski and this study demonstrate, the importance of experiential knowledge and its amalgamation with theoretical information cannot be underestimated.

### **Pre-diagnosis: tentative learning**

During the tentative learning phase, individuals start to learn about their condition. Kralik et al. (2001) describe how, across different studies, the experience of diagnosis was a memorable event but one considered infrequently in the literature. They do not however discuss the importance of the stage before diagnosis, particularly with regard to the knowledge being collated at this time, for those with a long-term condition. It is clear from my study that many people begin to learn about a LTC before they receive a diagnosis, and that this learning, whilst tentative, remains with them and forms an important aspect of their knowledge.

The concept of awareness is relevant to this study. Several authors have discussed awareness in connection with illnesses which have an inherited component (Cox and McKellin 1999; Brain et al 2000; Lock et al. 2007; Forrest Keenan et al. 2009; Chilibeck et al. 2011). Geelen et al. (2011) identified the concept of “becoming aware of a familial disease” (p.1754) for familial hypertrophic cardiomyopathy. They found that individuals recognised the condition by linking their own symptoms to those experienced by others, or were informed of a possible family illness by health professionals, in the latter case either in conjunction with a family history or in isolation. This confirms the routes identified in the current study. The study by Geelen et al. (2011) does not however identify the importance of information gained, either through personal or family experiences, at this pre-diagnostic stage. In contrast, it is clear from my study that information gained at this point is significant to those affected by a long-term condition, and forms the basis for the knowledge held by individuals about it.

Information needs and sources are considered in the wider literature concerning long-term conditions. McLaughlin and Jones (2011) found that carers of people with Down’s Syndrome who were developing Alzheimer’s Disease had information needs which changed prior to, during and after diagnosis. Carers’ information needs were greatest prior to diagnosis, when they were able to detect differences in the person cared for, but were unaware of the reason for these. Individuals affected by cancer also identified information to be an important need pre-diagnosis (Wiljer et al. 2012, 2013). Participants in these questionnaire-based studies had a confirmed diagnosis, and were asked retrospectively to identify their needs whilst awaiting this. Individuals frequently sought out information after being advised by a healthcare professional that they may have cancer, and they used a range of sources for this (healthcare professionals, family, friends and colleagues, the internet, printed materials, and charitable organisations). Most found that their information needs at this stage had been met. Participants in the current study did not indicate whether their information needs were met pre-diagnosis; many did not know that they had a specific condition, and so were not able to identify specific needs. However, they did

use a range of information sources to learn about their condition, as indicated by Wiljer et al. (2012, 2013).

Hunt et al. (1989) used mixed methods to investigate the contribution made by medical consultations on patients' constructions of their illness. They found that prior constructs persisted even after consultation with a doctor. Although patients understood and remembered the diagnosis given, they maintained their previous ideas about what was wrong with them. These two sets of constructs were then integrated to offer a reason for their symptoms. According to the findings of Taïeb et al. (2010), beliefs about the causes of illness included some which were congruent with the biomedical model together with some which were not. This interpretive phenomenological analysis of interviews thus demonstrates that there may be discrepancies between the explanations offered by a healthcare professional and patients' constructs. Similarly, according to the findings of a further interpretive phenomenological analysis study by Moore et al. (2008), those with thrombophilia had identified a cause for their thrombosis prior to receiving their diagnosis. These multi-causal models included surgery and stress. Although participants described their relief at being advised that their condition was inherited, they maintained aspects of these models which allowed them to believe that the condition was controllable.

Thus, constructs and beliefs about a condition may at least in part be maintained even after individuals have received a biomedical explanation of their condition from a healthcare professional. In most instances, individuals amalgamate these explanations with their own ideas. The findings of the current study demonstrate that constructs about a condition may arise from a range of sources – those which showed individuals that they could have the condition. These may be biomedical (for those advised by a healthcare professional of the possibility they have a long-term condition), or based on one's own and others' knowledge and experiences. These constructs will contribute to those used by individuals over time to manage their condition.

In contrast to these people, some individuals in my study were diagnosed with a long-term condition with no prior knowledge of it, meaning that they



were unable to begin to learn about it before this point. This includes those with asthma who were diagnosed at a young age. This idea is confirmed in the literature, for example, Goodman et al. (2005) found that individuals with lupus erythematosus were unlikely to have any knowledge of the condition prior to their diagnosis. Some of the knowledge which was held by those with the disease was determined to be incorrect and the authors state that

“this information was quickly dismissed on diagnosis and the provision of more accurate information, so it is unlikely that these ideas had any substantial effect on the illness representations of those participants.” (Goodman et al. 2005, p.613).

This conflicts with the findings of the current study, where those who had knowledge of the condition prior to diagnosis incorporated this into their constructs of the condition in an ongoing manner. However, it does confirm that not all individuals will have knowledge of a condition with which they are subsequently diagnosed.

The role of the pre-diagnosis stage is discussed by Stewart and Sullivan (1982) with regard to multiple sclerosis. Multiple sclerosis and thrombophilia are similar in that they exhibit symptoms which healthcare professionals and patients may not easily diagnose as being caused by this condition. The method of analysis used in the study is unclear, but the authors indicate that patients go through a non-serious phase, followed by a serious phase, during which time they perceive worsening of symptoms and begin to consult healthcare professionals. During this second phase, patients began to violate the normative expectation of healthcare professionals making the diagnosis, by self-diagnosing. This, together with the patients' reactions to misdiagnosis, demonstrates a rejection of the sick role by the patient and instead negotiation takes place between healthcare professional and patient of their respective roles. Participants in the current study tended to consult healthcare professionals in their search for information and a diagnosis. Those who were advised they could be affected by their condition by a healthcare professional or who had a family member diagnosed with it adopted the traditional role of seeking advice from such professionals. However, those who experienced the condition for some time before their

diagnosis had, as with participants in Stewart and Sullivan (1982), started to become knowledgeable and, although they were not at the time able to label their condition, they could identify times when medical help ought to be sought. Thus, although they did not renegotiate the patient and professional roles to the extent that they advised professionals what was wrong, they did utilise their knowledge by accessing medical care when they perceived it to be necessary, even in the absence of a diagnosis.

Tentative learning is the first point at which individuals learn that they might have some kind of long-term condition and start to develop constructs around this. Although unconfirmed at this stage, ideas and impressions will begin to form in their minds about the condition, potentially relating to who may be affected and why, how it affects people, and the symptoms and effect it has on them personally. These ideas might not be medically correct; however, they will form part of the knowledge built up by individuals about their condition. Early impressions may be difficult to change at a later date however, particularly if they have gone unchecked for a long period of time. The literature confirms the routes through which people learn that they could have a long-term condition, together with the likelihood that individuals will retain knowledge learned at this point. However, it does not indicate the significance of this phase in the acquisition of knowledge.

### **The diagnosis: confirming the condition**

All of the participants in this study had, either through a healthcare professional or self-diagnosis, confirmed that they had a long-term condition. This enabled them to label the condition, and the constructs they continued to develop were then focused around this label. These constructs were based on information acquired before diagnosis (where appropriate), and on the information offered at the point of diagnosis.

Although all of the study participants were able to give a name to their condition, this is not always the case, as shown by Saukko et al. (2007). This may result from those in their study not having been advised of their specific type of thrombophilia or of people retaining different information. It is possible

that, even where individuals are advised of the specific name for their condition, they do not find this information significant enough to retain it; other features and information might be more salient.

Unlike some long-term conditions, the labels of thrombophilia and asthma do not stigmatise those diagnosed. According to the findings of Fife (2005), the constructs developed by those diagnosed with HIV held a more negative meaning than those developed by people with cancer. This was particularly linked to the stigmatisation linked to HIV. In contrast, the constructs developed by those with thrombophilia and asthma did not indicate any stigma associated with the condition. Most people described constructs that were both positive and negative, and for some, having a label meant that they finally knew what had been causing their symptoms.

Most of those diagnosed with a long-term condition in the current study did so through a healthcare professional. This ability to diagnose may be seen to give healthcare professionals, and particularly medical doctors, an elevated status which separates them from their patients. Pilnick and Dingwall (2011) indicate that, despite an increase in patient-centred healthcare, there remains a fundamental power discrepancy between doctors and their patients, resulting from the knowledge held by doctors. Diagnosis by healthcare professionals offers legitimation of illness and affords affected individuals the opportunity to justify their ill status to others in addition to enabling them to access care and medication (Telles and Pollack 1981). It is useful here to consider the concept of the sick role, as defined by Parsons (1951). Parsons adopts a sociological perspective to illness, arguing that the sick role exempts individuals from their normal social role, and from being responsible for the illness, whilst also incurring an obligation to recover and to seek medical help to aid this process. Illness is considered to be deviant behaviour, as those who are ill fail to fulfil their expected role(s) in society. Parsons focuses on those with acute illnesses, though the literature demonstrates that others have attempted to apply the concept to chronic conditions such as back pain (Glenton 2003) and multiple sclerosis (Stewart and Sullivan 1982). For those with long-term conditions such as those under

consideration in the current study, it is not possible for affected individuals to seek a cure. On a day-to-day basis, they are unlikely to require exemption from their normal social roles; indeed, one feature of these conditions is that they do not tend to impact on individuals in this way. However, when their long-term conditions lead to acute illness, individuals may adopt the sick role, seeking exemption from their roles (for example, taking time off work to recover), seeking medical help or self-treating as appropriate, and trying to recover from their illness. Thus, whilst adopting the sick role and requesting legitimisation of illness are likely to occur during acute periods, these are not sought for much of the time by those with long-term conditions such as these.

Despite this, the power differential between healthcare professionals and lay people may result in missed or delayed diagnosis. Research into patient perceptions confirms that delayed diagnosis by healthcare professionals is not restricted to thrombophilia. Burgess et al. (2012) found that individuals who had diabetes and a stroke were not diagnosed and provided with appropriate treatment and care. Individuals with neurological conditions waited some time to receive a diagnosis; over a third waited more than a year, and almost two thirds did not believe they were offered adequate information (Peters et al. 2013). Lillrank (2003) analysed women's accounts of back pain and found that it was dismissed by healthcare professionals, despite having a profound impact on their daily lives. They were only diagnosed when they reached a 'turning point'; either their condition was affecting them to such an extent that they proactively sought alternative sources of help, such as paying for scans privately, or they encountered a new healthcare professional who listened to their stories and sought to help them. However, healthcare professionals also identified delays in diagnosing some conditions (Horton et al. 2010), which they recognised could result from misdiagnoses and from uncertainty in the characteristics of a condition and lack of diagnostic tests, and that this could negatively impact upon patients' experiences and views of healthcare professionals. Thus the literature confirms the findings of the current study; long-term conditions may go undiagnosed for some time, either due to delays and mistakes or simply

due to the unavailability of a mechanism for identifying the cause of symptoms.

Similar to the current study, other research has found that patients do not always seek medical advice immediately when experiencing symptoms of illness. Individuals affected by rheumatoid arthritis frequently managed their pain with over the counter painkillers for some time before seeking medical advice, and only did so once the painkillers failed to work (Townsend et al. 2013). A qualitative synthesis of research into reasons for patients with cancer to delay seeking medical help indicated that delay was often due to fear or lack of recognition and incorrect interpretation of symptoms (Smith et al. 2005). Finnegan et al. (2000) and Horne et al. (2000) also found that symptom recognition was a factor in people delaying seeking medical help for heart attack. Similarly, those with asthma may be unaware that their difficulty breathing is anything more than lack of fitness, leading them to delay seeking medical advice.

Some of those in the current study had been diagnosed at a young age. The age at which this occurs will affect the information they receive and gain about it. Diagnosis as a child will mean that their parents are informed of the implications of having the condition, rather than the individuals themselves, and children will learn from their parents and from experience. This is clear not only from the current study, but also from previous research (see for example, Stewart et al. 2011; Callery and Milnes 2012). Indeed, according to the findings of Koster et al. (2011), parental attitudes to medication are a significant factor in the likelihood of children's asthma being under control. This differs from those who are diagnosed as a teenager or adult, as this group will learn about the diagnosis from the healthcare professional managing their diagnosis and treatment (see for example, Stewart et al. 2012).

In addition, some people had been diagnosed some time ago, when access to information was more limited than it is today. These individuals had accessed information through the internet once it became available, but they did comment on their changing information sources.

This study found that a diagnosis of a long-term condition may be expected or unanticipated. The literature confirms that receiving such a diagnosis may be unexpected for the patient. A qualitative study undertaken with individuals affected by glaucoma (Green et al. 2002) identified that, despite the condition leading to restricted vision, those participants who had recognised that their vision was not normal had assumed that this was due to normal processes, either ageing or existing eyesight problems. Receiving a diagnosis of glaucoma was unexpected in all cases, and caused participants to reflect on the potential seriousness of losing their vision. Thus even when people are aware of a possible problem – either due to symptoms or advice from a healthcare professional – the diagnosis may still come as a surprise. It could be beneficial for healthcare professionals to be aware that their patients will not necessarily anticipate a diagnosis, even if they have been warned that it is suspected. Being mindful of the patient's potential shock or surprise at a diagnosis could aid the healthcare professional in ensuring that appropriate support and advice is offered, particularly as several participants indicated that they had not received information that they believed to be necessary, such as the seriousness of one's condition.

It is interesting at this point to consider two sociological concepts, which will be revisited throughout this chapter. The concepts of biographical disruption and body-subject/body-object are relevant to this research in a number of ways. According to Bury (1982), chronic illness represents a major disruption in the life of an individual, and in particular “the structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury 1982, p.169). This begins with people questioning what is happening to their body, as a result of their becoming conscious of their altered bodily state (this overlaps with the second concept to be considered, to which I shall return forthwith). The chronic illness considered by Bury is rheumatoid arthritis, a condition which may gradually begin to affect individuals, and is likely to be dismissed, at least initially, as aches and pains resulting from over-activity. Eventually individuals in his research slowly began to recognise that these were not fading, and either they or others started to entertain the possibility of arthritis. This finally led them to gain a referral to a specialist. The resulting

diagnosis leads to a more existential disruption of the self, involving a fundamental change to the individuals' beliefs about their self and their biography. They may respond to this disruption by mobilising resources in order to help them to manage their condition; this can include avoiding particular situations which are unsupportive. Thus, according to Bury (1982), chronic illness disrupts the biography of human beings and illuminates both the restrictions which may be imposed by a condition such as arthritis, and the resources people can access in order to help manage it.

Does being diagnosed with asthma or thrombophilia create a biographical disruption? The diagnosis of the condition alone **did not** seem to result in biographical disruption with the meaning implied by Bury for many participants. The diagnosis offered a reason for their illness, and as a result provided some certainty where there had been none. However, for at least one individual the diagnosis **did** represent a biographical disruption. This woman had not experienced any symptoms of thrombophilia, she was diagnosed purely due to a family history of the condition. Receiving the diagnosis caused a significant disruption to her life and biography by causing her to question her health and the severity of the condition. Her new biography was centred on the uncertainty the diagnosis had caused in her life, however she did not appear to have mobilised any resources in order to manage her new situation; this may be because a condition such as thrombophilia does not cause disability as rheumatoid arthritis does.

The concepts of body-subject and body-object (Merleau-Ponty 1962; Leder 1990; Toombs 1993) also hold relevance for this study. The body-subject occurs because the body is invisibly part of the self, despite being ever-present (Leder 1990; Toombs 1993). It sustains itself without conscious thought; it is not possible to control whether the heart beats or blood pumps around the body. Leder (1990) describes the recessive body, the aspects of the body of which we are unaware much of the time such as the liver and lungs. This does not equate to these aspects not existing or being present, merely that we are unable to experience them directly. Through the use of technology, it is possible for one to become acquainted with these aspects of

the body, but they are not liable to experience from within. The body usually exists as part of the self without any consideration, invisibly and yet essentially.

In contrast, when an abnormal event (for example, pain) occurs within the body, the affected part draws the attention away from the external world (Leder 1990; Toombs 1993). The body becomes thematic, demands attention and reminds one of its presence. In doing so, it becomes distant from the self – where previously I would say that I **am** my body, now I am aware that I **have** a body, a body which is thus an object whilst still being part of the self. The body in such circumstances can be described as “an alien thing” (Leder 1990, p.77). This reminder of the body’s existence may occur rapidly, in the case of sudden illness, or may take time to become apparent, for instance in the case of a dull ache about which one eventually decides to consult a doctor. Leder (1990) indicates that the threat of death enables the alien-ness of the body to “expand until it can threaten the entirety of one’s world” (p.83).

It is clear that the concepts of biographical disruption and body-subject/body-object overlap; according to Bury (1982), biographical disruption begins with persons becoming aware that their body has changed (for example, being in pain), which is the same experience as the body changing from being subject to object. However, the objectification of the body may not be maintained over the same time period as an individual undergoes biographical disruption, and would appear to take on a different aspect. Diagnosis of a condition may lead to an awareness of aspects of the body which have not previously been within one’s experience. For those with thrombophilia, there is a dawning awareness of the mechanisms involved in blood coagulation – not necessarily a scientific awareness, but an awareness that blood coagulation is happening and that it may go wrong, leading to a blood clot which causes illness. There is often recognition of the potential not only for illness but also death to result from this predisposition. Although blood clotting cannot be experienced, the threat it creates can be, and in fact may be the entirety of the experience if there is no prior experience of thrombosis.



As the threat recedes and thrombophilia does not lead to acute illness, this awareness of the body being separate from the self may also recede until the body-subject is achieved once again, though with an altered body which is now known to be at risk. The woman who experienced biographical disruption appeared to also experience her thrombophilia diagnosis as an awareness that her body was different from her expectations, and it seems from her comments that she was aware of it as creating a risk, but one which she could not know was happening. Her body appeared to have become object as she talked about having thrombophilia, and throughout the interview she drew attention to her risk of clots and awareness that these may not be apparent. It is possible that objectification of the body can lead to ongoing disruption and an inability to reconcile to a new self. This person however remained an exception in my research.

Similarly, individuals with asthma cannot directly experience the constriction of the muscles around the airways and inflammation of the lining of the airways. However, the body becomes object when one struggles to breathe; as such a basic function of life, one's attention is inevitably drawn to the need and inability to receive sufficient oxygen. This may be contrasted with the experience of those with thrombophilia, where clots may form without the individual's knowledge.

Another useful concept to consider at this point is that of identity. Identity is portrayed as how individuals describe, position and distinguish themselves from others, incorporating both mind and body (Charmaz 1995). The literature argues strongly that the diagnosis of a chronic illness leads to a change of identity, as individuals adapt to their altered bodies and new limits (see for example Williams 1984; Charmaz 1995). Charmaz (1995) discusses how people with serious long-term illness are forced into changing their identity – adapting to illness – as they reassess who they are as a result of their condition. This involves a staged process, whereby individuals experience their altered body, cope with changes to their appearance, change their identity goals and finally surrender to their sick body. Although this study is relatively old, it is nevertheless foundational and still valid today.

Similarly, the findings of a grounded theory by Asbring (2001) demonstrate that women with fibromyalgia and chronic fatigue syndrome experience significant biographical disruption which leads to partial loss of their identity. The loss is described as being partial as several of those interviewed were able to maintain at least some of the activities which were important to their identity. The women learned to come to terms with their new identity. This involved learning about what they could do and what their limits were and reorganising daily life. However despite this, most of the women described gains from their diagnosis, whether this involved living in the moment or gaining an increased understanding of what it was like to be ill. Those affected by arthritis also managed a shift in their identity resulting from a change to a life in which pain was a constant companion and the condition sometimes severely disabling (Kralik et al. 2004; Lempp et al. 2006). In contrast, mothers diagnosed with HIV experienced reinforcement of their motherhood identity whilst struggling with the stigma associated with the condition and the potentially fatal nature of it (Wilson 2007).

Thus chronic illness has been found in several studies to impact upon the identity of those affected, frequently in such a way that individuals come to terms with a new self which experiences more limitations and requires reorganisation of one's day-to-day life. Conversely, some diagnoses can lead to the reinforcement of certain identities. So the question can be asked as to whether those in the current study experience a change to their identity. Identity was not mentioned explicitly in the current study. Many of those interviewed experienced some changes to their daily life which they accepted as part of the condition. Despite this, they did not describe the kind of fundamental, life-changing disruption frequently discussed in the literature, and they did not describe these in such a way that indicated that they had to adapt to a new identity. However, it is possible that some individuals experienced a change to their identity upon diagnosis. Some found that they finally had a name for their condition, and experienced this positively; they could finally take charge of their condition now they knew what it was. Others found the diagnosis disquieting and became someone living alongside a long-term condition.

Receiving a diagnosis and confirming its impact on one's life and self enables individuals to gain knowledge about their condition which is personally meaningful. They will be able to start to determine which elements of the tentative knowledge that they hold are relevant, and those which may be dismissed. They may encounter a disruption to their biography as a result of the diagnosis, which can also cause them to experience their body as an object, and lead to changes to the concept of oneself.

## **Acquiring knowledge**

People diagnosed with a long-term condition acquire knowledge about it from a range of sources, and over different timeframes. Some will have gained knowledge even before their diagnosis, through their experiences of having something which causes them to experience symptoms or become ill or through discussions with others about the possibility they could have a particular condition. They have received some information from healthcare professionals who diagnosed them. This information provided by healthcare professionals may be insufficient, causing individuals to seek out further knowledge. Those who were diagnosed at a young age or had a hereditary condition were likely to have received information from family members. According to the findings of Gregory et al. (2007) information about haemophilia communicated between family members differed greatly from that provided by health professionals. Discussion with family members related to the practicalities of living with haemophilia, and was often based on experiences and perceived experiences, as shown in this study. Information in this study was also gained from books, the internet, other media and, most significantly, experience.

Information gained at each time point contributes to the constructs held by people about their conditions. These will relate to the entire process and experience of having a long-term condition, including potentially its cause, its effects on the individual, the potential treatments and ways to reduce the risk of becoming ill, activities which pose a risk of illness, and the way others perceive both the individual and their condition. During this phase, which is

likely to be ongoing for the rest of one's life, individuals amalgamate available information to form dynamic, meaningful constructs about their condition. These will be updated and revised as further information is gained, and will enable people to understand what their condition means to them. It is useful to note that, as personally meaningful constructs, these will differ even between people with the same condition and are likely to be substantially different to those held by healthcare professionals. This is because healthcare professionals perceive disease and illness to be biomedical entities, whilst those with a condition experience it in its entirety.

Many of those in the current study had not been informed how serious an illness caused by their condition could be, demonstrating that healthcare professionals may leave their patients with unmet information needs. Fleischman (1999), speaking of her own illness, describes how the specific use of language and communication resulted in her being unaware for a time of how serious her diagnosis was. It is however not clear from the literature or from my study whether healthcare professionals deliberately omitted to tell individuals how serious their condition was, or whether this was accidental. Participants in the current research indicated that they thought they were either being protected from the information, or that healthcare professionals assumed that they already knew the potential severity of their illness.

Other studies have also demonstrated that patients with long-term conditions can have unmet information needs, including those with cystic fibrosis (Sawicki et al. 2007), thrombophilia (Hellmann et al. 2003; Saukko et al. 2007), asthma (Caress et al. 2002; Canonica et al. 2007; Abadoğlu et al. 2010; Zahradnik 2011), systemic lupus erythematosus (Moses et al. 2005), depression (Barney et al. 2011), spinal cord injury (Burkell et al. 2006) and dementia (Orrell et al. 2008). The literature thus confirms the finding in the current study, that individuals affected by long-term conditions require further information than that provided by health professionals. However, as the findings demonstrate, many are able to meet this need themselves, by acquiring information from other sources.

Previous research has shown that patients remember a limited amount of the information provided in consultations with healthcare professionals (Jedlicka-Köhler et al. 1996; Michie et al. 1997a). Anderson et al. (1979) assessed memory of information, and found that individuals only recalled 40% of the information provided and that much of the information 'remembered' was misconstrued. Michie et al. (1997b) undertook a similar study and found that information recall ranged from 33% to 100%, with a mean of 76%. Kessels (2003) states that

“40-80% of medical information provided by healthcare practitioners is forgotten immediately” (p.219).

Limited information recall could have been one of the reasons why those who consulted a health professional about thrombophilia some time subsequent to their diagnosis indicated that they received more understandable information. Although those participants with asthma indicated that they had regular follow-up appointments, these did not specifically focus on information and did not check that individuals were sufficiently knowledgeable about their condition.

Missed diagnosis of thrombosis is seen in other experiences of having a clot (Harvey and Runner 2011), and the literature indicates that other conditions also result in incorrect diagnoses. Several participants believed that they had been labelled by their healthcare professionals, who used these labels as other reasons for their symptoms. Hale et al. (2010) confirm that GPs depersonalise those who consult them frequently, and label them as hypochondriacs or the worried well. People with encephalitis struggled to gain a diagnosis for their illness and were labelled as having psychiatric illness, having a profound effect on their identity (Atkin et al. 2010).

According to Earnshaw and Quinn (2012), individuals who believed they had experienced stigma from healthcare professionals in relation to a long-term condition anticipated being stigmatised in further consultations, causing them to access care less frequently and leading to reduced quality of life. Chin (2001) indicates that “Trust is fundamental to the physician-patient relationship.” (p.580). The concept of trust is defined by Quick (2006) as “to

let go, to be vulnerable and deferent to another's competence and responsibility." (p.35). Although some studies have shown that other types of competence, particularly interpersonal competence, are more important in the doctor-patient relationship (Thom and Campbell 1997; Mechanic and Meyer 2000; Thom 2001), the current findings indicate that trust in health professionals' technical competence is a stronger theme for those who had experienced clots and gone undiagnosed. Those whose illness had gone undiagnosed were led to question their doctor's technical competence and lost trust in the abilities of the person concerned. Although it was not discussed in interviews, it is possible that this loss of trust transferred to other illnesses; some people did say that they would not consult that health professional again in connection with thrombophilia symptoms.

Although those with asthma did not come to distrust their healthcare professionals, they still experienced perceived difficulties, particularly in gaining an appointment at an appropriate time. Given that asthma is a potentially fatal condition, but one which those with the condition did not always prioritise as a reason for seeking emergency treatment, this may contribute to the reasons for those with asthma maintaining unexpectedly high death rates in the UK (Royal College of Physicians 2014).

Information from healthcare professionals was also provided in written form, and participants variously considered this to be useful, too complicated, or too basic for their needs. Other studies also indicate differences in the usefulness of written materials relating to health conditions (Newell et al. 1995; Hallowell and Murton 1998; Helitzer et al. 2009). According to the findings of Raynor et al. (2004), individuals with asthma found information leaflets to be of little use and frequently threw them away. It appears that some of the leaflets provided to those in the current study were written in too technical a format to be easily understood. This is supported by Helitzer et al. (2009), who found that written cancer prevention information was too complex for the majority of readers. Alternatively, leaflets were found to confirm information already known to participants and so were not considered useful. This may not have been the case in other studies. Those

with asthma in my research did not indicate that they wished for written information, possibly because they were able to access information from other sources and because the condition is better known than thrombophilia.

One of the alternative sources of information which caused conflict amongst participants was the internet. Previous research has found that 70% of internet users have searched for health information online and 52% have searched for information relating to a specific disease (Pew Research Center 2013). When considering people with chronic conditions, more than 70% of those with internet access searched for health information. These figures were not reflected in the current study, though its small size and geographical differences (the Pew Research Center survey was US-based) are likely to account for this difference.

Perspectives of the use of the internet varied in this study; some people used it to find out about their condition, whereas others found the information contained there to be too technical. This is confirmed repeatedly in previous research (Diaz et al. 2002; Bass et al. 2006; O'Connell and Sheahan 2011), though Rainie and Fox (2000) found that 92% of internet users searching for healthcare information found it to be useful. However, this survey was undertaken with individuals who use the internet at least every month to search for health information, and so this could have provided a sample biased towards people who were knowledgeable and experienced in searching the internet. Childs (2004) indicates that

“Judging the usefulness or quality of a website is very personal. Individual users are looking for information that suits them and their family circumstances. This might be different for other people with the same medical condition. A good-quality site may be in the eye of the beholder. The nature of medical information causes lay people problems, because of specialised terminology” (p.16).

This confirms the experiences of some of those interviewed for the current study, who mentioned that medical terminology could be too difficult for them to understand. Despite this, others had used the internet to find out about their condition and found it to be useful.

Acquiring information from different sources required both access and confidence that the information would be understandable. In addition, searching for information was only undertaken by those who felt a desire to find out more; some individuals had both access and the confidence that they would understand the available content, but did not feel that they needed any further information.

Both the current study and existing literature demonstrate that information requirements vary between individuals. Whilst some information may be considered to be too medical or scientific by one person, another may actively engage with complex information. Some individuals wish to find out a lot about their condition, whilst others are content with a small amount of knowledge. Also, different people prefer their information to be provided in a range of formats, either in person from a healthcare professional, in writing, on the internet or from other people. Thus information needs and wishes are highly personal to the individual.

In contrast, experiential knowledge was acquired by all participants, without any need to seek out or request information from others. Experiential knowledge comprised not only information which confirmed that offered by healthcare professionals or acquired from alternative sources, but also offered significant insights into how individuals could manage their condition on a day-to-day basis. It was not possible to gain these insights from other information sources, as they related specifically to the nuances of one's everyday life and one's reactions to their condition. Experiential knowledge resulted in a range of constructs about their condition which individuals were able to use as the basis for making decisions.

According to Comaroff and Maguire (1981), the parents of children with leukaemia sought to complete the limited knowledge offered by healthcare professionals by seeking out knowledge and experiences of others, classifying these according to similarities between others' case studies and their child's situation. Similarities can be observed to the individuals interviewed in the current study, who supplemented medical information with experiential knowledge. Similar findings are reported by Ziebland and



Herxheimer (2008), of their study exploring patients' use of others' experiences. Their study demonstrated that individuals used the experiences of others to help make meaning of illness and to support their decision-making. For those with a long-term condition, medical information alone offers a limited and insufficient insight, as they are not given any detail about what it may be like to live with a condition and to experience it on a daily basis. Medical information may be incomplete and, in such instances, individuals may have no alternative but to adopt an experiential approach to finding out what is possible. Experiential knowledge may be the only way for an individual to learn about their condition sufficiently for their needs, as this will allow them to learn about the condition as it affects them on an individual level, and provides information about day-to-day existence with it.

Returning to the findings of Stewart and Sullivan (1982) and the concept of the sick role (Parsons 1951), most participants in the current study rejected the sick role at least to a certain extent. They all became knowledgeable about their long-term condition. Some clearly negotiated with their healthcare professionals to obtain a role which recognised this knowledge. In contrast, some simply refused to consult particular healthcare professionals with regard to their condition, using their knowledge to identify others who were more likely to help them appropriately. Others appeared to adopt the role of the patient whilst consulting their GP, but would use their own knowledge to make decisions about their condition outside of this setting; thus they allocated themselves a role which enabled them to use their knowledge.

Information and knowledge are acquired by individuals affected by a long-term condition from a range of sources. Experiential knowledge appears to be particularly important in enabling people to develop constructs about and to create meaning in connection with their condition. Constructs are not necessarily medically accurate, and some may be disputed by healthcare professionals. However, they represent the condition as it exists for that individual, and so form the basis on which an individual manages and undertakes day-to-day activities in relation to that condition. Constructs will differ between individuals, even those affected by the same condition, as

they will have gained different information and undergone different experiences. Previous research findings also demonstrate that a range of sources are used by people to gain knowledge. The literature also offers theoretical concepts such as the sick role which are useful in considering how individuals respond to a long-term condition.

## **Living with a long-term condition**

Living with a long-term condition is the core category identified in this study. This stage begins at the point of diagnosis and continues. However, changing circumstances may cause some people to move between acceptance and non-acceptance and thus move between living with or alongside their condition. Those with the two conditions under study made different decisions about treatment and lifestyle choices, as appropriate to their circumstances; these then contributed to their knowledge and understanding. Those with either of the study conditions were able to accept the condition. Similarly, living **with** their condition, rather than **alongside** it, was possible for both those with asthma and those with thrombophilia.

These findings have implications for how self-management of a long-term condition can be perceived by individuals. It may include:

- identifying risks other than those advised by healthcare professionals,
- acting in an appropriate manner towards these (not necessarily avoiding them),
- determining the medication and levels one believes to be appropriate,
- making lifestyle decisions which help one to manage the condition, and
- seeking medical advice when this is believed to be necessary.

This is supported by the research by Ong et al. (2011) into the effects of knee pain resulting from osteoarthritis. Ong et al. (2011) state that

“Because knee pain is considered to be part of normal ageing and is not seen as a medical condition that requires professional help, self-management tends to be viewed as normal and integrated in

everyday life decisions. Thus, the emphasis subtly shifts from managing the condition (with knee pain not being classed as a medical one) to getting on with life” (p.7040).

However, the current study demonstrates that those with asthma and thrombophilia also mostly wish to get on with life, despite requiring professional help at least on occasions such as feeling ill or requiring medication prescriptions. Some are unable to do this, due to their lack of acceptance. However, the decisions made by and acceptance of the condition by the majority of participants shows their desire to live their lives with as little interference as possible from their LTC.

### **Making informed decisions**

Based on the knowledge acquired about their condition, individuals make decisions. These relate to a range of choices, including what to do in the event of symptoms being present and how to approach medications, risks and other lifestyle activities. The decisions made vary according to several factors; people have different views of risk and what constitutes an acceptable risk; they hold a range of knowledge which provides them with varying information about what they ought to do; they have differing views about what is necessary; and they will be exposed to different choices which need to be made, for example whilst some people with thrombophilia stated they would not be taking long-haul flights, others indicated that they were planning to do so.

Individuals may on occasion have symptoms which cause them to question whether they are ill. The findings of this study indicate that some will seek medical advice immediately, whilst others may delay as they do not recognise that they are ill. Research into why people seek help from health professionals indicates a number of reasons, including consideration of symptoms, perceived risk, previous experience, psychological and emotional factors, use of the NHS and context of the event (Pattenden et al. 2002). Fear, embarrassment and denial of symptoms were all reasons for people to delay seeking medical advice (de Nooijer et al. 2001; Pattenden et al. 2002; Horrocks et al. 2004; Smith et al. 2005); these were not found to be reasons

in the current study. Instead, reasons for delaying seeking help, despite being aware of the possibility that symptoms may be indicative of illness, included being busy. O'Brien et al. (2005) show that many men are unlikely to seek help for what they consider to be minor complaints and that, even with more serious symptoms, they are still reluctant to seek medical advice. Some of the men interviewed for the current study tended to seek medical advice only when encouraged to by others or when they felt particularly ill, partially supporting these findings. Participants in my study needed to identify whether symptoms they were experiencing indicated that they could be ill, and act appropriately. The literature shows that people don't always recognise symptoms of illness; however, most of those in this study had already been ill, and they looked for symptoms they had previously experienced in order to determine the likelihood that they were ill and needed to seek medical advice or manage their symptoms themselves.

Of particular relevance to the findings of the current study is the research by Janson and Becker (1998), who found in a survey undertaken in the US that 86% of respondents delayed seeking medical attention for severe asthma symptoms. The reasons offered for this were: past experiences of emergency services; financial reasons; uncertainty; disruption; a desire to minimise the illness; a desire to avoid taking corticosteroids in tablet form; and a wish to manage the episode oneself. My study found that some people did not immediately seek medical advice for asthma symptoms, however, financial reasons were not given. Instead, some people found that seeking advice was too complicated due to other commitments and the opening hours of their local practice. Several had visited emergency services and received treatment through these. One person had managed a severe asthma exacerbation himself, and explained that at the time he was going through a particularly bad time in his life and felt that being ill was preferable. He did however recognise in hindsight that he probably ought to have sought emergency treatment. Those with thrombophilia did talk about past experiences of seeking medical advice, though through their GP rather than emergency services, and a wish to avoid disruption to their lives, reflecting the findings of Janson and Becker (1998).

Several of those in the current study could be considered to be non-compliant with medical advice, as they rarely took medication exactly as it had been prescribed. Patients' decisions regarding compliance with healthcare professionals' advice have been variously described over the years as compliance, adherence and concordance (Fraser 2010). The terms compliance and adherence are now considered to be judgemental and constitute little involvement by the patients in their treatment decisions; these terms, though still used, are beginning to be replaced by concordance (Fraser 2010) or dialogue involving patient-centred care or shared decision-making (Bissell et al. 2004).

Studies undertaken in the US (Nair et al. 2011; Bezreh et al. 2012) indicate several reasons for non-adherence, including mistrust of the pharmaceutical industry and the inclination of health professionals to dole out medication, a move from patients as passive accepters of prescribed medication to decision-makers, forgetfulness, being too busy, travel, hospitalization or illness, disruption of daily events, inability to collect the prescription and paying for prescriptions. Some of these are passive responses to circumstances. They can be compared with the active decisions taken by participants in my study and in other research, such as a survey by Barber et al. (2004), in which patients taking medication for chronic conditions were found to quickly become non-adherent (38% within 10 days). Of these, 45% intentionally did not take their medication as prescribed. Individuals consider the medications they are prescribed and take them or not according to what they feel is appropriate on a personal basis (Atkin and Ahmad 2001; Pound et al. 2005; Teh et al. 2009; McHorney and Gadkari 2010). This is mirrored in the findings of the current study, where both medications and other advised activities were considered and decisions made about each one, rather than about all advice concerning the individual's condition.

Conrad (1985) describes how individuals with epilepsy 'self-regulated' their medication by consciously altering it in order to control their epilepsy seizures, reduce worry or live a normal life. This reflects my study findings, where some individuals (particularly those with thrombophilia) stopped taking

medication due to its side effects. In doing so, they tested out what would happen, whether or not they became ill. One participant was actively doing this at the time I interviewed her.

A review of the literature (Kneeland and Fang 2010) found that poor adherence to warfarin for atrial fibrillation and venous thromboembolism was linked to younger age, being male, having a low risk of stroke, decreased cognitive function, poverty and homelessness, higher levels of education, being employed and attitude of the patient. It would appear from this study that the factor common to several of these could be the impact of warfarin on one's life. As warfarin requires close monitoring, and requires only small changes in lifestyle or diet to cause the blood to thin excessively or for the drug to stop working, it is likely to have a significant impact on those who take it and so adherence levels are likely to be low. These were certainly offered as reasons in the current study.

Kopnina and Haafkens (2010) argue that asthma patients make evidence-based decisions regarding their medication, though this may not be in compliance with recommended treatments. This is confirmed by participants with asthma in the current study; this group tended to use experience to determine their need for medication. Forgetting to take one's inhaler on the odd occasion was not necessarily seen as a serious mistake, as previous experience demonstrates that one will not normally suffer an exacerbation as a result. Experiencing an exacerbation may require different or increased medication and those who were particularly affected by colds and flu were aware of the need to amend their treatment, or seek an alternative from a healthcare professional.

Although at least some of those interviewed could be considered to be non-compliant with treatment advice, it is important to consider the context in which they became non-compliant. All those who chose not to follow medical advice did so based on the knowledge they had gained about their condition from non-medical sources. Thus, common patterns can be discerned, although individuals all had unique stories to tell. People weigh up the perceived effects of treatment against the perceived benefits, and make

informed decisions regarding what to do. They appear to have an internal scale against which they measure these choices. Individuals could be described as having 'personal reference points' which they use in order to make decisions. The choices they make may not always involve discussions with their health professionals and may be considered inappropriate by health professionals dealing with them; however, the individuals concerned will have made the choices which they feel to be personally appropriate at that time.

In addition, particular activities were considered to influence the risk of becoming ill. It appears that some of these - those which can easily be incorporated into daily life such as keeping the legs raised or keeping mobile - become habitual. They become automatic, at least in part (Verplanken 2006; Verplanken and Melkevik 2008), and so are economical in decision-making resource (Lindbladh and Lyttkens 2002). Despite this, some changed behaviours did not become habitual (for example, changes to diet and drinking more water). It is possible that the perceived benefit was not substantial enough to maintain this changed behaviour, particularly if people did not believe that the behaviour would impact upon their likelihood of becoming ill. In order to change habits, people will need to believe that this is necessary and be prepared to change their behaviour, so that habitual self-control ("a latent trait that is activated when an intention has been formed whose enactment is effortful and involves non-hedonistic behaviour" (Schroder and Schwarzer 2005; p.860)) is activated. It seems that replacing existing habits with new behaviours occurs only some of the time, and that some habits remain even after people have been advised to change them.

Returning to the concepts of body-subject and body-object, some of the lifestyle activities identified by individuals as potentially constituting a risk for illness are not clearly identified by healthcare professionals as known risk factors. In particular, those with asthma were alert to the different effects of particular environments on their condition. They were aware of a change to their breathing which was less than illness. It is also possible that illness symptoms can lead to the objectification of the body. The body when

experiencing symptoms is no longer the self, but is objectified and alien, acting outside of self-control. This objectification may cause people to seek to remove themselves from particular situations, for example by changing their environment or seeking treatment, thus informing their decisions.

Those with a long-term condition such as thrombophilia or asthma are able to recognise factors which may affect their condition and make decisions about whether the associated risks are acceptable. For some factors, such as exercise, there may be a known benefit to undertaking the activity and they may wish to accept the risk, at least in certain instances (for example, undertaking particular types of exercise and avoiding others which they found to particularly aggravate their condition). Some factors, such as the external environment, were unavoidable and individuals managed these either by choosing to not place themselves in that environment or by ensuring that they could take their reliever inhaler if necessary. Food and drink offered interesting insights into individuals' approaches to managing their condition; although some people had identified causes of exacerbations, they would not necessarily avoid these. In contrast, others would manage their diet so that they did not increase their risk of becoming ill. Of particular interest was the individual who had been very interested in using her diet to manage her risk of clotting, until she stopped taking warfarin, at which point she also adopted a diet which placed her at increased risk. The decisions made by individuals with regard to lifestyle activities were informed particularly by experience. Those who found that particular circumstances may aggravate their condition may decide to avoid these in future, or to be aware of the potential risk. These decisions, as with others made by people with a long-term condition, will be based on personal reference points which determine what is acceptable to each individual.

It is useful to consider existing models which may explain or contribute some indication of the reasons individuals have for deciding to adopt certain actions and behaviours in favour of others. Those which will be considered herein are the Health Belief Model and the Common Sense Model of Self-Regulation.



The Health Belief Model offers an explanation of why some individuals may adopt certain health behaviours in preference to others, and other people will take no actions (Pender 1987; Noar and Zimmerman 2005). Although originally used in relation to public health screening and immunisation programmes (Nutbeam and Harris 2004), it has also been used to explain behaviour in a number of illnesses (Harrison et al. 1992). The model indicates that the probability of someone adapting behaviour in light of a threat to their health relies upon several factors:

- their perception of how susceptible they are to a particular condition;
- how serious they believe the condition to be;
- how likely a particular behaviour is to reduce their susceptibility or minimise the outcome;
- what barriers are in place to prevent them from taking action;
- demographic variables (education, age, gender)
- cues to action (media campaigns, experience of the condition, advice from others)

Amalgamated, these produce an overall perceived threat of a particular disease (Pender 1987; Cottrell et al. 1999). It is clear from this study that individuals are aware of their condition and thus know that they are at risk of illness as a result and they knew that their condition could be fatal if left untreated (addressing the first two factors). They were aware that particular behaviours were likely to reduce or increase their risk of illness. However, barriers were a significant factor for those with a long-term condition in determining behaviours; these included:

- personal reference points which placed the perceived risk as being outweighed by the benefits gained from undertaking an activity;

- the perception that risks could be reduced but not entirely removed, and one could still become ill even if one avoided all known risks;
- habits could be difficult to break, particularly those which did not appear to affect one's risk of illness
- some risk factors being unavoidable (for example, external environment for those with asthma)
- side effects of medication could be sufficiently severe that individuals did not feel safe taking it, or were not prepared to accept the way it made them feel.

Thus it can be seen that despite those with a long-term condition being fully aware of their risk of becoming ill, a number of barriers exist which impact upon the likelihood that they will adopt all recommended risk-reducing measures.

Leventhal et al. (2003) offer a Common Sense Model of Self-Regulation, which indicates that individuals adopt an experimental approach to construction of an illness threat. This cycle comprises the identification of an illness threat, which leads to the identification and use of procedures to control this perceived threat. These are then appraised for their effectiveness and this information, together with new information about the illness threat such as symptoms, feed back into a revised representation of the threat. The system operates according to an individual's goals, so that people will appraise the effectiveness of their actions in achieving their goals.

The cognitive representation of a threat comprises five domains, these being identity (symptoms), timeline (duration of symptoms), consequences (expected outcome of the symptoms), cause (perceived by the individual) and control (whether or not this is possible). These are subjective and based on personal beliefs and experiences, so the same condition may represent a different level of threat between individuals or for the same individual at a different point in time (Shiloh 2006).

According to the findings of my research, in the context of experiencing symptoms of unknown cause (for example, prior to diagnosis of a long-term condition), individuals do follow the model of self-regulation. They consider their symptoms, may wait a few days and appraise whether the symptoms are still present, and if the symptoms are present for sufficient time and are sufficiently concerning them, they may consult a health professional. Others may consult a health professional only when other people encourage them to do so, potentially legitimising their feeling ill (Pattenden et al. 2002). If they are not diagnosed, and the suggested treatment does not work, they will re-visit the health professional for further advice. For some of those experiencing blood clots, this continued for a period of years before an appropriate diagnosis and correct advice was received. When faced with symptoms of unknown cause, it appears that an individual's goal will relate to identifying the cause of and recovering from the symptoms.

In the context of having been diagnosed with a long-term condition, and therefore being aware of the risk of illness, individuals' goals may be different. Individuals may experience symptoms for a sufficient period of time for it to be clear that they require treatment, and in the case of asthma attempt to manage this through changing their medication. They may also recognise that the illness could be fatal if they are unable to control it (for those with asthma) or if left untreated (thrombophilia). Some people will as a result seek treatment. However, some people will not do so. It may be that, for these people, their primary goal is to get on with life, rather than recovering from the symptoms (Marteau and Weinman 2006; Huyard 2008). Alternatively, the goal to be well and healthy may be overridden by more immediate goals, such as attending college or work, leading to a delay in seeking treatment. The phase of *making informed decisions* offers an important contribution to the model of self-regulation for people with long-term conditions, as it demonstrates some of the considerations which contribute to their representation of danger.

These study findings indicate that individuals' actions are congruent with the model of self-regulation when faced with symptoms of unknown cause which

are later diagnosed as resulting from asthma or thrombosis. However, once a diagnosis of a long-term condition has been determined, people may have other goals besides being healthy, and as a result they may not seek help when experiencing illness, although they will be aware of the risks this may entail. Therefore, although the common sense model of self-regulation offers some insights into the actions individuals may take, it is important to consider their goals at a given time.

It is clear that individuals with a long-term condition are able and willing to make informed decisions about their condition. They do so within the wider context of their lives, and use personal reference points to determine what may or may not be acceptable to each individual. However, this offers an interesting comparison with the intentions of healthcare professionals. Healthcare professionals may be working with the aim of supporting or treating the individual so that illness can be avoided wherever possible, so that individuals' reliance on the healthcare services is reduced, and so that risks are reduced or avoided when possible. In contrast, this study indicates that those with a long-term condition wish to live their life without excessive interference from their condition. They wish to take part in day-to-day activities, live without too many side effects of treatment and take risks when they feel this to be appropriate. Individuals use their personal reference points to determine which risks, activities and medications or side effects are acceptable to them at that point in time. However, being based on personal reference points rather than on the safest or most medically appropriate option, these may conflict with the intentions of healthcare professionals. As can be seen in the analysis presented above, some individuals acted against medical advice and, for example, took long-haul flights without taking any medication, stopped taking their medication completely, or refused to have the influenza vaccine. Others ate foods they were aware increased their risk of clots, whilst some people with asthma undertook activities such as smoking which are a known risk factor. These can be compared with those individuals who worked with healthcare professionals to determine the best course of action, taking account of the risks involved and the wishes of the person affected by the long-term condition. These include the woman who

chose to stop taking warfarin as a result of excessive bleeding, who had been advised that she could bleed to death, and the man who worked with his GP to determine the appropriate response to asthma exacerbations, whether this was increasing his steroid inhaler or seeking a nebuliser.

This study therefore offers some reasons for non-adherence to recommended activities, ranging from seeking advice for symptoms, taking medication and managing risks, to more mundane day-to-day activities. In doing so, it also demonstrates to both patient and healthcare professional the potential benefits of working together.

It is useful here to consider the literature on decision-making. Prospect theory (Kahneman and Tversky 1979) provides one theoretical contribution which offers an insight into how people make decisions regarding their long-term conditions. One begins making a decision based on a range of options which current information identifies as being available. According to the theory, individuals determine the desirability of each option together with the likelihood of their occurrence. Reference points are used, these being one's current state (for example, taking or not medication, experiencing illness at this time). Several principles apply, these being: a tendency to maintain the steady state; decisions tend to be made using the least possible cognitive effort; consequences are assumed to be linked to actions.

It is possible to see how prospect theory may be applied in the current study to the decision-making of participants. An example is offered in detail, in order to apply the principles of the theory, but others could have been chosen.

Example of prospect theory in action:

Individuals with thrombophilia are considering taking a long-haul flight, which increases their risk of having a clot. They have experienced clots previously, and are aware they could be fatal. They do not now usually take medication, and on previous occasions they had been prescribed too much, causing them to experience blood in the urine. They have previously flown long-haul

and not had clots. They are offered heparin or aspirin for the flight. They could alternatively choose to take no medication.

What does this mean to the individuals? They are aware they could have a clot as a result of flying, they also know that on previous occasions this did not happen. They remember having blood in their urine, something which concerned them at the time. So their decisions are based on the following choices:

1. clot
2. no clot
3. excessive bleeding

According to Prospect theory, decisions are made based on the available information. Available information shows that:

Option 1 is undesirable but is also unlikely (they have not previously had clots due to long-haul flying). It is known to be fatal, but the individuals are also aware that taking medication does not guarantee that a clot will not form; it can only reduce the risk.

Option 2 is desirable. It is also likely, based on previous experience, that a clot will not occur even in the absence of medication.

Option 3 is undesirable, and is likely (based on their experiences) if the individuals take medication. Having excessive bleeding as a result of medication remains a strong focus for these people, thus least cognitive effort is expended in assuming that medication is likely to lead to a clot, rather than re-considering this assumption. Consequences are linked to actions; taking medication leads to excessive bleeding.

Thus the most desirable outcome is not having a clot; this is considered to be likely even if one does not take medication and is thus the option decided upon. Having a clot is unlikely, so discounted. Experiencing excessive bleeding is considered to be likely if medication is taken, and is undesirable so is also rejected.

Prospect theory can be considered to be a likely route through which individuals make informed decisions about their condition. It should be noted however that, as in the example above, the choices may not be those considered to be options by an external figure. The choices offered were whether or not to take medication – and if so, which type. The individual then applies these to their situation, which means instead they consider their choices to be whether or not to increase their risk of having a clot, no clot or excessive bleeding. These are based on the individual's experiences of what it means to take medication; constructs around the condition and its consequences therefore form the basis of a decision, rather than the objective choices.

Prospect theory is not considered by Gamble et al. (2007) in their phenomenological study of people with asthma taking corticosteroids. Their findings demonstrate, as does the current study, that individuals desired knowledge in order to make decisions, they adopted a cost/benefit assessment, including consideration of the side effects, and many expressed concerns about their loss of self when taking the medication. The benefits of a grounded theory approach to my study include the dialogue with relevant literature which, in this instance, offers a theoretical basis for the findings in addition to formulating a theory from them.

Decisions made inform the constructs created, and connections can be seen with the experiential knowledge discussed in chapter four. Thus, a feedback loop exists through which decisions made and their outcomes provides further information which further inform existing constructs about the condition. As a result, future decisions are informed by the experience of previous ones. Both knowledge and informed decision-making are necessary in order that one can live with a long-term condition.

### **Accepting the condition**

Accepting one's condition comprises several factors, beginning with acceptance of the diagnosis itself. All participants in this study were aware of and accepted their diagnosis. It is also necessary for individuals to feel

informed about their condition before they are able to accept it; otherwise, they will continue to seek further knowledge. Acceptance of a condition thus relies on people both accepting their diagnosis and perceiving that they have sufficient knowledge about it.

Those who accept their condition acknowledge several factors, these being its consequences and implications, any uncertainty it confers and, for some people, related past events. The consequences and implications of a condition include the need to accept responsibility for its management, recognition of the need for medication (or otherwise) and potential side effects, the effects on the individual of having the condition, and any lifestyle implications. Most conditions confer some degree of uncertainty; the two under study are both uncertain in particular situations. Past events may cause people to dwell on the condition and on what may have been if events had been different. Those who accept these will be able to accept their condition. It is possible that circumstances may change over time, and on occasion this can lead to a change in one's acceptance status.

The literature indicates that previous research has also identified the concept of acceptance with regard to long-term conditions. McCracken (1998) and Viane et al. (2003) indicate that acceptance of pain is linked to mental well-being for patients. Adams et al. (1997) found that the majority of asthma patients could be described as either deniers/distancers or acceptors. Deniers/distancers were those who rejected the diagnosis of asthma and claimed that the condition had little effect on their lives; they did not take prophylactic medication, but instead relied on reliever medication when experiencing symptoms. Conversely, acceptors accepted the condition into their lives and self-image, and took prophylactic medication. These people considered that they were not ill with asthma, so long as they controlled their symptoms.

This group designated 'acceptors' by Adams et al. (1997) appear to correspond to those in the current study who accept and live with their condition; they did not simply accept advice from health professionals, but used an experimental approach to determine which aspects of their advice



could and should be incorporated into their lives. However, acceptors and those who live with their condition differ. Adams et al. (1997) indicate that acceptors have higher levels of knowledge of both the condition and its treatment. This can be contrasted with those in my study who accepted and lived with a long-term condition; for these people, it was essential that individuals had sufficient knowledge for their own needs, rather than possessing greater levels of knowledge *per se*. However, the current study also indicates a possible third group of individuals, comprising those who are unable to accept their condition but are also unable to distance themselves from it. This group is oppressed by their condition, as it draws their attention, asks questions of them and burdens their lives. This group does not seem to be identified in the study by Adams et al. (1997).

A number of studies have found that those who accepted their illness were less likely to experience anxiety (Schüssler 1992; Helder et al. 2002). In particular, Berntsson et al. (2007) found that it was necessary to have appropriate and sufficient knowledge in order to accept illness and disability, and that compliance did not necessarily result automatically from either knowledge or acceptance. Jensen and Allen (1994) indicate that

“individuals could conceivably experience disease as wellness by accepting disease as an integral part of themselves” (p.361).

This is confirmed by the current study findings, if wellness is equated with living with the condition. Acceptance is a pre-requisite for being able to live with a long-term condition, and this is confirmed by the literature.

One aspect of accepting the consequences of a condition is the acceptance of responsibility for its management. Willig (2011) indicates that accepting the condition is not a legitimate action when confronted with a diagnosis of cancer. This results from cultural pressure to refuse to accept defeat by the illness; responsibility in this context relates both to the responsibility to fight the condition, and the responsibility for cancer occurring in the first place. There may be a moral concern attached to cancer which results in those who have the disease being held responsible – through their actions –for developing the disease. This kind of responsibility was mentioned in the

current study, but only in connection with healthcare professionals misdiagnosing their patients (the issue of labelling) and in connection with making choices. Individuals did not feel themselves to be responsible for having their condition, but recognised that the choices they made could lead to an increased risk of illness.

As with my study, Kivits (2004) also found that some participants accepted responsibility for managing their condition. Conversely, Henwood et al. (2003) found that, for women interested in gaining knowledge about HRT in relation to symptoms of the menopause, many did not accept any responsibility. They did not search for further information, either because they felt it was a doctor's job to provide information or because they did not wish to be perceived as challenging the doctor's expertise, and felt unable to make informed decisions. This offers an interesting contrast to the findings of the current study, which found that most people sought out other information. Thus, most participants had taken responsibility for finding out about the condition if they felt it to be necessary.

With specific regard to hereditary thrombophilia, Moore et al. (2008) undertook an interpretative phenomenological analysis of interviews with women who had recurrent clots prior to their diagnosis. They found that women tried to maintain control over venous thromboembolic disease, and that the uncertainty was accepted. The authors claim that acceptance of the uncertainty "was an important element of adjustment" (p.781), and this is confirmed by the current study, where adjustment is deemed to enable one to live with the condition.

The concept of uncertainty has been identified to be a part of the experience of a number of long-term conditions, including back pain, stroke, hepatitis, fibromyalgia and multiple sclerosis amongst many others (Osborn and Smith 1998; Lillrank 2003; Johnson et al. 2006; Carlsson et al. 2009). In contrast to the current study, the findings of Lillrank (2003) demonstrate that, for those with long-term back pain, uncertainty can occur when individuals are unable to obtain a diagnosis. This is supported by the findings of Durham et al. (2010) in connection with those affected by, but unable to obtain a diagnosis

of, temporomandibular disorders. At this point, it is important to determine what is meant by uncertainty with regard to the current findings, in comparison with the concept found in the literature. Mishel (1990) describes uncertainty in the context of long-term conditions. Uncertainty, as described by Mishel, is defined as the inability to determine the meaning of illness-related events occurring when the decision-maker is unable to assign definite values to objects or events and/or is unable to accurately predict outcomes (Mishel and Clayton 2008). In the current study, uncertainty relates to the prediction of outcomes; people are unsure whether they may become ill again, if and when this might happen, and the circumstances under which illness may occur. According to research looking at people with different conditions, acceptance for those with long-term conditions occurs over a period of time and alongside the construction of a new reality for those affected (Baier 1995; Brashers et al. 2003). My research shows that acceptance can occur quickly – some individuals did not indicate that this had taken time for them to achieve – and a new reality was not a prerequisite for acceptance of uncertainty. Indeed, as will be seen later, several participants clearly indicated that they did accept the uncertainty inherent in their condition, but had not achieved a new reality. Thus the findings of my study demonstrate that there may be additional nuances to Mishel's theory of uncertainty which occur for some people with less severe and life-changing long-term conditions.

The findings of the current study demonstrate that one aspect of this phase was the acceptance of past events relating to their condition, such as its cause and missed diagnosis and resulting illness. Some individuals had inherited thrombophilia and mentioned not blaming anyone for this. Those for whom past events had had a profound effect on their life were not all able to accept that which had gone before. It may be possible for healthcare professionals to control some of these, in particular, the rate of missed diagnoses of thrombophilia, resulting in fewer people being unable to accept their condition.

Despite a wide range of literature relating to the misdiagnosis of various conditions, I was unable to find any specifically exploring patients' perspectives of such mistakes. A survey undertaken in the US by Blendon et al. (2002) to investigate patients' and practitioners' views of medical errors identified that over one third of each group had experienced an error personally or in a family member. However, the survey found that respondents did not consider such errors to be a major problem facing healthcare, despite most blaming healthcare professionals for the error they had experienced. Despite their views, the current study indicates that non-acceptance of medical errors may be one factor which denies individuals the opportunity to live with their long-term condition.

A significant change to one's circumstances can lead to a change in acceptance status. For those in the current study, such changes included starting a family (relevant to thrombophilia as the condition can cause miscarriage), exiting the grieving process and a change of lifestyle due to a change of career. These changes altered the constructs held by individuals, causing a modification in their perspective of their condition.

The literature does not mention the possibility that acceptance may change to non-acceptance, though it does, as previously mentioned, assume that acceptance can take some time to achieve. This is a significant contribution from the current study, which may result from the approach taken to the research in considering the whole process of having a long-term condition.

Accepting the condition requires that one is sufficiently knowledgeable about it. In order to live with it, it is necessary to accept it with all its nuances and consequences, including the need to take responsibility for its management, any inherent uncertainty, and, in some instances, any relevant past occurrences. The concepts of acceptance and uncertainty are found in the literature, but may hold different meanings for some conditions, particularly those with which a moral dimension is associated. I have been unable to identify any previous studies which consider acceptance of mistakes made by healthcare professionals, or which demonstrate that it is possible for individuals to move from acceptance to non-acceptance.

## Living with a long-term condition

Living with a long-term condition is the final phase identified in this study. It results from acceptance of one's condition, together with being knowledgeable about and understanding it and making decisions in relation to it. Some of those in the current study were living **with** their long-term condition, having accepted it as part of their identity. For these people, the condition merged into the background of their lives for much of the time and was focused on only when necessary for a short while.

Others lived **alongside** their condition. This group comprised of those who were unable to accept their condition in some way. The condition drew their attention and caused them to seek information, knowledge, certainty or solutions. For these people having a long-term condition represented a burden and restriction with which they found it difficult to live. My findings suggest that, at least for these conditions, this group were in a minority compared to those living with their condition.

As a result of a change in their acceptance status, individuals can move between living with and alongside a long-term condition. This happens rarely, those who described it indicated it had happened once in their lives, though it cannot be confirmed through the current study that it cannot happen more often.

Some people in the current study spoke about other illnesses, and compared theirs with these. They generally spoke of their condition as not being too serious, being liveable with and being something that allowed them to get on with life. Etchegary et al. (2008) also found that individuals compared their diagnosis with other illnesses. These might influence how serious or otherwise they considered their condition to be; if it was not the only condition affecting them, it tended to acquire a lower level of importance than when it was the only condition of which they had experience. Other conditions mentioned by those interviewed in my study included: high levels of cholesterol, high blood sugar levels, rheumatism, altered blood pressure, severe symptoms of the menopause, congenital abnormality of the kidney,

back problems, having had polio as a child and a resulting weak arm, arthritis, cancer, dementia and diabetes. As holistic beings, people were able to live with their condition, particularly if it was contextualised as having less impact than the other conditions of which they had knowledge.

In the current study, those who lived with their condition indicated that they generally did not think about it. This contrasts with young people with thalassemia major or sickle cell disorder (Atkin and Ahmad 2001), who were often unable to forget about their illness and ignore its impact on their life. This may result from the different age groups interviewed (no-one interviewed for the current study was under the age of 18) or the different conditions concerned, as both sickle cell disorder and thalassaemia major are life-limiting.

Several studies describe concepts which are similar to living with the condition in the current study. For example, Delmar et al. (2005) describe the concept of achieving harmony for those with a chronic illness. They state that

“To be in harmony with oneself can concern learning and/or accustoming oneself to living with one’s new situation. To learn is processual work where the patient actively relates to one’s new situation. Accustoming oneself to something entails reconciling oneself to the illness and disease, acknowledging the condition and the illness as a part of oneself. To learn and to accustom oneself thus constitute a movement towards and a form of acceptance.” (p.208).

The current study identifies acceptance as a prerequisite for living with a long-term condition, and also demonstrates that this is separate from learning about the condition. However, both studies confirm the need for learning to take place in order that one can live with a long-term condition.

Carel (2007) asks the question of whether it is possible to be both ill and happy, and concludes that this is achievable if one considers the concept of health within illness. If thrombophilia and asthma are to be described as ‘illnesses’ (I have consciously not adopted this word in this thesis as participants did not use it), then many of those interviewed for the current study indicate that health within illness is achievable, and that adapting to having a condition is possible.

Drummond (2000) used an ethnographic approach to determine what quality of life meant to people with asthma. His findings show that some of those with the condition, as with many participants in this study, did not consider the condition to be the core concept in quality of life. Instead, asthma becomes part of their normal, everyday life, one in which moments of illness existed as “niggles” (Drummond 2000, p.244). Others described the severe restrictions posed by their condition and their quality of life was severely curtailed. These reflect the findings of the current study, and represent the two groups identified, those who live with and those who live alongside a long-term condition. Similarly, Snadden and Brown (1992) used an interpretive approach to interview data which asked participants to consider their entire asthma experience. Diagnosis was a pivotal timepoint, though acceptance was defined as the point at which people stopped feeling anger and low self-esteem as a result of their condition and accepting it. Knowledge and understanding, as with the current study, were found to be important in enabling what is described by the authors as ‘control’. This stage resembles that of living with the condition, with people taking control of it and managing it rather than allowing it to control them. In comparison with the current study, there was no recognition of the time before diagnosis. Although those with asthma in this study had not spent long periods of time seeking diagnosis, those who were diagnosed in adulthood had reflected back on their experiences before receiving the diagnosis and learned from these. This time appears not to have been discussed by those in the study by Snadden and Brown (1992).

Feeling well was identified by Sanderson et al. (2010) as possible for those with rheumatoid arthritis, despite disease severity and symptoms. The concept comprises of four dimensions, these being living in the body, being in the mind, adapting to illness and being in the world. Those with the condition adapted to it, and in doing so accepted it (as found in this study). Being well was multi-dimensional and included not only one’s experiences of the condition, but also their wider lives. This compares with the final category of this study, living with a long-term condition, which, although focused on

the condition, describes a state where individuals live with it and are able to get on with their lives.

Aujoulat et al. (2008) interviewed people with a range of chronic conditions using phenomenological and grounded theory approaches to analyse the data. They found that empowerment was possible through a combination of integrating illness into the self and differentiating the self from illness. This differentiation was not apparent in the current study, but I did not seek to specifically investigate the concept of empowerment in relation to thrombophilia or asthma. In addition, as previously discussed, finding a new identity was not found for those with thrombophilia and asthma, despite being apparent in the study by Aujoulat et al. (2008).

The theory of self-efficacy helps to explain how people can live with a long-term condition. Self-efficacy is the belief in one's capabilities to organise and carry out actions required to achieve a particular goal (Bandura 1977; O'Leary 1985). It is possible that individuals who live with a long-term condition also have high levels of self-efficacy; they recognise that their condition is uncertain and partially outside of their control, but are knowledgeable and make informed choices regarding which treatments and behaviours to adopt, and accept responsibility for its management. However, they also undertake activities (whether lifestyle or treatment focused) which they recognise may cause an increased risk of illness. It is possible that, rather than having high levels of self-efficacy solely in relation to preventing illness, individuals instead have high levels of self-efficacy regarding their ability to live with and manage the condition. This would offer a different perspective. Individuals' goals would relate to getting on with life even in the presence of the condition. Those who live with a condition would be confident that they are able to manage it. This would also contribute to the explanation of why individuals make decisions about treatments, risks and lifestyle behaviours which conflict with medical advice. If correct, this would imply that further studies considering self-efficacy in the context of long-term conditions may wish to first consider people's goals; these may not be avoiding periods of acute illness, but instead living with the LTC.



Returning to the concept of biographical disruption (Bury 1982), which occurs where illness or a condition leads to major existential change for an individual, it is possible to identify its relevance to those with a LTC. As previously discussed, it is possible for **diagnosis of the condition** to lead to biographical disruption for some individuals, though this was not the case for most of those interviewed. In contrast, several people appeared to experience biographical disruption as a result of **becoming ill**, in the form of a clot or severe asthma exacerbation. For these people, being ill caused their outlook on life to change dramatically, due to the threat being ill posed to their life. These people were able to move on from the disruption, in the manner suggested by Bury (1982), albeit with a changed outlook which recognised that they had experienced and survived life-threatening illness.

From the findings of the current study it is possible to identify a further type of biographical impact on an individual's life, this can be described as a biographical interruption. This occurs where the condition leads to a 'blip' in the individual's biography, this is specifically caused by a short-term acute event such as a clot or severe asthma exacerbation. Individuals experiencing a biographical interruption describe an occasion where they became aware of the potential seriousness of their condition, in these instances the risk of death, but following their recovery it had minimal lasting impact on their biographies. It is possible that this new category, of biographical interruption, may only occur for some individuals, or in connection with certain types of condition. The two conditions under study herein have been selected as a result of their potentially insignificant impact on the individual on a day-to-day basis, but they can lead to life-threatening illness. Neither are conditions which are deemed to be life-limiting, they do not tend to restrict most day-to-day activities, nor do they lead to social isolation.

The literature demonstrates that other conditions can cause biographical disruption (Asbring 2001; Rasmussen and Elverdam 2008; Sångren et al. 2009; Jowsey et al. 2014). However, these do not reflect the findings of the current research, which indicates that long-term conditions do not necessarily lead to biographical disruption.

Considering biographical disruption, interruption and congruency in the light of the study findings, it is possible to determine the following:

- Those who **live with** their condition may have experienced no impact on their biographies, may have had a temporary interruption to their lives or have experienced a biographical disruption.
- All those who **live alongside** their condition and do not integrate it into their lives had experienced or were going through biographical disruption.
- Many of those who had experienced a biographical disruption and were living with their condition at the time of interview indicated that there had been times when they did not accept their condition and lived alongside it.

Considering the concepts of body-subject and body-object in the context of the study findings as a whole, it is possible to say that both diagnosis of a condition and illness may lead to the objectification of the body. Osborn and Smith (2006) found that people living with chronic pain also experience a split between body and self, and particularly that those parts of the body which are linked to pain are no longer part of the self. Paterson et al. (1999) argue that, for those with diabetes, transformation to living with the condition was possible by separation of the self from the body, and hence from the illness. Paterson (2001) presents a model of chronic illness which indicates that perspectives move between illness in the foreground and wellness in the foreground. Wellness, according to this model, is possible through the objectification and distancing of the body. This did not seem to be the experience of those people interviewed for this study, as those who lived with their condition were not objectifying, and therefore separate from, their bodies.

This research has identified the process gone through by individuals affected by a long-term condition, beginning before their diagnosis and ending with their living with or alongside the condition. This includes tentative learning

before diagnosis, confirmation of the diagnosis, understanding the condition, making informed decisions about and accepting it, and living with it. For those who do not accept the condition, or feel they have insufficient knowledge to understand it, living with it may not be possible and they will live alongside their condition. The literature indicates that aspects of this process are supported by existing research and by theoretical concepts which may help to explain peoples' experiences and how they make decisions. However, it does not consider the importance of the pre-diagnosis phase on individuals' knowledge of a condition. Nor does it suggest the possibility that, in addition to the experience of a biographical disruption as a result of a long-term condition, others may go through a biographical interruption, a blip in their biography which is resolved as they recover from serious illness without significantly altering their identity. The theory proposed as a result of these findings and discussion can be found in the final chapter, and offers a contribution to knowledge about the process through which people make sense of a long-term condition.

## **Chapter 7: Reflections on this study**

In this chapter, I will reflect on this study, considering my position when I began the project, and how this has changed over time. I will also discuss external influences which may have affected me in relation to the research. This will include thoughts on the data collected, and my progress as a qualitative researcher. The chapter will end with some considerations of the limitations of this project, and my focus on participants as experts in this work.

### **Background to this study**

I have had a longstanding interest in long-term conditions, of which several affect members of my family. In particular, I have been interested in individuals' perceptions of their condition, how they experience and live with something which might affect them, but often does not generate problems for them. As a result of this, I had a strong desire to undertake research exploring what it is like to live with a long-term condition. When considering a sample population and reviewing the literature, it was clear that much of the previous research in this area focused on conditions which constantly affect people, suggesting that it would be useful to explore the experiences of people with a condition which may have little impact on a day-to-day basis though it could occasionally become serious. I explored via various connections which groups of patients I could access. Eventually this led me to the haematology departments of two local hospitals, where two consultants were particularly interested in the project and how it might help their patients. They agreed to support me to access their patients who had undergone testing for thrombophilia, and so this group was chosen.

My interest in long-term conditions was thus instrumental in my commitment to carry out this study. The availability of local support to help me access a particular group in the initial stages and the difference between thrombophilia and some other long-term conditions in terms of disease pattern were important factors in undertaking the research with people affected by thrombophilia in the first instance.

## Methodological framework

My training both leading up to and during my Bachelors degree was mainly quantitative (I have a degree in genetics). Although I respected qualitative research and recognised its use and importance – it can answer questions which simply cannot be answered by quantitative studies – I struggled during the early stages of this project with finding a qualitative home for myself. Initially, I frequently had to question my ideas and assumptions to ensure that they were not imposing my quantitative training on the study. However, over the course of the project, I believe I have found a mental place where qualitative research has become more natural and I now find that I don't automatically revert to objectivist thinking.

Particularly during the initial stages of the project, I returned frequently to a struggle to decide between constructivism and social constructionism. However, Crotty (2003) offers a useful distinction:

“it would appear useful, then, to reserve the term *constructivism* for epistemological considerations focusing exclusively on ‘the meaning-making activity of the individual mind’ and to use *constructionism* where the focus includes ‘the collective generation [and transmission] of meaning” (p.58).

Concepts of long-term conditions are, in my view, constructed by healthcare professionals and health scientists and then layered with constructs from the media, family and friends and other sources before they reach an individual – and so, though the participants will then themselves add something to this medley, many of their constructs will have been formed before the ideas reach them. Constructivism and constructionism are both variations of a constructivist epistemology. Assuming that Charmaz uses the word in its widest sense, rather than using Crotty's specific definition (she writes

“I assume that neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. *We construct* our grounded theories through our past and present involvements and interactions with people, perspectives and research practices ... Research participants' implicit meanings, experiential views and researchers' finished grounded theories are constructions of reality.” (Charmaz 2006; p.10)),

a constructivist grounded theory approach is appropriate to a project focusing on individuals' constructs of the long-term conditions thrombophilia and asthma.

Having reached the end of the study, I feel that this choice of constructionism has been validated by the findings. People's perspectives are based on a variety of sources and so their constructs regarding their condition are social ones.

### **Undertaking the study**

It is possible that participants and the information they provide, as well as my interpretation of the data, may be influenced by my gender, social, cultural and educational backgrounds and job. I made clear to all participants that I was not a health professional by background; I felt that this was an important point in gaining participants' trust, and in reassuring them that, whatever they told me, their healthcare would not be affected. I think this helped them to feel secure in giving me what they felt to be honest answers, even where these were critical of the health services. I cannot however be sure that these answers would have been the same had someone else undertaken this study. Richards and Emslie (2000) provide evidence that professional roles do have an impact upon participants' responses to interview questions, and so it is possible that an interview with a health professional would have included some different content. I also cannot be sure that the same answers would have been provided had the study been undertaken at a different point in time. However, this is common to all research studies; I am aware that I give different responses to surveys depending upon my mood at the time, and so it cannot be assumed that the potential for different responses means that those responses received inaccurately reflected participants' views. I did not feel at any point that participants were withholding information or giving deliberately misleading replies, and so feel it appropriate that I trust the data collected. All of the individuals interviewed face-to-face were white, as am I, enabling some common ground to be found with these participants. I did not ask telephone participants about their ethnicity, and so cannot be sure

whether this influenced the content of interviews. In contrast, a number of participants were not degree educated, and I found that I needed to maintain an awareness of the language I used (for example, during the first interview I asked about siblings, and the interviewee responded as though I had said children); this was particularly important in earlier interviews as I was more nervous at this point. Although I have no personal experience of thrombophilia, someone close to me was diagnosed with the condition during the course of the study, and this made the study more personal than it had been previously. I also have mild asthma myself, having been diagnosed during the course of the study. Indeed, it was my experience of having the condition which suggested its potential similarity to thrombophilia in terms of being another long-term condition which may not have a daily impact on those affected, but which can be life-threatening or even fatal on occasion. I could not, however, claim to have been in the same position as those who described life-threatening experiences; I have never been so ill that it put my life at risk in this way. As a result, when participants were talking about their experiences I showed empathy and a degree of understanding, but never claimed that this was based on similar experiences; I think this also helped to create a relationship between myself and participants. I considered participants to be experts and myself to be the novice; this may also have been helped by being younger than many of the participants. This may have helped to balance any discrepancies in power which could have been felt between myself as researcher and the study participants.

Whilst analysing the findings of the study, I referred back to the notes I had made immediately after the interviews. This helped me to maintain the context in which the interview took place, particularly with regard to my immediate thoughts about individuals' feelings and approach towards their condition, and any pertinent factors happening at the time. For example, one individual had just recovered from a particularly bad cold which had affected his asthma at the time of the interview. This was important as episodes such as these could influence people's words and perceptions of their condition. In this particular instance, I was able to re-interview the participant at a later

date and confirm that he was living alongside his condition, as it caused him concern and worry and restricted his activities, even when he was not ill.

Theoretical sampling was undertaken, with a different group of people – those with asthma – interviewed to explore the emerging concepts. This highlighted the existence of a feedback loop between informed decision-making and understanding and knowledge. Those with asthma were the only people to have been diagnosed at a young age; theoretical sampling enabled the identification of this concept as those with thrombophilia had all been diagnosed as teenagers or adults. Individuals affected by thrombophilia tend to either adopt medications as recommended, or stop taking them completely. In contrast, those with asthma often take their medication, but not necessarily exactly as prescribed. This was an important contribution as it influences many of the concepts elucidated by this research.

### **Preconceptions about long-term conditions**

Having grown up in a family where members were affected by long-term conditions, I believed very strongly that individuals ought to be allowed, and enabled, to make their own decisions about healthcare and their health. This includes decisions in relation to medications, lifestyle and the information they choose to seek out amongst other things. I did however assume that individuals who felt that they did not have sufficient information about a condition, particularly one which was long-term, would seek out further information, and that information from various sources would be important. This was a misconception – as the findings demonstrate, the most significant source of information for people is experience, particularly their own.

Using a grounded theory approach, where the findings take precedence and the theory developed is grounded in the data collected, meant that my preconceptions were not confirmed in the analysis: there was simply no evidence to support them. Professor Juliet Corbin (personal communication, 30 June 2012) explained that preconceptions will not be found in the findings and analysis of a grounded theory study if there is no evidence to support them. Thus, although I took care to maintain an awareness of my pre-



conceptions, those which can be found in the findings of the study are only those which were also seen in the data collected.

## **Personal conflict**

During the course of this study, a family member was informed that she should be tested for thrombophilia. This was my first personal experience of the condition. The individual was provided with a very limited amount of information, indeed, I believe I was her main information source, and I have had to remain aware of this during the analysis of the findings of this study.

Several months after diagnosis, this individual believed that she was experiencing several symptoms of a clot. Luckily, because of this study and her training as a health professional, she was fully aware of the potential risks of DVT. The health professionals she consulted did not take the risk particularly seriously, and without continued pressure from her it is unlikely that she would have been tested for a clot; the initial results came back positive. This seems to have been confirmation that health professionals do not take potential clots seriously enough; as a new mother, she was already at a higher risk of developing a clot, even without her thrombophilia diagnosis.

In addition to the experiences of this individual, I was diagnosed with mild asthma early in the study. At this point, the focus of the study was on thrombophilia, but over time I became aware of similarities between the conditions in terms of their (limited) impact on daily life for some of those affected. As a result, the condition immediately sprang to mind when searching for a second LTC which exhibits a similar disease pattern, as both may have little day-to-day impact but potentially may cause life-threatening illness with rapid onset.

As a result, I have a strong link to both conditions under consideration in this study. Interestingly, I found that I was more able to detach myself from the experiences of those with asthma, both whilst undertaking the research and writing up the study. This may be because I live with asthma daily and,

although I am aware of its potential risk, I do not consider the condition to be particularly severe in my case. In comparison, the risks associated with thrombophilia for my family member at the time of diagnosis and subsequently were far higher. I do not think it is possible to say that these links had no influence; however, they mainly reinforced the findings from the study, consolidating the interview data. They may however have encouraged me to emphasise particular aspects which otherwise would have had less significance; I have tried to keep the personal separate and think I have achieved this for much of the study.

### **Becoming a qualitative researcher**

At the beginning of this study, I viewed myself as a novice qualitative researcher who had a strong positivist leaning and for whom qualitative research would be targeted towards the more objectivist end of the spectrum. Initially I surprised myself when reading about the different types of grounded theory and feeling that constructivist grounded theory would be most appropriate for this study.

Whilst undertaking the analysis of the findings and in preparation for the discussion section of this thesis, I read various theories and philosophical ideas, and discovered that the sociological literature relevant to the body and self, and more especially the phenomenological literature relating to body-subject and body-object, hold particular resonance with the findings. This has been a surprise; I would have expected that any resonance would be found with the health promotion or chronic illness literature, particularly as early in the project I had identified the health belief model as possibly being of interest and relevance. As analysis has progressed and the theory identified from this study has emerged, it has become clear that the process is one of living with a long-term condition. This can be compared with the alternative of living alongside a condition. I now believe that I have, during the course of the study, become a qualitative researcher, and have an affinity for qualitative research and its potential to provide answers to non-measurable questions.

## **Limitations of this study**

Although this study offers interesting insights into the experiences of those affected by the long-term conditions thrombophilia and asthma, a number of limitations can be identified.

The study was based solely in England, where the National Health Service means that access to care and to treatments are both free at the point of need, and widely available (though it cannot be said that all possible treatments for the conditions under consideration are available, as not all medications are financed by the NHS). If the study were to be undertaken in another jurisdiction, access to care, treatments and testing, and their affordability, may have featured prominently in participants' accounts. Therefore, consideration of the constructivist aspect of this study, locating the findings in a time, place and culture, is important for anyone outside the UK.

The qualitative nature of the project meant that a small number of people were interviewed. Problems with recruitment through the NHS led to three access routes. However, recruitment was still limited and the confines of doctoral study restricted the possibility of exploring other access routes in different parts of the country. In addition, this led to a combination of interview modes; it is not possible to say with certainty that the same data would have been collected had all interviews been undertaken using the same mode. As a novice qualitative researcher, it is possible that, at least in the first interviews, data gathering was not as effective as it may have been for an experienced researcher. I was unable to re-contact some interviewees for further interviews, which meant that I was unable to follow up their responses.

In spite of these limitations, the research does provide an in-depth exploration of how individuals make sense of a long-term health condition. In doing so, it contributes to the literature in the field, in particular that concerned with conditions which may be deemed to be non-problematic for those affected, and offers a contribution to knowledge.

## **Participants as experts**

I was aware from the beginning of the study that whichever group of individuals were interviewed, they would be experts and I would be a naive and unknowing researcher. The data confirmed this, particularly as I gained confidence in the interview technique and was able to concentrate on people's stories rather than on the interview process. Participants were living with their condition on a daily basis. Some, due to their personal risk of becoming ill, incorporated the facets and effects of the condition into their daily lives, whilst others were able to continue daily life with little consideration of the condition except at pertinent times. However, they were all experts and I believe it is important both to acknowledge this, and to ensure that I represent their stories as accurately as possible in the study findings. Grounded theory necessarily removes personal stories from the theoretical concepts arising from the data. However, I found that at times I was writing about the findings in such a way that all personal involvement and emotion was removed. This felt unfair to participants who had clearly shown that some aspects of having a long-term condition were emotional. This led me to change my writing style to more accurately represent the emotional side of having such a condition. I hope that I have done this, and that the findings now accurately represent perspectives of a long-term condition from the point of view of the experts – those who have thrombophilia and asthma.

The following chapter will draw conclusions from this project, and make recommendations for further research and practice based on the study findings.

## Chapter 8: Conclusions

As described in chapter three, the aim of this study was to explore and explain how people make sense of their long-term, potentially life-threatening, health condition. The specific conditions under consideration were asthma and thrombophilia. This was achieved by:

- a) investigating where and how individuals obtained information and exploring its contribution to and usefulness for their understanding of the condition;
- b) illuminating beliefs and understanding of information about the condition; and
- c) examining other factors which may affect the process experienced by individuals living with these conditions.

Through the findings, I learnt about the process which unfolded for those with a long-term condition, beginning before diagnosis and finally progressing to living with the condition.

*Gaining knowledge* comprises three phases. The first, pre-diagnosis phase occurs for those individuals who become aware that they may have some sort of illness. This can result from the diagnosis of a family member, a healthcare professional suspecting a particular condition, or from the linking of symptoms by individuals who recognise that these may all have the same cause. Some people will experience their condition for some time prior to diagnosis. As a result, individuals will begin to form ideas about their possible condition.

This is followed by the second phase of diagnosis itself, which is the point at which individuals are confirmed as having the condition. All participants had either thrombophilia or asthma, and most had been diagnosed by a healthcare professional. Some people will expect their diagnosis, whilst for others it will be unanticipated. Individuals who are diagnosed at a young age will gain most of their information from family members and experience; they are unlikely to acquire much of it from healthcare professionals. A number of

people will not be diagnosed immediately they begin to experience symptoms, either due to healthcare professionals missing the diagnosis, or because they delay seeking medical advice.

As indicated by the third phase, individuals will gain understanding of their condition from a range of information sources. Healthcare professionals will offer information, although written information was frequently found to be of little use. Family members and friends or other acquaintances offer some information, and more is acquired from books, the internet or other forms of media. As indicated in the literature and described earlier, the internet can be useful or considered to be too technical, depending upon the individual perspective. Personal experiences and the perceived experiences of others were significant sources of knowledge, and provided information about what it is like to become ill, what triggers exist to cause illness, and how one can manage the condition on a day-to-day basis.

The core category identified in this study is *living with a long-term condition*. People make informed decisions in relation to their condition. They decide whether or not to seek medical advice when experiencing symptoms, using past experience as well as other information to aid the decision-making process. They choose whether to continue taking medication, and whether to adopt non-drug treatments. In addition, they decide whether to accept risks and consider their lifestyle behaviours. Considering these experiences from a theoretical perspective, the health belief model (Pender 1987; Noar and Zimmerman 2005) and common sense model of self-regulation (Leventhal et al. 2003) offer reasons for some of the behaviours of these individuals. The literature regarding decision-making, particularly prospect theory (Kahneman and Tversky 1979), is useful as it offers insights into specifically how decisions are made. This study can also offer insights into how these models may be applied to those with a long-term condition.

Some people accepted their condition. This included any uncertainty it created for them and its consequences and implications, including the need to accept responsibility for its management. For those who had experienced a delay in receiving a diagnosis, and particularly those who had become ill as

a result, the past may also need to be accepted. Individuals did not blame themselves for the existence of their condition, but recognised that only they could make decisions about living with and managing it. Some people do not accept their condition and all its nuances. However, a change in individuals' circumstances can cause them to move from acceptance to non-acceptance or vice versa.

Living **with** their condition was possible for some of those interviewed, and this led to it becoming part of their identity. The condition was focused upon only when necessary. People may adopt a changed outlook to life, may acquire professional roles relating to their condition, and may place it in the context of other illnesses they may have or be aware of. The literature offers a variety of concepts which incorporate the ideas of acceptance and well-being in connection with conditions, including harmony and empowerment, and it is possible that the phenomenological themes of body-subject and body-object hold relevance to the study findings. In contrast, other individuals lived **alongside** their condition, which they found difficult to accept. It caused them concern and restricted their activities whilst drawing their attention. For these people, the condition existed separately from the self and was not part of their identity.

Conceptualisation of this process enables a theory to be developed, of how individuals with a long-term condition might learn to live with it. This is presented as:

1. Information and knowledge, including that based on experiences, result in constructs which represent a condition as it exists for that individual; these constructs will differ between people, even those with the same condition.
2. Constructs are used as the basis on which individuals make decisions relating to a range of activities. A feedback loop offers further understanding which may reinforce or update existing constructs, or lead to the formation of new ones.
3. Individuals may accept the condition affecting them. Acceptance of the condition depends on how a person understands and conceptualises it before diagnosis, at diagnosis and post-diagnosis in an ongoing process.

4. Individuals who are knowledgeable about their condition, who are able to make informed decisions and who accept the condition in all its guises may be described as living **with** the condition. For these people, the condition is part of their identity and integrated into their everyday life. This may be contrasted with those for whom the LTC exists **alongside** their self, drawing their attention and causing them to seek information, knowledge, certainty or solutions. For this group, the condition has not become part of the self and their everyday life, but is an unwelcome burden which interrupts their day-to-day life by causing concern and restriction.

Knowledge is acquired through the gathering of information from a variety of sources, which is then amalgamated with knowledge gained from one's experiences. Some information will be gained prior to diagnosis for some people, whilst all will acquire information from the point of diagnosis onwards. The content and extent of knowledge which is considered to be sufficient to meet current needs may differ between individuals; some may feel that they need to know more information, whilst others may be satisfied with only a small amount. Knowledge of the condition may or may not be scientifically correct, particularly where it is based on experience, though it will still influence people's actions.

Making informed decisions requires that individuals make decisions autonomously and that their knowledge, however extensive or limited, contributes to these. Choices become increasingly informed as they continue to be made, as past choices and their outcomes inform future decisions, forming a feedback loop. The extent to which an individual may need to be informed will differ between people. Prospect theory offers a theoretical explanation for the way in which individuals use their knowledge to make decisions.

Acceptance of the condition includes its consequences and implications. Many conditions are uncertain, and past events may not be accepted by those who experienced illness as a result. Changing circumstances may lead to a change in one's acceptance status.



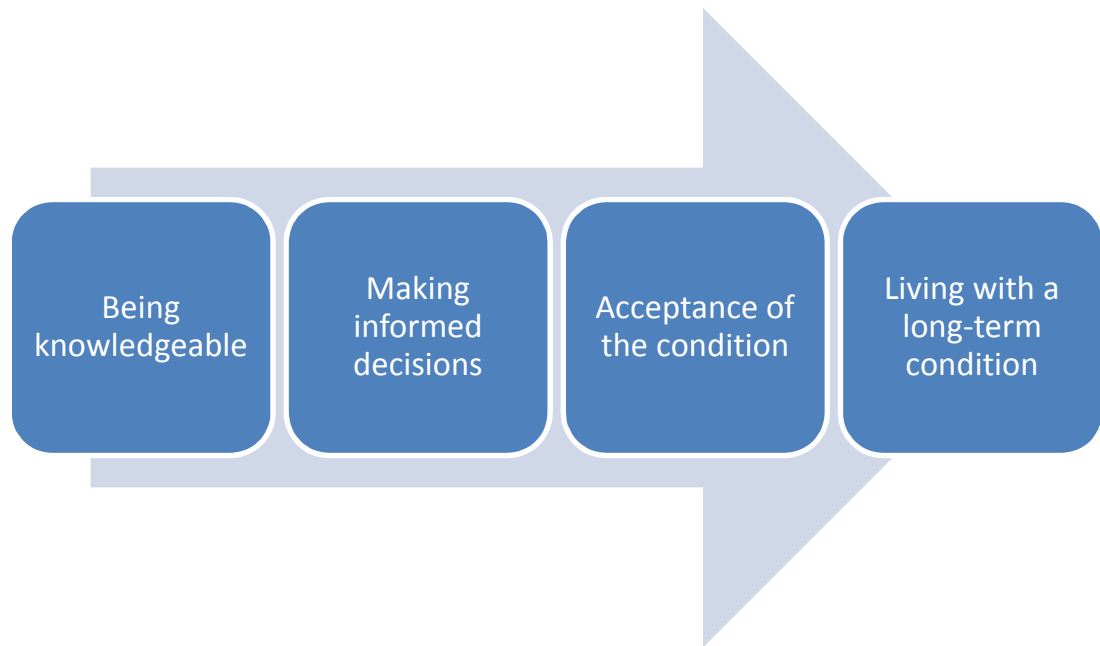
Many people will learn to live with their condition, incorporating it into their identity and their everyday life. They will be knowledgeable about it and confident in making decisions. In contrast, some individuals will exist alongside their condition and will not easily accept it.

For many people, a long-term condition is part of who they are. This was confirmed in the words of a number of those interviewed. The condition is recognised as conferring a risk, but is not considered to be especially serious for much of the time. Those affected are able to recognise times when they may be ill, and are able to make appropriate decisions to medicate or seek treatment. They are also able to make other decisions, such as those regarding treatment, often without a great deal of effort because they are aware of the parameters of what they consider to be acceptable. Any impact on their lives is considered to be acceptable. They will return to consider the condition at pertinent times, for example when needing to make different treatment decisions, but for much of the time it will exist in the background of their lives.

Conversely, for other people, a long-term condition is a burden. It draws their attention, asks questions and causes concern. They are unlikely to feel knowledgeable and do not accept at least one aspect of the condition. In particular, they may struggle with the uncertainty implicit in having a long-term condition whose progression is not necessarily clear, with the consequences of it or with past events which they may struggle to let go of. The condition exists alongside these people and holds a negative meaning.

The theory presented offers an explanation of how those with a long-term condition can learn to live with it, through the acquisition of knowledge, through making informed decisions, and through acceptance. This hypothesis may be used by both individuals who have a long-term condition, and health professionals working with this group of people. Those diagnosed with a condition will be able to use the theory to identify the circumstances under which they will be enabled to live with it. Health professionals will recognise where they may be able to offer help, advice and support to aid patients to learn to live with their condition.

The factors that lead to the theory are shown diagrammatically in Figure 5.



**Figure 5: Diagrammatic representation of the factors which enable individuals to live with a long-term condition**

## **Contribution to knowledge**

Exploration of people's experiences of living with a long-term condition in its entirety has previously been limited, as demonstrated by the literature review presented in chapter two. There has previously been a strong focus on life-changing and particularly life-limiting conditions. Previous research has also tended to study specific aspects of the process, such as medication adherence and compliance, information sources or self-management, rather than the process of how information is collected and contributes to life with the condition. There is little research on thrombophilia, and all of it focuses on a single aspect of having the condition. Although extensive research exists into how people manage asthma, no-one has previously explored this particular topic in connection with the condition. My research has focused on conditions which may exist in the background of one's life on a day-to-day basis, but can lead to life-threatening illness on occasion. These are not life-limiting and are not necessarily considered to be problematic by those affected.

The use of a constructivist grounded theory approach has enabled consideration of the entire experience of having a long-term condition, including the stage before diagnosis and the longer term phases of acceptance of and living with the condition. No known research has previously identified the pre-diagnosis phase as being important for individuals' knowledge of their condition. In addition, no research in my knowledge has indicated the potential for previous negative events to prevent acceptance of a condition. This research attempts to provide the evidence to demonstrate that people can live with a long-term condition, provided they are knowledgeable, able to make decisions about it and accept it. In addition, as a constructivist approach was adopted for this research, it has enabled exploration of what it may mean to have a long-term condition for those affected.

This study provides a theory, grounded in the data collected, relating to how those with a long-term condition can live with it. The theory could be applicable to other long-term conditions, particularly those which include long periods when the condition is stable or invisible, interspersed by acute phases. It may also hold some relevance for other, life-limiting conditions, though, in keeping with the principles of grounded theory, revisions could be required.

## **Implications for Research**

There are a range of implications for further research resulting from this study. This project involved those affected by long-term conditions which can exist in the background of one's life on a day-to-day basis, interspersed with occasional life-threatening incidents of illness. Further research is required to discover whether other individuals with a long-term condition, particularly one which they consider to be problematic, also go through the same process.

I have offered, based on the study findings, an alternative to biographical disruption (Bury 1982) which I designate a 'biographical interruption'. Further research is required to identify whether this phenomenon is peculiar to those with this type of condition, or whether others with more problematic and life-

changing conditions also experience biographical interruptions. It could also be interesting to investigate this concept with other groups outside of healthcare, for example people changing jobs or being made redundant.

Further research is also needed to determine other circumstances which can result in a change of perspective so significant that it alters one's acceptance status, and to discover whether these differ between conditions.

It has been suggested by participants that further support, advice or access to information may help those who are unable to accept their condition, to do so if they wish. Whether any of these options would be successful, in what format they ought to be offered and to whom they should be offered need further investigation. It is possible that acceptance and learning to live with a condition is a personal journey which cannot be achieved through external agency, and so these support options would not be useful. Alternatively, where this cannot be achieved due to a lack of information and lack of confidence in one's ability to discover necessary information oneself, these options may be helpful. It was suggested by one participant that different personality types may be linked to which people were able to live with their condition, and who was unable to do so. This was not considered as part of this study, but offers an interesting topic for future research.

It is not possible, on the basis of a small study such as this, to indicate with any accuracy what proportion of people go through the different aspects of the phases or, importantly, what proportion accept their condition and learn to live with it without any additional support, and how long it takes for this to happen. This study would suggest that a high proportion achieved this over time, but quantitative studies are better placed to measure this and achieve accurate figures.

## **Implications for Healthcare Practice**

There are a number of implications for practice arising from this study. Even when advised that a particular condition is suspected to be causing symptoms, people can be surprised or shocked by a diagnosis. Being

mindful of this could help healthcare professionals to ensure that appropriate support and advice are offered.

A number of participants indicated that they would, or may in future, like ongoing support or information about their condition. In particular, it seemed that many participants did not clearly recall the information they were offered at the point of diagnosis and that the written information provided was not helpful or understandable. Most people in this study also indicated that healthcare professionals left them with unmet information needs. It is possible that information was provided and patients, due to the stressful situation in which they found themselves, forgot it. It may therefore be useful to recall patients a short time after their diagnosis in order to reinforce information. This may provide individuals with confidence that they are knowledgeable about the condition, and help them to live with it. It could also be useful for written information to be revised in conjunction with patients. Individuals in this study indicated that their information needs may change over time and under changing circumstances. It will therefore be of use to patients to know where they can go for further information, for example, that they may revisit their GP either to discuss their condition with them or in order to obtain a referral to specialist services.

The findings of this study indicate that past events, and particularly a missed diagnosis which leads to illness, can cause a lack of acceptance for those with a long-term condition. These can be errors made by one's current healthcare professional, or by previous general practitioners. Where these prevent acceptance, they will cause people to live alongside their condition. Thus it is important for healthcare professionals to be aware of past events, and to deal with these sensitively. Working with patients to deal with their anger or grief over past events could help them to come to terms with and accept these, and thus become able to accept and live with their condition.

Individuals' reactions to their long-term condition and its treatment are based on information and both their own and others' perceived experiences, some of which may have been gained before diagnosis. This knowledge may not conform to the advice offered by health professionals, and so patients will

make choices which appear to be irrational or wrong – but in fact are informed by a different perspective. Understanding the patients' goals and reasons for their decisions could help professionals to find alternative medications, offer information which corrects misunderstandings, or at the very least to help them to recognise that their patients do understand the implications of their condition but that their primary goal lies in getting on with their life. In addition, health professionals may, by spending time with patients, be able to recognise whether individuals have accepted their condition and live with it, or whether one or more aspects is missing. If this is information, they can provide it and so support patients to reach a point of living with their condition.

## **Summary**

This study explored how individuals make sense of their long-term, potentially life-threatening, health condition. The use of a constructivist grounded theory approach enabled the elucidation of a process grounded in the data collected. Based on the study findings, a theory is proposed of how individuals with a long-term condition may learn to live with it through the acquisition of knowledge, informed decision-making and acceptance of the condition. Implications for both further research and for practice arise from this project.

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## Appendix 1: Literature search

Table 1: Literature search terms and databases searched

Search term	Databases searched
living with a long term condition	Cochrane Library Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
experience of long term condition	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
long term condition	Cochrane Library
asthma	Cochrane Library
thrombophilia	Cochrane Library
liv* with asthma	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
liv* with thrombophilia	Cinahl Complete Academic Search Complete Global Health British Nursing Index

	Journals@Ovid Medline Complete ScienceDirect Scopus
asthma and experience	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect (abstract) Scopus
thrombophilia and experience	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
Information and long term condition	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
information and thrombophilia	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
information and asthma	Cinahl Complete Academic Search Complete (abstract) Global Health British Nursing Index

	Journals@Ovid Medline Complete (abstract) ScienceDirect Scopus (information about/regarding/relating to asthma)
wellbeing and asthma	Cinahl Complete Academic Search Complete (abstract) Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus
wellbeing and thrombophilia	Cinahl Complete Academic Search Complete Global Health British Nursing Index Journals@Ovid Medline Complete ScienceDirect Scopus

## **Appendix 2: Participant Letter, Information and Consent Forms – accessed through the NHS**

Version 2 13.08.08



Dear patient,

### **Factors that influence lay understanding of inheriting thrombophilia: a grounded theory.**

You are invited to take part in a study about views of genetics in relation to the blood clotting disorder thrombophilia. This happens when someone's blood is 'stickier' than normal and has an increased tendency to clot inappropriately. There are two aspects to the project. One part involves answering some questions in a face-to-face interview. The other involves your consultation with Dr [X] or Dr [Y] (consultant haematologists) being observed. If you choose to take part in the study, you may choose to be interviewed or observed or both. You may alternatively decline to take part.

If you think you might be interested in getting involved in this study, please read the attached information sheet to find out more. Once you have read the information, please take some time to think about whether you would like to take part. Please feel free to discuss the study with family and/or friends if you wish.

If you decide you would like to take part in this study or require further information, please complete the reply slip at the end of the attached information sheet, and I will contact you at a time convenient to you.

Thank you for taking the time to read this.

Jenny



## **Participant Information - Interviews**

### **Factors that influence lay understanding of inheriting thrombophilia: a grounded theory.**

I am a PhD student carrying out a study looking at people's ideas of the genetics of the blood clotting disorder thrombophilia. You are invited to take part in this project, which will involve you answering some questions in a face-to-face interview.

Here is some information to help you decide whether or not you'd like to be involved. Please take some time to read the following information, and discuss it with friends and family if you wish. Please contact me using the slip below if there is anything that is not clear or if you would like more information. Thank you for reading this.

#### **What is the purpose of the study?**

The purpose of this study is to look at what people from families affected by an inherited blood clotting disorder – thrombophilia – think about genetics. I am not looking specifically for information about genes, but instead I want to talk to people about what it means for them to know that there is a blood clotting disorder in the family.

#### **How much time will the study take?**

I hope to carry out interviews lasting around 60-90 minutes each. I may wish to interview some people in the study more than once, up to a maximum of 3 times over a period of up to 6 months. I won't know who these people may be until I have begun interviewing. Anyone who is asked to take part in further interviews may decline to be interviewed more than once.

#### **Why have I been chosen?**

You are being asked whether you'd like to take part in this study because yourself or a family member has been in contact with Dr [X] or Dr [Y] at [Hospital A] or [Hospital B] regarding the blood clotting disorder thrombophilia. You may or may not have had a test to try to find out whether specific types of this blood clotting disorder are found in your family. You

may or may not have already spoken to a health professional about this. This study plans to explore inherited thrombophilia specifically, so you will not be included if you have a blood clotting disorder which is not inherited or if you are affected by a different blood clotting disorder.

### **Do I have to take part?**

It is up to you to decide whether or not to take part.

If you do decide to take part, you will be asked to sign a consent form and you will be given a copy of both the signed consent form and this information to keep.

If you decide to take part, you are free to change your mind and withdraw from the study at any time without giving a reason. You will also be asked at the start of each interview to verbally confirm that you still consent to taking part in the study. Again, you are free to change your mind and withdraw from the study at any time.

A decision to take part in the study or not to take part, or to withdraw from the study at any time, will not affect the care you receive or your access to any part of the health services.

### **What will happen if I take part?**

If you wish to take part or would like further information then please contact me - Jenny Roddis – using the form on page 4 of this information, indicating when and how you would prefer me to respond.

If you decide to take part in the study, I will arrange to meet with you so that you can sign a consent form. I will also arrange a time convenient to you to meet again to conduct the interview. This may be in your own home or elsewhere, as is convenient to you.

At the interview, which is likely to last between an hour and 90 minutes, you will be asked questions about the blood clotting disorder and genetics and your ideas about these. The interview will be tape recorded so that I do not need to write accurate notes whilst talking to you, and typed up later.

I may wish to interview you again – you are free to decline this if you wish.

### **What are the possible benefits of taking part?**

I hope to find out how people view the genetics of the blood clotting disorder thrombophilia. This information will then be used to help people in a similar position.

### **What are the possible risks of taking part?**

I appreciate that this study combines a number of potentially emotional topics, including blood clotting disorders and family relationships. As a result,

I will be conscious of the risk of you becoming emotional and will offer to halt the interview. You may also ask to halt an interview at any time if you wish. Your care and access to services will NOT be affected whether you do or do not take part in this study.

### **Will my taking part in this study be kept confidential?**

All information I collect about you will be kept confidential and anonymous, subject to law. All data relating to you will be kept in a locked filing cabinet which only I will have access to, and you will be referred to in any conversations or publications relating to this study by a unique reference number. I will not inform either [Hospital A] or [Hospital B] whether or not you took part in interviews for this study. However, the Research Ethics Committee have requested that I inform your G.P. that you are involved in this study, and I will ask for your consent to do so.

### **What will happen to the results of this study?**

The results of this study will help me to understand how people from families affected by this blood clotting disorder view the genetics behind the condition. I hope to use this information to develop a website to help other families in the same position. Also, the results will be written up and published in academic journals within 6 years. You will not be identified in any report or publication.

### **Who is organising the research?**

The research is being organised by Bournemouth University in conjunction with the [Hospital A] and [Hospital B].

### **What is the researcher's connection with the [Hospital A] and [Hospital B]?**

I have a background in genetics and work for Bournemouth University. I am not a clinician and, although I have an honorary contract with both [Hospital A] and [Hospital B], this is only because it's a requirement for this research. As such, I will not be involved in your care in any way and I am not qualified to give you advice about blood clotting disorders, including thrombophilia.

### **Who has reviewed the study?**

This research has been reviewed by [C] Research Ethics Committee.

Contact for further information:  
Jenny Roddis  
Email: [jroddis@bournemouth.ac.uk](mailto:jroddis@bournemouth.ac.uk)  
Telephone: 01202 962785

**Thank you for taking the time to read this information**



**Factors that influence lay understanding of inheriting thrombophilia: a grounded theory.**

**Face-to-face Interview**

Dear Jenny,

I would like further information relating to this study.

Please contact me by (please tick):

Telephone

Email

I would prefer you to contact me at the time/days indicated below (please tick):

Monday to Friday, between 8am and 12 noon

Monday to Friday, between 12 noon and 5.30pm

Monday to Friday, between 10am and 2.30pm

Monday to Friday, after 5.30pm

Weekends, between 8am and 6pm

Weekends, after 6pm

Name:

Telephone number (please provide as appropriate):

Email address (please provide as appropriate):

Signature:

Please return this slip to: Jenny Roddis, School of Health and Social Care,  
Bournemouth University, Royal London House, Christchurch Rd,  
Bournemouth BH1 3LT

**Consent Form - Interviews**

**Factors that influence lay understanding of inheriting thrombophilia: a grounded theory.**

Principal Researcher: Jenny Roddis

Please read each statement and initial the box to confirm that you have done so:

- I confirm that I have read and understand the information sheet dated 14.08.08 (version 3) for the above study
- I understand that my participation in this study is voluntary
- I understand that I am free to withdraw from this study at any time without giving any reason, without my medical care or legal rights being affected
- I understand that I will be asked to give ongoing verbal consent at any subsequent interviews, and may withdraw this at any time without giving any reason, without my medical care or legal rights being affected
- I understand that the researcher holds an honorary contract with the [Hospital A] and [Hospital B] and is a PhD student at Bournemouth University
- I consent to my G.P. being informed that I am taking part in this study
- I understand that all information I provide will be kept confidential and anonymous (subject to legal constraints)
- I understand that any interviews will be tape recorded
- I agree to take part in the above study

Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature
_____	_____	_____

## **Appendix 3: Participant Information and Consent Forms – accessed through a charity**



### **Participant Information**

#### **Factors that influence lay understanding of inheriting thrombophilia: a grounded theory.**

I am a PhD student carrying out a study looking at people's views of the inherited versions of the blood clotting disorder thrombophilia. You are invited to take part in this project, which will involve you answering some questions in an interview (face-to-face or over the telephone or internet, depending on your location and preference).

Here is some information to help you decide whether or not you'd like to be involved. Please take some time to read the following information, and discuss it with friends and family if you wish. Please contact me by telephone, email or post if there is anything that is not clear or if you would like more information. Thank you for reading this.

#### **What is the purpose of the study?**

The purpose of this study is to look at what people from families affected by inherited versions (*Factor V Leiden, Protein C deficiency, Antithrombin deficiency, Prothrombin 20210, Protein S deficiency*) of a blood clotting disorder – thrombophilia – think about the condition. I want to talk to people about what it means for them to know that there is a blood clotting disorder in the family.

#### **Why inherited thrombophilia?**

Both acquired and inherited thrombophilia can lead to blood clots. However, I wish to explore particularly how people experience the condition being inherited in their family, and so only wish to speak to people affected by an inherited form of thrombophilia (*Factor V Leiden, Protein C deficiency, Antithrombin deficiency, Prothrombin 20210, Protein S deficiency*).

#### **How much time will the study take?**

I hope to carry out interviews lasting around 30-90 minutes each. I may wish to interview some people in the study more than once, up to a maximum of 3

times over a period of up to 6 months. I won't know who these people may be until I have begun interviewing. Anyone who is asked to take part in further interviews may decline to be interviewed more than once.

### **Do I have to take part?**

It is up to you to decide whether or not to take part.

If you do decide to take part, you will be asked to sign a consent form and you will receive a copy of both the signed consent form and this information to keep.

If you decide to take part, you are free to change your mind and withdraw from the study at any time without giving a reason. You will also be asked at the start of each interview to confirm that you still consent to taking part in the study. Again, you are free to change your mind and withdraw from the study at any time.

A decision to take part in the study or not to take part, or to withdraw from the study at any time, will not affect the care you receive or your access to any part of the health services.

### **What will happen if I take part?**

If you wish to take part or would like further information then please contact me - Jenny Roddis – my details are provided on page 3 of this document.

If you decide to take part in the study, I will arrange for you to receive and sign a consent form, and return this to me. I will also arrange a time convenient to you to conduct the interview. This may be by telephone or over the internet, or, if you are local to Bournemouth, face-to-face in your own home or elsewhere, as is convenient to you.

During the interview, which is likely to last between 30 and 90 minutes, you will be asked questions about the blood clotting disorder and your experiences of living with thrombophilia. Telephone and face-to-face interviews will be tape recorded so that I do not need to write accurate notes whilst talking to you, and typed up later.

I may wish to interview you again – you are free to decline this if you wish.

### **What are the possible benefits of taking part?**

I hope to find out how people view the inherited form of the blood clotting disorder thrombophilia. This information will then be used to help people in a similar position.

### **What are the possible risks of taking part?**

I appreciate that this study combines a number of potentially emotional topics, including blood clotting disorders and family relationships. As a result,

I will be conscious of the risk of you becoming emotional and will offer to halt the interview. You may also ask to halt an interview at any time if you wish. Your care and access to services will NOT be affected whether you do or do not take part in this study.

### **Will my taking part in this study be kept confidential?**

All information I collect about you will be kept confidential and anonymous, subject to law. All data relating to you will be kept in a locked filing cabinet which only I will have access to, and you will be referred to in any conversations or publications relating to this study by a unique reference number. You are free to discuss your involvement in the study with family and friends if you wish.

### **What will happen to the results of this study?**

The results of this study will help me to understand how people from families affected by this inherited blood clotting disorder view the condition. I hope to use this information to develop a website to help other families in the same position. Also, the results will be written up and published in academic journals within 6 years. You will not be identified in any report or publication.

### **Who is organising the research?**

The research is being organised by Bournemouth University.

Who has reviewed the study?

This research has been reviewed by Bournemouth University School of Health and Social Care Research Ethics Committee.

Contact for further information:

Jenny Roddis

Email: [jroddis@bournemouth.ac.uk](mailto:jroddis@bournemouth.ac.uk)

Telephone: 01202 962785/07592755420

Post: School of Health and Social Care, Bournemouth University, Royal London House, Christchurch Road, Bournemouth, Dorset BH1 3LT

### **Thank you for taking the time to read this information**

#### **Contact details of supervisory team:**

Professor Immy Holloway:

School of Health and Social Care, Bournemouth University,

Royal London House, Christchurch Road,

Bournemouth BH1 3LT

01202 962168

[ihollowa@bournemouth.ac.uk](mailto:ihollowa@bournemouth.ac.uk)

Dr Carol Bond:  
School of Health and Social Care, Bournemouth University,  
Bournemouth House, Christchurch Road,  
Bournemouth BH1 3LT  
01202 961748  
[cbond@bournemouth.ac.uk](mailto:cbond@bournemouth.ac.uk)

Professor Kate Galvin:  
School of Health and Social Care, Bournemouth University,  
Bournemouth House, Christchurch Road,  
Bournemouth BH1 3LH  
01202 962167  
[kgalvin@bournemouth.ac.uk](mailto:kgalvin@bournemouth.ac.uk)

**Consent Form - Interviews**

**Factors that influence lay understanding of inheriting thrombophilia: a grounded theory.**

Principal Researcher: Jenny Roddis

Please read each statement and add your initials next to each to confirm that you have done so, and sign below:

I confirm that I have read and understand the information sheet dated 05.05.11 (version 4) for the above study

I understand that my participation in this study is voluntary

I understand that I am free to withdraw from this study at any time without giving any reason, without my medical care or legal rights being affected

I understand that I will be asked to give ongoing verbal consent at any subsequent interviews, and may withdraw this at any time without giving any reason, without my medical care or legal rights being affected

I understand that the researcher is a PhD student at Bournemouth University

I understand that all information I provide will be kept confidential and anonymous (subject to legal constraints)

I understand that any interviews will be tape recorded

I agree to take part in the above study

Name of participant

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of researcher

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Appendix 4: Advertisement, Participant Information  
and Consent Forms – accessed through local  
networks**



**DO YOU HAVE THROMBOPHILIA (AN  
INCREASED RISK OF BLOOD CLOTS)?**

**ARE YOU AGED 18 OR OVER?**

**WOULD YOU BE INTERESTED IN  
TAKING PART IN A RESEARCH STUDY  
TO DISCUSS YOUR EXPERIENCES?**

If so, please contact Jenny Roddis, at Bournemouth University, for more  
information

Email: [jroddis@bournemouth.ac.uk](mailto:jroddis@bournemouth.ac.uk)

Telephone: 01202 968258 or 07592755420





DO YOU HAVE ASTHMA?

ARE YOU AGED 18 OR OVER?

WOULD YOU BE INTERESTED IN  
TAKING PART IN A RESEARCH STUDY  
TO DISCUSS YOUR EXPERIENCES?

If so, please contact Jenny Roddis, at Bournemouth University, for more  
information

Email: [jroddis@bournemouth.ac.uk](mailto:jroddis@bournemouth.ac.uk)

Telephone: 01202 968258 or 07592755420

## **Participant Information - Interviews**

### **Living with a long-term condition: a grounded theory study**

I am a PhD student carrying out a study looking at people's views of living with a long-term condition. The two conditions being looked at are thrombophilia and asthma. You are invited to take part in this project, which will involve you answering some questions in an interview (face-to-face or over the telephone or internet, depending on your location and preference).

Here is some information to help you decide whether or not you'd like to be involved. Please take some time to read the following information, and discuss it with friends and family if you wish. Please contact me by telephone, email or post if there is anything that is not clear or if you would like more information. Thank you for reading this.

#### **What is the purpose of the study?**

The purpose of this study is to look at what people who are affected by asthma or thrombophilia - a blood clotting disorder - think about the living with the condition. I want to talk to people about where they got information about their condition, and what effects this may have on their view of the condition. I would also like to discuss anything else they think is important in shaping their view of having asthma or thrombophilia.

#### **Why asthma and thrombophilia?**

This study set out to explore people's views of thrombophilia, as very few researchers had looked at this before. I would like to interview more people with thrombophilia, to add to the information I have collected. I would also like to see whether the ideas that have arisen relating to thrombophilia also

apply to another condition. Asthma has been chosen as it may exist in the background of someone's life for much of the time, with people not being affected by their asthma very much, and yet may also lead to life-threatening illness.

### **How much time will the study take?**

I hope to carry out interviews lasting around 30-90 minutes each. I may wish to interview some people in the study more than once, up to a maximum of 3 times over a period of up to 6 months. I won't know who these people may be until I have begun interviewing. Anyone who is asked to take part in further interviews may decline to be interviewed more than once.

### **Do I have to take part?**

It is up to you to decide whether or not to take part.

If you do decide to take part, you will be asked to sign a consent form and you will be given a copy of both the signed consent form and this information to keep. If you decide to take part, you are free to change your mind and withdraw from the study at any time without giving a reason. You will also be asked at the start of each interview to confirm that you still consent to taking part in the study. Again, you are free to change your mind and withdraw from the study at any time.

A decision to take part in the study or not to take part, or to withdraw from the study at any time, will not affect the care you receive or your access to any part of the health services.

### **What will happen if I take part?**

If you wish to take part or would like further information then please contact me - Jenny Roddis – my details are provided on page 3 of this document.

If you decide to take part in the study, I will arrange for you to receive and sign a consent form, and return this to me. I will also arrange a time

convenient to you to conduct the interview. This may be by telephone or over the internet, or, if you are local to Bournemouth, face-to-face in your own home or elsewhere, as is convenient to you.

During the interview, which is likely to last between 30 and 90 minutes, you will be asked questions about how you got information about your condition (either asthma or thrombophilia) and your experiences of living with it.

Telephone and face-to-face interviews will be tape recorded so that I do not need to write accurate notes whilst talking to you, and typed up later.

I may wish to interview you again – you are free to decline this if you wish.

### **What are the possible benefits of taking part?**

I hope to find out how people get information about and view life with asthma and thrombophilia. This information will then be used to help people with long-term conditions such as thrombophilia and asthma. One of the people interviewed to date has said that she enjoyed talking to me about her experiences of having thrombophilia.

### **What are the possible risks of taking part?**

I appreciate that this study combines a number of potentially emotional topics, including living with a long-term condition, having asthma attacks and having blood clots. As a result, I will be conscious of the risk of you becoming emotional and will offer to halt the interview. You may also ask to halt an interview at any time if you wish. Your care and access to services will NOT be affected whether you do or do not take part in this study.

### **Will my taking part in this study be kept confidential?**

All information I collect about you will be kept confidential and anonymous, subject to law. All data relating to you will be kept in a locked filing cabinet which only I will have access to, and you will be referred to in any conversations or publications relating to this study by a unique reference

number. You are free to discuss your involvement in the study with family and friends if you wish.

### **What will happen to the results of this study?**

The results of this study will help me to understand how people with asthma and thrombophilia, both of which are examples of long-term conditions, view their condition. The results will be written up and published in academic journals within 6 years. You will not be identified in any report or publication.

### **Who is organising the research?**

The research is being organised by Bournemouth University.

### **Who has reviewed the study?**

This research has been reviewed by Bournemouth University School of Health and Social Care Research Ethics Committee and NRES Committee South Central – Southampton A.

### **Contact for further information:**

Jenny Roddis

Email: [jroddis@bournemouth.ac.uk](mailto:jroddis@bournemouth.ac.uk)

Telephone: 01202 968258

Post: School of Health and Social Care, Bournemouth University, Royal London House, Christchurch Road, Bournemouth, Dorset BH1 3LT

**Thank you for taking the time to read this information**

### **Contact details of supervisory team:**

Professor Immy Holloway:

School of Health and Social Care, Bournemouth University,  
Royal London House, Christchurch Road,  
Bournemouth BH1 3LT

01202 962168; [ihollowa@bournemouth.ac.uk](mailto:ihollowa@bournemouth.ac.uk)

Dr Carol Bond:

School of Health and Social Care, Bournemouth University,  
Royal London House, Christchurch Road,  
Bournemouth BH1 3LT

01202 961748; [cbond@bournemouth.ac.uk](mailto:cbond@bournemouth.ac.uk)

Professor Kate Galvin:

Faculty of Health and Social Care, University of Hull,  
Hull HU6 7RX

01482 463336; [k.t.galvin@hull.ac.uk](mailto:k.t.galvin@hull.ac.uk)

## Consent Form

### Living with a long-term condition: a grounded theory study

Principal Researcher: Jenny Roddis

Please read each statement and add your initials next to each to confirm that you have done so, and sign below:

- I confirm that I have read and understand the information sheet dated 3.10.13 (version 5) for the above study
- I understand that my participation in this study is voluntary
- I understand that I am free to withdraw from this study at any time without giving any reason, without my medical care or legal rights being affected
- I understand that I will be asked to give ongoing verbal consent at any subsequent interviews, and may withdraw this at any time without giving any reason, without my medical care or legal rights being affected
- I understand that the researcher is a PhD student at Bournemouth University
- I understand that all information I provide will be kept confidential and anonymous (subject to legal constraints)
- I understand that any interviews will be tape recorded
- I agree to take part in the above study

Name of participant

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of researcher

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Appendix 5: Risk Assessment

Bournemouth University **General Risk Assessment Form** Your Reference No:

Notes:

Before completing this form, please read the associated guidance on 'I: Health & Safety/Public/Risk Assessment/[Guidance](#)'.

Use this form for all risks except from hazardous substances, manual handling & Display Screen Equipment (specific forms are available for these).

If the risk is deemed to be 'trivial' there is no need to formally risk assess.

All completed forms must give details of the person completing the assessment.

Risk assess the activity with its present controls (if any) -then re-assess if action is to be taken and after further controls are put in place.

The completed form should be kept within the School/Service/Department.

1. Describe the Activity being Risk Assessed:

Interviews to be undertaken as part of PhD project – interviews will be undertaken by Jennifer Roddis in participant's own homes (though some may take place on University premises if own home is inconvenient).

2. Location(s): Participant's own homes – various. Likely to be [county] and surrounding areas.

3. Persons at potential Risk (e.g. Specific Staff only, General Staff, Students, Public etc.):  
Jennifer Roddis and participants only

4. Potential Hazards i.e. What Could Happen?(NB: List hazards without considering any existing controls):

Potential hazards relate to Jennifer's personal safety and potential distress and the potential for participants to become distressed.

5. Control Measures Already In Place:

To ensure Jennifer's safety, the following precautions will be undertaken:

- All interviews will be booked in advance, so will take place at a pre-arranged time and place. A colleague at BU will be made aware of these appointments, and any changes.
- A colleague will be informed when Jennifer arrives at an interview so that they know it is due to begin, and they will also be informed of the time it is anticipated the interview will finish.
- The colleague will be contacted to inform them that the interview has been completed.
- Jennifer will have a mobile phone with her at all times, and will leave it on (though silent).
- Jennifer will inform the participant at the start of the interview that the interview will be terminated if at any time she feels intimidated, threatened or in any personal danger.

In order to reduce the risk of causing distress to participants, the following measures will be put in place:

- Participants will be made aware of the nature of this research, of both their own and Jennifer's role and of their right to withdraw consent at any time
- All participation will be confidential and participants' names will not be disclosed at any time
- Adequate time will be allocated for the interview to be conducted
- Participants will be asked to give their verbal consent to participate at the start of each interview, in addition to their signed informed consent
- Participants will be informed at the start of the interview that, if they become distressed at any point in the interview, they will be asked whether they would like to continue.
- Participants will be provided with the contact details of a counsellor (etc) in case of distress resulting from the interview
- Participants will be asked at the start of interviews whether they are happy for Jennifer to record the

interview and, as and when appropriate, take notes

6. Standards to be Achieved: (if necessary, refer to Guidance on Risk Assessment)

7. Are the risks adequately controlled (bearing in mind 4. & 5.)? **Write 'Yes' or 'No': Yes**

If **Yes**, Step 8: Ensure that those affected are informed of the Risks and Controls:  
 Confirm how you have done this (or intend to do this) e.g. written instructions: Jennifer has completed this form and so is aware of the risks affecting her. Participants will be given written and verbal information before agreeing to be involved in the study and at the start of each interview. Then, complete boxes below and the assessment is finished until the review date(s):

9. Person(s) Who did Assessment:	Jennifer Roddis	10. Date:	16.5.07	11. Review Date:	
12. Checked By: (as necessary)		13. Date:		14. Review Date:	

If **No** to Qu 7, go to next section and estimate 'Residual Risk'.

Estimating the Residual Risk:  
 15. Choose a category that best describes the degree of harm which could result from the hazard, then choose a category indicating what the likelihood is that a person(s) could be harmed. Check only **ONE** box within the table which matches both of your choices.

Degree of harm likelihood	Slightly Harmful <i>(e.g. minor injuries such as minor cuts/bruises not always requiring first aid)</i>	Harmful <i>(e.g. serious but short-term injuries such as broken bones or curable disease)</i>	Extremely Harmful <i>(e.g. would cause fatality, major long-term injuries or incurable disease)</i>
<b>Highly Unlikely</b>	Trivial Risk <input type="checkbox"/>	Tolerable Risk X	Moderate Risk <input type="checkbox"/>
<b>Unlikely</b>	Tolerable Risk <input type="checkbox"/>	Moderate Risk <input type="checkbox"/>	Substantial Risk <input type="checkbox"/>
<b>Likely</b>	Moderate Risk <input type="checkbox"/>	Substantial Risk <input type="checkbox"/>	Intolerable Risk <input type="checkbox"/>

16. Then note the advice below on suggested action and timescale

Residual Risk Level	Action and Timescale
Trivial Risk <input type="checkbox"/>	No action is required and no documentary records need to be kept.
Tolerable Risk <input type="checkbox"/>	No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained
Moderate Risk <input type="checkbox"/>	Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures.
Substantial Risk <input type="checkbox"/>	Work should not be started until the risk has been reduced. Considerable resources may have to be allocated to reduce the risk. Where the risk involves work in progress, urgent action should be taken.
Intolerable Risk <input type="checkbox"/>	Work should not be started or continued until the risk has been reduced. If it



	is not possible to reduce the risk even with unlimited resources, work has to remain prohibited.
--	--

17. If 'Moderate' 'Substantial' or 'Intolerable': What New Control Measures are to be Considered to reduce risk?  NA	18. Referred to:	19. On Date:
---	------------------	--------------

20. Ensure those affected are informed of the Risks & Controls Confirm how you have done this (or intend to do this) e.g. written instructions: please see above					
---	--	--	--	--	--

21. Person(s) Who did Assessment:	Jennifer Roddis	22. Date:	16.5.07	23. Review Date:	
24. Checked By: (as necessary)		25. Date:		26. Review Date:	

## Appendix 6: Demographic information collected from participants

Participant	Male/Female	Age	Internet access?	Highest qualification	Condition
P081	Female	51-65	No	None	Thrombophilia
P083	Male	36-50	Yes	GCSE	Thrombophilia
P091	Female	36-50	Yes	CSEs and GCEs	Thrombophilia
P093	Male	36-50	Yes	HND	Thrombophilia
P094	Male	51-65	Yes	O-levels/City and Guilds	Thrombophilia
P111	Female	51-65	Yes	Works for relevant charity	Thrombophilia
P112	Female	25-35	Yes	Degree	Thrombophilia
P113	Male	51-65	Yes	Degree	Thrombophilia
P121	Female	36-50	Yes	Degree	Thrombophilia
P143	Female	36-50	Yes	Masters	Thrombophilia
P131	Male	51-65	Yes	PhD	Asthma
P141	Female	25-35	Yes	Masters	Asthma
P142	Female	25-35	Yes	Degree/equiv	Asthma
P145	Male	36-50	Yes	Degree	Asthma
P146	Female	36-50	Yes	PhD	Asthma
P147	Male	36-50	Yes	PhD	Asthma

## Appendix 7: Interview Guide Examples

### Version 1:

Tell me about thrombosis in your family

Tell me about inheritance/genetics of thrombosis

What does having thrombosis in the family mean to you?

(May have been answered in Q1 - in which case expand) How did you learn about thrombosis being in your family?

Did you look for/seek out other information after initially finding out?

This could go 2 ways - if they answer yes:

Where did they look for info?

Where did they get any info?

When did they look for info?

What was most useful info? What was least useful info? - Can you tell me about the info you found?

if they answer no:

Why?

What did you do with the info you already had?

Did you already know anything about genetics/inheritance before learning about the inherited thrombophilia in your family? What did you know? When and where was this gained?

Did you give anyone else info about thrombosis? What was important about that info and that person?

What do you think is most important info about inherited thrombophilia to give to families learning they are affected?

Is there anything else you think I should know about how you view thrombophilia genetics?

Is there anything you'd like to ask me?

### Version 9 (similar questions were included in the guide for those with asthma):

*(Diagnosis and story)*

Tell me about your life with thrombophilia

How was thrombophilia diagnosed (tests carried out)? Did the tests/diagnosis feel out of your control? Were you informed that thrombophilia was suspected before tests carried out?

Did you know anything about thrombophilia before tests were carried out/ before thrombophilia was suspected?

Who first suspected that you may have thrombophilia?

How did you feel about the diagnosis of thrombophilia? Did you believe it?

Were there any missed opportunities for diagnosis?

Did you feel your GP took your/your parents' concerns seriously re: original diagnosis?

What do you think caused you to get thrombophilia/thrombosis originally?

When you realised how serious the condition (thrombosis) was, how did you feel? Any resulting actions?

How serious do you feel thrombophilia is - meaning of this

What do you believe caused thrombosis on this occasion specifically? Why?

You mention .... symptoms. Tell me more.  
 What made you seek advice about these symptoms but not those?  
 Do you take any medication for thrombophilia-what? as prescribed?  
 why/not? how do you feel about it?  
 Did you ever question whether you should take/continue taking your  
 medication  
 How do you feel about taking the prescribed medication/behaving as  
 advised?  
 You mention that you don't take your medication as prescribed. Please can  
 you tell me more? At what point did you stop taking them as prescribed?  
 You mention that you take medication as prescribed but don't do .... Can you  
 tell me more?  
 How would you approach any situation where your medication needs may  
 change? would this depend on what you were prescribed?  
 Have you experienced any serious thrombophilia/thrombosis incidents?what  
 happened,how did you feel,what medication did you take,what was the  
 outcome-can you tell me about any serious thrombotic events/attacks you  
 have experienced?  
 What is life with thrombophilia like on a day-to-day basis?  
 What impact does thrombophilia have on you/your life?  
 Have you made any changes to your lifestyle as result of having  
 thrombophilia? Eg flights, physical activity etc  
 What about preventative measures such as the heparin jab?  
 Does your thrombophilia affect work or school? other activities? how does  
 that make you feel?  
 Pick up on anything about acceptance-do you feel you have accepted having  
 thrombophilia?  
 Is asthma just something that exists as part of you, don't accept as that  
 involves a process...  
 How do you feel about living with thrombophilia?

*(Information and knowledge)*

Where did you get info from?  
 Did you look for info?  
 Did you ask others for info?  
 Did you see any info about thrombophilia in the media? Did this have any  
 effect?  
 Were you aware of others having thrombophilia? What effect did this have on  
 you?  
 Were you satisfied with the info you received from gp/nurse?  
 Do you have ongoing followup for your thrombophilia? Who deals with this,  
 what does it involve?  
 How do you feel about health professionals/ the way they are with you in  
 connection with your thrombophilia?  
 Do you feel you can discuss your thrombophilia with others? who,why/not?  
 Was any info/source more/less useful? Did different sources reinforce  
 knowledge? Was any particular experience more useful than others?  
 Do you feel there are circumstances when your info needs might change?  
 How would you deal with this?  
 How do you feel about the knowledge you have of thrombophilia?

Did you ever have a moment of recognising this is thrombophilia?  
Do you have any unmet info needs?  
What does having thrombophilia mean to you? Has this changed over time?  
Is there anything particular you feel you don't know? Anything you feel you should know but don't?  
Is there anything you wish you'd been told sooner?  
Is there anything you think I should know? Is there anything you'd like to ask me?

Phrases to use

Tell me about .... Thoughts, feelings re:  
Can you describe....  
How have ? changed since?  
What has changed or happened since  
Tell me about the effect that had on you  
Does ? stand out in your mind?  
Who has been more helpful throughout ? experience?  
Has any organisation been particularly helpful throughout ? experience?

Struck by/fascinated by use of ?  
You used ? – can you tell me a bit more about that?  
When you say  
You mean by that?  
Can I come back to you  
Inherited?