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**PARTICIPATION IN BOWEL CANCER  
SCREENING: A QUALITATIVE  
EXPLORATION OF THE FACTORS  
INFLUENCING PARTICIPATION AND  
UPTAKE**

**IJEOMA PRISCA AZODO**

**PhD**

**2013**

# **PARTICIPATION IN BOWEL CANCER SCREENING: A QUALITATIVE EXPLORATION OF THE FACTORS INFLUENCING PARTICIPATION AND UPTAKE**

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A thesis submitted in partial fulfilment of  
the requirements of the University of  
Northumbria at Newcastle for the  
degree of Doctor of Philosophy

Research undertaken in the Faculty of  
Health and Life Sciences and in  
collaboration with the North East  
Yorkshire and the Humber Quality  
Assurance Reference Centre

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# Abstract

## Introduction

Bowel cancer is major global public health problem. In the United Kingdom, it is the third most common cancer in men and women and second major cause of cancer deaths. It has been suggested that the risk of bowel cancer deaths can be reduced by 16% through regular bowel screening. However, screening uptake remains low. This research explored factors influencing participation in the NHS bowel cancer screening programme, specifically ‘the faecal occult blood test (FOBt)’ in the North East, Yorkshire and the Humber, (NEYH) regions.

## Methodology

Drawing on grounded theory, (GT) a qualitative research approach enabled the development of an understanding of participants’ experience of the FOBt and the processes involved in the choices they made. Twenty-six research participants were recruited through the bowel cancer screening hub in accordance with ethical approval. Data collection was by semi-structured, face-to-face interviews. Analysis was done using grounded theory techniques of constant comparative method and theoretical sampling aided by Nvivo and mind genius software.

## Findings

Awareness of the FOBt prior to screening invitation was found to be low. Knowledge of bowel cancer seemed to come mostly from past personal experience and family history. Decisions to participate in the FOBt were largely influenced by three main themes: Social contexts such as demographic, cognition and cultural issues; Knowledge and awareness; and Practicalities associated with obtaining samples for FOBt. Knowledge and awareness seemed to be a key influence in participation and pivotal to social contexts and practicalities.

## Discussion

Screening was viewed positively by all participants particularly in relation to health protection. Within the social contexts and practicality issues, there are facilitators and potential barriers. The interactions of social and practical contexts tend to dissuade people from participating in the FOBt. However, knowledge and awareness seem to mediate the two in such a way as to encourage people to participate. A tentative explanatory model called “awareness-led behaviour model” was developed and appears to have commonalities with the health belief model typically used to explain health behaviours. This study is one of the few studies to investigate factors affecting uptake of the NHSBCSP in the NEYH. The results obtained in this study are likely to have high policy and practice importance as they represent user-focused perspectives. Recommendations and implications for further research, policy, practice and education are offered in the concluding chapter.

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## Acronyms

BC	Bowel cancer
BCSP	Bowel cancer screening programme
FOBt	Faecal occult blood test
GT	Grounded theory
HBM	Health belief model
IPA	Initial project approval
NEYH	North East Yorkshire and Humber
NHS	National Health Service
QUARC	Quality assurance reference centre
R&D	Research and development
REC	Research ethics committee
SCT	Social cognitive theory
SI	Symbolic interactionism
WHO	World health organisation
UKNSC	UK National Social Marketing Centre

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Above all my profound gratitude goes to the Almighty God who gave me the good health and the strength to undertake this research.

## Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my work. I also confirm that this work fully acknowledges opinions, ideas and contributions from work of others. The work was done in collaboration with the North East Yorkshire and the Humber Quality Assurance Reference Centre for cancer screening (NEYHQARC).

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Research Ethics Committee and County Durham and Tees Valley NHS Research Ethics committee

Name: Azodo, Ijeoma Prisca

Signature:

Date:

Word count: 80, 522

# Chapter 1

## Introduction

### 1.1. Chapter overview

This chapter begins by introducing the researcher and the background to her interest in the research topic. This is followed by a description of the purpose of this doctoral study and a brief introduction of the National Health Service bowel cancer screening programme (NHSBCSP) which set the study in context. The rationale for undertaking this study and the general aim of this study are also outlined. The chapter ends with an overview of the chapters that make up the thesis.

### 1.2. Researcher's Background

The first person will be used to introduce myself instead of the academic convention of the third person. I came into the health profession from economics background as a result of my keen interest in healthcare. After qualifying and working as a nurse in different areas of nursing which spanned from provision of evidence based care to acutely ill patients and chronic health problems, my passion for health protection and promotion, disease prevention, general population health and wellbeing as well as evidence for underpinning practice grew strongly. Undertaking a master's degree in public health took my passion to a profound level. During the master's study, I was exposed among other things to public health policies and interventions, epidemiology and health protection and research methods. This extended my appreciation of screening from a personal to a professional level; as a valuable intervention for protecting and preserving health which should be underpinned by evidence such as this research study. It has been identified that research topic is often suggestive of professional experience and interest, (Strauss & Corbin, 1990). Indeed, researching a topic of interest has kept me motivated and the study alive throughout the whole process.

My position and background may have the potential to affect data collection and analysis. However, I feel that data not been affected. This is because the study

followed grounded theory techniques such as constant comparative analysis and theoretical sampling. These put researchers under check in relation to their own bias and help to make sure that data is not forced. In addition, the NHS bowel cancer screening is operated on the principle of informed choice. People are given necessary information to aid their decision. As a nurse and being aware of this informed decision making, I tried not to be seen an advocate of screening but as a researcher exploring people's views and experiences about the FOBt. This was one of the reasons why I chose semi structured interview which could enable the interviewee to express their views without leading.

### **1.3. Purpose of study**

This PhD thesis presents a grounded theory study carried out to explore factors influencing participation in the NHSBCSP in the North East, Yorkshire and the Humber, (NEYH) regions. The study product - 'awareness-led behaviour model' provides a tentative contextualised explanatory model for understanding the factors influencing the decisions to participate or not in the NHSBCSP from service user experiences and perspectives. The crucial goal of this study is to generate possible knowledge and insights that can assist in understanding these factors. Also to understand how improvements if necessary could be made to enhance uptake, screening services and the wider public health agenda. This is important in alleviating the overall burden of bowel cancer, (BC).

### **1.4. Background to the National Health Service Bowel Cancer Screening Programme, (NHSBCSP)**

The NHSBCSP is a population wide screening service introduced in July 2006 in England following a randomised controlled trial and a series of pilot programmes, (Public Health England, 2013). Screening is offered to all men and women between 60 to 74 years old every two years. It was initially targeted at those between 60 and 69 years old and later extended to 74 years in 2010. The programme is in its third round. BC is more prevalent in people over the age of 60; about 8 out of 10 people diagnosed with BC are over the age of 60, (Public Health England, 2013). Screening looks for early signs of a disease in people who do not have symptoms (asymptomatic individuals). Therefore, the aim of the NHSBCSP is early detection of BC at a stage when treatment is

more likely to be effective, (Cancer Research UK, 2013a) in order to reduce BC deaths, (NHSBCSP, 2008). There are two main ways for detecting BC. One is testing for blood in the stool using the FOBt and the other is by examining the inside of the bowel using special scope with a camera at the end, (colonoscopy and sigmoidoscopy). This doctoral study focuses on the first type of screening method, the FOBt, which is a home test kit.

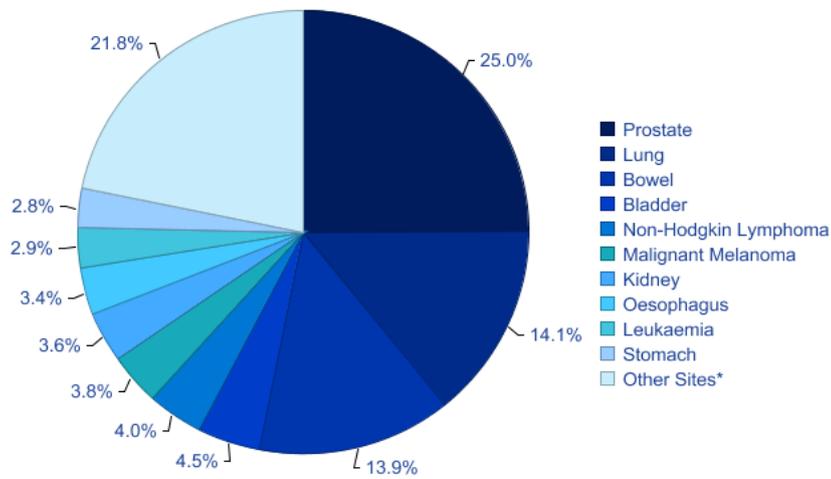
The English BCSP uses a guaiac- based FOBt, (gFOBt) rather than an immunochemical test, (iFOBt), (Halloran, 2009). The gFOBt is ten times cheaper than the iFOBt but with lower analytical sensitivity and specificity than the iFOBt, (Halloran, 2009). However, the iFOBt loses clinical sensitivity in high temperature making it necessary to repeat the tests to get a valid result as was the case in Italy, Netherlands and Australia, (van Rossum et al., 2009). The FOBt is not a diagnostic test but helps to identify suspicious signs for diagnostic investigations.

The BCSP is delivered nationally via five programme hubs, (Midlands & the North West, Southern, London, Eastern and the North East) who work in partnership with the screening centres attached to them. Each programme hub covers a geographical area of health regional clusters and relates to one local service provider. The main roles of each programme hub are to: manage invitations for the screening programme; provide a telephone helpline for invitees; dispatch and process test kits; send test result letters to patients and notify GPs; book the first appointment at a specialist screening practitioner-led clinic for patients with an abnormal test result; work with screening centres to ensure that the programme is provided in accordance with national standards, (NHSBCSP, 2008). Screening kits are automatically sent out to people in the age range. Individuals participate in the screening programme by providing 2 stool samples per bowel motion on three different occasions making a total of six samples and returning it by post to the hub for testing. The test identifies any hidden blood in the stool which may suggest BC. Test results are sent to patients within two weeks explaining the result and further steps to take if necessary. A normal result means no further action but another screening invitation in two years' time. Unclear result means a retest while an abnormal result is referred for a diagnostic test such as colonoscopy. The local screening centres provide specialist screening clinics and diagnostic investigations for

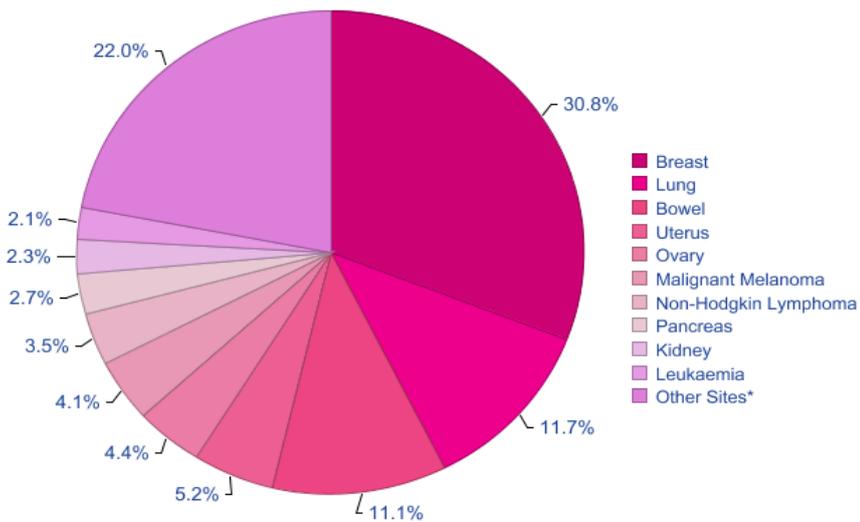
individuals with abnormal FOBt result who require further investigation. BC screening is deemed important because of many reasons:

- Even though BC deaths in the UK fell from 19,958 in 1992 to 16,007 in 2007, BC is still the third most common cancer (after prostate and lung) in men, (figure 1.1) and women (after breast and lung), (figure 1.2) and the second major, (after lung) cause of cancer deaths in both gender (Figure 1.3), (Halloran, 2009; Cancer Research UK, 2012; 2013b; Office for National Statistics, 2012) making it the fourth most common cancer. BC is also among the three most common cancers globally, (WHO, 2003).
- The life time risk of developing BC is about 1:14 in men and 1:19 in women (Cancer Research UK, 2010) with around 35,000 diagnoses and 16,000 deaths per annum.
- Approximately 1 in 20 people in the UK will develop BC during their life time.
- UK BC incidence is close to the average for all European countries. The five year survival rate currently around 47%, (Coleman et al., 2008) is below other EU counterparts, (Office for National Statistics, 2003, Berrino et al., 2007).
- The annual cost of treating bowel cancer to the NHS is over £300 million and this includes surgical, adjuvant and palliative care, (Macafee et al., 2006).
- However, it has been shown that regular BC screening using the FOBt can reduce the risk of BC death, (Cancer Research UK, 2013a).
- Studies including randomised controlled trials have indicated that the risk of dying from BC can be reduced by 16% through regular bowel screening using the FOBt, (Hardcastle et al., 1996; Hewitson et al., 2007; 2008). This indicates that mortality and morbidity could be prevented or minimised by early detection of cancer through screening. BC deaths could be reduced by 20,000 over the next twenty years; achievable only through uptake by at least 60% of the target population, (Cancer Research UK, 2007).

**Figure 1.1: The ten most common cancers in men in the UK, 2010**

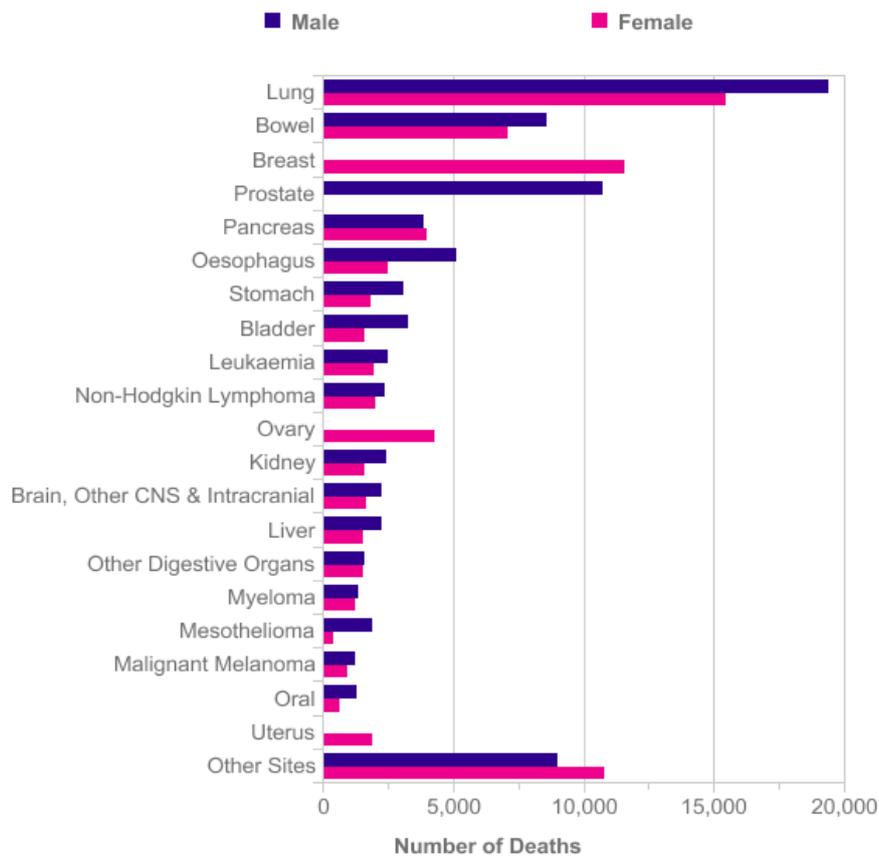


**Figure 1.2: The ten most common cancers in women in the UK, 2010**



(Cancer research UK, 2012)

**Figure 1.3: Cancer mortality statistics, 2010**



Despite the overall burden of BC to the NHS and affected individuals and the benefits of screening, uptake in the screening programme has remained low, below the government’s 60% target, (Alexander & Weller, 2003; Weller et al., 2006; 2007; Taskila et al., 2009; Moss et al., 2012;). A major challenge to screening seems to be low participation and uptake by the invited population particularly in more socially deprived areas, by men and by ethnic minorities, (Alexander & Weller, 2003; Weller et al., 2006; Moss et al., 2012). In the North East, Yorkshire and Humber region, the uptake of the NHSBCS (FOBt) in the three rounds so far: February 2007 to January 2009, February 2009 to January 2011 and February 2011 to January 2013 were 54.37%, 57.84% and 57.89% respectively. This represents an average of 56.66% (unpublished data from the North East bowel cancer screening hub). Although there is an increasing amount of research studies being carried out on the NHSBCSP, an appraisal of existing knowledge, (chapter 2) revealed fewer studies exploring reasons for low uptake in England particularly in the NEYH where there seems to be no published research available. Evidence suggests that diseases like cancer appear to be more prevalent in socially deprived areas, (Office for National

Statistics, 2012). NEYH are among the 10 most socially deprived areas in England according to the 2004, 2007 and 2010 indices of multiple deprivation, (IMD), (Office for National Statistics, 2013). This adds to the uniqueness of this study.

## **1.5. Rationale for the study**

It is important to understand factors influencing participation in screening programmes. This is likely to offer insights into the types of interventions and strategies necessary to enhance participation in such programmes. For example, provision of information, creation of awareness and improvement in screening services are all necessary for improving participation and uptake. This is in line with the cancer reform strategy which advocates the development and implementation of strategies for early detection and diagnosis, (Department of Health, 2011), (see chapter 2). The limited number of empirical studies on factors influencing decisions around the uptake of BC screening in England particularly in the NEYH could be attributed to the NHSBCSP being relatively new. The majority of the available studies focused on the effectiveness of screening invitations in increasing uptake, (Myers et al., 2007; Hewitson et al., 2011) health professional facilitation, (Damery et al., 2012) and service user reminder letters to boost uptake, (Cole et al., 2002). In addition there has been educational interventions aimed at increasing knowledge and awareness, (Wolf & Schorling, 2000; Stokamer et al., 2005). However, these studies tend to be organisational interventions rather than individual level research. Such interventions have not been able to show substantial positive effect on uptake.

Other studies focusing on factors influencing uptake of the FOBt have been done in other countries such as America, (Holt et al., 2009). However, this limits generalizability. Therefore there is a need for a bottom up approach to examining the factors that influence participation in BC screening from service users' perspectives in England. An in depth understanding of these factors is likely to hold the key to devising appropriate strategies for increasing uptake. This study sets out to explore these factors especially in the NEYH. Underpinned by the study findings, the current study could offer implications for policy, practice and further research that may potentially contribute to improvements in participation and uptake of BCSP.

Discussions among the researcher, the supervision team and the North East Yorkshire and the Humber Quality Assurance Reference Centre for Cancer screening, (NEYHQARC) also highlighted/directed the need for focusing the study on the North East Yorkshire and the Humber regions where uptake has been relatively low.

## **1.6. Research aims**

The research aim is underpinned by the points made above and the literature review in chapter 2. The study addresses some of the gaps in existing knowledge through exploration and understanding of the factors influencing people's participation and uptake of the NHSBCSP. Due to the study being one of the first studies in NEYH, the overall aim is a general understanding of factors affecting participation and uptake.

### **Overall study aim:**

- To explore factors that influence people's participation in the NHBCSP

### **Objectives:**

- To develop an understanding of peoples' experience and knowledge regarding BC and the screening programme.
- To explore peoples' understanding of the information provided /gathered regarding the screening and how this influences their decision to participate or not.
- To describe the similarities and differences in how different groups of people (for example, men and women) perceive BC screening programme (FOBT).

The aim and objectives were met by conducting a qualitative grounded theory research on service users' experiences and feelings when deciding to take part or not in the NHBCSP.

## 1.7. Structure of the thesis

**Chapter 1:** This chapter gives a general introduction of the thesis by providing background information of the researcher and the National Health Service BC Screening Programme; outlining the purpose of the study, the rationale and general aim of the study; followed by brief introduction of the rest of the chapters.

**Chapter 2 (Preliminary literature review):** Chapter 2 provides a broad exploration of literature from historical, policy and theoretical perspectives and a review of research literature. The chapter begins with an acknowledgement of the arguments relating to literature review in grounded theory studies and statement of my position relating to this issue. Screening falls within the domain of public health, so a brief overview of public health and its domains are presented. This is followed by the historical and theoretical context that underpins the topic of study which includes the global and national policies in public health relating to cancer screening particularly BC screening. The chapter also explores screening participation and uptake and factors influencing uptake from available literature. Health behaviour theories and decision making are also examined as screening participation may be viewed as a health behaviour which involves making decisions. These explorations led to the identification of gaps in literature and the subsequent development and statement of the research objectives.

**Chapter 3 (Philosophical and methodological stance):** This chapter lays out the philosophical assumptions underpinning this study, the methodological approach taken and justifications. A grounded theory methodology has been employed which sits within relativism and social constructionism. This enabled the exploration of the lived experiences of people's decision making process as they consider whether to take part or not in the NHS BC screening programme. A brief history of grounded theory, its strengths and limitations are also outlined in this chapter

**Chapter 4 (Research design and methods):** The purpose of this chapter is to provide a detailed description of all the activities undertaken for generating data using qualitative grounded theory approach. They include the activities prior to

field work, during field work and the tools used for data collection and analysis. Chapter 4 is divided into three phases. The preparations made prior to field work are detailed in phase one. These activities include: ethical considerations and governance; approaching the research site; recruitment and sampling strategies. In this section a clarification of two sampling strategies (purposive and theoretical sampling) is provided. Phase two provides an overview of the field work encompassing the process of actual data collection, the research setting and the research relationship. Finally, phase 3 presents the data analysis process, the steps taken to enhance rigour and maintain reflexivity. The Use of Nvivo and mind genius enabled an audit trail of the analysis process; this in conjunction with the grounded theory techniques of theoretical sampling and constant comparative analysis enhanced the rigour and credibility of the study. Chapter 4 also presents the summary of the data analysis process showing the iterative and concurrent processes involved during coding particularly during the axial and selective coding stages leading to the development of the 'Awareness-led behaviour model', (ALBM). This tentative explanatory model is also presented in this chapter. The chapter ends with a summary.

**Chapters 5, 6 and 7:** The findings of this study are presented across chapters 5 to 7 organised around the three major emergent conceptual categories generated from the data. Chapter 5 (social contexts branded 'contextualising') shows an analysis of ways in which various social contexts such as demography, psychosocial and socio-cultural contexts contribute to participation and uptake decisions relating to NHSBCSP. Chapter 6 (Knowledge and awareness, conceptualised as 'Knowing'), presents and analyses the participants' different ways of 'knowing' and how these influence their participation in the FOBT. Knowledge and awareness played significant role in decision making and behaviour towards the NHSBCSP and largely acquired through past personal medical experiences (bowel and other diseases), family history, friends, work related and the FOBT kit artefacts. Chapter 7 ('Practicalising' abstracted from practicalities associated with the faecal occult blood test) presents the practical issues involved in the uptake/non-uptake decisions as narrated by participants. These were either facilitators or barriers.

Suggestions for improvement made by study participants as a result of their lived experiences of the NHSBCSP are also outlined in this chapter.

**Chapter 8 (Discussion of results):** This chapter begins by restating the aims and objectives of this research, assessing the extent to which they have been met followed by a discussion and interpretation of the key study findings located within wider literature and research. The findings are also discussed in relation to behaviour models and theories and how the current study findings contribute to these. To enable the appreciation of the influence of methodological constraints on the overall findings and justify my claim of making contribution to knowledge, the methodological strengths and limitations of study are appraised using qualitative research credibility criteria, (Lincoln & Guba, 1985). Reflections on the sampling procedures, data collection and analysis and ethical issues are also presented. Thus providing critical and transparent account of the research process which relates to the researcher's position and personal values which could potentially influence the process of data collection, analysis and interpretation enhance the rigour of an inquiry.

**Chapter 9 (Study implications and conclusions):** The final chapter of this thesis presents the implications of the study to policy and practice as well as suggestions for further research, improving uptake and its contributions to knowledge. These are underpinned by the study findings particularly 'the awareness-led behaviour model' (the product of the current study). The chapter ends with concluding remarks.

## **1.8. Contribution to knowledge**

This study makes original contribution to knowledge in several ways: conceptual, practical and methodological. At the conceptual level, factors influencing participation and uptake of the NHSBCSP using the FOBt are presented in the tentative explanatory model developed from this study which adds to existing health behaviour theories. Participation and uptake could be influenced by social contexts, knowledge and practicalities associated with the screening test. The abstract of preliminary findings of this study has been published in the Lancet, (Azodo, Steven & Geddes, 2012, appendix 1) and the

full paper is being prepared for publication. Power points and posters have also been presented at seminars and conferences.

The explanatory model (awareness-led behaviour model) could be used in practice to explore and explain similar phenomenon in the same context and could also provide insight in different contexts. Social cultural context, poor knowledge and practicalities of test emerged as potential barriers to uptake. Therefore at a practical level, these will help in developing appropriate interventions to address these barriers; the study has suggested social marketing as a possible approach in helping to raise awareness and increase uptake.

At a methodological level, the use of grounded theory offers a unique contribution to knowledge by approaching participation from a qualitative stance which provided in-depth and rich explanations from participant's perspectives and a model grounded in the data in ways in which a quantitative stance may not have allowed.

These 9 chapters form the main body of the thesis. References and appendices follow at the end of chapter 9.

## Chapter 2

### Preliminary literature review

#### 2.1. Chapter overview

Given the debates regarding the place of literature review in grounded theory (see section below and chapter 4, section 4.1) only a general literature overview was undertaken as reported in this chapter. A more detailed comparison of literature with the study findings is presented in chapter 8. Literature search was carried out using Nora, (Northumbria university search engine), CINAHL, Web of science, PubMed, Science direct, Google scholar and Cochrane database using studies in the last ten years. Other documents such as government publications and grey literature were also hand searched. The overview of extant literature when this study started in 2009 sets the context of this study. This revealed very few studies in England that focused on factors responsible for low participation and uptake of NHSBCSP. However, there are many international studies in countries such as America. There are also many studies in the UK focused on other more established cancer screening programmes such as breast and cervical cancer. This is not surprising given that the NHSBCSP is relatively new. The few studies in the UK focusing on the FOBt were mainly in the southern part of the country and included the evaluation of the pilot rounds of the screening programme prior to the national rollout. No published study was found in the NEYH regions specifically exploring factors influencing uptake of FOBt at the commencement of this study. The scarcity of previous studies highlighted the need for a qualitative approach and the rationale for adopting grounded theory as discussed in chapter 4.

This chapter begins with an overview of public health and the historical and theoretical context that underpins the topic of study. This includes the global and national policies in public health relating to cancer screening particularly BC screening. The section also explores screening uptakes and factors influencing uptake, health behaviour theories and decision making. Brief discussion of broader health behaviour theories and decision making are provided so as to consider their relevance to participation and uptake of NHSBCSP. A working definition of 'participation' is also provided in relation to Arnstein's ladder of

participation. This chapter sets the boundaries of this inquiry and ends with a summary of identified concepts and prefigured questions that informed the study. However, it is pertinent to briefly outline some issues relating to the use of literature in grounded theory studies before proceeding with this preliminary literature review. More of these issues will be covered in chapter 4.

### **The place of literature in grounded theory (GT) studies**

Many arguments and contentions exist regarding the role and extent of research literature review among grounded theorists, (Charmaz, 2006). The arguments relate to the necessity and the timing of conducting the review. For example, whether to use literature earlier before data collection to inform the study, or later after data analysis as theory is emerging to fortify the study. Classical grounded theorists such as Glaser argue against conducting literature review prior to data collection. Glaser argues that literature should be checked towards the end of analysis to allow inductive emergence of theory, (Glaser, 1992). According to Heath, (2006), literature can be used at that stage as data to compare, support and challenge the emerging theory and to locate the new theory in existing body of knowledge, (Wolcott, 2009).

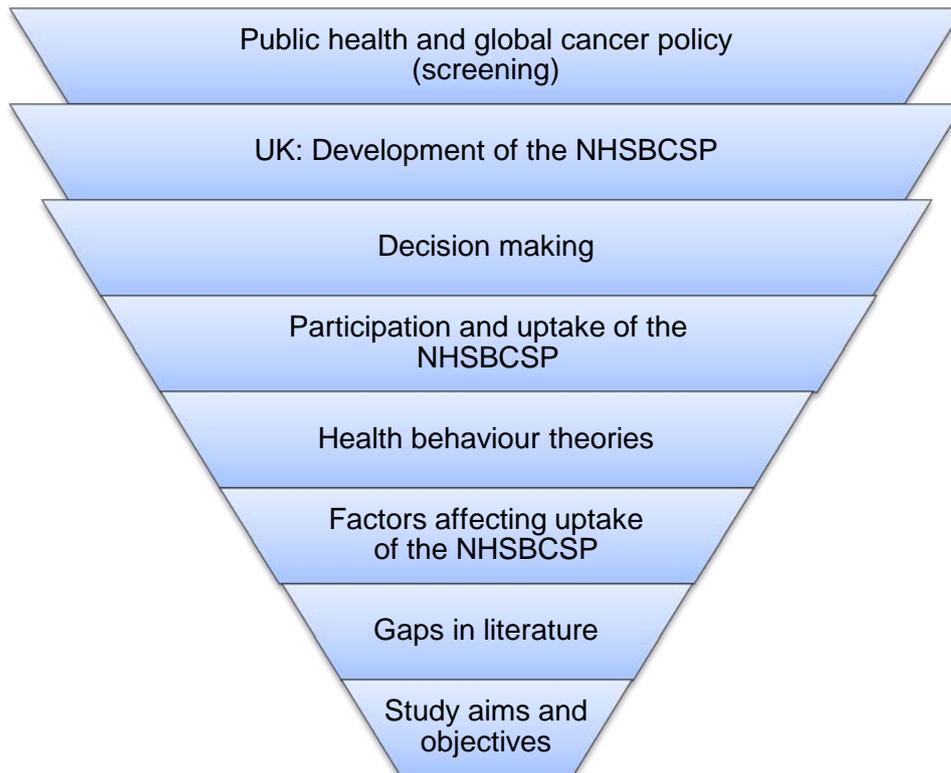
It is argued that literature review could introduce preconceived ideas which could lead to the forcing of data during collection and analysis, (Glaser & Strauss, 1967). Forcing could lead to researcher 'bias' i.e. generating themes from literature instead of from the emerging data. Other grounded theorists (Strauss & Corbin, 1990; Charmaz, 2006; McGhee et al., 2007; Corbin & Strauss, 2008) support prior use of literature arguing that it helps in selecting the appropriate methodology for the study. However, Corbin cautions against being overly immersed in literature and allowing literature to over influence the process, (Corbin & Strauss, 2008) suggesting that researchers should go into research with an open mind not with an empty head and care should be taken not to allow previous knowledge influence current research. In other words, literature should help in the recognition/identification of 'leads' but not to be 'led' by the literature, (Morse, 1994a; 1994b; Becker, 2007). Strauss and Corbin's approach has been adopted for this study, (see chapter 4).

In addition to the arguments above, there may also be institutional tension relating to prior literature review. The university and external ethics bodies

require researchers to submit research proposals for approval. This means that the researcher should be able to demonstrate: firstly, any gaps in literature to provide justification for the study and choice of methodology; secondly, to prove that the research is not being carried out just for the sake of it and that it will make a unique contribution to knowledge. These justifications need to be provided before approvals are granted; hence the need for literature reviews before data collection.

I decided to carry out a general literature appraisal which provided the opportunity to identify some ideas, concepts and questions about factors that might influence participation and uptake of the FOBt with an open mind rather than an empty head. This initial literature review highlighted other relevant studies in other countries and other screening programmes which added insights. By maintaining sensitivity to prior literature, I was able to co-construct new knowledge with the participants, (see chapter 3- social constructionism) about factors that influenced their decision to participate/not participate and subsequent uptake of the FOBt. Having outlined my stance in relation to a priori literature in GT studies and in particular this study, it is appropriate to commence the review by examining wider historical perspectives starting with the meaning of public health, global policies, the meaning of screening and development of the NHSBCSP. Subsequently participation, factors influencing uptake of the NHSBSCP, health belief theories and decision making are also examined. A statement of gaps in literature, prefigured questions and summary of the chapter are provided. The figure below shows the sequence of this review.

**Figure 2.1: Sequence of literature review**

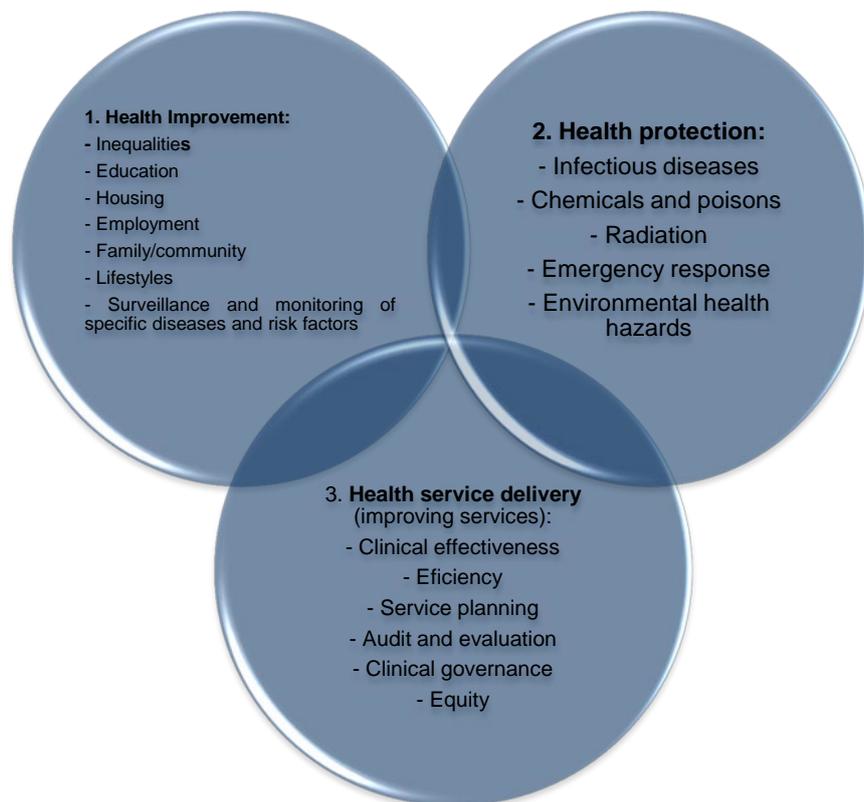


## **2.2. What is public health (PH)?**

PH is an umbrella concept defined by the UK faculty of public health as “the science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of the society”, (Macdowall et al., 2006, pg. 9; UK Faculty of Public Health, 2010). This is the most widely used and lasting definitions of public health developed by Winslow in 1923 based on the potential benefit for the whole population rather than the need of one person, (Macdowall et al., 2006). This definition depicts three public health domains which are often used differently in different countries, (figure 2.2); sometimes used interchangeably. It is important to note that even though they are interlinked, they do not mean the same thing. Health promotion has been defined as “the process of enabling people to increase control over the determinants of health and thereby improve their health”, (Macdowall et al., 2006; WHO, 2009). Public health has had a complex history and development which could be traced back to the European and North American movements of the 19<sup>th</sup> century as a result of fatal communicable disease epidemics, (Macdowall et al., 2006). The aim of public health in that era was to understand

the mechanisms of infectious disease transmission. Through the actions of UK social reformers, Chadwick and Simon, public opinions and political actions were influenced and promoted respectively which led to better sanitation, improved housing, and food supply and improved working conditions, (Macdowall et al., 2006). In recent years there has been an increasing shift from the term 'health promotion' to terms such as 'health improvement'. Health improvement signifies a wider population based strategy which encompasses the three major concepts/domains of the new public health model (Figure 2.2) advocated by the UK Faculty of Public Health, (2010), while Health promotion tends to focus on individual health education, (Griffiths et al., 2005, UKFPH, 2010)

Figure 2.2: Public health model - the three key domains of public health



This conceptual model of public health provides a framework for the organisation and delivery of public health interventions which fosters multi-sectorial and multidisciplinary working, (Griffiths et al., 2005). Public health interventions can cut across the three overlapping concepts of the model. For example, screening cuts across the three domains; screening is one way of protecting and improving health through effective service delivery. This study

looks at BC screening. Therefore, the definition, strengths and limitations of screening will be outlined in the next sections before looking at cancer prevention policies and their historic development with particular attention to BC.

### **2.3. What is screening?**

Screening is a public health intervention which, according to the UK national screening committee (UKNSC) is ‘a process of identifying apparently healthy people who may be at increased risk of a disease or condition’ (Raffle & Gray, 2007; UKNSC, 2013). It has also been defined as ‘the use of simple tests across a healthy population in order to identify individuals who have disease, but do not yet have symptoms’ (WHO, 2013a). It is a public health service where a defined population who: may not feel they are at risk; are at risk; or have experienced a disease and/or complications are tested in order to identify those who are more likely to benefit than harmed from further investigations and treatments. In other words, it involves looking for signs of abnormalities that may indicate presence of a disease before physical signs and symptoms could be noticed by the individual. This indicates that screening itself is not a diagnostic test, rather abnormal screening result is an indication of increased likelihood of the condition screened for and a need for further diagnostic tests, (NHSCSP, 2003).

Screening can take the form of questions or physical tests. The key importance of screening is the reduction of risks and/or complications typically among asymptomatic individuals by early detection, treatment and prevention of further spread of a disease. According to Hewitson, (2007; 2008) screening could yield a relative risk reduction of 15 to 16% in cancer mortality. There are different methods of screening for BC. More invasive methods require passing a small tube with a camera called ‘scope’ through either the rectum up to the sigmoid colon, (sigmoidoscopy) or all the way through the entire large intestine (colonoscopy). BC can also be screened for through a less invasive procedure using the FOBt. The FOBt is currently offered to 60-74 year olds in the UK. Although flexible sigmoidoscopy is also offered to those in their 50s, the current study only explores the factors that could influence uptake of the FOBt.

## **Strengths and limitations of screening**

The aim of every screening programme is to save lives through early detection, diagnosis and treatment. Early detection and diagnosis of diseases can make treatment easier and more effective at saving, prolonging and improving quality of lives, than when detected at an advanced stage. Screening also reduces the incidence of cancer in the long term. For example, the reduced incidence and mortality rates from breast and cervical cancers seemed to have been as a result of screening programmes for these cancers, (Blanks et al., 2000; Raffle et al., 2003). The breast screening programme screens around 1.3million women annually with approximately 10, 000 breast cancer diagnoses and this could equate to a 35% reduction in breast cancer mortality, (NHSBCSP, 2006). Also regular cervical cancer screening using smear test prevents around three quarters of cervical cancer saving around 4500 lives per annum in the UK, (NHSBCSP, 2006).

It has been estimated that the FOBt could prevent 16% bowel cancer deaths if at least 60% of those invited for screening are screened; a 20% or more reduction could be achieved through biennial or annual screening respectively after a 10 years interval, (WHO, 2013b). At the moment this target has not been achieved. The World Health Organisation, (WHO) warns that unless high compliance is achieved, much benefit will not be achieved in the wider context in terms of the money spent on the screening programmes, (Weller et al., 2009; WHO, 2013b). Hence the need to embark on this study to explore factors influencing participation and uptake from service users' perspectives; this may give insight on ways of improving uptake and aid in attaining the screening goals and targets.

Despite the advantages, screening has some potential disadvantages such as over diagnosis and misdiagnosis as it is not 'fail-safe', (Weller et al. 2009). Screening tests may show false positive results for those who do not have a disease. This can lead to stress and anxiety, unnecessary investigation and treatment and other costs to the individual and healthcare service. On the other hand, a false negative result for someone who actually has a disease may be seen as more serious than the false positive result. This individual is given a false sense of security which delays diagnosis while the disease is advancing.

This is particularly dangerous for those conditions that do not readily show obvious signs and symptoms such as BC. BC could be developing for years without clear-cut signs and symptoms. A major setback in the use of the FOBt for cancer screening is its lack of specificity, particularly when sample is rehydrated and lack of sensitivity in detecting adenomas, (WHO, 2013b) which leads to further diagnostic tests. A summary of the advantages and disadvantages of screening is presented in table below, (Weller et al., 2009)

**Table 2.1: Advantages and disadvantages of screening**

Advantages	Disadvantages
Proven benefits in population screened	Risk of individual harm
Perceived benefits and reassurance	Anxiety and personal cost
Reduced burden of illness in population	Unnecessary treatment of individuals with false positive results
Raised awareness of target cancer	Reduce available funding for primary prevention and treatment
	Potential overburden of services

Screening could also have some ethical concerns despite the strong attributed advantages. For example, as screening generally targets asymptomatic individuals, it should be noted that it does not guarantee protection/detection and that no screening is 100% accurate. Thus the UKNSC, (2013) emphasises that screening helps to reduce risks rather than promoting it as complete protection. NHS cancer screening services are also operated on the policy of informed choice (see later section on decision making). Individuals are provided with all the necessary information including the limitations of screening to help them make informed choices about screening. However, the contents and adequacy of such information on FOBt decision may be questioned. Due to the ethical issues and limitations associated with screening as discussed earlier, the World Health Organisation, (WHO) in 1968 published principles and guidelines to guide evaluation and implementation of screening tests and the disease screened for, (Table 2.2), (Wilson & Jungner, 1968).

**Table 2.2: WHO principles of screening**

<b>Principles of screening</b>
<ol style="list-style-type: none"><li>1. The condition should be an important health problem</li><li>2. There should be a treatment for the condition</li><li>3. Facilities for diagnosis and treatment should be available</li><li>4. There should be a latent stage of the disease</li><li>5. There should be a test or examination for the condition</li><li>6. The test should be acceptable to the population</li><li>7. The natural history of the disease should be adequately understood</li><li>8. There should be an agreed policy on whom to treat</li><li>9. The total cost of finding a case should be economically balanced in relation to medical expenditure as a whole</li><li>10. Case finding should be a continuous process, not just a “once and for all” project</li></ol>

Countries are encouraged to consider these principles while devising and implementation screening services. The following section appraises some of the global cancer policies.

## **2.4. Global cancer policy development**

Cancer is a global leading cause of death causing around 7.6 million deaths in 2005 and potential 84 million by the year 2015, (WHO, 2007). These figures called for a global action on cancer particularly as evidence suggest that deaths from cancer could be prevented through screening. A series of policies and publications from WHO have reinforced the importance of planning, prevention, early detection, diagnosis and treatment, palliative care, policy and advocacy. These were to enhance population-wide comprehensive cancer control activities and meeting the needs of ‘at risk’ groups. A cancer prevention plan was drawn up in 1948 by the world health organisation. Three levels of prevention were identified in this plan: the first level is primary prevention which involves encouraging positive behaviour change in life style; secondary prevention relates to screening for early detection and treatment of cancers and tertiary prevention is aimed at improving treatment and condition, (WHO, 2002a; 2002b). The NHSBCSCP falls within the second level of the WHO plan for preventing pathologies, improving therapy and social rehabilitation of patients. BC screening is offered to aid early detection and treatment of

BC/precancerous lesions or any other bowel problem such as 'polyps'. According to WHO, secondary prevention could limit the disability from a disease by averting or delaying the adverse effects of the disease progression thereby reducing the duration of the disease on the individual or the prevalence of the disease in the population.

However, not all countries have the wealth and resources to tackle the cancer problem. More than 70% of all cancer deaths occur in low and middle income countries, where resources for prevention, diagnosis and treatment may be limited or even non-existent' (WHO, 2007). A guide was published following world health assembly in 2005 to encourage member states to develop and implement stronger strategies for cancer control. The four basic components of WHO cancer control guide could be used within each country's capacity to prevent, treat as well as provide palliative care to cancer sufferers, (table 2.3).

**Table 2.3: WHO guides for effective cancer programmes**

1. Prevention, which could be achieved by making important life changes
2. Early detection – which could be achieved through awareness of early signs and symptoms and screening programmes
3. Diagnosis and treatment
4. Palliative care.

In response to the WHO guidelines, many countries have implemented screening programmes. Breast and cervical cancer screening programmes have been implemented in the UK for many years and BC screening programme introduced in 2006 following successful pilot programmes, (<http://www.cancerscreening.nhs.uk/>). Other countries have begun implementation of BC screening programmes at a target population level although many are still at an infancy stage. However, disagreements exist in different countries on the best screening method, (Grau et al., 2010). According to Grau et al., the European Union, (EU) in 2003 recommended the use of the FOBt in asymptomatic population aged 50 to 74 years. Even though 70% of the EU countries have implemented the FOBt as a population wide screening intervention, there is wide discrepancy in practice. For example, Spain targets 50 to 60 year olds every two years while England targets 60-74 every two years.

It is the opinion of the researcher that the discrepancies may be due to organisational culture and varying healthcare system operating in different countries. The next section focuses on the development of the NHSBCSP.

## **2.5. Development of the NHS BC Screening Programme**

As a result of the burden from cancer and the benefits of early detection, 'Our Vision for Cancer' (1995-2020) was developed in 1995, (Imperial cancer research fund, 1995). The 'Our Vision for Cancer' document was a 25 year plan aimed at developing and directing government policies in the UK on promoting cancer prevention, screening and treatment. It was highlighted in this report that BC kills 20, 000 people which could be reduced by 40% through improved screening, (Imperial Cancer Research fund 1995). This report was a major influence on planning a national screening programme for BC. However, implementation of a national health intervention programme requires good evidence base. In order to provide evidence, there have been four randomised controlled trials of BC screening using the FOBt as a mass screening programme conducted in Denmark, (Kronborg et al., 1996); the UK (Schofield et al., 2002); Sweden, (Kewenter et al., 1994); and USA, (Mandel et al., 1993). These trials aimed to investigate and demonstrate the impact of screening on BC rates. The findings from the trials demonstrated that BC screening using the FOBt could reduce the number of deaths from BC (Kronborg et al., 1996). It could save approximately 2,500 lives per year in the UK. It can also in the long run, bring down the incidence and prevalence of BC, (<http://www.cancerscreening.nhs.uk/bowel>). The benefit of the FOBt was further strengthened by Hewitson et al., (2007) in a meta-analysis of the above four randomised controlled trials and found that BC specific mortality could be reduced by up to 16% among those screened.

The UK randomised trial led the UK department of health to propose implementing a national screening programme for BC, (Department of health, (DH) 2000) to be tried initially through a pilot programme. The research evidence from the randomised controlled trials helped the NHS to run two 2year pilot schemes in two sites in 2000-2002 and a third pilot in Feb. 2003-April 2005. The pilot programme was aimed at exploring the practicality, feasibility and acceptability of the FOBt before the department of health could roll it out as a

national programme (<http://www.cancerscreening.nhs.uk/bowel>). People aged 50-69 with normal population risk of colorectal cancer were screened using the FOBt. These were the people who were registered with participating GP practices in the pilot sites.

The evaluation of the pilots programmes showed significant evidence that the findings in the randomised controlled trials of the FOBt could be achieved in a population programme, (Alexander & Weller, 2003; Weller et al., 2006) using the same model as the pilot. The pilot schemes achieved nearly the target of 60%, though uptake was higher in the first pilot. The evaluation team recommended FOBt for inclusion as a new national strategy for reducing BC. The pilots identified lower uptake in men, younger people in the age range, deprived areas and minority ethnic group, (Alexander & Weller, 2003; Weller et al., 2006). This study seeks to explore some of these groups to find out reasons behind the trend and what could be done to increase uptake among them, particularly in socially deprived areas.

In addition to the strong evidence provided by the pilots and trials, FOBt seemed to be a screening method of choice by other stakeholders as FOBt is less invasive (Weller et al 2006). Therefore the National Bowel Cancer Screening Programme (FOBt) was announced in the 'Our Health, Our Care, Our Say' White Paper, (DH, 2006) and rolled out the same year. The implementation phase was 3 years to ensure full national coverage by 2009. Men and women aged 60-69 years were sent the screening kit to their homes which they are required to complete and send back to the hubs for testing, (Chapter 1). The 'Cancer Reform strategy', (DH, 2007) revised the age group to include those aged 60- 74 years from 2010. The cancer reform strategy outlined actions to be adopted for improving national cancer services, access to service and outcomes and subsequently a reduction in incidence inequalities. It was hoped that by adopting the reforms, the UK screening service will become one of the best in Europe.

It was recognized that creating awareness is important in achieving the aims of the cancer initiatives because ignorance of signs and symptoms and late presentation via delay in seeking help have been associated with the poor cancer survival rate in the UK. The 'National Awareness and Early Diagnosis',

(NAEDI) and 'National Cancer Equality', (NCEI) initiatives were then launched. The main role of NAEDI is to raise awareness of cancer across the population. As a result, a BC awareness campaign 'Be Clear on Cancer' was launched and piloted across some regions with a media version beginning in January 2012.

The NHS BC screening committee coordinates the screening centres while the quality assurance reference centre (QUARC) for cancer screening (A co-sponsor of this study), monitors the screening process to ensure minimum national standards are set and maintained across the regions while the strive for excellence continues. Table 2.4 provides a summary of some of the UK cancer initiatives from 1995 before moving on to participation and decision making.

**Table 2.4: UK cancer initiatives**

<b>Year</b>	<b>Initiative</b>	<b>Aim</b>
1995	Our Vision for Cancer (1995-2020)	Finding cures and saving lives.
2000	Cancer Plan, (2000): A plan for investment, a plan for reform.	Saving more lives. Ensuring right professional support, care and treatment for people with cancer. Tackling inequalities. Investing in cancer workforce, research and genetics
2004	The NHS Cancer Plan and the new NHS (2004a): Providing a patient centred service.	An update of the cancer plan 2000 aimed at: Reducing cancer deaths Improving the quality of cancer care and treatment Reducing inequalities in health
2006	Our Health, Our Care, Our Say white paper, (2006)	Better prevention services with earlier intervention. More choice and more voice for the people.
2007	Cancer Reform Strategy (2007)	Actions to improve UK wide cancer services within the NHS and reduce inequalities in incidence, access to services and outcomes
2011	Improving Outcomes: A strategy for cancer	The aim is to save an additional 5000 lives per year by 2014/15 through early diagnosis, improvements in screening and treatment
2011	The National Awareness and early Diagnosis (NAEDI) and National Cancer Equality (NCEI) initiatives	NAEDI: Raising awareness of cancer within the general population. NCEI: Identifying and bridging inequalities within cancer in terms of key indices (gender, age, ethnicity, socio-economic status, religious belief, disability, sexual preference and language).

## 2.6. Decision making

Decision making is a process which involves movement through a series of phases, (Rosenstock, 2005). According to Rosenstock, the movement entails the interaction of the individual with events and people; which directly or indirectly influence the individual's decision and subsequent behaviour. Decision making is a complex phenomenon which could be influenced by a myriad of factors such as race, age, gender, occupation, environment, socialisation, (Galdas, Cheater & Marshall, 2005; 2007). Decision making can involve a lot of deliberations on options and their consequences, although Doya and Shadlen, (2012) recognise that decision making is a cognitive function and many decisions are reactive and automatic.

Three types of decision making models have been observed in health services: Paternalistic, shared decision making (SDM) and informed decision making (IDM). Paternalistic approach sees decision making as the role of the healthcare professional as the expert which the patients is expected to accept and comply with, (Barnes, 1999; Rimer et al., 2004; Wackerbarth et al., 2007). However, there has been a shift from the paternalistic model to SDM and IDM. In SDM, the decision making process is shared by the health professional and the individual. IDM entails an individual's understanding of the disease/condition/intervention and its clinical significance including the benefits, risks, limitations and alternatives; consideration of his/her preferences and makes a decision consistent with the preferences at his/her desired level, (Sheridan et al., 2004). However, due to limited resources IDM are not always fully implemented. For example, the NHSBCP decision support artefacts does not offer service users alternative screening choices, rather necessary information is given to aid decision regarding the screening on offer.

IDM and SDM may only happen with decision intervention such as decision support/aids resulting in or a combination of improved knowledge, beliefs and perception of risks, (Rimer et al., 2004; Wackerbarth et al., 2007; Jackson et al., 2008). According to Jackson et al., (2008) systematic review, decision aid is anything that helps in gathering enough information and clarifying an individual's values. They are intended to aid informed decision making and choice, (DH, 2004). They include but are not limited to tailored and untailored

print material, video/audio tapes, counselling; group education, mail, computers and decision boards, (Chan et al., 2003; Briss et al., 2004; O'Connor et al., 2009) and could be individualised. It can also include testimonies from others, (Jackson, et al., 2008). However, it is uncertain whether decision supports lead to participation commensurate with the individual's preference and satisfaction.

It should be borne in mind that most health-related decisions are influenced by symptoms and may be challenging for asymptomatic conditions and their interventions such as bowel cancer and screening respectively. People may find it unnecessary undertaking screening in the absence of symptoms. There may be unintended consequences of decision aid intervention which need to be carefully considered, for example, simply offering screening does not necessarily lead to desired response, (Rimer et al., 2004) neither does providing information that promotes particular course of action fully cater for all the decision needs of individuals, (Jackson et al 2008). Volk et al., (1999) has shown a reduction in screening (prostate) uptake after exposure to IDM/SDM. Nonetheless, others have also shown small increases (breast and colorectal screening), (Dolan & Frisina., 2002; Rimer et al., 2002). IDM intervention may only lead to short term improvements.

In addition, individuals may not always make informed decision. For example, individuals may not consider the pros and cons of all possible intervention before making their choice; and potential limitations of an intervention may be underestimated while placing too much weight on the potential benefits, (Braddock et al., 1999; Rimer et al., 1999; Rimer et al., 2002). Interestingly, Gattellari et al., (2001) noted a mismatch in roles patients want to play relating to cancer screening and treatment. Patients may prefer sharing decision making about treatment which reduces patient's anxiety and increases their satisfaction. In addition, the level and delivery mode of desired information can vary among individuals, (Rimer, et al., 2004; Jackson et al., 2008) and may need to be individualised.

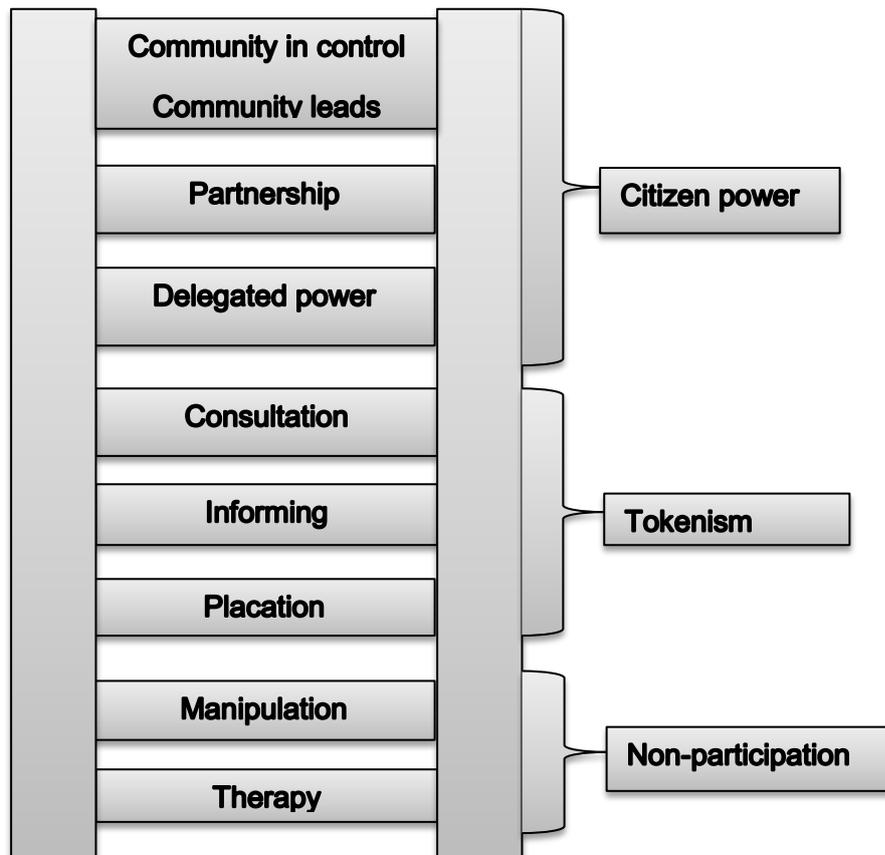
## **2.7. Participation**

Participation is a very broad term and a concept used in many ways. It could simply mean involvement. However, the involvement may be of different

shapes and forms; ranging from active involvement to little or no involvement. Participation has been cited among the most misunderstood ideas that emerged from human relations; comprising basically in creating opportunities under suitable conditions for people to make decisions in issues affecting them, (Pateman, 1970). Participation means to sensitize people and thus increase the receptivity and ability of local people to respond to development programmes as well as to encourage local initiatives, (Oakley, 1989). Participation is very important in health care because the success of any healthcare intervention aimed at improving health depends on getting as many people as possible to take part, (Rifkin, 1990). In this way resources are used in a way that brings greatest possible benefit to greatest possible number of people. The WHO advocates active involvement of individuals in assessment, planning, implementation and evaluation of health care services, (McHunu, 2009). This means partnership working among significant stakeholders from the community and healthcare providers. However, it has been noted that most times partnership is in principle rather than in practice. It has been reported that the development of healthcare intervention hardly involves active participation of the people except in passively partaking in the end product, (Brown et al., 2005).

Different levels at which communities and individuals could be involved in health interventions or services concerning them are well illustrated in the Arnstein's ladder of citizen participation, (Arnstein, 1969; McHunu, 2009) (figure 2.3).

**Figure 2.3: Arnsteins's ladder of participation**



The levels or 'rungs' in the ladder correspond to the level of involvement of the people. The top levels on the ladder are where people exercise their full citizen power as they are involved in the assessment, planning, implementation, monitoring and evaluating programmes. The middle levels are where the individuals in the community could participate in programme activities by airing their views; whether it will be taken into account during policy making is a matter for debate. Traditional citizen involvement has been criticised as being used nominally by organisations in fulfilment of statutory obligations while in practice continue with implementation of pre-agreed management goals, (Moote et al., 1997). The last level is where members of the public enjoy services provided by agencies such as health improvement programmes, immunisations and screening programmes (Arnstein, 1969; Rifkin, 1990; Brown et al., 2005; McHunu, 2009). At the last level (therapy and manipulation) participation is passive rather than active which seems to be the case in most community oriented health programmes. People are expected to take what is on offer often presented as a benefit which should be taken advantage of. Although the

ladder is a good illustration of the levels of participation among communities and agencies, distinct levels may not exist in reality; there could be many more facets of participation in and along the continuum.

For the purpose of this study, participation is argued to be located at the lowest level of the ladder as participants do not take any active role in the planning and implementation of the NHSBCSP. They are only required to complete the FOBt. Perhaps, the implications of current qualitative research could act to promote the target population to next level of participation 'tokenism' at the 'consulting rung' where the output of this study is anticipated to contribute to future policy and practice. However, decisions are needed to be made on whether to participate in screening or not. Therefore the next section examines decision making

## **2.8. Population uptake of the NHS BC Screening Programme**

The evidence that screening saves lives cannot be overemphasised. The success and effectiveness of screening largely depends on participation while non-adherence hinders success. If the target population does not take up the screening offer to a sufficient level, this will yield no benefit and could be a waste of public health fund. However, several studies have reported low uptakes of screening tests for BC and other cancers (Youngman, 2005; Weller et al., 2007; Chapel et al., 2008; Waller et al., 2009; Weller et al., 2009). Uptake means the proportion of invited people who actually complete the screening test within the specified time, (Weller et al., 2007) and therefore participate fully in the screening. As mentioned earlier, average uptake for the NEYH is 56.66% for the three completed rounds of the programme, (2007 - 2013; unpublished data, North east hub).The evaluation of the NHSBCSP English pilot showed that overall uptake average was around 58%, this is lower than the DH target of 60%. The Initial evaluation of the first and second round of the FOBt in England at the pilot sites, identified low uptakes of 58.4% and 51.9% respectively with  $P < 0.0001$ , (Alexander & Weller, 2003; Weller et al., 2007). 52.1% out of the 127, 746 men and women aged 50-69 returned their kit. The evaluation of the second pilot indicated high uptake of 81% among those who participated in the first pilot who had negative results. There was a lower cancer detection rate (0.94/1000) in the second pilot than there was in the first pilot, (Weller et al.,

2007). Among the differences in uptake were age, gender, and level of deprivation. For example, uptake was consistently lower in men, increased with age, and fell as deprivation increases, lower among ethnic minority, higher in those who participated in the first round, (Weller et al., 2006; 2009). The uptake in the third pilot was 58.7%. Uptake continued to be lower in men but continues to decrease in gap in comparison with women than in earlier pilots, (Moss et al., 2012). Moss and colleagues found further association between low uptake of screening and deprivation; also within minority ethnic groups.

England is not the only country with low up take of bowel cancer screening. There have been poor compliance rates in other parts of the world. For example, the first and second pilot programme in Barcelona, Spain indicated uptake of 17.2% and 22.5% respectively, (Peris et al., 2007). There was cancer detection of 2.1/1000 and 2.8/100 of those screened in the first and second round respectively in Spain. The screening uptake was also low in Scotland at average of 50% in the three Scottish pilot rounds, (Steele et al., 2009). In Hungary, compliance was between 30-45% while around 33% of those with positive FOBt refused colonoscopy, (Döbrössy et al., 2007). This clearly indicates that participation is linked with uptake, (Moss et al., 2012) and that there has been a suboptimal participation and uptake rate in the FOBt.

Although, some of the reasons for low uptake have been hinted at, the next section will appraise in more depth possible factors that could influence people's decisions to participate in the FOBt from existing literature when this study started in 2009.

## **2.9. Factors influencing uptake of the FOBt**

Previous studies have identified several factors that may influence participation decisions in different types of cancer screening including BC. In England, evidence on factors influencing participation in BC screening comes particularly from studies evaluating the BC screening pilot programmes, (Alexander et al., 2003; Szczepura et al., 2003; Weller et al., 2007; 2009; Steele et al., 2010). These factors seem to act either as barriers which could prevent people from taking part in the screening; or as facilitators/motivators in peoples' choice and decisions to take part in the screening. In the UK, studies around factors

affecting uptake of FOBt appear to be very few and were carried out mainly in the south, midlands and Scotland, (Jepson et al., 2007; Chapple et al., 2008; Steele, et al., 2009; Taskila et al., 2009). Some studies have explored attitudes to BC screening. For example, O'Sullivan & Orbell, (2004) focus group study explored people's understanding and attitudes to FOBt. The focus group study was conducted before national roll out of the FOBt and participants of that study had not carried out a FOBt and may not have provided a description of actual experience.

The evaluation of the UK BC screening (FOBt), (Weller et al., 2006; 2007) using the routine data of responders showed that age, gender and level of deprivation affects participation and uptake. Uptake was lower in men but increased in older age group; lower in more socially deprived areas and higher with previous participation. However, a pitfall in the use of routine data is that it only shows patterns or characteristics of participants without an in-depth exploration of the causal factors or the reasons behind these patterns.

Evaluation of the first pilot, (Alexander et al., 2003) revealed similar characteristics using surveys and focus group. The surveys illustrated lower uptake in men, younger age group, minority ethnic group, high confidence in FOBt, perceived seriousness of BC, fear of positive result and above all issues with the ease and difficulty of completing the kit. In addition to the survey, the focus group suggested positive attitude towards the FOBt, awareness from past experience, simplicity and privacy of test, perceived threat and not embarrassing or hygiene compromised as reasons for uptake. Reasons for non-uptake included low perception of efficacy of FOBt, perceived psychosocial distress, perceived barriers, problem with storage and low social support, (Alexander et al., 2003).

### Attitudes and perceptions

As mentioned above, participation in cancer screening in general has been associated with positive attitudes, (Subramanian et al., 2004; Woodrow et al., 2006) while low uptake may be associated with ethnicity, (Jerant et al., 2008; Johnson et al., 2008; Robb et al., 2008), age and gender, (Subramanian et al., 2004; Weller et al., 2007), poor knowledge, embarrassment, fear, (Subramanian

et al., 2004; Klabunde et al., 2005; Smith et al., 2005; Holt et al., 2009) and socio-economic status, (McCaffery et al., 2002; Wardle et al., 2005; Szczepura et al., 2008). From the appraisal of existing literature, it appears that participation in any kind of screening is motivated by perceived benefits. Some of these motivational factors include; early diagnosis and treatment of cancer, reduction in the mortality rate, peace of mind from worrying over cancer and assurance from negative result, (Rawl et al., 2000; Chapple et al., 2008; Marshall et al., 2010). Marital status and the use of other health services were also reported as important facilitators for the FOBt, (von Euler-Chelpin et al., 2010). Studies from other countries, (Klabunde, 2005; McGregor & Bryant, 2005; Beydoun & Beydoun, 2008; Holt et al., 2009) have also reported similar factors.

### Fear and anxiety

Pain and anxiety about test result could act as barriers to screening, (Vernon, 1997; Busch, 2003). An American focus group study on screening uptake identified fear, pain, embarrassment, lack of wider public awareness, insurance cost and misconception on risk factors as the factors that influence participation in the FOBt in the US, (Holt et al., 2009). Fear was noted to be the greatest 'culprit' for low uptake. The talk of cancer was also reported to cause fear as cancer was associated with death. Thus white American women perceived the diagnosis of cancer as a death sentence, (Holt et al., 2009). However, the women were aware of the importance of early diagnosis and very proactive in seeking medical help, (Holt et al., 2009). This is akin to the construct of 'perceived threat' in the health belief theory, (discussed in the next section).

Holt et al., (2009) also reported that people expressed anxiety over quality of life after diagnosis and treatment. For example, people were not happy about the possibility of carrying a colostomy bag. However, the study found that there was a strong belief that spiritual and mental resilience capacity could determine quality of life even after treatment. There were persistent differences in uptake demographically. For example African Americans present at a more advanced stage than the white Americans (Jemal et al., 2007). Nevertheless, it was noted by Holt et al., (2009) that physicians would not ordinarily recommend screening unless someone presented with symptoms, despite the asymptomatic nature of

BC. This could be explained by the institutional and systemic dynamics that operate in different countries.

### Gender and ethnicity

Age, gender, race and deprivation were also found to influence uptake, (Szczepura et al., 2003; Seeff et al., 2004; Kim et al., 2005). It has been revealed that more women participate in BC screening than men, (Weller et al., 2006; Holt et al., 2009; Weller et al, 2009). According to Holt et al., (2009) some men attend after much encouragement from significant others, community organisations, the local church and physicians. In England uptake was lower in men but increased with age, and fell as deprivation increases, (Weller et al., 2006; 2009). Weller and colleagues also reported low uptake among ethnic minority groups. Szczepura et al., (2003) survey and focus group study on uptake of FOBT among minority ethnic group in Coventry and Warwickshire revealed similar findings to those of earlier studies. For example age, poor knowledge about test, fear of screening outcome and concerns over hygiene were among the common barriers among the ethnic minority. Other barriers noted included difficulty understanding the test and procedure as a result of language barrier, literacy, length of residency and race discrimination by health practitioners. It was noted in that study that barriers abound as result of ethnic origin; the most important being language and literacy barriers.

A survey component of Szczepura et al., (2003) study indicated that poor knowledge and awareness of the FOBT and lack of past experience also affect uptake. Differences in gender were not accounted for. Neither perceived susceptibility to cancer nor its severity was associated with uptake among the Asians in contrast to the white population as reported in Alexander et al., (2003). Szczepura et al., (2003) reported overall positive attitude and confidence towards screening after information giving and education. Their study highlighted the need for a tailored education intervention targeting different segments of the target population as 'one size may not fit all'.

Studies in the UK focusing on other methods of BC screening and other screening programmes have revealed both similar and different factors affecting uptake of screening programmes. For example, studies exploring reasons for

uptake of flexible sigmoidoscopy revealed lower uptake in women and illustrated that facilitators include positive attitude, peace of mind, perceived reduction of risk and reassurance while demography, health status, absence of symptoms, embarrassment, tempting fate and discomfort were among the barriers, (Wardle et al., 2000; McCaffery et al., 2001; 2002; Wardle et al., 2003; Wardle et al., 2005).

### Socio- economic status

McCaffery et al., (2003) reported poor knowledge and attitude which varied by age, gender and economic status to be influencing factors of uptake of screening test. According to McCaffery et al., (2003), those from low socioeconomic group were more likely to decline screening than those from higher economic status. The study noted that flexible sigmoidoscopy was perceived as frightening and of less benefit by the low socio-economic group. This is associated with higher level of stress and lack of social support. A report relating to cervical and breast cancer screening showed similar barriers such as limited knowledge, embarrassment, indecision, fear of pain, fear of the result, unsure of test accuracy, underlying health and cultural belief, language barrier for some ethnic minority groups and unhelpful attitude from healthcare professionals, (Furlong, 2002; Youngman, 2005; Waller et al., 2009). Although aforementioned studies, (Wardle et al., 2000; McCaffery et al., 2001; 2002; Wardle et al., 2003; 2005) addressed other modes of BC screening, they provided insights into what might be happening indicating a need for an exploratory study on the FOBt.

### Knowledge and physician recommendation

Poor knowledge and lack of physician recommendation are among reported barriers to bowel cancer screening, (Rawl et al., 2000; Woodrow, et al., 2006). Perceived barriers to screening uptake include lack of awareness about risk factors, the importance of screening and the recommended guidelines, (Beeker et al., 2000). Other international studies, (Taylor et al., 2003; Klabunde et al., 2005; Ogedegbe et al., 2005; Wee et al., 2005) have also identified lack of healthcare provider input as a significant barrier to uptake of BC screening. The studies identified that there were lack of adequate counselling and

recommendation by physicians about screening. A pattern seen across American studies for non-uptake was lack of insurance and physician recommendation. This is peculiar to America where there is no free for all health service unlike the UK where health services are free. Health service in the US is mainly accessed via insurance policies which limit access for people without health insurance. Also, preventive health services such as screening are not always covered in the insurance. As a result of this, many who cannot afford the cost of the test would simply not have it. The effect is the widening of the health inequalities gap that already exists in the society.

Furthermore, it has been reported that screening invitations have traditionally been brief and only provided information about the benefits, (Mann et al., 2009). This suggests inadequate information to aid informed choice. However, Mann et al., (2009) acknowledged that providing limited personal benefits and/or potential adverse effects/harm of screening to facilitate informed choice may actually deter people particularly in low literacy and socially deprived areas.

Other UK studies (Chapple et al., 2008; Taskila et al., 2009) have also revealed factors similar to those presented so far affecting participation in the FOBt. Chapple and colleagues noted that screening systems; gender, cognition and cultural differences could all contribute to the process of decision making and need to be taken into consideration, (Chapple, et al., 2008). However, the location (south of England) of Chapple's study may limit generalisation across the UK. On the other hand, Taskila's study employed questionnaire which is good for answering the question of what is happening without the 'whys'. Understanding of reasons 'why' would help in the planning and delivery of tailored interventions to improve uptake in specific areas such as the NEYH.

Having examined possible factors influencing uptake of bowel cancer screening programmes particularly the FOBt, the next section examines behaviour theories which have been commonly used to understand people's health behaviour. Behaviour theories offer theoretical explanations about concepts or combination of concepts which might be responsible for decision making concerning the individual's health. Theory driven interventions with sound evidence base are more likely to yield favourable outcomes than those without, (Green, 2000). Understanding health behaviour drivers may allow the

formulation of appropriate strategies that encourage positive behaviour change such as screening uptake.

## **2.10. Health behaviour theories (HBT)**

Behaviour theories, modules and frameworks have been widely used to understand and explain or even predict human behaviour. HBTs are models developed to help understand and even predict people's behaviour towards a given health interventions. This helps in understanding the factors that influence decision making and choices that people make. There exists a well-established pool of psychology and behaviour models, (Green, 2000; Nutbeam & Harris, 2004). Green, (2000) noted a recent move and emphasis towards evidence based and improving the cost-effectiveness of health promotion interventions and health behaviour theories have been widely welcomed as one of the ways to achieve evidence based practice. Green argued that empirical evidence alone would not be enough to inform practice in designing and evaluating health promotion programmes or interventions.

There seem to be two major assumptions underpinning health behaviour theories. Firstly, that behaviour depends on the value placed on a particular goal by the individual and secondly on an individual's perception that the goal can be achieved through a given action, (Rosenstock, 1974; Ajzen, 2002). These two positions have formed the basis for most health behaviour theories in understanding behaviours towards social and health interventions. When translated into the context of health, it means that people's behaviour could depend on the perceived threat of an illness and their desire to avoid the illness. Behaviour may also depend on the belief that the threat could be reduced by a particular action that they are able to perform.

Theories can guide the formulation of appropriate strategies used to implement and assess health intervention programmes, (Macdowall et al., 2006). Many health behaviour theories exist which are used in different areas to understand, predict and change behaviours depending on the changes sought. For instance, the focus could be on understanding and changing the individual; the community/organisation or at an interpersonal level. A systematic review of literature, (Painter et al., 2008) found the most common theories in health

research to be ‘the health belief model’; ‘the trans-theoretical/stages of change’ and ‘the social cognitive’ theories, (Rosenstock, 1966; 1974; Bandura, 1998; Prochaska et al., 2002; Bandura, 2004). Given the word restrictions of this thesis, the key theories most widely used in health will be discussed in this section as shown in table 2.5. However, there are other health related behaviour theories such as community organisation theory, (Rose, 1981) and diffusion of innovation theory, (Rogers & Shoemaker, 1971).

**Table 2.5: Summary of key health behaviour theories**

Theory	Key constructs
The Health Belief Model (HBM) (Rosenstock, 1974)	Perceived susceptibility Perceived severity Perceived benefits Perceived barriers Cues to action
Stages of change/Transtheoretical model (Prochaska & DiClement, 1983, Diclement & Prochaska, 1998)	Pre contemplation stage Contemplation stage Preparation stage Action stage Maintenance stage
Social Cognitive theory (Bandura, 1998)	Behavioural capability Reciprocal determinism Outcome expectations Self-efficacy Observational learning Reinforcement
Theory of planned behaviour (Ajzen & Madden, 1986; Ajzen, 1991; 2002)	Intention and ability One’s attitude towards a behaviour Subjective norms Outcome expectancy Perceived control (high)

### **The health belief model (HBM)**

The HBM was developed in the 1950s by social psychologists Hochbaum, Rosenstock and Kegels at the U.S. public health service, (Rosenstock, 1974; Glanz et al., 2002). This was to help in understanding why there was a generally low uptake and compliance to preventive health interventions such as screening particularly for asymptomatic diseases. HBM is a psychological model that focuses on an individual’s attitudes and beliefs. It is underpinned by the understanding that an individual will adopt a health related behaviour (e.g. screening) if the individual feels susceptible, that an adverse health condition could be avoided; expects that taken such an action will avoid the adverse

health condition and believes that he/she can effectively perform the health action, (Rosenstock, 2005). The HBM is the most popularly adopted model in health promotion and education, (Glanz et al., 2002). The HBM was initially made up of four constructs that determine a person's readiness to act. Self-efficacy was later added to the model.

Perceived susceptibility – refers to one's perception of his/her likelihood of developing a disease. According to Rosenstock, (1974), the chances of adopting target behaviour increases with increased perception of susceptibility. Perception of susceptibility is a strong motivator for preventative health behaviour such as flu vaccination and sunscreen use have been well supported by a number of studies, (Belcher et al., 2005; De Wit et al., 2005; Chen et al., 2007). However, this construct has failed to acknowledge that this may not always be the case for some individuals, people who feel that they are not at risk of a problem even when there is evidence that they are may not worry about the seriousness and may continue with the unhealthy behaviour. For example, studies, (Yep, 1993; Maes & Louis, 2003) have found that older adults and people of Asian origin do not practice safe sex as a result of their low perception of risk.

Perceived Severity – is one's perception of the seriousness and threat of a given disease, (Rosenstock, 1974; 2005). It depends on knowledge of the condition in question. Knowledge helps the person to examine the effects of the disease on his life and general health. If a person attaches a low importance to a health condition then he/she will not attach seriousness to that condition. For example a headache that could easily be taken care of with a couple of painkillers may be perceived as a minor ailment over a persistent migraine which could result to sick leave from work or even a hospital admission. This analogy could also be another factor on how a person perceives illness other than medical knowledge.

Perceived Benefit – is the perception that adopting a new behaviour will help to reduce the chances of developing a disease. According to the HBM, people tend to adopt a new behaviour if they feel that quitting smoking, getting screened, vaccinated; exercising and so on will mean better health and less chance of disease and comorbidity for them. In other words, those who believe

there is a benefit for adopting a behaviour are more likely to do so than those who do not perceive any benefit from doing so, (Graham, et al., 2002; Frank et al., 2004). These studies reported that colonoscopy and breast self-examination were always adopted by those who perceive some benefit. However, the question that remains is why do some people fail to adopt behaviour even when they believe it is beneficial?

**Perceived Barrier** – refers to perception of barriers and obstacles in achieving target behaviour. People are motivated to change their behaviour when they could perceive that the benefit of the new behaviour outweighs the consequences of their old behaviour. It is the motivation brought by the benefit that pushes people to overcome the barriers along their way to the new behaviour. However, perceived barrier could have a greater influence on behaviour than perceived threat or seriousness. For example, the barriers to breast self-examination in women had a greater effect on carrying out the exam than the threat of breast cancer which is a deadly disease, (Champion & Menon, 1997; Umeh & Rogan-Gibson, 2001)

**Cues to action:** These are the factors that ‘spark’ or trigger action. HBM also suggest that cues to actions could influence people’s adoption of certain behaviour. Examples of cues to action include: media campaigns, experience of family member or a friend, invitations to services and reminders from health services, (Weinrich et al., 1998; Ali, 2002; Graham et al., 2002; Hanson & Benedict 2002).

**Self-efficacy:** is the perception of one’s ability of carrying out a task by oneself, (Bandura, 1977). Lack of self-efficacy could be a barrier to changing behaviour despite the perceived benefit. This is because under normal circumstance, people try new things if they believe that they are able to perform the task. Fear of not being able to carry out self-examination of the testicles by men or breast self-examination by women, (Umeh & Rogan-Gibson, 2001) could actually stop them from doing so despite the seriousness of the diseases.

In order to effect positive behaviour change in public health intervention, the four constructs need to be moved in the right direction. For instance, increasing perceived severity, susceptibility, benefits, cues to action and self-efficacy and

reducing the perceived barriers could foster behaviour change in the desired direction. However, issues relating to behaviour change are not always 'clear-cut'.

### **Stages of change theory**

The stages of change theory or the transtheoretical model of behaviour change was proposed by Prochaska and DiClement, (Diclement & Prochaska, 1998; Prochaska, et al., 2002). The theory suggests that human beings do not spontaneously make up their minds and immediately carry out a change of behaviour in a linear and binary manner. Rather they go through five stages in the change process.

- Pre-contemplation stage: being aware or not of a new behaviour such as smoke cessation or screening, but not interested at the moment.
- Contemplation stage: consciously evaluating or considering the personal benefit of the new behaviour.
- Preparation stage: decision to change and trying to gather measures required to carry it out.
- Action stage: giving the behaviour a go.
- Confirmation or the maintenance stage: commitment to the behaviour and no immediate intention to relapse, (DiClement & Prochaska, 1998; Hasting 2007).

Appropriate behaviour change intervention depends on the individual's or population's position along the five stages. Interventions needs to be introduced gradually if sustained behaviour change is to be achieved, (Andreasen, 1995). One of the setbacks is that this theory was validated with questionnaires. Questionnaire is a quantitative tool which lends itself to positivist philosophical stance and does not take into account personal and sociocultural factors, reasons for behaviour and how individuals could be supported. The same yard stick is used for all; when in practical terms what drives people are not always the same but could depend on the subjective sociocultural and psychological context.

The theory has also been criticised on the basis that interventions based on the theory could leave behind the target population who are still at the pre-

contemplation stage. In addition, people do not move in a linear fashion through the stages; people could change behaviour without consciously going through the stages and relapse may occur along the way, (Davison, 1992). So, Basler, (1995) suggested that behaviour change is rather spiral. However, Prochaska et al., (1992), argued that some people could move quickly and rapidly at a particular stage than at other stages. In response to the criticisms, DiClement, (2005) said that the theory is not to be treated as a religion or heuristic rather it provides intelligence on the thought process of how close people are towards a particular behaviour change intervention, (DiClement, 2005; Hasting, 2007). In order to understand why people are at a particular stage and what moves them on to the next stage, other theories may need to be considered, (Buxton et al., 1996). Nevertheless, the theory has been successfully applied to several types of behaviour change interventions e.g. smoke cessation, weight control and it seemed to have worked, (Prochaska & Velicer, 1997)

### **Theory of planned behaviour**

Theory of planned behaviour was proposed to predict behaviours that are beyond people's complete volitional control. The model proposes that an individual's intention to change behaviour, (motivation) and ability to perform an action, (behavioural control) could predict certain behaviour, (Ajzen & Madden, 1986; Ajzen, 1991; Ajzen & Driver, 1991). This was based on the argument that behaviour is jointly influenced by intention and ability. Theory of planned behaviour has these key components: behavioural intention, subjective norm and perceived behavioural control.

Behavioural intention: a person's perceived likelihood of carrying out behaviour. According to Ajzen, (1991) behavioural intention is directly measured by attitude toward the behaviour. It is also indirectly measured by outcome expectation and the value attached to the expected outcome. Subjective norm: Perception of other people's (referents) approval or disapproval of behaviour. This is determined by one's normative beliefs and motivation to comply whether important referents approve or not. Therefore positive subjective norm is very likely with positive referent approval and high motivation and vice versa. However, low motivation to either referent approval or disapproval will lead to a neutral subjective norm, (Montano & Kasprzyk, 2002)

Perceived behavioural control: Perception of one's control over behaviour which is influenced by control belief (facilitators and barriers) and perceived power (effect of facilitators and barriers). Ajzen, (1991) argues that high behavioural control with high intention is likely to lead to desired behaviour. Also that perceived control could be an independent determinant of behaviour if subjective norm and attitude are held constant although these could vary for different behaviour and population,

When the theory was applied to smoke cessation, the behavioural intention was determined by a person's positive attitude towards cessation, increased perceived behavioural control to stop smoking and high perceived social norm to do so. The theory of planned behaviour is very similar to the stages of change theory. A limitation of this psychological construct is that they use quantitative methods such as questionnaires which do not take into account the wider social context. The theory of planned behaviour uses dimensional variable like the likert scales to explain and predict behaviour, while stages of change model classifies people into dichotomous algorithms or stages (Prenger et al., 2012).

### **The social cognitive theory (SCT)**

The social cognitive theory was developed by Bandura, (1986). The theory proposes that human behaviour is influenced by two major factors; interpersonal and environmental factors, (Bandura, 1986; 1997; Glanz et al., 2002) in a process of 'reciprocal determinism' (Bandura, 1978). Reciprocal determinism implies the triad simultaneous interaction of a person, a person's behaviour and the environment; the constant influence of these three components on one another, (Glanz et al., 2002). The interpersonal factors could be the person's knowledge of a task and person's ability to carry out the task (self-efficacy), (Bandura, 1986; Maibach & Cotton, 1995). The environmental factors include availability of resources in the person's immediate environment and the economic status of the community. The influence of the environment could come directly from a person's immediate family, friends, colleagues, church members and indirectly also from the wider social context such as the societal values/norms, socio-economic conditions. In the SCT, there exist a two way association between the personal and environmental

factors. Maibach & Cotton, (1995) noted that environment shapes a person and also the way they behave, the person in turn also shape their environment through these behaviours. For any health intervention to be successful these two dimensions of the SCT need to be taken into consideration. Hasting, (2007) argued that expecting people in socially deprived communities to eat healthily, such as fruits and vegetable, while these are not available in their local store would simply not work. Hasting further argued that this could be viewed as blaming the victim - 'putting unfair degree of responsibility on their own predicament on people who are already suffering and disempowered' (Hasting, 2007, pg. 28).

SCT is underpinned by the idea that since societal norms shape people's behaviour, then 'de-normalisation' or 'normalisation' of certain behaviours will make people change the old norm and adopt a new one which is perceived as common and normal in the society, (Sussman, 1989; May et al., 2007). SCT suggests that people are likely to take up behaviour if they perceive it to be common and acceptable in their immediate and wider environment. In order to make them stop the behaviour the counter message is the trick; making the behaviour less attractive and abnormal by anti-norm campaigns and normative education. Many studies have suggested that normative education could be effective in the prevention of drug misuse, (MacKinnon et al., 1991; Donaldson, et al., 1994). However, SCT has failed to recognise that knowledge is not the only prerequisite to behaviour change. People may decide to adopt a new behaviour for so many other reasons. For example people may choose to exercise and eat healthily to lose weight simply because they want to look more attractive rather than for any health gains. SCT also failed to identify how people might be moved on to the next stage of behaviour change, (Hasting, 2007) such as recognition of benefit of adopting new behaviour that could lead to sustainability.

### **Criticisms of health behaviour theories**

Most of the behaviour theories such as the HBM, (Rosenstock, 1974; 2005) have been criticised as a result of their suggestions that people would always act in a protective manner if there is perceived susceptibility and severity and if they believe that taking action will be of benefit in minimising the risks and

seriousness of a condition. These theories are based on psychosocial cognition and depend largely on the assumption of rational behaviour. However, people do not always act rationally, (Rothschild, 1999). Humans are complex and understanding what drives them is even a more challenging task. For example people chose to drink alcohol not because they don't know that it is bad but may be that they have evaluated their overall situation and out of self and social interest choose to do so (Rothschild, 1999). Hence, the need to explore people's lived experiences within their individual and wider sociocultural context.

Most of the theories used quantitative approaches (questionnaires and likert scales) to test their hypothesis, for example theory of planned behaviour and stages of change model. Quantitative approaches are located within the positivist paradigms. The issue here is that people's behaviour are also shaped among other things by subjective environment. People need to be located within their individual and wider socio cultural context rather than generalisation from different contexts. Therefore there is a need to explore lived experiences within individual and wider sociocultural context as recognised by the SCT.

Amidst the criticisms, it is important to note that these theories provide a guide to understanding and predicting behaviour. An understanding which Rosenstock, (2005) advises should precede persuading behaviour change. Theories help to identify: at what stage people are towards target behaviour; identify personal and environmental influencers of behaviour and the best way forward in terms of moving the people a step towards the desired target. Theories provide a great insight and guide on the development, implementation, sustainability and evaluation of various health education intervention programmes. This is as a result of their empirically proven ability to explain and predicts behaviour and behaviour change.

The next section presents the gaps in literature and reaffirms the rationale for undertaking the current study

## **2.11. Gaps in literature and rationale for study**

Evidence from this review has shown that BC is a global public health problem which could be reduced by early detection and treatment through screening.

However, screening uptake is generally low. Many studies explored in this section have tried to investigate factors which might be affecting participation and uptake. Some of the factors include:

- Attitudes and perception
- Knowledge
- Deprivation
- Ethnicity
- Gender

A number of gaps have been identified in research literature. Firstly, studies investigating trends in uptake highlighted lower up take in more deprived areas and in men indicating a correlation between deprivation and uptake. However, there was no existing published research identified in the NEYH looking at factors influencing uptake prior to undertaking this study.

Secondly, available qualitative studies were conducted in other locations in the UK, (Jepson et al., 2007; Chapple et al., 2008; Steele et al., 2009) and in other countries, (Klabunde et al., 2005; McGregor & Bryant, 2005; Beydoun & Beydoun, 2008; Holt et al., 2009) and little is known about the people in the NEYH particularly the men, on what influences their participation and uptake of the FOBt. Therefore this highlights the need to explore this area.

Also, studies that explored other forms of long established screening such as breast and cervical cancer screening provided insights into possible factors affecting their uptake, (McCaffery et al., 2001; Wardle et al., 2005; Szczepura et al., 2008; Waller et al., 2009). However, the extents to which these are generalisable to the FOBt are not known.

In addition, the qualitative studies that explored the factors influencing uptake (section 2.9) employed focus group methods, (Alexander et al., 2003; Szczepura et al., 2003; O'Sullivan & Orbell, 2004). Focus group method is deemed a good way of fostering group interaction and provision of a wide range of information in a short space of time, (Krueger, 1997). However, for sensitive issues such as BC screening, the amount and quality of information gathered could be jeopardised, (Krueger, 1997). People may be embarrassed,

particularly for taboo subjects like 'going to the toilet' and may not air their experiences as fully and openly as possible in a focus group. Hence the need for a more individual approach to gathering information such as the one-to-one interview method which can give participants more freedom to express themselves in their private environment which could be less embarrassing and no pressure of adhering to a group norm. The current study therefore, employs this more individualistic approach of one-to-one interviews.

Furthermore, some studies explored both the FOBt and endoscopy at the same time. This may prove confusing to the study participants in these focus groups which could lead to confusing/conflicting answer if one test is mistaken for another. The studies revealed no significant variation in uptake among age groups but factors influencing uptake varied across the different countries. This is probably as a result of different institutional and organisational systems operating in these countries. However, this literature review revealed limited published research in England that explored factors influencing FOBt participation and uptake from service users' perspective. The majority of available studies, (section 2.9) just looked at the trends in uptake using quantitative methods, (Alexander & Weller, 2003; Weller et al., 2003; Taskila, et al., 2009) others, (Weller et al., 2006; 2007) used routine data from the screening database. These types of studies only show observed trends and patterns in the screening uptake without much detail about the reasons for such trends. Therefore, this also gave rise to the need for the current qualitative study which explores factors influencing people's decisions to participate/not participate from their own views.

In addition, most of the studies were done prior to the roll out of the FOBt in 2006 or at its earlier stage; currently the screening programme is in its third round. This makes it a crucial time for an exploration of participation and uptake after the programme has reached wider population in order to obtain a clearer picture. Many people would have received the FOBt kit at least once and will be in better position to describe their lived experiences as opposed to the earlier stage of the programme when screening was still in its infancy and had not reached the whole country.

## **2.12. Contribution to knowledge**

Through global and national history, there has been a persistent call for implementing preventive health interventions, (Sections 2.4 and 2.5) particularly for diseases which could be prevented. However, preventive interventions such as screening have been challenged by poor uptake. Given the newness of the BC screening programme, it is not surprising that there is currently limited body of knowledge around participation and reasons for participation in the programme. Previous literature such as randomised trials, (which are mostly policy oriented) have mainly focused on the effectiveness, feasibility and successful implementation of the FOBt. The current study findings will add to the existing body of knowledge which will further broaden understanding of the reasons for low uptake. This is anticipated to inform policy, practice and service improvement in the delivery of the FOBt.

This study will add in unique ways to the evidence base as a result of the demographical and geographical characteristics of the study population, and the anticipated specific recommendations based on the study findings. The identified gaps in this preliminary literature review have prompted the current research aims and a set of objectives for this inquiry as set out below. Research aims guide the research; they set the boundaries of what is going to be explored as it will not be possible for a researcher to address all aspects of a problem in a single research project.

### **Research aim**

- To explore factors that influence people's participation in the NHBCSP

### **Objectives**

- To develop an understanding of peoples' experience and knowledge regarding BC and the screening programme
- To explore peoples' understanding of the information provided /gathered regarding the screening and how this influences their decision to participate or not

- To describe the similarities and differences in how different groups of people (for example, men and women) perceive BC screening programme (FOBT)

### **2.13. Summary of chapter 2**

This preliminary literature appraisal shows that cancer is a global burden which needs to be tackled if the associated morbidity, mortality and other costs are to be reduced for the individual and the community as a whole. There has been ample evidence to suggest that screening is a good way of preventing the devastating effects of this disease; though the benefit at individual level has been a subject of debate particularly concerning those at a lower risk. This appraisal suggests that at population level the limitations are outweighed by the overall benefits. This has led to different global and national policies and strategies to achieve this aim. RCTs have shown that BC could be combated using the FOBT. However, studies explored so far have reported consistent low uptake particularly in men and socially deprived areas, not just in the UK but in other parts of the world as result of multiple factors.

Different behaviour theories have also been explored to understand some of the reasons behind behaviours. Some of these theories tend to be based on cognition and are also quantitatively generated and/or verified. Human behaviour is very complex and may not be explained by a single theory but perhaps by a combination of the theories. On-going effort is required to minimise inequalities in uptake in relation to deprivation, gender and ethnicity. However, this requires an understanding of factors influencing people's decision regarding taking part in the screening programmes as many of the existing studies only show the trends in uptake. Therefore this provides the rationale for this study and for the philosophical and methodological approaches used, which are described in more detail in the next two chapters.

## Chapter 3

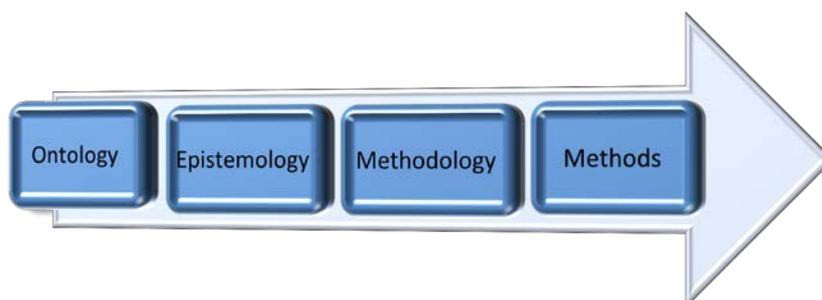
### Philosophical and methodological stance

#### 3.1. Chapter overview

Chapter 3 and 4 provide detailed description of the research design and methodology employed in carrying out the current inquiry. These encapsulate an outline of the paradigms or world view that underpins the study; including the beliefs and assumptions that define my world view alongside possible alternatives. The aims and objectives of this study which are stated in chapter 2, (section 2.11) allow making relationships and connections for the choice of philosophical approaches clearer. This chapter presents my guiding principles for employing a qualitative approach; and my choice of philosophical assumptions, (ontological, epistemological and methodological). Guba and Lincoln, (1994) suggested that it is worthwhile to make clear the guiding philosophical assumptions of an inquiry from the beginning while Crotty, (1998) emphasised that philosophical stance lays the foundation for the methodology being used and clarifies the reason why a research is being carried out in a certain way. The research methods are outlined in chapter 4.

Research paradigms are predominantly differentiated into quantitative (positivist) and qualitative (naturalist) paradigms, (Polit-O'Hara & Beck, 2004). Each paradigm is underpinned and different from the other based on its assumptions and beliefs around four philosophical questions (figure 3.1) that make up the research strategy, (Guba & Lincoln, 1994). The four components have key influence on the process and interpretation of the inquiry, (Hall et al., 2013).

**Figure 3.1: The research strategy**



**Ontology** - addresses the question of the nature and form of reality and what can be known about reality, (Guba & Lincoln, 1994; Creswell, 2007)

**Epistemology** - relates to the nature of knowledge, in other words it is about how we find out about reality. Epistemology clarifies the question about what is known, what can be known and the relationship between the knower (the researched) and the would-be knower (the researcher), (Guba & Lincoln, 1994).

**Methodology** – after answering the epistemological question, methodology poses the question about how the researcher could go about finding out what he/she believes could be known, (Guba & Lincoln, 1994; Hall, et al., 2013). Research methodologies tend to depend on the type of ontology and epistemology, (the nature of reality and knowledge)

**Methods** – clarifies the question about the means by which knowledge could be gathered, sometimes called the research tools. These are all the different tools that are employed by the inquirer to help in constructing knowledge. This is the procedure of the research; the process of collecting and analysing data

### 3.2. Philosophical perspectives

My main goal for undertaking this study is to examine and understand people's experiences and the factors influencing their decisions to participate/not participate in bowel cancer screening, (the FOBt). Given the currently limited work on the subject in the NEYH and complex nature of human health behaviour (section 2.10), a qualitative research paradigm was deemed appropriate for addressing the study aims and objectives. This is because qualitative paradigms generally allow an exploration of a phenomenon using descriptive, pragmatic and unstructured approaches, (Bryman, 1988). Qualitative paradigms seeks to make sense of a given phenomenon by using different methodologies to investigate real world settings, generating rich descriptions grounded in the meanings attached to the phenomenon by participants, (Fraser, 2004; Corbin & Strauss, 2008; Machin et al., 2012). These attached meanings are influenced by the interactions and relationships in the environment, (Fraser, 2004). In contrast to qualitative approaches, quantitative approaches, (mainly positivist) focus on predictive ability and generalisability of findings, (Lincoln & Guba, 2003; Polit-O'hara & Beck, 2006). According to

Corbin and Strauss, (2008), qualitative approaches are more suited to phenomenon that may not be adequately explored by quantitative approaches.

As mentioned earlier research strategy starts with the ontological position of the researcher. Given the aim of the current inquiry, reality or truth (ontology) has to come from those who lived the experience, (the attendees and non-attendees of the screening programme). They are in a better position to describe the factors that influenced their decisions regarding participating in the FOBt. Therefore, reality is viewed from their individual understanding and interpretation of their experiences of the screening programme which is influenced by the social world in which they live, (Gergen & Gergen, 2004). As Gergen, (2009) simply puts it, what we believe to be the truth depends on how we approach it, which in turn depends on the social relationships around us and which we are part of. In the current study, I have positioned my ontological stance towards relativism and my epistemological standpoint draws on symbolic interactionism and social constructionism. The chosen methodology was Grounded theory (GT) after careful consideration of other alternatives such as ethnography and phenomenology. The methods were those associated with GT. The chosen research paradigm appreciates the individual participant's construction of their experience and the influence of their social world lending itself to the epistemological claim of symbolic interactionism.

## **Social constructionism**

Social constructionism views reality and knowledge as constructed rather than discovered (Berger & Luckman, 1991; Schwandt, 2003; Andrews, 2012). Social constructionism has been interchangeably used in the past with social constructivism, but they do not mean exactly the same thing. Social constructivism suggests that experience is mentally constructed through an individual's cognitive process but social constructionism has a collective social focus that incorporates the social world, (Gergen & Gergen, 2004; Hall, 2013). Social constructionism has some links with interpretivism and symbolic interactionism as they share common philosophical views. They both seek understanding of lived experiences from the perspectives of those who live or lived in it. Unlike interpretivism, social constructionism is more concerned with subjective experience of everyday life; interpretivism may seek objective

interpretations of the same, (Andrews, 2012). Social constructionism advocates multiple constructions of reality, (relativism) through the interactions of the researched and their social world; and the interaction of the researched and the researcher as the former tries to understand, narrate and interpret their lived experiences while the latter interprets these experiences in a more understandable concept to a wider audience.

## **Relativism**

Relativism assumes multiple constructions of reality which are subjective unlike realism, which assumes objective reality. Relativism assumes that 'the truth' or 'reality is what we know for the point in time in relation to the local contexts, (MacDonald, 2001; Lincoln & Guba, 2005). It has been argued that assumption of a relativist position subjects the findings of an inquiry to being rendered less useful or 'nihilistic' in contribution to knowledge if no one reality transcends over another, (Gergen & Gergen, 2004). In contrast to relativism, it can be problematic in qualitative research to assume a realist position as it ignores how researchers construct and interpret findings but assumes the findings as true independent reality. Subtle realism has been suggested as a way of avoiding the two extreme of aforementioned ontologies. Subtle realism assumes the existence of independent reality without direct access but rather social representation of it (Hammersley, 1992). This seems similar to holding subjective reality of everyday life as well as objective reality, (Berger & Luckmann, 1991). However, the major aim of this study is to find out from participant's perspectives the factors that influenced their decision regarding participation in the NHSBCSP. Therefore, the findings will represent sets of different discourses among many others, (Andrews, 2012). The discourses may be influenced by social, cultural, historical and political contexts. Hence my symbolic interactionism assumption, which according to Denzin, (1978) is concerned with the interactions of the individual and the social world and how social structures develop from the repeated interactions.

However, it has been argued that the social structures (institutionalisation) formed from repeated interactions could become objective reality over time, (Berger & Luckmann, 1991). Nevertheless, reality in this study is from the perspective of the participants. From the one-to-one data collection and

constant comparison there was a strong suggestion that what influences one might not be the same as what influences another person's behaviour towards the NHSBCSP, and that those factors might actually change over time. Here reality is subjective. This seems in agreement with Corbin in Corbin & Strauss, (2008); Corbin is very much of the opinion that knowledge advances and could change over time. However, this view could be mistaken for the 'postmodernism' radical relativism which seems to assume that since we cannot prove one version of interpretation to be true or certain therefore no version of interpretation should be accorded any certainty, (Denzin & Lincoln, 1994). The relativists have been accused of finding a way of insulating their beliefs from refutation, (Benton & Craib, 2001). Taking this ontological position, Wisker, (2008) argued that "we make meanings rather than discover it as a fixed entity; that we understand through making links, interpreting contexts and perceiving; and that our understanding of the meanings we make from the findings produced by our research could be interpreted differently in different times and places by different people", (Wisker, 2008: page 66)

Corbin in Corbin & Strauss, (2008) pointed out that there is no single 'reality waiting to be discovered, rather there exist multiple realities from our attempt to understand and construct our social world (Grant & Giddens, 2002). In this study, I explored these multiple realities by looking at the meaning people give to their behaviours and experiences of the FOBt.

Things that happen are usually combinations of multiple factors interacting in complex and unimagined ways. Previous studies suggested that different factors such as age, state of health, gender and culture have a significant influence on people's behaviour towards screening. Therefore as a result of this complexity, methodology that sets out to understand and explain the events that are happening has to be complex. Nevertheless it will be very difficult if not impossible to capture the entire complexity. Attempts should be made to capture as much as possible by obtaining as much multiple perspectives as possible to build variation into the analytical process. Thus analysis takes into account the political, social and cultural, framework in order to understand the experience. These factors cannot be separated from the experience of the researcher and are meant to be important aspects of the analytical process. An advantage of relativism is an acknowledgement of how the researcher

constructs and interprets the findings; hence, an extension of my epistemological claim of symbolic interactionism. In contrast, realism seeks to bracket the researcher in order to maintain objectivity and avoid researcher bias.

### **Symbolic interactionism (SI)**

SI has its origins from pragmatism and interactionism schools of thought and as such proposes that human development is a process of evolution and human beings give meaning to the environment through their active and dynamic nature and interactions with one another made possible by language, (Charon, 2007). This special type of interaction is called 'symbolic interactionism', (Blumer, 1969) which Blumer acknowledged to be the result of problematic situation that needs solution where it is difficult for an individual to act in isolation. In other words to understand a problematic situation better (in this case, low uptake of FOBt), the researcher needs to interact with the research domain to find out the possible influential factors and possible solutions and then conceptualises and interprets it in a way that could be understood.

Symbolic interactionism is based on three assumptions. Firstly, human actions are determined by the meaning a phenomenon has for them. Secondly, the meaning is developed by the social interaction. Thirdly, the meaning is directed and modified through an interpretive process, (Blumer, 1969; Hall, 2013). The intention for using SI in this study is to highlight the symbolic meaning of the FOBt to the study participants. This symbolic meaning is then interpreted by the researcher. Like interactionism, pragmatism believes that knowledge is acquired collectively. This means that individuals are socialised by their inherited perspectives such as culture in which they find themselves in. Although this is a widely held view, there are still some philosophers who still give undisputed primacy to the individual knower, (Strauss & Corbin, 2008).

Social constructionism argues that during the course of our action and interaction that we 'construct' meanings for our world, but there is no knowledge except that of those being studied. The reason for the later argument being that as researchers try to abstract/conceptualise from the construction of knowledge (data gathered) our own (the researcher) becomes less authentic from the actual testimonies of the researched. In other words meanings are developed through social interaction and modified through further interactions in the

interpretive process, (Blumer, 1969) using reflective abilities. Nevertheless, the job of the researcher is to interpret/present the construction in a manner that will be easily understood by wider audience as mentioned earlier.

According to Benton & Craib, (2001) the end point of pragmatism seems very close to that of neo-Kantianism which claims that in social science 'knowledge is based on the shared culture of the community;' in contrary culture as a process is prone to change. So interactionism is more interested in the process. The researcher is of the opinion that in GT there is clear interaction between the researcher and the researched; however, it remains open for debate how the interaction affects the emerging theory, (Cutcliffe & McKenna, 1999). The researcher at this juncture also agrees with Charmaz's constructivist view that theory is not 'discovered' but rather 'made' by the social interaction between the researcher and the researched in relation and reflection to the contexts and the research process. The researcher as a social actor constructs theory from the data collected based on different factors such as his/her personal and professional experience and social interaction with the researched on a given phenomenon, (Charmaz, 2006).

From the last statement above, in constructivist stance it means that it is difficult or even impossible for researchers to take the passive role (bracketing). The researcher is an integral part of the process and will always bring some elements of previous experience and personal interest to an inquiry, but should remain reflexive. Bryant & Charmaz, (2007) also encouraged researchers to get a grasp of the wider literature before conducting their own study. This is to maintain novelty and currency and to avoid being overwhelmed with too much data and repetition of current and old ideas. However, one of the founding fathers of GT (Glaser) is against this and advocates bracketing, (Glaser, 1992). Omitting literature review poses a difficult situation for some researchers particularly students who are required by their institutions to provide initial proposal document for the study and this requires some knowledge of the area under study. This tension made it difficult to adopt Glaser's approach for this study but rather Strauss and Corbin's approach to GT. However, the core principle of GT is always maintained no matter whose approach is adopted. These core principles are discussed in chapter 4.

### 3.3. Methodology

Methodology is another key component of research paradigm. Methodology addresses the issues about how the researcher could go about finding out what he/she believes could be known, (Guba & Lincoln, 1994). The methodology for this project has been carefully chosen by considering the phenomenon and the research aims it sets out to address. The ontological and epistemological positions of the research have helped to underpin/determine the kind of methodology that will be appropriate to address the identified study aims and objectives. However, there is still the dilemma about how methodology could be determined. There seems to be a general consensus that philosophical and methodological positions influence each other and depend on the research aims. Research questions/aims often help to direct the methodological approach that can be used to conduct a research, (Creswell, 2007; Corbin & Strauss 2008; Holloway & Wheeler, 2010).

The ontological and epistemological assumptions of this study are that reality is subjective and could be explored through the researcher/researched interaction respectively. There are several theoretical approaches that could be used to address and explore human activities. This research was structured within the qualitative research framework which allows the researcher to gain/discover an inner experience of participants regarding BC screening and helps to develop an understanding of factors that could influence their participation in the screening programme. However, there abound many qualitative approaches. Given that little is known about factors influencing people's participation in the FOBt in the NEYH; and the primary focus of the current study is to directly generate understanding from the views of the participants, a grounded theory approach was deemed appropriate. Adopting grounded theory enables generation of theories which Glaser asserts emerge out of a social process that could not have been known before hand, (Kaplan & Glaser, 1996). Albeit generating new insights, grounded theory would also assist in identifying changes to improve policy and practice in the NHSBCSP which could lead to increased uptake of the FOBt and reduction in BC burden.

Grounded theory, (GT) is the development of theory directly based and grounded in the data collected by the researcher, (Creswell, 2007; Corbin &

Strauss, 2008; Holloway & Wheeler, 2010). This is a major difference between GT and some other methods. The researcher in GT starts with an open mind not 'an empty head' and lets the data collected generate the theory while other research methodologies such as quantitative approaches often start with a preconceived theory which they try to prove or disprove. Preconceived theories according to Glaser & Strauss, (1967) could prevent the development of the research by blocking awareness of emerging concepts from data. GT seeks to find explanation rather than description. Thomas & James, (2006) have criticised this openness in GT by suggesting that being free from preconception as Glaser and Strauss advocate is impossible. The rationales for choosing GT include:

Firstly, the systematic bottom-up approach used in allowing the theory to emerge from data collection through to analysis without being influenced by previous theories or preconceived researcher perspective, (Creswell, 2007) but being reflexive and sensitive to data.

Secondly, this research aims to build theory at the end around behaviours towards the NHSBCSP and GT does not just stop at reporting the experience of participants (generation of categories) like some qualitative research but goes further to generate theories (relationship between concepts-interpretations),(Holloway & Wheeler, 2010).

Another advantage of GT is the flexibility from beginning to the end of the study, constantly comparing data for similarities, differences and making connections, (Holloway & Wheeler, 2010).

GT also has the advantage of getting the data analysed as earlier on as possible in the project as there is a constant interplay between data collection and analysis (constant comparative analysis) contributing to the credibility of the study, (Myers, 2008).

Other approaches were also considered at the proposal stage of this study while deciding on the appropriate methodology to employ giving the research question and the philosophical stance. Ethnography was considered as it studies the human activities in relation to the culture. This requires that the

researcher get immersed in the community in order to get substantial understanding of the culture and how it affects everyday activities, (Creswell, 2007). A limitation of this method is that the researcher could become over involved, could become an advocate taking on the views of the researched and it may necessitate observing the processes and interactions being studied – this is not appropriate for the FOBt.

Phenomenology could also have been employed which, like grounded theory, is an inductive approach aimed at understanding the meaning of human experiences, (Beck, 1997). They both seek to describe a phenomenon as it is consciously experienced by research participants without preconception. Unlike the Strauss and Corbin's grounded theory approach adopted for this research, a phenomenological approach would entail bracketing of researcher's previous knowledge and understanding of the FOBt in order to explore the real lived experiences of the participants. Given my nursing background and training, it will be difficult to maintain a bracket approach because I already know about cancer and screening. However, I approached the study with open mind and sensitivity to data.

In addition, my ontological and epistemological stance of multiple realities and construction of knowledge through the symbolic interaction of individuals and their social world and that of the research participants and the researcher limits the use of phenomenology for the current study. Participating in the NHSBCSP is a social process which Charmaz, (1990) acknowledges that grounded theory researchers are part of the process as they (researchers) continuously create the social process. Unlike ethnography and phenomenological approaches, grounded theory generates theory. This research seeks to generate theory that could offer insights into factors influencing uptake of the NHSBCSP; as such ethnography and phenomenology were laid aside. Next section provides an overview of the development of GT and a summary of the common differences in Glaser and Strauss and Corbin's GT approaches followed by the strengths/limitations or criticisms of GT.

### 3.4. Development of Grounded Theory

Grounded theory was originally developed by Barney Glaser and Anselm Strauss in the 1960's. This was as a result of their argument about orthodox methodologies in use at that time making qualitative research seen as poor quality in relation to quantitative counterparts and to provide theoretical rigour and robustness for qualitative research. It is the widely used qualitative method for researching human subjects. Grounded theorists argued that research should not begin with preliminary hypothesis or preconceived ideas rather with an open mind in the quest to gain understanding of the researched leading to the discovery of significant qualities upon which conceptual explanations could be anchored and grounded theories developed, (Bryant & Charmaz, 2007). This could be argued to contradict the genesis of GT which was born out of Glaser and Strauss personal experiences and insights as a result of their bereavements.

It could also be argued that it is good for a researcher to start with topics of interest in order to stay motivated. Although Glaser and Strauss came from different backgrounds in American schools of thought; Glaser from quantitative background of the Columbia school of sociology, Strauss from qualitative background of the Chicago school linked with 'symbolic interactionism' and interpretive approaches, their research relationship resulted from parental loss, evidenced in their work about death and dying, (Glaser & Strauss, 1965). The approach was initially called 'substantive theory' then, 'the constant comparative method' and later 'Grounded theory' in 1967 with the publication of 'the discovery of Grounded theory', (Glaser & Strauss, 1967). The constant comparative process has always remained at the centre of the approach despite the argument and divisions about 'substantive' and 'formal' theory. A main characteristic of GT is its practice orientation from the beginning. The early work of Glaser and Strauss has much practice implication that helped the co-author of their first book to make profound nursing practice impact in palliative and hospital care system. This could be the reason why GT is a popular methodology among people working in care settings.

### 3.5. Differences in Glaserian and Straussian GT

Grounded theory has changed through the years into many different ways of building theory that is still grounded in the data, (Corbin & Strauss, 2008). This happened as a result of different factors. One of which is the conflicting opinion between the founders of GT (Glaser and Strauss) over how GT should be carried out (Cutcliffe & McKenna, 1999). The 'Straussian' approach was thus developed largely involving the work of Strauss and Corbin (Strauss's former student). Strauss and Corbin's approach provides clear guidance on how to organise and structure data through the coding paradigm, (Strauss & Corbin 1998; Robson, 2002; Corbin & Strauss, 2008). Although their guideline has been criticised as over-formulaic, (Cooney, 2010), it is particularly helpful to both novice and experienced researchers. The difference in Glaser and Strauss & Corbin's approaches is illustrated in the table below.

**Table 3.1: Summary of the differences between Glaser and Strauss & Corbin GT approaches**

Characteristics	Strauss & Corbin	Glaser
Research question	Developed from initial literature appraisal but could be modified as study progresses	Emerges during the process of study
Literature review	Initial and later literature review enhances and strengthens theoretical sensitivity and emergent theory respectively	Comparative literature review after fieldwork
Philosophical assumptions	Multiple realities, (relativism) socially constructed through researcher/researched interaction (researched as the experts in their lived experiences)	Positivist stance of objective and external reality, (realism) portraying the researcher as expert neutral observer
Data analysis	Well-structured and deductive data analysis process, (Coding)	Mostly inductive and unstructured data analysis process
Outcome of inquiry	Generation of a grounded theory or thick rich description	Insists on generation of a grounded theory

However, most researchers have taken little or no notice of this rift between the two founders' while others approached GT with suspicion ranging from calling it quick and dirty method, (Bryant & Charmaz, 2007). Nevertheless, some

quantitative researchers feel it is more rigorous and systematic than other qualitative approaches. It seemed to have met the need for a methodology through which the process of theory building could be tracked and validated, (Goulding, 2005). The other factor stems from the efforts to modernise the original GT to be more acceptable in the contemporary era of thought. In line with this contemporary thought, Corbin acknowledged that she no longer believes that theory construction is the only way to develop new knowledge, (Corbin & Strauss, 2008). She recognises that case analysis, thick and rich data description and storytelling are all important parts of research. However, the researcher should make clear from the beginning what they have set out to do.

In the 3rd edition of Strauss and Corbin's book, Corbin admitted to dropping a lot of dogma, flexed some of the approaches and explored how computers could enhance the research process. Though the use of computer programmes to support analysis of qualitative data has remained a subject for argument and objection by some qualitative researchers as will be discussed in the methods section. The initial grounded theory is termed 'classic' while the most recent by Charmaz is known as 'constructivist' grounded theory. Here Charmaz emphasized the importance of full engagement of the research subjects in the construction of the theory, (Charmaz, 2006). Charmaz acknowledges the interaction of the researcher and the research subjects and the subsequent interaction of the research with the data during the coding process, (Charmaz, 1990; 2003). In both situations there is an active engagement of the researcher. Hence my epistemological position of social constructionism and symbolic interactionism.

### **3.6. Strengths and criticisms of GT**

One of the major strengths of GT is that it can provide a rigorous foundation for qualitative research (Bryant & Charmaz 2007). Prior to the development of GT, qualitative research has been criticised as mentioned earlier as a weak and poor method of inquiry lacking in systematic approach, so GT was embraced as solution/answer to this criticism. However, the attempt to provide this systematic procedures to inquiry, particularly evident in Strauss & Corbin (1990) was greatly criticised by Glaser, (see table above) and also argued by Bryant and Charmaz as having the potential to serve as a mere recipe for carrying out GT.

Nevertheless, it was acknowledged as a guide to the novice researcher and other experienced researchers on how to go about GT as the use of GT depends on experience and skills of the researcher, (Bryant & Charmaz, 2007)

Charmaz acknowledged that GT may not be a straightforward method and researchers could be faced with conceptual issues, institutional and other issues associated with most qualitative research methods. The ambiguity of the guideline/criteria for evaluating some aspects of GT such as 'saturation, fit and theoretical sensitivity' has often attracted criticisms to the methodology. Charmaz, (2011) recognises that this unclear guideline may show lack of conceptual strength. Student researchers find this lack of clear criteria difficult while more experienced researchers may dismiss the guideline as mere formulae, (Cooney, 2010; Charmaz, 2011)

GT has also been criticised as a 'cop-out' route for undermining or avoidance of fundamental protocols for doing research which requires clear statement of problems, hypothesis, procedures and validity of the finding, (Titscher et al, 2000), as is the case in quantitative methods. This is not always the case. As mentioned earlier research is not just about the validity or the truth as these notions depend on ontological position but also a process that may provide good insight and conceptual innovation in understanding a phenomena and possible solutions to a problem. GT has actually helped to clarify some of the issues relating to qualitative research prior to 1990s, (Charmaz, 2011).

According to the founding fathers of GT, researchers should strive to take the data beyond rich descriptions to conceptualisation and theory. Some GT researchers have been criticised as just providing a rich grounded description of data in the name of GT, (Crotty, 1998). However, as mentioned earlier some notable researchers such as Corbin have acknowledged that the final aim of a research should not only be about producing theory but that rich and thick description of finding is also as important, (Corbin & Strauss, 2008).

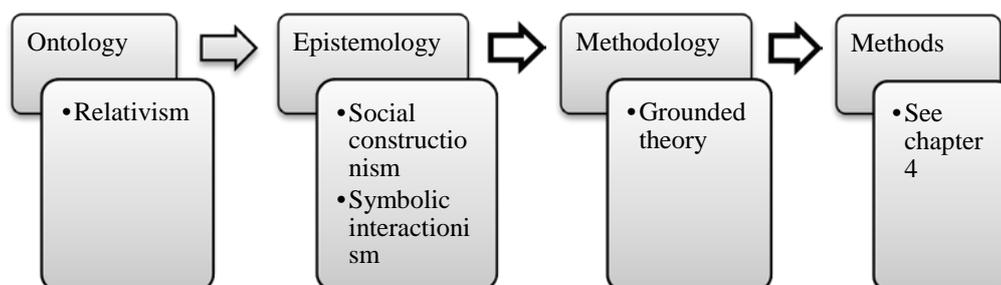
The neutrality or the passive role of the researcher during data collection and the primacy of data, (Glaser & Strauss, 1967; Glaser, 1992) have been the centre of criticisms and argument. These are seen to be more common in the positivist approaches (i.e. quantitative methodologies). It has been argued that

a researcher cannot possibly blot out personal experiences from the data collection process, (Thomas & James 2006). Bryant & Charmaz, (2007) criticised Glaser and Strauss as trying to outdo the positivists as they tend to ignore what and how data was collected. They acknowledged a controversy about the use of theoretical sampling; which was traditionally sampling for participant selection, rather Glaser and Strauss used it to denote a strategy for verifying emerging categories during data collection and analysis (comparative data analysis), (Bryant & Charmaz, 2007).

Generalisability has been cited as another major weakness of GT, (chapter 8). This criticism has seemed to come from the quantitative positivist group. Despite Glaser acknowledging that GT researchers could adopt objectivist stance, the positivists tend to reject it on the grounds that the findings of GT could not be generalised or replicated, or hypothetical (Bryant & Charmaz 2007). However, Charmaz, (2011) suggested discarding the 'metaphysical nature of reality' and taking a pragmatist view which considers the usefulness of the concepts rather than how true they are. According to Rorty, (1999) truth is not the main objective of human research but rather to reach an agreement about: what to do; goals to be reached and the best ways of achieving the goals. In other words, how useful is the theory and the concept, is it 'fit for the purpose' 'is it workable' rather than whether it corresponds to reality or not, (Charmaz, 2011).

The figure below summarises the philosophical/theoretical framework of this study before moving on to present the methods utilised.

**Figure 3.2: Summary of my philosophical/theoretical framework**



### 3.7. Summary of chapter 3

This chapter has outlined the key philosophical arguments relating to research in health and the social sciences. The arguments have helped in choosing the appropriate methodology for this study. The aim of this research is to find out the factors that influence participants' behaviour towards the NHSBCSP. The study of human behaviour and lived experiences can be a very complex task and requires an approach that will be able to capture these lived experiences from the participants' perspectives, although we can never capture these in entirety. Qualitative methodology was deemed the right pragmatic approach that will be capable of capturing some of these complex human behaviours. The process of qualitative research is inductive rather than deductive. This is as a result of the bottom up approach used in allowing the theory emerge and then shaped by experience gathered from the field while collecting and analysing the data, (Creswell, 2007).

The ontological assumption, relativism suggests that there are multiple realities and the symbolic interactionism acknowledges the special interaction between the researcher and the researched during the construction of the lived experiences of the researched. Social constructionism recognises that the experience of the researcher cannot be divorced from the social process but should be accounted for. These philosophical perspectives are well demonstrated in Strauss and Corbin's grounded theory approach hence the choice over Glaser's classical approach for current study. A brief history of GT was also out lined. The methods used in this inquiry will be discussed in the following chapter.

# Chapter 4

## Research design and methods

### 4.1. Chapter overview

The envisaged goal of an inquiry affects the method of inquiry. Inquirer's past and present perceptions also directly/indirectly affect the inquiry. The purpose of this chapter is to present the activities that were undertaken for generating data. They include the activities prior to data collection, during data collection and the tools used. The chapter has been organised in three phases. However, in practice they occurred simultaneously congruent with grounded theory approach, particularly phases one and two. The preparations made prior to field work is detailed in phase one incorporating all activities before approaching potential participants. These activities include: issues around literature review in grounded theory; ethical considerations/dilemma; ethical approval processes; the research site and the recruitment/sampling strategies. Phase two provides an overview of the field work; the process of data collection, the research setting and the research relationship. Finally, phase 3 presents the data analysis process, the necessary steps taken to enhance rigour and maintain reflexivity and the summary of the chapter.

### 4.2. Phase one: Preparation before field work

#### Literature review in GT

Literature review was one of the initial activities carried out prior to approaching research participants. A brief outline of some arguments regarding preliminary literature review in GT was presented at the beginning of chapter 2. In this section, rather than dwelling too much on the arguments against initial literature review, (Cutcliffe 2000; Charmaz, 2006), the usefulness of preliminary literature is discussed. Given the aim of the current study which is to generate possible explanations of factors influencing uptake of the FOBt, GT was chosen for the inquiry as it aims to generate possible theories and models which offer possible explanations of people's behaviour and lived experiences regarding a given phenomenon. Classical grounded theorists such as Glaser as mentioned in chapter 2, argue against conducting literature review prior to collection; warning

that literature review could introduce preconceived ideas which could lead to the forcing of data during collection and analysis, (Glaser & Strauss, 1967). This could lead to researcher 'bias' i.e. generating themes from literature instead of from the emerging data. Theory should be allowed to emerge from the data rather than from preconceived ideas. Corbin & Strauss, (2008) advises against being overly immersed in literature prior to data collection and cautions against allowing it to over influence the process which could constrain or even stifle the researcher 'leading to literal paralysis', (Becker, 2007; Corbin & Strauss, 2008). So literature should be used cautiously and should not lead the researcher. (Becker, 1986; 2007)

Nevertheless, preliminary literature could be useful in many ways as suggested by Corbin & Strauss, (2008, pg. 37):

- Source for making comparisons: literature should not be used as data per se but concepts derived from it could be compared with the data at the property and dimensional level to identify similarities and differences. For instance 'positive attitude' towards cancer screening in general but at the property and dimensional level have many differences for 'cancer survivors' and 'victims of cancer' depending on their previous individual experiences.
- It can increase researcher's sensitivity to subtle nuances in data. The recurrence of certain concepts from literature and subsequently from data demonstrating their significance which may not be possible without prior knowledge. However, researchers need to constantly question whether the concepts are truly derived from the data or from concepts which they have become very familiar with. Thus thinking 'outside the box' enables appropriate judgement.
- Provision of questions for initial observation and interviews to show overall intent of the research. Although these initial questions might change over the course of the investigation; they are useful in satisfying ethical committee.
- A cache of descriptive data without much interpretation: A pool of concepts and themes from other relevant studies may be useful in a researcher's investigation to stimulate thinking and sensitivity to what his/her current data is saying.

- Stimulates questions during analysis, particularly when there is a discrepancy between the emerging finding and those in technical literature. The researcher is stimulated to ask: 'What is going on?' Am I overlooking something important?' Are conditions different in this study? and 'If so, how and how does it affect what the researcher is seeing'
- Suggestion for theoretical sampling. Technical literature might suggest areas for data collection which the researcher has not thought of.
- Confirmation of findings. Findings on the other hand could identify flaws in literature (i.e. incorrect, simplistic, partial explanation of phenomenon). Locating findings within published research does not only show scholarship but also allows extension, validation and refining of knowledge in the field, (Corbin & Strauss, 2008)

The important issue to note is not whether we use our previous knowledge but how it is used. Researcher's knowledge and experience which come from profession, literature, age, gender and culture enable sensitive response to what the data is saying, (Corbin & Strauss, 2008). I agree with Corbin and Strauss that prior experience could hinder correct reading of data as well as enhance quick understanding of the significance of certain things in the data. Therefore researchers need to develop 'sensitivity' which comes from experience. This section continues next with measures taken for obtaining ethical approval for the present study.

## **Ethical issues**

In any research, accessing research sites and participant recruitment may raise some ethical issues that need to be well considered and dealt with where possible before conducting the actual research, although some issues may not be anticipated. As a result of this, the university has a set of approval milestones that need to be sought and obtained before undertaking any research project. Hence the initial practical step was to go through the University of Northumbria internal peer review process. The initial project approval, (IPA) (appendix 2) was obtained by submitting a written study protocol/proposal. The North East, Yorkshire and Humber quality assurance reference centre (NEYHQARC) for cancer screening is a co-sponsor of this research and their input towards the proposal process ensured its potential

relevance to policy and practice improvement. As soon as IPA was obtained, university ethics sub-committee approval was sought and obtained (appendix 3) after making necessary amendments as recommended by the committee. This internal review process was very useful as the feedback helped provide a strong base for the subsequent external submission and review by the NHS ethics committee. For instance, the university ethics sub-committee advised that the consent form should be amended to include letting the participants know and agree that the output from the research could be used for academic and publication purposes. It also helped to risk-assess the research and to develop ways of dealing with any anticipated issues during field work.

The next stage was to apply to the regional NHS research ethics committee, (REC) (appendix 4) and the research and development department, (R&D) (appendix 5) of the identified research site. This later process is very necessary particularly where the research participants are NHS patients. It is a widely held view that health research and interventions should seek to promote beneficence and minimise malevolence which means that there should be more 'good' than 'harm' arising from research. In order to make sure that the ethical principles of beneficence and justice are maintained the ethical approval processes has to be undertaken. The final ethical process for this research was to attend an ethical review panel meeting where ethical concerns were raised and addressed. I attended this ethical review meeting with my principal supervisor. One of the issues raised was how to make sure that study invitation letters were not sent to deceased participants as this might cause distress for the relatives. Due to the nature of this research, it was felt that there will be no significant harm to participants. As soon as this issued was clarified favourable ethical approval was granted, (appendix 4).

I found the ethics processes very helpful although some people may see them as a hurdle to be jumped over and as a 'ticky-box' type of stage they had to pass in the research journey. I did not see it this way as the research involves human subjects and I wanted to make sure that harm to my potential participants are minimised as much as possible. Nevertheless, the ethics process could be seen as posing a delay to research particularly where time is involved. Research ethics process could take between four weeks to a year as

result of different factors. In the current study, the NHS REC process took four months in total because there were no major amendments to be made.

There are also ethical issues around the safety of a lone worker conducting interviews in peoples' homes. The NHS and the University's lone worker protocol were adhered to, to ensure the safety of the researcher and the need to report any untoward incidence to the supervisory team. For example I always informed the supervisory team before going into any home and after interviews had finished. Due to an incident that occurred with another researcher, my supervisor advised that I also inform the supervision team inside a participant's home so that the participant is aware rather than before going in.

In addition there are also ethical issues in relation to participants. As noted by Corden & Miller, (2007) research involving human participants and the personal identification data could pose a number of ethical issues. Recruitment, obtaining consent, confidentiality, data protection and management, potential harm, avoiding coercions and distress are some of the ethical issues that could be encountered in research involving human participants and their personal data. Lofland et al., (2006) stated that it is an obligation as well as respect for researchers to ensure confidentiality of research participants. This was done in the current study by anonymising participants' personal identifiable information with pseudonyms. These therefore need to be addressed. As mentioned earlier, obtaining ethical approval helps to identify potential issues and measures to address them. However, Guillemin & Gillam, (2004), noted that there is a difference between this procedural ethics and ethics in practice. They noted that ethics in practice is an on-going process which remains with the researcher and that most issues may not very easily be anticipated notwithstanding the approvals gained. Nevertheless, the procedural ethics and the vast literature on ethical issues encountered by previous researchers could provide useful ideas which current and future researchers could draw upon that may help them to prepare in advance, (Heath, 2007).

### **Informed consent and right to withdraw**

In order to obtain informed consent, an information pack which included letter of invitation (appendix 6), study information sheet (appendix 7), reply slip (appendix 8), informed consent form (appendix 9) and summary of result form

(appendix 10), was developed and given to participants to ensure that they have all the necessary information they need when deciding whether to take part or not. They could also discuss the information with any significant other. Contact number of the supervision team was provided should the potential participants need further information or have any concerns. Verbal consent was also obtained at every interview and it was iterated to participants that they were under no obligation and had the right to opt out at any point if they no longer wished to take part. It was also made clear that withdrawal would have no effect on any health service that they receive, particularly if they felt distressed or felt that their privacy is being invaded, (Robson, 2002). At this point their details would be removed from the study. However, any data already collected would be used in the analysis as stated in the information pack.

A stamped envelope was also included in the information pack to ensure that participants do not incur any financial expenses. Participants were required in the reply slip to tick 'yes I would like to take part' and then provide a contact information through which the researcher could make contact to arrange interviews or 'No I will not like to take part' in which case there will be no further contact. During the telephone contact participants were asked a suitable time and where they would like to be interviewed after explaining the options of a booked private room in community centres such as local library or their homes. All of the participants expressed a preference for being interviewed at home. There was also contact information should they wish to contact the research team for clarification. Most of the participants sent back their reply slip and a signed consent form at the same time. However, the consent forms and the information sheet were revisited at the beginning of each interview. This was to make sure participants understand the details of the research and that they were still happy to be interviewed and to clarify any question that they may have. Participants were also required to fill in the summary of results form if they wished to receive the summary of the study findings (appendix 10).

### **Confidentiality and data protection**

It is an obligation to maintain confidentiality of participants' personal identifiable information. Confidentiality and data protection were maintained as per data protection act 1998. Paper and electronic data were encoded, anonymised and

password protected to ensure confidentiality and privacy of participants. Once the raw data containing participants' personal information had been coded, they were thereafter identified by codes and pseudonyms. Information cannot be given to a third party without the consent of the participant to maintain privacy. All data collected were stored securely in a locked storage and managed appropriately. However, confidentiality could be broken where potential harm is involved. It was made clear to participants in the information pack that during the course of interview if there was information or action that might lead to potential harm of the participant or others, that the researcher is under obligation to report this. This will first be reported to supervision team who decides if there is any course for action and participant informed if any.

### **Approaching research sites/negotiating access**

Only one research site, the NEYH BC screening hub, was involved by default. This is because the focus of current study was participation in BC screening. As already explained in chapter 2, the hubs organise the mail out, the testing and the call back activities of the programme. The screening hub for the NEYH is located in the North East where I live and study which minimised travelling time during the planning of participant recruitment. The NEYH BC screening hub was selected as a local collaborator at the point of REC and R&D ethical approval applications. The aim was for the hub to recruit the participants. This is because the potential participants are NHS patients and due to data protection policy the researcher is not allowed access to patients' personal identifiable information until their consent is obtained. Thus I was removed from the initial recruitment. This is deemed a good research practice, (Hegney & Chan, 2010) as it ensures that there was no coercion on potential study participants which enhances the quality of the study. Once all ethical approvals were obtained, and letter of access given to me by the local NHS research site, the hub was approached for the recruitment of potential participants.

The data analyst at the hub was identified as the appropriate staff to help with recruitment. Together with the analyst, I examined the FOBt response rate for the first round of the programme. I felt that it will be important given the aim of the research to sample participants from areas of low as well as high uptake. This is to ensure balanced representation of people's views and voices and to

make sure that certain parts of the region are not marginalised. I used the word balanced as I recognise that it will be difficult to obtain equal representation. The screening response map showed that uptake was lower in the low socio economic areas. We also looked at areas with higher concentration of minority ethnic groups to try and make sure that this group was represented. The data analyst then processed the details of the potential candidates from the central response register using the study inclusion and exclusion criteria (Table 4.1). Recruitment letters were then sent out as detailed below.

**Table 4.1: Inclusion and exclusion criteria**

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Men and women aged 60-69years (this research focuses on the first round of the programme when screening only included this age group); Who live in the North East, Yorkshire and Humber area; Who completed and returned the FOB test kit in the first round; Who did not complete and return the FOB test kit in the first round; Who have indicated willingness to take part in the research via return of reply slip; Who seem able to consent.	People awaiting result of their FOB test. People with positive FOB test. People awaiting/undergoing further tests and some form of treatment/procedures as a result of the FOB test. People seeming unable to give consent. People that need interpreter.

### **Recruitment of participants**

A total of 400 participants were identified and 395 invitation letters were sent out. Five were abandoned as they did not meet the inclusion criteria. The large numbers of invitation letters were sent as I anticipated a response rate of around 10% will give adequate number for the study. The recruitment sample was informed by the available data generated from attendees and non-attendees on screening register (e.g. gender, ethnic minority group, socially deprived areas) at the hub of the NEYH BC screening services. Recruitment age was those between the ages of 60 and 69, this is the age range for the initial round of the screening programme although it has been extended to 75 years. However some of the participants who completed the initial round are now in their seventies. Only the people with a negative FOBt were included in

order to reduce any risk of psychological or emotional harm. There is a risk that those who have had positive results and are undergoing treatment for BC might be exposed to emotional and psychological harm through opening up sensitive issues in their lives; and it would therefore not be appropriate to include them.

The initial plan was to recruit and interview between 20 and 60 research participants from high and low BC screening uptake areas using purposive sampling strategy. This number was deemed achievable and adequate to reach data saturation. Data saturation is the point in data collection where there are no more new ideas evolving about the emerging theory. Corbin and Strauss, advise collection and analysis until theoretical saturation is reached if the study aim is to generate theory or rich thick description, (Corbin & Strauss, 2008). There seem to be a lot of arguments around determination of saturation and sufficient number of interviews. Creswell, (2007) advocates that between 20 to 30 samples will be adequate in grounded theory in order to develop a well saturated theory while others suggest up to 60 (Charmaz, 2006). I planned to conduct between 20-60 interviews, in this way I would be able to manage any eventuality that may arise as result of individuals withdrawing from the interview and also the risk of the study finding being dismissed as a story of few voices, (Yates, 2003). According to Corbin and Strauss, saturation could be jeopardised by time, resources and availability of participants which could affect the quality of the theory, (Corbin & Strauss, 2008).

The Primary Care Trust (PCT) and general practice surgery map for the response rate revealed that areas of low uptake were mostly the deprived low socio-economic group while the higher uptakes were the more affluent areas. Hence data was sampled via the data analyst at the screening hub looking at these and also at areas of higher concentration of ethnic minorities. This was to aid distribution of invitation letters to participants and to help obtain maximum variation in the sample in terms of areas of low and high uptake, gender and possibly ethnic minority. Charmaz suggests that variation in sample spread can enhance the conceptual strength of the findings, (Charmaz, 1990). Obtaining a wide spread of participants would strengthen the richness of the views and opinion captured. The response is summarised below.

Total number of letters sent = 395

Response received = 106 replies

Number declined participation in research = 66

Number interested in research = 40

Number opted out = 14

Final number included and interviewed = 26

Men = 10

Women = 16

Forty individuals expressed interest by providing their contact details in the reply slip (appendix 8). The participants were then contacted by the researcher to arrange a mutual convenient place and time for interview. The overall number of participants interviewed was 26 out of the 40 that expressed interest. There were 10 men and 16 women. The recruitment was influenced by a number of factors. For example: some people were undergoing further investigations; some phone numbers and emails provided were incorrect; others were not able to take part due to inconvenient time and other commitments. This contributed to the difficulty in obtaining variety in the sample of participants. However, every effort was made to interview all participants interested in the research even when data saturation was reached. There were no participants from ethnic minorities or from people who have continued to decline the screening. Two participants declined in the first round but have completed subsequent screening invitations. I feel that the reason for low response rate from non-attenders of FOBt may have been as a result of negative attitude towards the FOBt. People who may not like the idea or not feel susceptible to BC are likely to show low enthusiasm in research involving the same. Those who English is not their first language may have found it difficult to opt into the study. However, it would have been interesting to have participants who have continued to decline the screening, which is in the third phase now, and from ethnic minorities.

It is my opinion that the recruitment strategy made it challenging to access this group. The use of interpreters may have helped to recruit them. Also, recruitment via GP surgeries may have been more successful because patients have already built good relationships with their doctors and tend to trust them

more. Nevertheless it has been reported that removing the researcher from the initial consent process until they have decided and are willing to take part helps to minimise coercion, (Hegney & Chan, 2010) and enhance the quality of the research. The aim of my chosen methodology - grounded theory, is not about generalizability of findings as in quantitative approaches but a rich explanation of each individual experience which is then interpreted to the next level of conceptualisation; emergent theory which is still grounded in the data. Grounded theory is about theoretical sensitivity, theoretical sampling and constant comparative analysis leading to a credible theory which provides a nuanced description of the phenomenon under study.

### **Sampling strategy**

In the following sections, I will first of all present the general sampling strategy employed for participant recruitment in this study. Secondly, theoretical sampling which is also used more specifically in grounded theory will be explored. According to (Goulding, 2005) sampling procedure in grounded theory can be quite different from other qualitative methodologies.

### **Purposive sampling**

Purposive sampling is used in most qualitative studies and is often carried out before data collection begins, (Coyle, 1997). Purposive sampling involves recruiting participants who are by default best suited for the study; the people who have experienced the phenomenon under study. For example, in this study of factors influencing uptake of BC screening, the purposive sampling strategy was the recruitment of those who have had the experience of the screening or at least been invited for screening. This was one of the criteria for inclusion. However, in GT sampling strategy also takes additional format.

### **Theoretical sampling**

Theoretical sampling is a sampling technique which is guided by ideas of importance for the emerging theory, (Corbin & Strauss, 2008; Holloway & Wheeler, 2010). In the current study, theoretical sampling involved the initial interview of those participants who are best suited for the inquiry as mentioned above, (purposive sampling); who provide the initial early insight. The initial interviews were then analysed by open coding, (figure 4.2) which looks for

provisional meanings and concepts in the interview. Further samples can evolve as the researcher compares cases in the data, (Strauss & Corbin, 1998), and then makes a decision on where to collect the next data to explain and clarify the dimensions of the emerging concepts to aid in clarifying understanding, (Glaser, 1978). Traditionally, further samples are theoretically identified in relation to individual, locations and type of questions as guided by the emerging concepts, (Goulding, 2005). However, it may not always be possible in practice to adhere to this principle in its entirety. This was recognised by Corbin and she gave a series of ways by which researchers could conduct theoretical sampling such as during data collection, (Corbin & Strauss, 2008). In a nut shell, theoretical sampling is based on the emerging theory, (Heath, 2007) which guides the whole research process, (Duffy et al., 2004). The emerging theory informs or provides the lead for subsequent data collection, and the main focus is on situations.

In the present study, it was not possible as a result of different practical issues related to ethical approval process to theoretically select participants, rather data were theoretically collected by way of constant comparative analysis, (section 4.3). The analysis of the initial interviews guided the subsequent interview, which according to (Glaser & Strauss, 1967) is essential to the inductive-deductive process of GT. Theoretical sampling leads to the discovery of variations and similarities in experiences of research subjects over the given phenomenon. It offers the flexibility to follow the clues from the analysis which helps to develop variation and density into the findings, (Corbin & Strauss, 2008)

An example of theoretical sampling in the current was when participants identified 'stoicism' as a reason for men not seeking medical help and as a possible influencing factor on screening. I decided to find out if this was a shared reality and had to explore more about the issue in subsequent interviews until this was theoretically saturated. Theoretical sampling is not a rigid technique. There are flexible ways of carrying it out as long as it is properly done; remaining open and sensitive to the data. It is not just about the location, or the people but also the data and the emerging theory. It has been noted that sampling procedure in GT is used to examine how concept differ along a

dimensional range rather than the measurement of the distribution of participants along some dimensions of a concept, (Corbin & Strauss, 2008).

Furthermore, theoretical sampling based on locations was not possible as a result of ethical issues. As mentioned earlier, the participants in this study were NHS patients and the research collaborator was an NHS site. Due to NHS ethics on data protection and confidentiality I could not have access to participant's details until they opted into the study. According to Corbin & Strauss, (2008), I was not a 'lucky' researcher who has full and unlimited access to research sites to choose where and when to find comparable situations that will aid the elaboration and extension of the concepts that are emerging from the data. The argument may remain that qualitative researchers may never be sure of where and who will provide the variations they look for in the emerging concept, rather they are guided by what is within reach (convenience) and sensible logic which perhaps provides the answer.

### **4.3. Phase Two: Conducting field work**

#### **Data collection**

Data collection has to be given proper consideration while undertaking this GT inquiry. Even though interview method is congruent with GT, it may however be a challenging task choosing the type of interview, (Duffy et al., 2004). There seem to be questions of what should be the best interview method in grounded theory approaches, this question was addressed based on the purpose of the study. In this study, I employed one to one semi-structured interview for data collection after due consideration of other types. I chose the one-to-one method as a result of the nature of the topic under study. I felt that focus group may not be ideal because participants may be embarrassed to share their experiences regarding the BC screening. Haslam, (2012) stated that defecation/bowel movement is one of the cultural taboo subjects which people are not very keen and comfortable to engage in open discussions. Therefore, I might not capture the true reality of this lived experience. Sensitive and distressing issues may also arise which may not be appropriate in a focus group. In order to capture as much as possible participants' experiences and views I thought it will be best

to make the participants as relaxed and in control as possible and to create a good rapport through one-to-one interview. In addition, observation would not be appropriate, since this is a retrospective description of past experience.

Semi-structured interviews help researchers gain more focused information by asking specific questions. He/she opens the discussion, listens and uses prompts to guide the respondents, (Duffy et al., 2004). The use of this method also allows the flexibility of exploring issues that are particularly significant to the research question, and the clarification of comments made by participants, (Rose, 1994). This means that the researcher could ask the same key questions each time. Fielding, (1994) noted that the depth and sequence of exploration is always flexible and the researcher could also draw from prior knowledge.

Even though I chose a semi-structured interview, I found out that the beginning of the interviews and initial data collections were more or less following an unstructured format. Participants were eager to tell their stories. Having no fixed sequence of questions allows the participants to define their reality in their own way; their personal issues and concerns are better captured and may lead to the discovery of issues that the researcher had not even considered which might be significant to the inquiry, (Fielding, 1994; Guba & Lincoln, 1981). Glaser & Strauss, (1967) advised that during the early stages of grounded theory research, it would be useful to listen to the participants define their own world of reality (tell their story).

As mentioned in previous chapter, GT is often used where little is known about the phenomenon under study, (Morse, 1994a). Given the limited research on the topic under study and the location, I needed to gather more focused information which can only be obtained by asking specific questions. Semi-structured interview is deemed the appropriate approach in achieving this goal and is consistent with GT methodology. Therefore I developed an interview topic guide, (appendix, 11) as a guide for the questions to be asked, (Fielding, 1994; Wimpenny & Gass, 2000), rather than rigid set of questions as in structured interviews.

Semi-structured interview gave me the flexibility to explore new ideas, which are significant to the research question as they emerged (Rose, 1994; Duffy et al., 2004). Fielding, (1994) suggested that the questions could be phrased or asked in any format. I used the questions to invite the participants to tell their lived experience of the screening programme. I was very careful as Glaser suggested, not asking direct questions as this could 'force' data instead of allowing data to emerge, (Glaser, 1992) and might cut off interesting leads, (Charmaz, 2003). Participants' responses could be influenced by the way questions are framed and paced. Charmaz acknowledges that interviews in grounded theory are directed conversations, (Charmaz, 2003). Therefore, I was very careful; for example, as a novice researcher, I asked participants whether they took the screening test or not as my open question. I quickly realised that this might affect the quality of the data or force data as the participants may think that being a nurse, I might be an advocate of screening and might say things in favour of screening. As a result, I changed this to come later on in the interview but general questions about their experience and views of the screening test were asked first.

I was also aware of my nonverbal communication which may have a wrong effect on participants' responses and might introduce interviewer influence, (bias). In order to minimise this influence I practiced my verbal and nonverbal communication skills as a mock interview with my fellow students and at home with my family asking them to critically appraise my conduct and make suggestions. This practice helped me to be more confident as well before commencing actual data collection.

Recording of the interview was another practical and technical issue to be given due consideration. The interviews were audio recorded and later transcribed. There have been arguments and criticisms over the use of electronic tools for data collection. They have been criticised as being intrusive to the process and the possibility of developing technical faults, (Lincoln & Guba, 1985 ). However, Charmaz, (2003) suggested that the devices can be a more useful tool in capturing data than hand written notes. It was explained to participants and they all gave their consent to be audio recorded. Nevertheless important striking points were jotted down during interview, including comments made after the audio recorder has been switched off.

As a result of the critical issues raised above, it has been advised that prior to commencing data collection, researchers should plan well ahead all the practicalities so that the quality of the data is not affected by any technical issues (Rose, 1994). In relation to this I made sure that the digital recorder, spare batteries and any other equipment I needed were properly checked to ensure they are in good working condition as advocated by Easton et al., (2000). As suggested by Duffy, et al., (2004), I also developed a checklist to remind me of practical things I need to do before the interview, during the interview, and after the interviews. For example prior to any interview, I had to make sure that the recorder is switched on, the battery has sufficient life, and a new file has been selected for the fresh interview and at the right volume. The interview guide, (appendix 11) acted as a good guide for the interview questions. However, questions were constantly rephrased to enable the participants to understand what was being asked and participants were offered opportunities to raise issues of importance to them that are not covered in the interview guide. The interviews were conducted over 4 months.

### **Research setting**

There was the potential that sensitive, emotional and unpleasant issues may arise during the interview given the topic. My priority was to make sure that participants were as comfortable and relaxed as possible during the interviews. I was also aware that distractions would not be good given the nature of the topic under study. These issues were well thought about which was why I felt that public setting particularly focus group might not be appropriate. Conducting the interviews in their own home setting appeared to have made it more relaxing and comfortable for the participants

The advantages were that they were not inconvenienced unnecessarily as they did not have to travel. It appeared to make them feel more in control with some confidence that they were not being taken advantage of. There was also less distraction which enhanced openness. It has been noted that a home setting interview could lead to increased openness but also challenge confidentiality, (Yee & Andrews, 2006). Many unanticipated ethical and methodological dilemmas could arise as a result of conducting interviews in participants'

homes. Home setting represents family personal space, therefore it may be difficult to control who was present, the length and conditions of interview.

I noticed that when I was in the participant's home, I felt that they are in control in a good way, it is their space, and this will be very good for the field work as mentioned above. However, there was a constant challenge and struggle on my part as acknowledged by Yee & Andrews, (2006) to be a good guest as well as remain true to my professional role of a researcher. I had less control over the interview conditions. Nevertheless, it is of paramount importance that the autonomy of the research participants is respected. For example, I struggled when a participant chose to be interviewed in a conservatory. I was conscious that it was raining and the noise of the rain on the conservatory roof will adversely affect the quality of my recording. I had to be a good guest by respecting the wish of my host. It was very difficult to transcribe but not as bad as I had thought. Secondly, there was also problem of having relatives around which could have consequences on confidentiality and informed consent, though not as much as could be expected in a public setting. Maintaining privacy was not much of an issue as family members left the room once the interviews were about to start. Nonetheless, one participant's spouse commented on the topic at the end of the interview. In order to maintain ethical principle of informed consent, I did not include this in my analysis as there was no provision made in my protocol about dealing with this issue. This family member did not receive the research information pack and does not know the details of the study. However, Yee & Andrews, (2006) argued that in a family space other family members have the right to be present during the interview and could also be used to augment the actual respondent's response. However, Yee and Andrews acknowledged that family members could in fact contradict the respondent response posing a challenging task to the researcher. In this case sensitivity was more important to me than practicality

Another incident was where pets are concerned. Personally, I like pets but get quite scared of dogs and would rather they do not distract the interview. Participants seemed very proud of their pets, always eager to show them off to people and I was not an exception. One of the participants might have noticed that I was quite scared of the dog, so had to take the dog into another room while most of the others kept their pets in the same room which was a constant

distraction to the interview. I had the option of controlling the interview conditions by asking for a more quiet location. However, I chose to remain a 'good guest' as I was not sure how it will make them feel in their own homes. My priority was to ensure that their comfort and autonomy are maintained which are perquisites to a good researcher-participant relationship. Therefore the researcher's command of the research in a home setting is reduced.

### **The research relationship**

In qualitative research such as this, it is not possible for the researcher to be removed from the object of the study. In quantitative inquiry where the outcomes of the research could be objective, replicated and quantified it is possible for the researcher to be removed from the object of the research, (see chapter 3). Human subjects and their behaviour may never be predicted and replicated, instead there needs to be a mutual relationship between the researcher and the researched and this brings a lot of 'baggage' with it.

Qualitative research is a social event which is ethically locally situated in each interview, (Hammersley & Atkinson 1995; Kaplan & Glaser, 1996; Lincoln & Denzin, 2000). It involves a social interaction between the researcher and the participants, the researcher engages in developing interpersonal relationship with the researched without which the research might not be successful. A good interpersonal relationship is critical and paramount to data collection, (Eide & Kahn, 2008) in order for the dialogic process of interview to take place. During this process of dialogue, it may be inevitable that experiences, stories, and memories are remembered and reconstructed posing potential dilemmas and controversies for the researcher. The dilemma may vary according to the skills, knowledge and professional background of the researcher.

In the current research, I had the dilemma of multiple identities, (Blackwood, 1995) as a nurse, a researcher, a mother and a woman. Revealing my research identity was always the first and easy thing to do as well as my biographies which were self-evident. However, my other personal identities such as profession, motherhood and country of origin were an awkward one which only came from participants. When these personal questions are asked, it meant revealing more of myself than I am comfortable with but I felt obliged to reciprocate as not responding could be viewed as exploitation in which the

researcher only takes without giving back, (Crozier, 2003). Therefore I tried not to reveal too much as it has been warned that too much bonding through personal stories could lead to misunderstanding and assumptions which could hinder the interview process, (Vincent & Warren, 2001) although it is not always easy to take a detached stance particularly when participants life stories resonate with the researcher's.

Having lived in the North East for more than a decade, it was easy to find a common experience with which to build a rapport. Also, I felt that my status as a female student from minority ethnic group instigated confidence in my participants who are mostly from white background. I was anxious of the effects and signals these might have on the relationship and the research as a whole. As a woman, I was sceptical of gender issues, for example how the men might feel having a woman interviewer. This is because traditionally, women are expected to play attentive and assenting role, (Green et al., 1993). Eventually, this was not a problem. I was surprised that the participants being older than I am particularly the men were happy to share their experiences.

The primary aim of the study was to find out about the lived experiences of my participants regarding the FOBt and factors that affect the choice that they made about it. As acknowledged by Berg, (2001) qualitative research is a social interaction between the researcher and the researched which takes place in the social world. In order for this interaction to be mutual I needed to make necessary effort to develop a good relationship. However, sometimes interaction may be unequal to some degrees. For example, participants may see the researcher as a professional who is more knowledgeable. This is why it has been advised that attention should be paid to how researchers present themselves as this might affect the relationship, (Berg, 2001; Gerson & Horowitz, 2002). As a result, I was aware of the fact that I was interviewing people in their home setting and they may be in casual clothing. In order to identify with them and build better rapport I dressed moderately but neat.

Appropriate contact via telephone and email was another measure I used to maintain good relationship. As soon as interests in the study were confirmed by sending contact details, participants were contacted to organise and agree a date for interview. Every effort was made to conduct the interviews as soon as

possible. At the end of the interview, participants were sent thank you cards. Some of the participants acknowledged the receipt of the card via email.

One of the ethical principles of research which deals with human beings is that of benevolence; doing 'good' and causing no harm. This is congruence with the nursing ethics of assuming a caring role. As a nurse I am expected to care for these participants who are involved in the NHSBCSP. As a researcher, the level of this care is not clear cut. The extent to which I can distant myself from the participants was a constant dilemma. My caring role may push me towards being seen by the participants as promoting the NHSBCSP, as a form of health protection and disease prevention. In practical terms, I don't see myself from that angle. This is because part of nursing care is providing patients with the right information and allowing them to make their own choice (autonomy), (Beauchamp & Childress, 2001). Most of the participants asked for further information as they saw me as one who would provide answers to some of the burning questions they have about the FOBt. For example one of the participants asked whether the test could be completed any time outside the time frame given for the return of the FOBt as the kit had always arrived while she is away on routine family holiday.

As a nurse I was tempted to say yes because I knew that that it is ok as long as she eventually completes it. On the other hand as a researcher, I know that the screening hub expects them to return the completed test within certain time for record and statistics purpose. So I advised her to contact the hub and let them know about her situation as they may be able to change the date they send out her kit. This participant seemed very happy with this advice as she never thought about it that way. This incidence actually made me think that as a qualitative researcher it is a good practice according to Eide and Kahn, (2008) to have a good understanding of the phenomenon under study, issues around it and current literature as well as means, resources and connections with which to assist participants as the need arises. Another participant asked about the reliability of the test, I had no choice than to give honest answer as the test could be 'hit and misses and not 100% accurate. I gave the participants information leaflet and advised to contact the GP or the hub if he needs further information. There was also the issue of accepting offer of refreshments from participants. Here my social interactions with the participants competed with my

professional role. Having lived in the region a long time, I knew that polite rejection of cup of tea will not constitute any problem. Yee & Andrews, (2006) argued that accepting simple refreshment shows that the researcher is relax whereas in some culture rejection could be misunderstood.

In addition, there were issues around the therapeutic aspect of interview which may vary depending on the level of rapport built between the researcher and the participant, (Eide & Kahn, 2008) and which the researcher might not be equipped to deal with. Some of the participants who live alone are mostly elderly and have some degree of disability that limits their movement; I realised that this group found the interview to be rather comforting and therapeutic. A participant informed me that she lives alone and this is quite lonely for her and that I have made her day as she has no one to speak to. Her interview finished in 45 minutes but she engaged me in discussion, I had to stay another 15 minutes chatting with the lady as I felt that abandoning a lonely woman as soon as I had completed the interview may be unethical. It could be perceived as using her (exploitation) to get what I wanted - the data, (Yee & Andrews, 2006). This actually made me ponder over Robley, (1995), relating to the extent to which people are 'used' as a means to further knowledge. This participant said I could come again if I wished and would always be welcome. This touched me quite a lot as things we take for granted are so much valued by others. However, it would be unethical for me to just turn up at her door. Rather, as a 'good guest' I suggested community centres such as the leisure centre, day centres and the local library where she might be able to socialise.

During the course of data collection, I was constantly aware of my position as a researcher that could influence the research. There is the need for me to maintain research stances and at the same time remain true to the nursing caring role. This is because the interview process is an active process which may not only evoke memories and reflections but could also bring about unsettling issues and life changes for both the researcher and the researched. It has been acknowledged that the researchers bring in personal and social self to the research process, (Reinharz, 1997) but Yee & Andrews, (2006) advice guarding against sharing beliefs/values or emotional attachment with the participants. They later recognised that it can be difficult to maintain the necessary appropriate distance. Letherby, (2000) suggests that identifying with

the participants' experiences not only creates good relationship but may also bring to the fore better insight to the social process. However, this needs to be minimised if the researcher is to be able to mine raw data, refine and polish it into a coherent narrative which could be disseminated through publication for wider audience. However, some researchers are able to reduce to a greater level the amount of self they bring into qualitative research than others.

I tried as much as possible to maintain a safe boundary and distance from the participants in order to allow them to tell their stories without leading. However, it was not always possible to completely distance myself. It is good practice that these instances are reported as they enhance transparency and quality of the research process. For instance, when a participant had built a good rapport and saw me as a friend they were able to share personal things which are very close to their heart - the pre-term birth of their grandson and how the NHS was very wonderful to them and the care that they received. I had an unconscious empathy as I had the same experience having had my youngest child pre-term too. We both shared our story (self-disclosure). This genuine exchange of personal and sensitive information through empathy can enrich the quality of the data, (Sixsmith et al., 2003). However, this happened at the end of the interview and has not affected the story that he shared about the BC screening.

This chapter continues with data analysis in the next section.

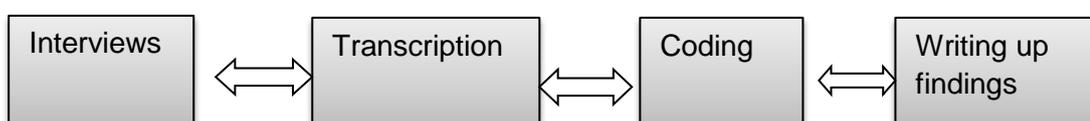
## 4.4. Phase Three: Working with data

### Data analysis

Analysis is a dynamic process of brainstorming, trying out different ideas, elimination and expansion of data (i.e. generating and developing concepts) before arriving at a ‘feel right’ conclusion. It turns raw data into concepts that promotes better understanding and contribution to professional knowledge. In GT, data collection and analysis is a concurrent process. Data is analysed simultaneously as it is collected, (Strauss & Corbin, 1998; Corbin & Strauss, 2008); this is to allow the emergent themes to direct subsequent data collection. Strauss & Corbin, (1998) noted that beginning researchers might be so enthusiastic about data collection that they conduct a series of interview without concurrent analysis. However, they highlighted that there are situations where it may not always be possible to analyse previous interview before conducting the next one. Recorded interviews need to be transcribed first and this is a lengthy process. In this case a researcher will make every effort to keep diaries and theoretical memos which aids in the subsequent interviews.

On two occasions I was not able to transcribe interviews before the next one (the participant was going on holiday and that was the only availability, and I needed to squeeze in that interview). I had to listen to the interview recording over and over again and wrote theoretical memos before proceeding to the next interview. This was very helpful. Other times I made sure I leave enough time between interviews (Duffy et al., 2004; Corbin & Strauss, 2008) to aid the comparative analysis which is a core feature of GT. GT analysis follows a typical iterative pathway – interview, transcription, coding, preliminary analysis then another interview, (figure 4.1) with the aid of theoretical sampling and memos. In this way the previous interviews I did were able to inform, help develop and suggest some focus points to be explored further in the next interview.

**Figure 4.1: Iterative data analysis process**

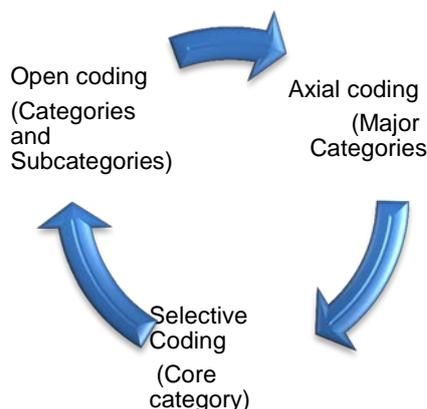


The interviews as discussed earlier followed a semi-structured format. Having undergone a computer literacy training and doing the PhD full time, I had enough time and good computer skills, so I chose to transcribe the interviews myself. Transcribing the interviews helped me to immerse myself in the data and become familiar with the data; a major advantage over paid transcription. Paying someone to transcribe the interviews could save considerable amount of time, (Corbin & Strauss, 2008) but could also introduce transcription errors (Duffy et al, 2004) which will take even more time to correct and if not detected could affect the quality of the data. However, the transcription could be overwhelming as well as the immersion in the data.

A core principle of GT is theory building which involves conceptualising and abstraction still grounded in the data. Over immersion in the data could lead to inability to see the true picture of what the data is saying and could lead to frustration, boredom and difficulty of conceptualisation. I overcame these issues by discussing the data with my supervisor who saw the data from a different angle and suggested a number of concepts. I also discussed the anonymised data with other PhD students (peer review) who are more advanced than I am in the process. These peers also made constructive criticisms and suggestions. I also stepped aside from the data to try to think 'outside the box' and do other things such as reading and later returned to further collection and analysis with a fresher mind.

The transcribed data was then analysed using Corbin & Strauss, (2008) grounded theory techniques which involve three concurrent phases of coding- open, axial and selective (figure 4.2).

**Figure 4.2: Three phases of coding**



Open coding involved the line by line coding of the transcript which is sometimes termed micro analysis of data, (Corbin & Strauss, 2008). It is the microscopic break up of data to enable consideration of all possible meanings and attaching appropriate conceptual labels, (interpretive meanings). It raises the raw data from description towards conceptualisation. The early initial interviews involved a very close examination of data to help in developing categories that are strongly embedded in the data and grouped into nodes as they are termed in Nvivo. Nvivo 9 software was used as a tool for assisting the coding and analysing of data into emergent themes. It made it easier to break down, organise, and store the large amount of data collected, compare, refine and categorise them, (Walker & Myrick, 2006). Similar data were placed in similar categories, while different data were used to form new categories.

In axial coding stage the categories were examined looking for dimensions and properties of the data which aids the reassembling of the data deconstructed during open coding. I was looking for the reasons for participants' behaviour towards the screening programme, the dimensions, properties, similarities, differences and any disconfirming cases. The categories through further data collection and analysis were subsequently filled in, linked, extended and validated but still grounded in the data. The selective coding process facilitated the development and interconnecting of the categories, which was very helpful in the development of further themes and sets of conceptual theoretical propositions (major categories) for the topic under study, (Strauss, 1987; Strauss & Corbin, 1998; Walker & Myrick, 2006; Creswell, 2007). At this level of coding, data was again recoded and reconstructed which led to even a much

higher level of conceptualising and abstraction that aids generation of theory/theories that could explain what was happening and may also be capable of explaining the dimensions of the participants' experience of the faecal occult blood test. Core category was generated from the major categories which were able to interconnect all the categories and provide an explanation for participants' behaviour across all the interviews, (Chapter 5). According to Corbin & Strauss, (2008), selective codes are chosen by checking that the emerging theoretical framework fits the empirical reality it seeks to represent. I applied this in this study by using in-vivo codes. In-vivo codes are words which were used by participant in explaining their experiences of the phenomenon under study. Table 4.2 is an example of coding from raw transcript, (see transcript in appendix 12).

At selective coding, the relationships and variations between categories could be explained by a single defining concept. This according to Bryant & Charmaz, (2007) can only be achievable through reflexivity and imaginative thinking - a prerequisite for the development of a credible theory. The core category should be able to explain the basic social process that accounts for most of the participants' behaviour. For example in the present study some of the initial major categories identified were culture, past experience, family history, age, practicalities, education/awareness which led to even higher conceptual categories of social context, education and awareness, and practicalities and the core category was awareness. Corbin noted that as researchers move up the conceptual ladder, explanatory nature of the concepts becomes broader and specificity could be lost, (Corbin & Strauss, 2008). Therefore, I tried to make sure that the lower level concepts are still within the higher level concepts in order to avoid losing sight of the data, (table 4.2)

**Table 4.2: Coding example**

Open coding	Axial coding	Selective coding
<p>I did not want to get bowel cancer <u>like my father did</u></p> <p>Yes, yes I have <u>two cousins</u> who um...suffered from bowel cancer. And...so ... I was <u>aware</u> of that...that there was a tendency for bowel cancer <u>in the family</u>.</p>	<p>Family history</p> <p>Awareness</p>	<p>Social context</p> <p>Awareness</p>
<p>I completed the test for <u>peace of mind</u> (<u>peace of mind is an in-vivo code used as a category in the axial coding stage</u>)</p>	<p>Peace of mind</p>	<p>socio-cognitive (Perceived benefit - health protection)</p>
<p>I have done, no I have not <u>sort out information</u> particularly ... but I have been aware and have <u>read articles</u> in the newspapers, magazines and things like that.</p>	<p>Information seeking</p>	<p>Awareness</p>
<p>Oh not at all, I mean I, it struck me that this was <u>a necessary... useful thing to do</u>. The fact that you can do a screening for that potential condition seems to me to be a very <u>good way of monitoring and of preventing serious effects</u>. So you might as well take advantage of, in fact it's a good thing to take advantage of that service that is offered.</p> <p>Well I think it's um... it might be <u>embarrassing</u> for people. It's one thing doing a blood test; <u>it's another thing doing a faecal test</u>. ... <u>people may be a bit squeamish about it</u>. And I think that's silly. It's a test that has a potential to save your life and it doesn't matter how easy or how difficult or unpleasant and or how.... If you can have the test done that's great.</p>	<p>Prevention</p> <p>Importance</p> <p>Embarrassment – nature of test, unpleasant</p> <p>Taboos</p>	<p>Socio cognitive (perceived benefit, perceived threat)</p> <p>Practicalities</p> <p>Socio- cultural</p>

It was only possible to get to the conceptual level by asking critical and analytical questions about the data during the coding process such as

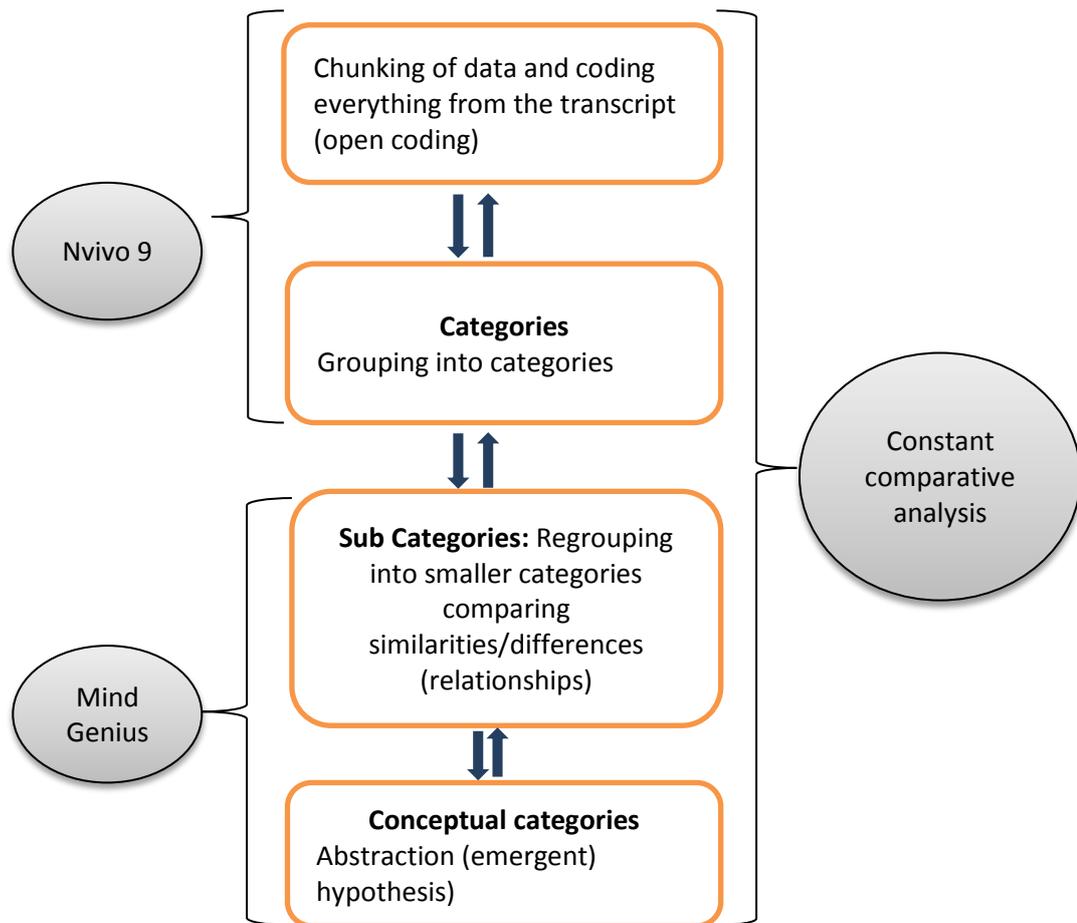
- What is the participant saying here?
- What could this mean?
- Who is involved?
- Where is this taking place and what context?
- How does this influence the topic under study? And so on

The answers to these questions provide initial tentative concepts which were bound to change as collection and analysis progressed. There was constant and numerous revisiting of the transcripts; research diaries and memos were scrutinised many times. This made it possible to condense the initial categories into sub categories by looking and findings similarities and differences and grouping and sifting accordingly to establish relationships. Taboo subjects, ostrich syndrome, stoicism were all grouped under culture; fear was regrouped under old age

This relationships and associations continued until categories of factors influencing participant's decision on uptake of BC screening emerged. These were all interrelated and would be discussed in more details in the next chapter. Nevertheless, the process of coding demands a lot of intellectual and creative skills. Being aware of this, I had undergone some post graduate research skills courses, particularly computer soft wares for analysis.

The coded and categorised data were transferred from Nvivo to Mind Genius software. I found Mind Genius very helpful in presenting the whole information in a pictorial form all at one place at the same time. This was very helpful in helping me to reach theoretical proposition (conceptualisation and abstraction) for the topic under study. I also manually drew colour coded diagrams to aid critical and better nuanced analysis. However, the process of coding was not a linear process but involved iterative and systematic interplay between the 3 levels of coding. This required going backward and forward at all times. Figure 4.3 provides a practical illustration of the coding activities.

**Figure 4.3: Steps of data analysis**



**Argument for computer assisted analysis**

Computer assisted analysis is increasingly becoming standard practice in qualitative research as a result of the benefits they offer. For example, computer programmes augments the researcher’s creative mind in many ways. Firstly it aids in the tedious job of sifting, taking to bits and sorting through the data a lot easier, (Corbin & Strauss, 2008). According to Corbin & Strauss, using computer software in analysis avails the researcher more free time of thinking that leads to quality and creative analysis. Nonetheless, computer software do not replace the human mind, they only do what they are programmed to do. With his/her intellectual and creative abilities, researchers use computer software to organise and sort data into a more systematic and presentable format. Nvivo software was very useful in the open and axial coding. It helped me to sort and store the data in an easily accessible format all in the same place. However, there have been scepticisms over the use of computer programmes in data analysis. For example, novice researchers may

be blinded by the software programmes. In other words holding tenaciously to the software programme may prevent them from active and critical thinking involved in data analysis, (Corbin & Strauss 2008) particularly during conceptualisation.

The Nvivo software was useful in this study in storage of the interviews and theory building. Writing memos, retrieving, sorting and organising the data into categories or nodes as termed in Nvivo (open coding) were made simpler and quicker as everything was all in one place. I was able to retrieve and reorganise the categories into subcategories (child nodes) (part of axial coding); examining the data from different angle looking for relationships in what the data is saying.

Corbin advised that computers should be used flexibly by the researcher to make the tedious job of analysis easier and not to let the computer direct the research. One thing I noticed in using Nvivo was that things are sorted and stored in boxes resulting to opening one box after another. I needed a tool which will display everything in a pictorial form, Nvivo does this but everything is not displayed all at once. This is when Mind genius- a mind mapping tool came into the picture. This was very helpful during the selective coding stage while trying to conceptualise the data. There are other mind mapping tools but I find mind genius easier to use as everything was displayed in one place all at once, I was able to just collapse the sections of the data that I do not require at the point in time and expand the ones I want to look at just by the click of the mouse.

When making decisions about choice of computer software, consideration should be given to ease of learning and understanding, ease of use and navigation. Otherwise, one could be lost trying to learn and navigate the programmes thereby wasting useful time. Nevertheless, the job of transparency in qualitative research is made easier; software provides good audit trail of how analysis has been carried out, (Seale, 2002). It is easy to retrace how conclusions were reached by the researcher and others who may be interested in the study. This enhances the credibility and reliability of the analysis (Corbin & Strauss, 2008). I found the use of computer programmes very useful as well as the audit trail it provides during writing up. I was able to, according to Corbin

& Strauss, (2008) easily access the codes, return to the raw data to use as example/quotes, retrieve memos, do diagrams, correct mistakes, find gaps in logic and possibly rewrite. This section continues with measures taken to enhance rigour.

## **Enhancing rigour**

Qualitative research has been criticised in the past as unscientific and lacking in quality and rigour by some quantitative researchers mainly as result of the inability to generalise the findings as mentioned in the previous chapter. In present years there has been increased and wider use of qualitative research in health and social care. As a result of this, the quality of qualitative research has to be enhanced to avoid these criticisms and to strengthen the credibility. There is considerable body of literature on how the credibility of qualitative research could be enhanced. However there is no general consensus on the criteria for ensuring this credibility or quality, (Long & Johnson, 2000; Lincoln & Guba, 2003; Meyrick, 2006). Rather, there have been various debates and arguments on ways of improving and ensuring quality. The guess is that there are many approaches to qualitative research and each has its own distinctive characteristics and risks associated with it. Unlike the quantitative approaches, it will be difficult to have a set of rigid guidelines or mechanisms for 'validity' in qualitative approaches. Therefore the quality has to be addressed within the context of the particular approach bearing in mind the philosophical paradigms, (Sandelowski, 1993; Strauss & Corbin, 1998). The general principle may be to make sure that the credibility of the research process is systematically well demonstrated and that the outcome of the research is a true representation of the participants reality of the phenomenon under study, (Tobin & Begley, 2004),

Enhancing the credibility of a study does not occur at a specific stage out of 'the blue' but is an on-going process from the beginning of the study till the end (Morse et al., 2002; McBrien, 2008). Different authors have suggested ways of ensuring and accessing the quality of qualitative approaches. In this section I will draw on the literature to present some of the measures taken to enhance the credibility of this study. Some of these have been discussed in the previous sections of this chapter. For example the constant comparative analysis is a strong tool that ensures the credibility of a grounded theory approach. However,

as discussed earlier there may be certain difficulties in achieving the ideal constant comparison through theoretical sampling such as problem with sample recruitment. Corbin & Strauss, (2008) gave some set of practical ways of achieving this where the ideal may not be feasible, as discussed in data collection section. The audio recording and 'verbatim' transcription of the interviews by me as mentioned earlier were also measures undertaken to ensure the rigour of this study.

Member checking or peer review was another strategy used in this study to ensure that threat to the credibility was minimised. During and after each interview I regularly sought to confirm from participants that what they have said was actually what they intended, (Crabtree & Miller, 1999), by paraphrasing the story they told me before asking the next question. This was to make sure that their reality is represented and consistent in subsequent findings, (Guba & Lincoln, 1989; Schwandt, 1996; Holloway & Wheeler, 2002). However, there has been an argument over whether reliance on participant checking at the analytical stage could compromise the significance and value of the findings, (Morse, 2001; McBrien, 2008). Morse argues that the amateur opinion of participants during this stage may never outweigh the expertise of the researcher, (Morse, 1998). It may be better to leave the analytical stage particularly conceptualisation to the researcher, who could then sought the input of other experienced researchers.

In order to further enhance quality, the interview transcript was sent to my supervisors for peer review. The input of my supervisor during the category building and conceptualisation stage was very helpful. It actually aided in the triangulation (seeing things from another point of view) of the findings. Some authors advocate that peer review is a practical way of enhancing the 'validity' of the findings, detecting and minimising researcher bias and any subjectivity in the interpretations, (Seale, 1999; Holloway & Wheeler, 2002; Graneheim & Lundman, 2004). I also shared the anonymised transcript and analysis with other colleagues who are independent from the study. This was to assess the persuasiveness and coherence of the study and to challenge the robustness of the emerging themes, (Angen, 2000). However, peers have not had the same in-depth familiarity with the data and the participants as the main researcher has had and may not be able to judge whether all aspects of the perspectives

from the data have been given due considerations in the interpretation. This position of the researcher is sure to affect the findings in a number of ways, (Morse, 1994a; 1994b; Cutcliffe & McKenna, 1999).

Another major strategy for enhancing the quality of qualitative research is a good audit trail. In this study, I have made transparent the reasons and logic behind my methodological decisions in chapter 3, interpretations, and some influences that may compromise the findings. This has put me in better position to defend my theoretical, methodological and analytical choices and hopefully enable others to follow my interpretive journey, (Guba & Lincoln, 1989; Whitehead, 2004; Koch, 2006). Although others may not agree with my interpretations, they will be able to independently see how my conclusions were arrived at. Guba & Lincoln maintain that under the same perspective and context, others should be able to reach non contradictory findings using the same data, (Guba & Lincoln, 1981). It will not be possible to repeat each and every audit trail here as they are embedded in the respective sections. A very good example is the data analysis section where the use of Nvivo and Mind Genius computer software was an invaluable tool, (Seale & Silverman, 1997; Seale, 2002) it was possible to retrace all the decisions made and how I arrived at the conclusions, (Koch, 2004). Though these software may have their drawbacks (section above), audit trails could be exaggerated and may offer little or no credibility to the quality of the findings, (Cutcliffe & McKenna, 2004)

The appropriate use and documentation of the systematic qualitative approach used is another way of enhancing the rigour of any research. Corbin asserts that the proper adherence to the principles and process of grounded theory is a strong way of strengthening the quality of the research, (Corbin & Strauss, 2008). Holloway & Wheeler, (2010) support this assertion by suggesting that audit trail could be further enhanced by providing systematic and reflexive evidence of the process, interview transcripts, memos and the findings. These processes have been the topic of this chapter as could be found by reading through each section. A summary of techniques as suggested by different authors for evaluating the quality of qualitative research are summarised in table 4.3 alongside those for judging quantitative ones and will be discussed in more details in chapter 8 after the discussion of the findings.

**Table 4.3: Summary of quality criteria**

Quantitative research/conventional	Qualitative research	
Internal Validity External validity Reliability Objectivity  (Lincoln & Guba, 1985)	Credibility Transferability Dependability Confirmability  (Lincoln & Guba, 1985)	Credibility Originality Resonance Usefulness  (Charmaz, 2006)

### **Maintaining reflexivity**

Critical reflective practice is deemed a pre requisite in qualitative research (Seale, 1999). This is the process of honest critical examination of the researcher’s influence (researcher subjectivity) on the research process, (Porter, 1993; Robson, 2002). It can serve many purposes; one of which is enhancing quality. In the current study particularly data collection, I had some physical and emotional feelings which I often overlooked as I tried to make sure that participants are well looked after and the research conducted as best as possible. However these feelings may have impact on the research process. Such emotions could have been conveyed to the participants who in turn might try to adjust to these emotional displays. It is very essential that these are examined and reported as it does not only show integrity but also ensure more transparency of the process, (Chesney, 2001; Yee & Andrews, 2006):

‘I support the autobiographical analysis of self, not as separate from or in competition with the ethnographic words of the women but as nurturing bed to place the research finding in and as part of the transparency of the research process. Reflecting honestly and openly has helped me retain some integrity and develop insight and self-awareness, and it has given me a certain self-confidence’ (Chesney, 2001 pg.131).

Despite the general consensus regarding reflexivity in qualitative inquiries, there are still some arguments about the feasibility and how much it means to researchers and how they carry it out. Some authors have purported that the philosophical orientation of the researcher has an impact on how relevant a researcher deems reflexivity and how it is carried out, (Strauss & Corbin, 1998,

Tobin & Begley, 2004; Bradbury-Jones, 2007). Reflexivity may be easier in methodologies that advocate total bracketing of the researcher from the research process and shunning of preconceptions for researcher subjectivity to be minimal. In GT, particularly Strauss and Corbin's approach adopted for this study, the interaction between the researcher and the participants in conjunction with the researcher's creative interpretation of the participants' story cannot be divorced from the process, although researchers are advised to enter the field with an open mind. In the long run we can never separate who we are from the inquiry and analysis, (Oleson, 1998), but through self-reflexivity report how our own experiences have influenced the research and vice versa.

However, Cutcliffe, (2003) argued that it may not be possible to completely account for self in research because much of what happens is within the deeper realms of consciousness. Seale, (1999) suggests that telling the story of how an inquiry was carried out involves a fallibility approach as well as placing the research beyond criticism, ('rhetorical claim of authenticity' pg. 177). It is based on the awareness of self which is most times partial, (McGhee et al., 2007).

Nevertheless, Finlay, (2002) maintains that reflexivity remains a valuable tool for:

'examining the impact of the position, perspective and the presence of the researcher; promoting rich insight through examining personal responses and interpersonal dynamics; empowering others by opening up a more radical consciousness; evaluating the research process, method and outcomes; and enable public scrutiny of the integrity of the research through offering a methodological log of research decisions', (pg. 532).

In this study I have become more reflexive than I have ever thought I would become, checking every decisions and rationale. I have become excited, anxious, frustrated and more pragmatic. I was able to keep an eye on my subjectivity by keeping a reflexive diary and memos particularly during the field work to enable me give equal and impartial attention to all my participants and the incoming data, (Hamberg & Johansson, 1999). There is the danger to feel more positive about some participants than others which may have enabling and disabling potentials (Peshkin, 1988). In GT, researcher's reflexivity is strengthened through the writing of memos. Memos enable the researcher to easily identify and deal with data that oppose their own prejudices, (Hamberg & Johansson, 1999; McGhee et al., 2007).

I was very excited and looking forward to commencing data collection after a long wait for ethical approval. I made all the necessary arrangements, mock interviews and got everything ready. I felt a bit nervous on the first day. I was anxious and did not know what to expect as this is now 'the real thing' and I wanted to get things right. On the other hand the participant was excited and eagerly waiting. Once the introduction was done, I felt better as I have got to be in control and confident or seem to be. The first interview went well. I felt more confident after that as could be seen in my reflexive entry below.

'Today is the first day of data collection; I have been excited but now feeling nervous. I did two today, both went well, better than expected. One had BC but very happy to have survived. P1m did not want to be excluded, very happy to be interviewed as he's had treatment and is in the clear. Had negative FOB, then developed symptoms, went to see doctor and was diagnosed. I felt bad. You would think P1m would lose confidence in the screening but informed me he knew the FOBt is hit and miss and one could have cancer in between screening but he still feels it is worthwhile'.

I felt very bad and empathetic that the FOBt failed P1m. Putting my nurse's hat on, I felt a bit unease that the FOBt missed the blood in the stool. Even though I knew that there are many explanations for that, I would have felt better if it was positive to show that the test is trustworthy. At this point I had to stop for a moment to review my position:

'I am not here to advocate for FOBt but to find out people's views and experiences about it; to report this as unbiased as possible. It is their story/account that matters not mine. Maybe this is a good thing, seeing someone 'let down' by the test and still very positive. It must be about 'knowledge and awareness'.

Furthermore, I tried not to take sides. There is the tendency towards taking sides in relation to gender, profession and ethnicity. I was always given a warm welcome in participants' homes which made me feel more comfortable and created quick and wonderful rapport. I noticed along the line that I was beginning to warm up more towards the women particularly in identifying with their past experiences of childbirth and other procedure peculiar to women. Nevertheless, I was also very keen to find out what the men thought about the FOBt specifically as it is the first screening that included both men and women. It became clear to me that I felt unease whenever I was interviewing in a home where only the man is in the house. I felt unsafe at this stage, even though I have taken the necessary precautions to ensure safety. However, there was no

untoward incident; I guess it is only natural for women to feel vulnerable being in the same house alone with a man she is meeting for the first time. I noticed that the men were as excited to be interviewed as the women, which was a good thing as it made them open up more.

On reflection, I previously thought that from my methodological stance of open mind, I was safe. The issues above made me acknowledge from the onset the unconscious influence I might bring to the process which could impact on the data collection and analysis and interpretation and to be very sensitive to my 'researcher voice'. Making sure that the participants' voices are as well represented as possible and not my views. It was a complex and challenging balancing act trying to put in the background my researcher voice and bringing to the fore the participants voices, (Gergen & Gergen, 2003). I became very conscious of the four ethical principles of respect for autonomy, non-maleficence, beneficence and justice on which actions in health research are based, (Beauchamp & Childress, 2001).

As I began to overcome the researcher voice, other exciting and challenging issues occurred. It was exciting because I was happy that I am now doing something practical, but on the other hand challenging as I was interviewing, transcribing and trying to make sense of the data all at once. I became frustrated trying to build categories and concepts. I was trying to present the finding in a creative and persuasive way that would 'wow' and excite my readers, (Mason, 2002). I was looking for novelty and unique ways of presenting the data to make the work stand out and have a 'grab' on the readers and still maintain the analytical rigour, (Whittemore et al., 2001), in a way that is both persuasive and coherent, (Holloway, 2005), I could not find the right words.

'I am now bored and frustrated at this stage, very boring and lengthy process transcribing. Then, the analysis is another thing. The frustration is overwhelming. I can't seem to think of inspiring words to use that would sound exciting, intelligent enough. I have gone through the transcripts and codes a thousand times now. Nvivo is quite good but I need something that will put everything there in my face, I think I will try the mind genius'.

Presenting research findings in a creative and imaginative way that would appeal to different readers is deemed a necessary venture, (Strauss & Corbin, 1998; Silverman, 2005). I became impatient as the frustration grew because I

was very keen and excited to move to the next exciting stage of the study. I kept looking at my Gantt chart and kept reminding myself that I need to be at a certain level by this stage. The frustration stood in my way. Then I felt that in order I to move forward I needed to seek my supervisors' input and advice:

'I need to see my supervisor now and that guy that has finished his thesis. They have more experience than me, I am sure Alison will be full of conceptual ideas; she kept on saying, abstraction and disconfirming cases'.

My supervisor and the experienced colleague provided me with a fresher outlook on the data and my findings. I knew that it is not the speed that matters but the quality of the work. So I needed to remind myself that rushing things might jeopardise the quality and might lead to mistakes that may take double the time to correct. I needed to be more pragmatic in my actions so that I do not lose focus.

'Just calm down, you are doing well. Others have done it, you too can do it, and you will get there. Everything will work out well and come together at the end'.

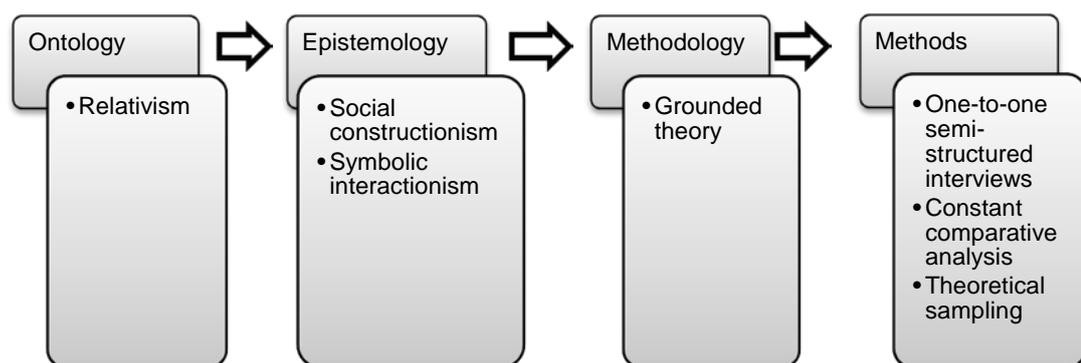
It took me a while to get to this stage of taking things slowly, appreciate my effort and looking for creative ways of making it better. All the feelings of excitement, frustration, boredom, impatient and articulation complimented one another. I could not have progressed in the process without having each of those feelings. Keeping a research diary and memos enabled me to become more aware of my influence and to move from raw data to conceptualisation. Bradbury-Jones, (2007) argued that researcher subjectivity could linger on in a research unnoticed but maintained that the acknowledgement of subjectivity could enhance the credibility of the research. Nonetheless, Glaser cautioned against 'reflexivity paralyses', (Glaser, (2001); which simply means that creativity might be stifled in the pursuit of reflexivity and could result to mere theoretical account instead of a rich thick description or theory. Therefore it is important to balance between practicality and creativity, as an imbalance could have a detrimental effect. Being aware of my subjectivity helped me to promote the positive effects it brings to the study as well as guarding against the negative impact it might have. As mentioned before reflexivity is an on-going process which enabled me to be sensitive to my personal and professional influence on the research process, particularly on the research setting, sampling, data collection and analysis. Therefore this reflexive practice will continue

throughout the course of the research process and will be presented at each stage in the course of this thesis.

#### 4.5. Summary of Chapter 4

This chapter has outlined the activities involved in data generation. These include ethical approval process and ethical considerations in terms of ensuring the safety of the participants and researcher. The sampling and recruitment strategies were also detailed with the difficulties encountered during the process. Data collection followed a semi structured format which allowed the flexibility of exploring issues that are of particular significance to the research question, and the clarification of comments made by participants. Conducting interviews in a home setting has its strengths and drawbacks. However, the priority was given to developing a good research relationship, the autonomy and comfort of the participants as I tried to be a good guest. The use of grounded theory coding techniques which included constant comparative analysis via memos, field note and theoretical sampling has helped in conceptualisation and theory building which is still strongly embedded in the empirical data; and also in enhancing the quality of this research. Reflexivity was also used to enhance rigour. A complete diagram of the methodological framework started in figure 3.2 is presented in figure 4.4.

**Figure 4.4: Complete diagram of my philosophical /theoretical framework**



The next section presents a summary of data analysis and study findings as well as the building of 'Awareness-led behaviour' model before moving on to present the detailed results.

## **Summary of data analysis/findings and development of the ‘Awareness-led behaviour’ model**

Chapter 4 detailed the analysis of raw data through coding using Nvivo and mind genius. This section provides a summary of the data analysis process showing eventual emergent process and how the product of the study ‘Awareness-led behaviour’ model emerged. These are presented in figures 4.7 and 4.8 respectively and form the basis for the discussions of the key findings in chapter 8.

During data construction, a number of themes, categories and sub categories were identified in relation to factors affecting participants' behaviour and decisions on whether to take part or not in the NHS BC screening programme, (open and axial coding). From these categories, subcategories and major categories were generated which in turn led to the development of the core conceptual category (selective coding), ‘awareness’ and the generation of ‘awareness-led behaviour’ model.

Coding was done for each interview. Memos and theoretical notes were written to aid the analytical process. As the transcripts, memos and notes were reviewed, a pattern showing participants’ journey/experience in the FOB test became clearer. I decided to track this pattern for each participant. This led to the formulation and development of participant decision trajectory, (table 4.4) which helped during the concurrent data collection and analysis and subsequent theory building. The trajectory tells each participant’s story and predominantly showed three emerging patterns for each individual although there were minor variations as can be seen in table 4.4; there were also few disconfirming cases. These patterns include:

1. Participants’ situations before the invitation to participate in FOB test
2. Participants’ feelings about the test as they received the FOBt kit and accompanying information
3. Participants’ experience of completing/not completing the test and reasons behind each decision.

**Table 4.4: Participant decision trajectories**

P2m: Did not do it the first time → was under the weather (**conflicting health problem**) → Aware of other cancers through (Family History - Mum & Dad) **past experience** + TV → not aware of BC and FOBt prior to invitation (**lack of awareness**) → **Fear, old age, cost nothing**, past experience → UPTAKE → Instruction leaflet was good + telephone advice (**information**) → Beneficial → Future uptake → will be discouraged by travel → Not very good on feet uses wheel chair (**Potential barrier is disability, wife helps with sample collection**) → hope of early diagnosis + treatment to spend more time with family was quite strong so may not mind anything as long as no travelling involved (**to spend more time with family**) → effect of screening - more awareness → suggestions: info leaflets, TVs and papers → doesn't mind if it is done by anyone else → family helps with test (**help of significant others**)

Gets most of his information from doctors

P7m: **Aware** of BC+ screening → **past experience** of family history → **read articles** in the papers and magazines → For **health protection** → benefit outweighs the discomfort or embarrassment as could **save your life** → Info sheet simple → (**Information leaflet**) Positive about test → significant **other positive about FOBt** as well → false understanding of test, false hope of continuing to be clear → however said will continue to do the screening (Education by researcher + fact sheets on the BCSP) → **home more convenient** → have problem giving samples in hospital → **suggests positive** messages on TV adverts → using celebrities → put in story line on **Coronation street** → as TV is there in front of people, it confronts them → Saves life and money → wants more for **men-Prostate cancer** → goes for well man clinic → not aware that screening is every 2years → indifferent about **GP** involvement

**Memo note**: Combined awareness from family history and personal knowledge facilitated participation. As a result feels that benefit outweighs the discomfort or embarrassment. **Misconception of test result as with P3m**. Suggest positive media message. **This gentle man feels strongly about men's health and goes extra mile to look after his health**

P14f: Aware of BC through **past experience** due to other **bowel investigations** → not aware of screening prior to kit (**Lack of awareness of screening**) → knowledge facilitated uptake → + **fear** from other bowel investigation (colonoscopy) → Info leaflet was ok (**Information Leaflet**) → not squeamish, done similar things like nappy change → reason; to see if everything was ok (**peace of mind**) → just to remember to mark the date → others might find it bad but not me → **privacy + convenience** =home → advertise on TV and newspapers about screening invitation letters

**Memo note**: lack of awareness of screening but knowledge and fear facilitated screening. She feels positive about the screening. Gender: being a woman was another significant factor in this lady's decision making process. Having gone through childbirth this was nothing in comparison. Does participation in other screening in the past influence participation in future screening?

Generally participants' decisions to take FOB test seem to be influenced by social issues such as cognition, demography and their culture or environment. Awareness also plays a significant role too. It can help them to make informed choice. Practicalities associated with the FOBt can work in two ways; it can either encourage or discourage one particularly as issues to do with bowel motions and cancer are perceived as taboos and hardly discussed openly

The trajectory with accompanying memo notes (see table 4.4) was helpful as it allowed me to follow the story of the participants; tracking the similarities and differences on how each participant perceive the screening and how these influenced their decision. This particularly aided the theoretical sampling process by constantly comparing data; and generation of the 'awareness-led behaviour' model.

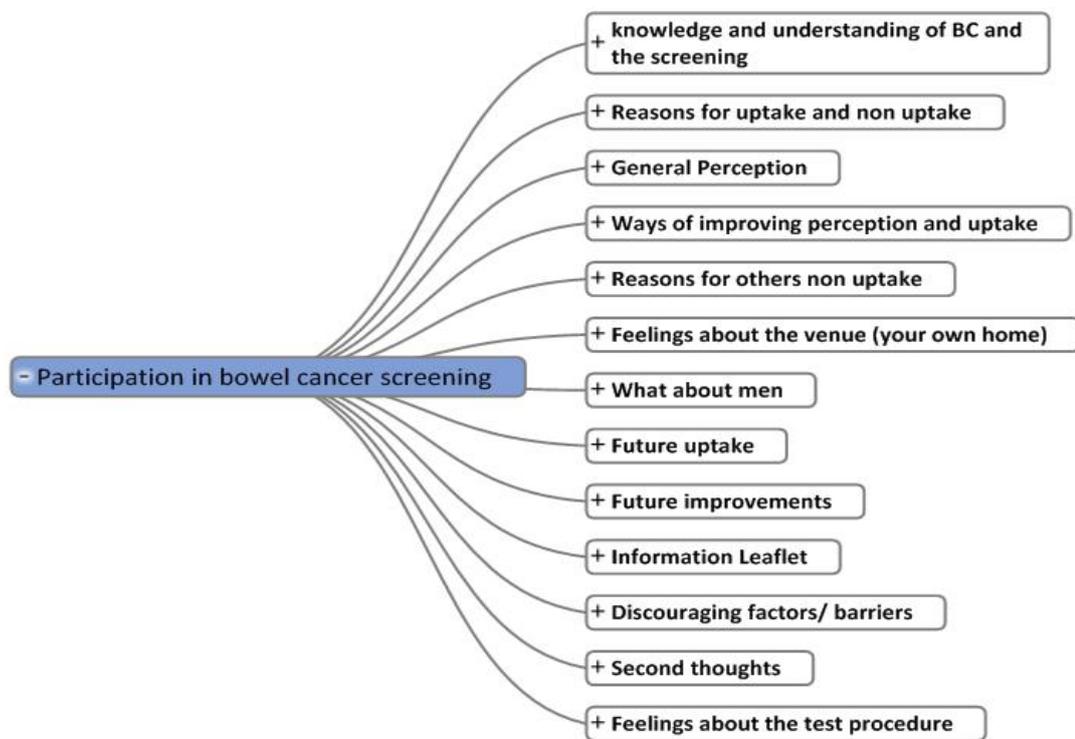
As mentioned earlier, during open coding process the data were broken down into many codes or nodes. Over 300 free nodes were generated in the open coding process. These free nodes were participant responses which were deemed good and important for data analysis. Table 4.5 provides an example of the open coding process from Nvivo.

**Table 4.5: Open coding sample**

<p>Code name: Previous knowledge and understanding of BC and the screening</p> <p><a href="#">&lt;Internals\Interviews\P12f&gt;</a> - § 3 references coded [12.70% Coverage]</p> <p>Reference 1 - 4.53% Coverage</p> <p>The only thing previous knowledge (<b>Knowledge/awareness</b>) I had was that my grandfather apparently died of BC (<b>Family history</b>). This is about years and years ago (<b>time</b>). But that is the only thing; I don't know anything else about it, (<b>Lack of knowledge</b>).</p> <p>Reference 2 - 7.36% Coverage</p> <p>P12f: um no, no wait a minute, there was a friend of ours, they had said they had um...these screening things as well and they were asking if we had it, (<b>Knowledge (FOBT) through a friend</b>) they're about the same age, (<b>age</b>). And um, I said oh not yet. But it did come along eventually (eagerly waiting for test kit).</p> <p>Reference 2 - 1.47% Coverage</p> <p>P24f: No I don't think I knew there was a screening system (<b>Lack of awareness</b>). Um...I have always been anxious (<b>anxiety</b>) that there should be a screening system, (<b>an advocate of screening</b>)</p> <p>Reference 3 - 3.25% Coverage</p> <p>My understanding (<b>knowledge</b>) of the stool test kit was that um...by providing the sample stool, they were able to um... to check the stools to see whether there were ...I think whether there was any blood in it or um... an abnormality in the stool which could indicate the presence of BC (<b>knowledge and understanding of FOBT</b>).</p> <p>Reference 4 - 1.42% Coverage</p> <p>No I understood and ....even if you are clear on the stool test it doesn't necessarily mean that you haven't got BC (<b>knowledge and understanding that test is not 100%</b>)</p> <p><a href="#">&lt;Internals\Interviews\P25f&gt;</a> - § 4 references coded [6.28% Coverage]</p> <p>P25f: I hadn't heard about it.</p> <p>Reference 3 - 1.08% Coverage</p> <p>Um....to find out if there are any symptoms or anything um....you know of cancer you know</p> <p>Reference 4 - 4.43% Coverage</p> <p>I didn't know anybody with BC (<b>Lack of awareness</b>), I didn't till my friend did the test, I didn't know anybody with BC then but um...my husband died of cancer not BC (<b>family member died of other cancer</b>) and I think anything to you know to check and to, you know, find out if you have got anything in you. So I think it's a good thing. I just think it's um.....yea I'm doing it, (<b>health protection</b>)</p>
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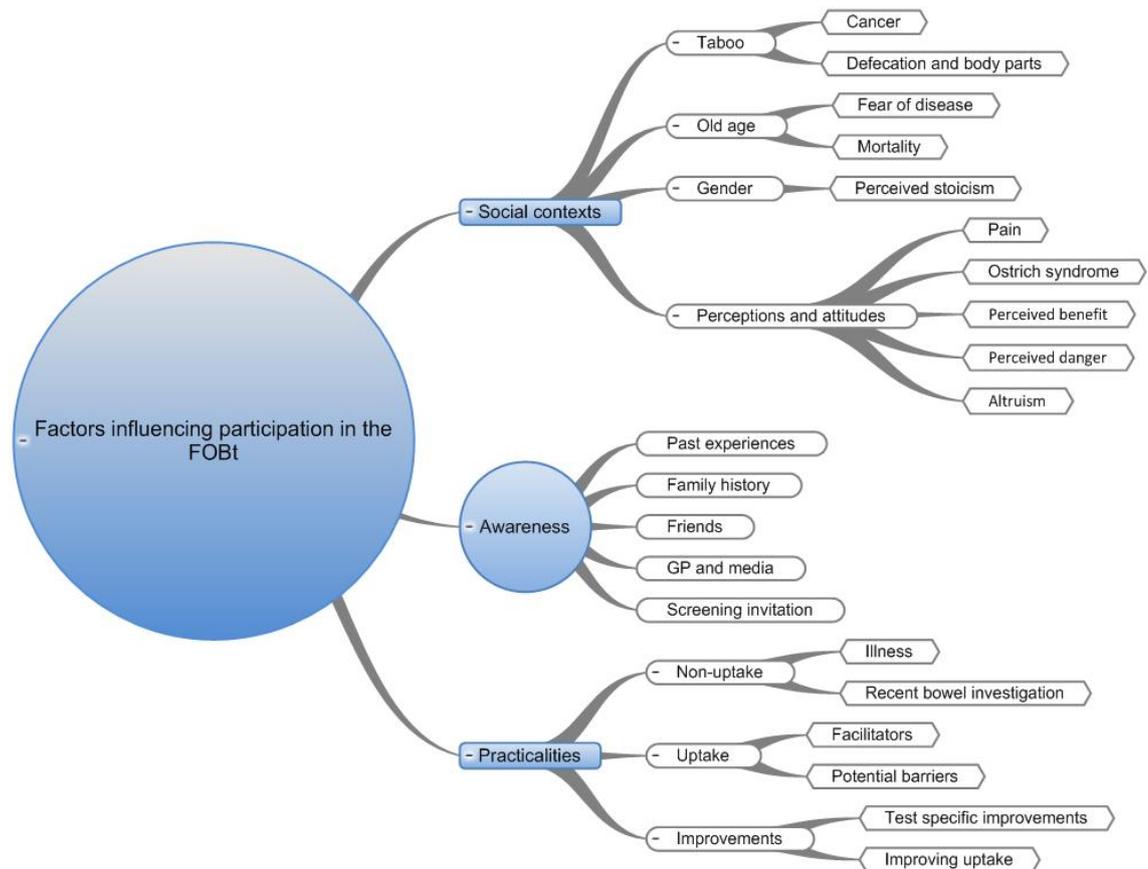
The free nodes were then collapsed into 88 nodes. It was at this point that I switched over to mind genius and manual sorting of the codes (part of axial coding process) to aid conceptualisation. These activities aided the conceptual analytical process which is still grounded in the data allowing me to see clearer the links in the categories. The nodes were sorted down again to 13 categories looking at their differences and similarities as discussed earlier in section 4.4. Each of these 13 categories has sub categories which could be expanded in mind genius. Figure 4.5 shows mind genius with the thirteen categories.

**Figure 4.5: Mind genius branch**



The categories were further reconstructed down to 3 major conceptual categories, (which their interactions constitute the study model) along with their sub categories, (lower level categories), (figure 4.6).

**Figure 4.6: The three major conceptual categories and sub-categories**

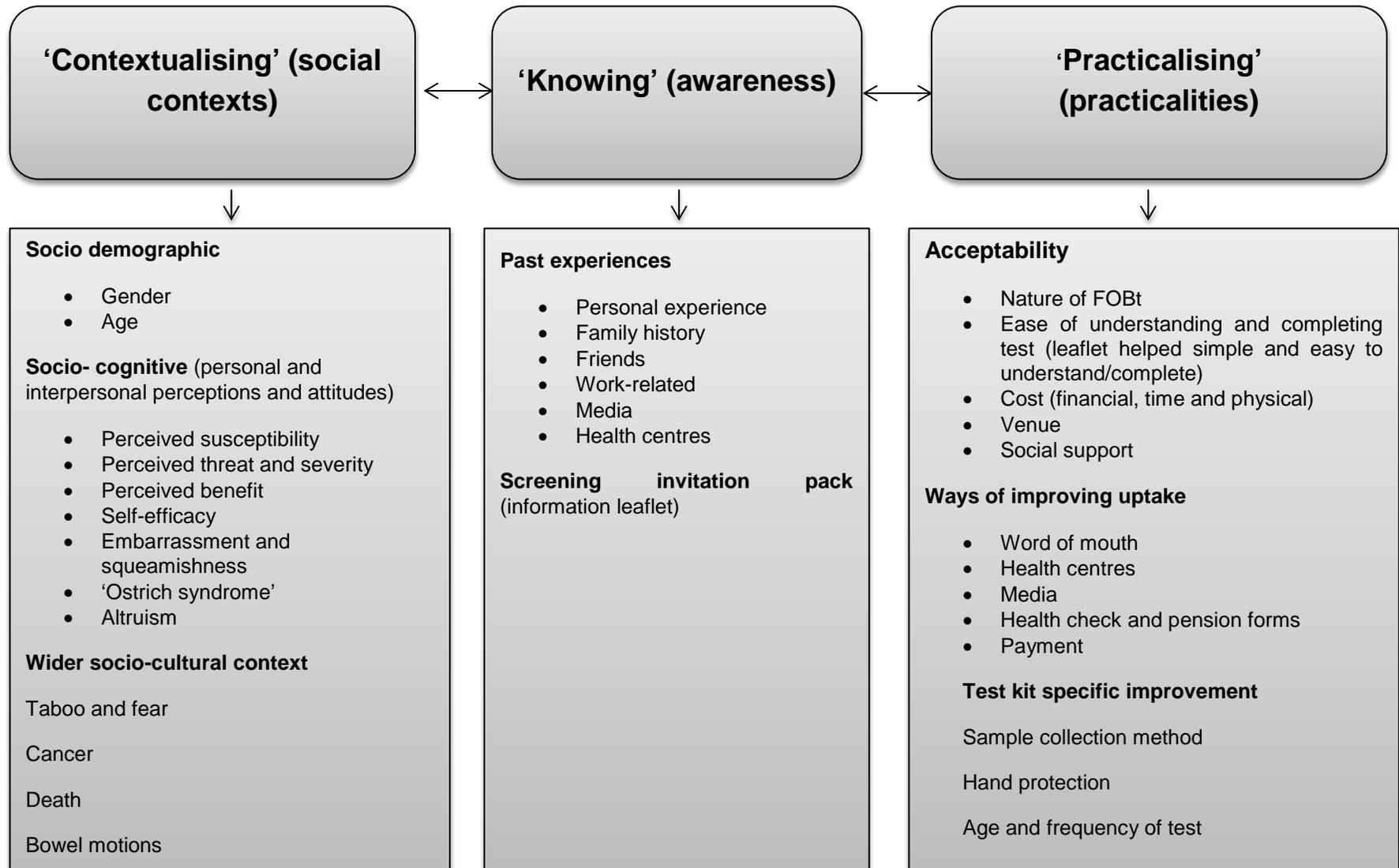


The major conceptual categories, (higher conceptual level) which were generated are social contexts; knowledge and awareness, and practicalities. They also denote higher conceptual labels that arose during selective coding. The core category ‘awareness’ emanated from these. Awareness was considered the core category because it seemed to be the pivotal point of the basic social process of participation and has significant effect on the other categories. For example, prior to invitation to screening, participants were filled with all sorts of social, environmental and psychological perceptions and beliefs. The participants seemed to be discarding some of these as they became formally informed of the screening test and the associated potential implications. This was evident from the stories of the participants as will be presented in subsequent chapters.

A tentative process of participation decision making emerging from this study is shown in figure 4.7 showing participation decision making components along with the minor elements of each. However, the variables are inseparable parts of the process with ‘knowing’ being the core component. The ‘social contexts’

include the social circumstances that participants carry with them prior to FOBt invitation. 'Awareness' represents all the different ways of 'knowing' such as past experiences and screening invitation which may remove or counter social and behavioural issues. 'Practicalities' relate to the impact resulting from the interaction of the different elements of 'social context' and 'Awareness'. In other words, it means the feelings and experiences of participants as a result of participation/nonparticipation in the FOBt. The inter-relationship of the three components, (contextualising, knowing and practicalising) and their interactions in influencing uptake of FOBt is makes up the 'awareness-led behaviour' in Figure 4.8 along with illustrations of further possible hypothetical deductions.

**Figure 4.7: The emergent process of participation decision making**



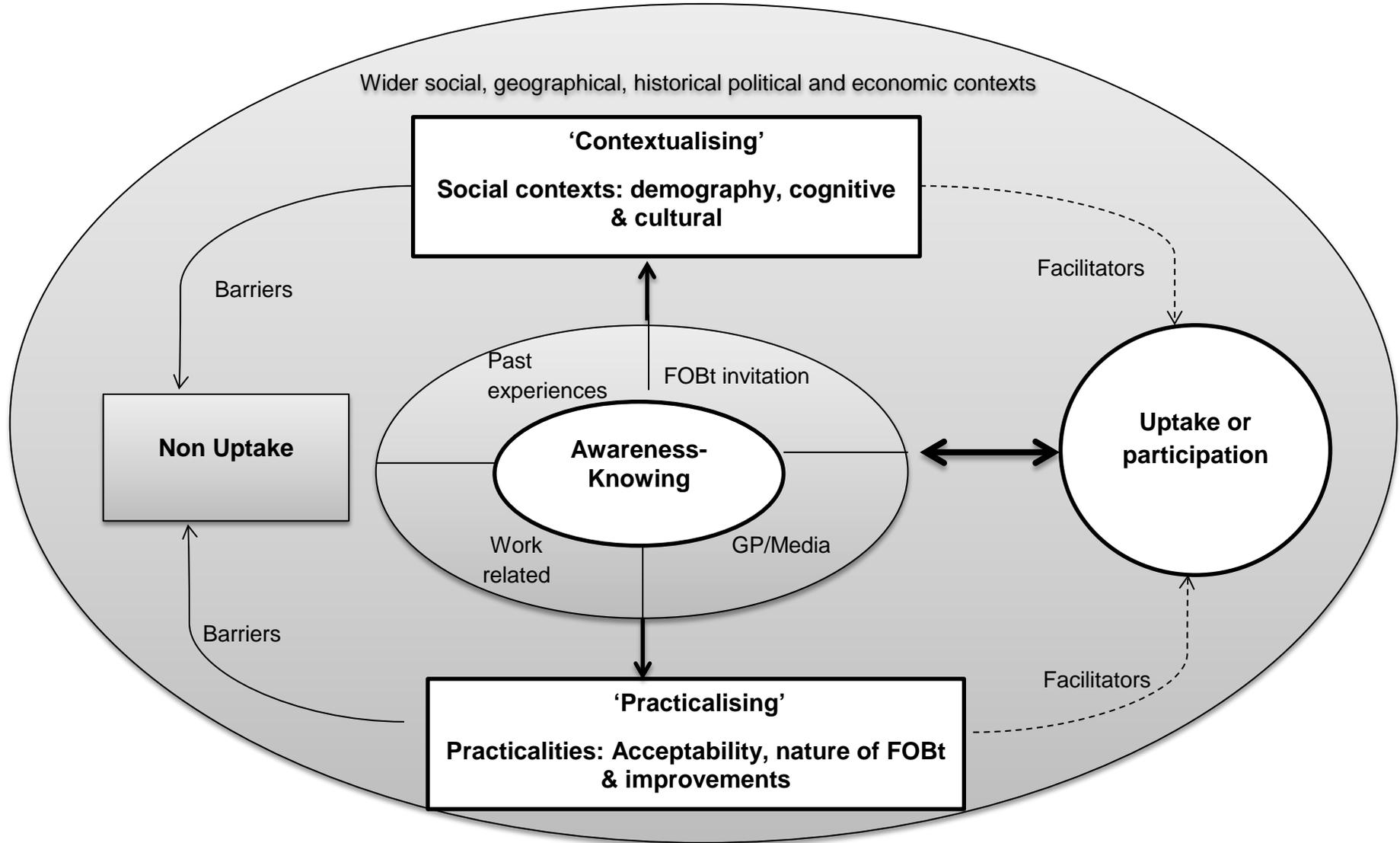
I have used the conceptual terms ‘contextualising’, ‘knowing’ and ‘practicalising’ for these three major categories to demonstrate participation decision making in BC screening programme as a process. All of the sub-categories under ‘social contexts’ in figure 4.7 above share the same properties as they are considered to show participants’ situations and conditions prior to being invited for the screening test. Sub-categories under ‘awareness’, illustrate different sources of knowledge and information relating to bowel cancer and the FOBt while ‘practicalities’ are considered as actual or potential practical issues involved with the FOBt. The major categories and their subcategories are chronologically presented in chapters 5, 6 and 7. The major categories seem to significantly influence people’s perception, decision making and participation journey in the BC screening programme and thus led to the formulation of the ‘awareness-led behaviour’ model, (ALBM).

#### **4.6. Awareness-led behaviour model, (ALBM)**

The aim of theory is to simplify things which might otherwise seem ambiguous in the real world, (Hasting, 2007); making them more practical. Theory aids in the pragmatic adoption of what works rather than an all-encompassing theory, taking care not to oversimplify but applied flexibly as human behaviour is one of the most complex phenomenon to comprehend (Hasting 2007). Theories are one way of helping us think about the complexity, plan and develop activities that will influence complex behaviour. Pawson & Tilley, (1997) reiterate this stating that ‘progress emerges through the process of theory building and testing’, (page xvi). However, theories might not always fit, so the need for flexibility and initiative. The ultimate aim of grounded theory methodology is the generation of theory around a core emergent category that sums up the events; their similarities and variations in data, (Corbin & Strauss, 2008). The identification of the core emergent category, ‘awareness/knowing’; its interrelationship with the other two major categories, ‘contexts’ and ‘practicalities’ abstracted ‘contextualising’ and ‘practicalising’ respectively; and their interactions in influencing participation decisions and uptake has led to the development of a tentative explanatory model – ‘awareness-led behaviour model’. The conceptual model was generated from data construction during the selective coding process (as shown in section 4.4, tables 4.2 & 4.4 and figures 4.5 & 4.6). The model explains the different factors influencing the decisions

people make regarding whether to participate or not in the NHSBCSP. This module could be used to explain behaviours towards other phenomena not just BC screening. The model, (figure 4.8) will be discussed and referenced throughout the remaining part of this thesis.

Figure 4.8: Awareness-led behaviour model, (ALBM)



## 4.7. Theoretical model explained

Awareness within the context of the model denotes having some knowledge or understanding of the bowel cancer screening programme and the FOBt. Soanes and Stevenson, (2003) defined awareness as a person's knowledge or perception of a phenomenon. The knowledge could be formal or informal. For most of the study participants, formal knowledge came from the screening invitation and the accompanying artefacts.

Awareness is at the centre of the model demonstrating its pivotal influence on social contexts and practicalities; subsequently leading to participation and uptake. The knowledge and awareness of potential threat of BC; and the potential benefit of bowel screening significantly facilitated people's decision to complete the FOBt. The left hand side of the model showing barriers with arrows leading to 'non uptake' is more tentative. It is tentative because it includes potential barriers that may have hindered participants from participating in the FOBt from their own experiences and perspectives. It is also largely based on 'hearsay' – participants-reported barriers for their friends and family.

Most social contexts and practicality barriers were ameliorated through awareness resulting to action - uptake. The consequences of the actions, for example informed knowledge can continue to have direct impact in further reducing the barriers created by social contexts such as taboo. In other words this means that people who have been squeamish or embarrassed about the subject may now feel that the benefit of doing the test outweighs the embarrassment. For majority of the participants this meant peace of mind.

A number of hypotheses could be propagated from the explanatory model:

1. Awareness is more likely to lead to uptake which then leads to more knowledge and awareness and further uptakes as illustrated by the thick two way arrow in the diagram
2. Awareness plus more facilitating elements in the social context and practicalities are more likely to lead to participation and uptake. For example, altruism (section 5.24.5 and 8.22) emerged as an interesting novel finding and a significant facilitator for participation in relation to

living longer and spending more time with family. Altruism falls within the socio-cognitive component of 'social contexts' in the awareness-led behaviour model, (figure 4.8) and as discussed in chapter 8 means doing things for the benefit of others, (family, society and the government) as well as one's self. This illustrates that health decisions can have meanings or be influenced by factors outside the health domain. This can have implications for designing future public health promotion messages for improving uptake of FOBt. Particularly in raising awareness via the FOBt invitation; a component of the core category – 'Awareness', figure 4.8.

3. Practicality and social context barriers with little or no awareness are more likely to lead to non-uptake as shown by the two continuous arrows from social context and practicality to uptake

The three hypothetical examples above are not exhaustive but could further be extrapolated. There are also disconfirming cases from this hypothesis. For example, there could be misconceptions and misinterpretations of screening test such as the participant who felt that completing the FOBt once covers him for the next ten years, (section 6.6, P7m). In this case, even though initial awareness led to uptake, the uptake has not led to improved awareness. This tentative model is however limited by the small sample size, (26) of participants; perhaps, it could be tested with larger sample.

This thesis continues with the results in the following section.

# Study findings

## Chapter 5

### Social contexts – major category 1

#### 5.1. Chapter overview

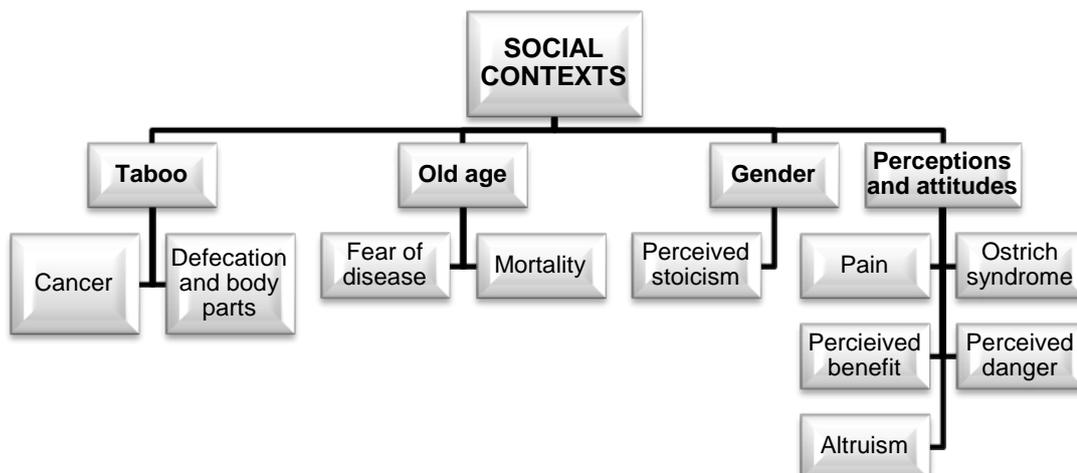
The findings of this study are presented in chapters 5, 6, 7 and discussed in relation to wider literature in chapter 8. Each chapter focuses on one of the three emergent major categories from data construction. I have used data construction because the results are completely grounded in the lived experiences of the participants as narrated by them. These experiences were then analysed and conceptually re-constructed through the systematic application of grounded theory procedures.

#### 5.2. Social contexts

Social contexts, (figure 5.1) include all the preconceived notions, views and beliefs which the individuals have formed prior to the screening invitations and these may be in relation to their age, gender, culture, attitudes and wider societal perceptions. These are most probably what they go into the screening test with and acting either as facilitators or barriers depending on individuals. A number of these social contexts were identified as possible factors that could influence uptake and participation decision making regarding the bowel screening programme. The majority of the social contexts seemed more likely to act as potential barriers rather than facilitators and may also be associated with perceptions of danger. However, some of the concepts acted as facilitators as well as potential barriers as will be illustrated throughout the result sections.

The diagram, (figure 5.1) illustrates hierarchy of the categories/subcategories showing the top branch, (social contexts) as the highest conceptual category.

**Figure 5.1: Social context**



### **5.21. Taboo**

There appeared to be cultural taboos around cancer, death, defecation and body parts. As reported by the participants, cancer and body parts, particularly bowel and motions were ‘taboo subjects’ that were not generally discussed openly as people find them embarrassing. It was also observed during data collection that people were reluctant and embarrassed to talk about these issues. However, once the interview started the participants seemed to be at ease and discussed the issues with certain type of ‘humour’. Could this be a psychological or socio-cultural issue? A striking fact reported by participants is that the more these are talked about (awareness), the more people seemed able to get over the taboo.

#### **5.21.1. Cancer**

Cancer appeared to be culturally perceived as a taboo subject. Most of the participants said that cancer is a subject not openly and generally talked about. Cancer seems to be widely associated with death and so nobody wants to talk about it as illustrated in the quotes below.

P25f: ‘.....people don’t speak about it, do they, you know bowel cancer. It’s a bit of a taboo, isn’t it? Yea (Laughs)’. But there was a lot of misconception. So I felt ....to bring things into the open, the more that can be done for screening; for things which particularly...for things that people don’t actually like talking about.

P20f: Yea, like I said people don’t talk about it too much, and yea it is such an important thing, isn’t it?

P8f: My mother had something but she kept it very much to herself. It wasn't till afterwards that we found out. She survived it all. Um..... but you know my father, he was um..... he couldn't accept it. So she kept things very much to herself. Um, we found out after that it was cancer

P21f: ... you see all those years cancer was a word that wasn't used a lot'.

The first and second quotes illustrate the misconceptions and taboo accorded to cancer which was yet acknowledged as an important issue. People perhaps felt 'if I do not know it would not happen to me'. Interestingly the last quote suggests that people could hide their diagnosis of cancer because they could not come to terms with it and families are devastated by such news which is often seen as fatal. Probably if kept secret other family members would get on with their lives without worrying about the sufferer.

### **5.21.2. Defecation and body parts**

The participants also reported that like cancer, body parts and bowel motion were not things people would normally and openly talk about as depicted in the quote below. It is also one of the taboo subjects and something very personal. It seemed like people do not want to be associated with bodily waste and are conscious about the subject. A participant was particularly worried about the sample oozing out in the post:

P21f: And yea, no you've got to do it, haven't you? Really, I kept thinking oh I don't want this to ooze out in the post, (both laughs). But they are pretty good aren't they? In fact they've improved them (FOBT kit)

This feeling of embarrassment and worry over what will happen to the sample during postage was also reported by Chapple et al., (2008) where the study participants worried about confidentiality and embarrassment should the sample open in the post. Generally, participants reported not normally touching and collecting stool samples. They seemed to find it awkward handling their own stool. Defecation and body parts seemed to be portrayed as very social personal issues which people seemed very squeamish and embarrassed about.

P20f: 'I don't think so but then again you know defecation is something people don't really talk about. You know it's like one of those taboos. You know bowel movements and you know it's something very personal, you know. English people are funny about stuff like that anyhow. Anything that is slightly 'hum, hum' you don't talk about'

P13f: No, I... you see I personally would find it harder, I wouldn't find it impossible but I would find it harder to go to the Doctor's to or .... You talk

about smear test, I didn't like doing that and if I could have done that at home, I would have done it alright. So this is the sort of thing really, you know, you don't like to show your bits to strangers. And if you can do it yourself, it's totally pain free and you just, as I say I can't understand why they don't. I really don't. It's just as simple as that.

However, the general attitude of the people who completed the screening is 'if it is going to do good...' That is, if dealing with this unpleasant substance was necessary in order to avoid cancer, then why not. So the fear of cancer and the wish to be healthy was stronger than the unpleasantness and taboo of dealing with defecation. This seems to suggest that people could go through unpleasant experiences as long as the experience is worthwhile i.e. will bring health protection.

## 5.22. Old age

Age also seemed to play an important role. Data seemed to suggest that people associate old age with different kinds of attitudes, ailment and diseases. For example participants reported that old people might not want to do things like faecal sample collection as these quotes illustrate:

P5m: I possibly think that people are put off. It's probably an age thing. I could imagine you know like an old lady, saying 'oh I'm not doing that' you know

P4f: I don't know ... some elderly people might find it not very nice I don't know it didn't bother me. As I said the older generation like my husband, he is in his eighties, no, I honestly don't understand people who won't have it..... No he wouldn't do it. He is a lot older than me, he is in his eighties and he didn't like the idea of smearing it onto cardboard. So quite a few people I have spoken to have said the same thing.....

P14f: I think the elderly ones might find it a bit awkward to do. They may need somebody to come and help them. I don't know. You know if you've an old lady on their own, something like that, you know is there any way if they needed help, they are the ones that will just say I'll just not bother.

P21f: I think you get.... as you get older you are a bit more fearful of there might be something.

P5m: ....my age is a dangerous age to be for cancer and things like that (cancer).

These quotes suggest that elderly people may be put off by the nature of test (handling faecal matter) posing a potential barrier to uptake of screening. Interestingly, P4f seemed not to be bothered about the nature of the test. This

may possibly be due to the perceived benefit of screening and early treatment; and/or the risks of not carrying out screening test:

P4f... I said as soon as there is something wrong, the sooner you get the results and you can be treated .....

In addition, participants reported that as people get older, there is the worry that they might develop certain diseases such as cancer. This worry appears to lead to fear. This correlation between old age and general health and wellbeing tend to make people not want to open 'cans of worms'.

### **5.22.1. Fear of disease**

There seemed to be fear of cancer and of mortality as people get older as mentioned above. Some of the participants noted that as a result of the fear of finding something untoward they were frightened to take the FOBt. This fear of uncertainty appeared to be worse while waiting for the test result.

P2m: I suppose the first time I heard about it I was frightened in a way in case they find out something wrong. If there something to fine out is better someone tells us, a lot of men about BC and that, if they've got or think they've got it, they are frightened like I said I was frightened, but I could..... they say I will sort it out for you. I think a lot of people are frightened in case there is something wrong and that's where the problems starts, but me if I have it and have it operated on or whatever and it means I spend more time with kids and wife. We've been married thirty one years.'

P21f: I have knowledge of it in the fact that my father died of it, bowel cancer, well it started in the bowel and of course it advanced to his shoulder blade because....then he went into his um.....and that was it, that was very quick, he was given a year. From Knowing what it was...

P2m: ...I mean my mum and dad; they had cancer, but not that cancer (BC)....heard some old friends having it but you never think it could happen at your front door.

This fear may come from knowing someone who has had cancer and could act as a barrier as well as a motivator. However, this may depend on whether the experience was positive or negative. A number of the participants completed the test because a relative was saved by the test or died from cancer:

P12f: Yes aha the only thing previous knowledge I had was that my grandfather apparently died of Bowel Cancer. This is about years and years ago. But that is the only thing; I don't know anything else about it.

Nevertheless, the fear did not seem to have stopped these participants from the FOBt as they had all done the test and felt that they will continue with the test in the future. All the participants seemed to have positive attitude towards screening particularly as a result of the knowledge and awareness gathered through previous experiences and mainly from the screening information (chapter 6) enclosed in the FOBt kit. Therefore, fear seemed to act as facilitator for uptake due to awareness especially of the success of early diagnosis and dangers of late diagnosis as P2m illustrated above. Nevertheless, fear could also act as a potential barrier: 'P15f: ....They might be frightened in case they get negative results back you know'. This needs to be explored further in future study targeting non-responders of the screening test. This group of people might provide a better insight as to whether fear was the barrier to non-response. However, as all data is data in qualitative research, (Glaser & Strauss, 1967; Corbin & Strauss, 2008), these accounts regarding participants' friends and families were also of importance. Participants reported how their friends and family members would not do the test because of fear of what the result might be and so simply put the test kit in the bin. For example, a friend of one of the participants did the test but did not want to be told the outcome as this friend was frightened of the test outcome:

P4f: There was one lady who had actually done it but doesn't want to know the results. And I said that is ridiculous! It's a one in the family.

P23f: ....and some are afraid and they don't want to know. Some may feel they've got symptoms um... they will or even go to the doctor with symptoms so they will be afraid of a kit.

### **5.22.2. Mortality**

It also emerged that people not only associate old age with illness and disease but also with mortality/death. Some of the participants felt that old age could be an indicator for disease and even death:

P21f: I think you get.... as you get older you are a bit more fearful of there might be something.

P5m: Happy with it. When you get a reply back saying that there is no problem, you know um...my age is a dangerous age to be for cancer and things like that. Um...you think, good that's one last thing I have got to concern myself about.

P22m: they ...are like an Ostrich, they put their head in the sand and they think uh no not for me, I don't want to know.

As a result of these feelings, some participants seemed not sure initially whether to participate in the FOBt or not. They seemed to feel that it might be better not to know than to know; I have called this feeling 'ostrich syndrome'. Ostrich syndrome simply means burying the head in the sand like the bird, Ostrich. In other words it means not wanting to know about something as would be discussed in section 5.24. The last three headings, (old age, fear of disease and mortality) are linked concepts. As has been discussed above old age could be associated with the fear of disease and death. The fear could lead to ostrich syndrome. These concepts could be summarised in the quotes above.

On another note, people who feel that they are fit and healthy may not see any reason why they should go for the test. This could be misleading and a serious issue given the asymptomatic nature of BC. However, this was not an issue for the current study participants. This may be because of a number of reasons. For example all the participants felt that screening was beneficial and have all taken part. Probably this idea of low susceptibility may be found more in non-responders to screening. There were literally 2 non-responders in this study that basically may not be classified as non-responders. This is because BC screening is a biennial routine test which is in the third round now and all study participants have completed the test at least once. Secondly, the increased awareness of the asymptomatic nature of BC may have countered the low susceptibility idea for these participants.

### **5.23. Gender**

There seemed to be a belief by the female participants and some men that women are more open than men and more likely to access healthcare services. Women also said that having had babies and other invasive procedures, they find bowel screening nothing in comparison although it is not the nicest thing to do, (P15f). On the other hand, more of male participants reported finding the FOBt unpleasant to do than the ladies but felt that it had to be done as illustrated below.

P15f: 'Um .....nothing, it didn't bother me that you had to sort of scrape and put.....I think to be honest as a woman, if you've had babies and you know you just, you seem to lose your dignity as you go for cervical screening so you don't really .....and they you have your breast swashed with the other....you know.....'

P17m: I think it was embarrassment at first time, no um and after that, it was alright. No. as I said the first time is the worst time after that, I find it straightforward. No, I'm quite happy with the test.

P3m: Yea it is a shame that it is a kind of a messy procedure.

Both gender seemed not to mind the unpleasantness as long as it is going to protect them. Interestingly, all the ladies who have done other embarrassing procedures like breast screening and cervical smear found the FOBt easier to do than men. This seems to generally suggest that previous participation in such invasive procedures could perhaps predict future participation. However this may not always be the case for everyone when it is individualised. In addition, there tend to be a perception about men not seeking help as a result of traditional male gender role expectations and therefore may not take part in the screening.

### **5.23.1. Perceived Stoicism- the traditional male gender role**

The traditional stereotypical male gender role assigned to men seemed related to stoicism and seemed to emerge as a potential influence on uptake. This stereotype appeared to be common among this study participants' age group (60-74) and particularly a perception of the 'other gender' perhaps as suggested by the data, though some men agreed that other men might be but exonerated themselves. Prior to screening invitations, data appeared to indicate that men were culturally seen as strong, not expected to cry or complain of pains otherwise they will be seen as weak. Men were not expected to feel pain.

I explored this notion further to find out from more participants whether the notion that men 'tend to keep things close to chest until they could no longer bear it' was the case. These were reported particularly by the ladies when they talked about their husbands or their fathers. Some of the ladies reported that their husbands had put off completing the test, but had to after much nagging by the wife as illustrated below, (P20f). However, others did not seem to have succeeded in convincing their husbands. The general consensus among the women seemed to be that men don't want to know and don't even seek for help until it is too late, (P21f).

P20f: Men are funny they don't like to know, they don't like to think of themselves as being ill or having anything wrong with them.....

P22m: I think there are a lot of men who don't seek help, they ...are like an Ostrich, they put their head in the sand and they think uh no not for me, I don't want to know.

P20f: Yes it was my husband who didn't the first time, I had to keep at him and keep at him and at him. I mean he thinks of himself as a very busy man. But I convinced him that no matter how busy you are that this is important. Men are funny they don't like to know, they don't like to think of themselves as being ill or having anything wrong with them.....They don't like going to the doctors, so he did not like the idea of doing it.

P21f: My father... he was the type of man that will put up with a lot of pain and discomfort until it got that bad. He was a clever man but he would hide it I think as long as he could which is now not encouraged.

I explored further to find out if the men felt the same about the traditional male gender role expectation particularly where screening is concerned. However, the men interviewed seemed to refute this perception as illustrated below. A few of the male participants said that it may be true for the young but not for them. They tried to distant themselves from the idea of men not seeking help. However, most of the men seemed to suggest that everybody no matter the gender feels like 'I don't want to know' when they were younger:

P10m: ...I would be at the doctor's like a shot,

P7m: I've been in to see my GP and said I would like a well man clinic, I will like to be able to come and talk to people about issues and have tests done um for...um preventive purposes; because I am responsible for my body and um I regard you as helping me to do it. It's not your problem; you are helping me to solve whatever problem I've got. I do think it's up to me to do it. It was when I just retired. Well I thought clean sheet, start afresh.

P22m: I am the type of person who ... if I think there is something not right, I will go and get it investigated. I think there are a lot of men who don't seek help, they are like an Ostrich, they put their head in the sand and think 'oh no not for me, I don't want to know, I think we are all like that when we were younger. I think we all think we will live forever. I think that's just being young. Yes your mortality comes into focus to you. It does really because I don't care what anybody (traditional male role) says but when you are young, you've got your life ahead of you, you've got optimism, you've got everything. As you get older you realise I have passed over the hills, instead of climbing that hill I am now climbing down it. So it is really a case of your own mortality you look at.

P7m: It saves also lives. I can't imagine what the counter argument is for not doing it. I think it's great. I very much support it. It is something I'm very pleased to ... to cooperate with. You know to help with and do whatever I can with it in all sorts of ways. I will like to see a bit more on prostate cancer. There are a lot on breast cancer and that is very vital. Um...prostate cancer doesn't get that kind of press. It doesn't get the same sort of um... impact

Most of the men tend to suggest that as they get older particularly after retirement, they care more about their health than when they were younger. It was reported that mortality comes into focus right there in your face as you get older particularly if you have had health problems. One of the men reported that he attends the well man clinic. Most of the men reported that they would go to the doctors if they have any suspicions. This may be related back to old age and fear of disease as result of life course. P7m reported that as a result of old age he cares more about his health as he felt that as people get older they tend to get a lot of health bother. Most of the male participants reported that they will be at the doctor like a 'shot' if they have any health concerns or for general health check and that they will like more tests for men. The quotes seem to suggest that men are becoming more mindful of their health by seeking help and doing screening tests. However, they tend to find it more embarrassing than the women as mentioned earlier. This seems to be an emerging novel finding that could start to challenge the long old held belief about some of the traditional male gender roles and perceptions.

Question: Could this be explained by the fact that this is the first screening that included men and women? And women seem to be coping better probably because they are more used to investigations as suggested in earlier quotes. Could it be that self-efficacy or previous uptake experience influences future and subsequent uptake? These will be explored further in chapter 8.

## **5.24. Perceptions and attitudes**

There were some common perceptions and attitudes widely held among the participants in relation to pain and behaviours similar to that of the Ostrich of 'burying head in the sand'

### **5.24.1. Pain**

Pain appeared to be generally perceived as an indication of disease. Therefore, if one gets real pain there must be something wrong and then they will see the doctor. Interview data revealed that people tend to think that if they get pain, it must be something serious, (P21f). However, the participants are becoming more aware that this is not always the case and that some diseases might not manifest any signs and symptoms but are still there, (P24f). The

participants seemed to perceive this asymptomatic nature to be very misleading. This means that the fact that one does not have any symptoms does not rule out that they have the disease. Therefore the participants said that they would be rather safe than sorry by completing the screening test.

P21f: I mean people tend to think if they get real pain, it must be something wrong but some of these cancers .....well my ..... you see, he must have had it a long time and till he well nobody can be sure if he did, he was quite a quiet man; he obviously hadn't been in lot of pain until suddenly, put up with enough I suppose,..... Probably this is it, you expect to get pain.

P24f: My understanding of the stool test kit was that um...by providing the sample stool, ... to check the stools to see whether there ... was any blood in it or um... an abnormality in the stool which could indicate the presence of bowel cancer. ... No I understood and ....even if you are clear on the stool test it doesn't necessarily mean that you haven't got bowel cancer.

### **5.24.2. Ostrich syndrome (burying the head in the sand)**

Burying the head in the sand is a form of denial which I have called 'Ostrich syndrome' as mentioned earlier. This can hinder participation in FOBt. There seemed to be these perceptions from the participants that older people are frightened of finding something untoward as mentioned in section 5.22, that people would rather not know. However, with increased awareness of the dangers of late diagnosis and benefits of early diagnosis, this perception may be changing. Data appeared to show that some people may still bury their heads in the sand, and say if I don't know it won't happen to me. This perhaps might be the reason for non-responders which could only be brought to the fore through further research on this group. There was also an attitude of privacy of saying it is none of your business; 'they don't want to be told', (P17m). Some of the participants also reported that sometimes they seemed to feel 'I'd rather not know', as illustrated by the following quotes:

P4f: Whether is kind of a fear and that things will be found that they don't want to be found, you know some people just like to stick their head in the sand, don't they whether it's a bit of that because they are smokers and have not got the best diet, so they might think I don't want to know what I don't know, it could be that; the devil I know is better than the one I don't know. They are very intelligent people. I guess people are people and they are all different, as it happens I don't know.

P22m: they ...are like an Ostrich, they put their head in the sand and they think uh no not for me, I don't want to know.

It is fascinating from the last quotes that this participant chooses to make this point about others rather than reporting what she thinks or did. Does this indicate that she may be trying to exonerate herself from being blamed?

### **5.24.3. Perceived benefit**

Knowledge and awareness have been identified to have potential impact on the societal concepts causing people to 'get rid of their inhibitions' and get screened. However, perceived benefit and perceived danger seemed to play a 'trigger' role in the choices that the participants made. Some of the perceived benefits reported by the participants include health protection, peace of mind, success of early diagnosis and treatment, 'saves life', necessity (it is worth it) as illustrated in some of the quotes below.

P15f: No ... until um... is after 60 that you get aha ... and once I became 60 I got the test ... you know do you want ..... , yes I do. I am the type that goes for everything. You know cancers anything like that. I do all the tests better safe than sorry.

P13f: Well no because I really think... I mean it is not a very nice thing to do but I mean it only takes seconds and the rewards are so great. I didn't find it... I suppose it depends on people, others might be squeamish, I'm not. No I'm not squeamish. So didn't find it.... I mean it's in your home it's not as if you are having to do it for your friend you know and you have to say bend over and you have to stick a stick in, you know.

P20f: ....Um.... I think ....I'll just like to know that I'm healthy. I like to know and I like to know ahead of time if I'm going to get something. I want to pay attention to the symptoms so that it can, all that can be done to stop it in its tracks can be done in time, because if you don't catch a disease in time, it does more damage.

P22m: For peace of mind yes hopefully to get the all clear and I defy anyone to say they are not worried when they do the test and send it away and wait for that letter coming back.

These quotes particularly the last quote clearly illustrate the health belief model prediction that people will adopt a behaviour if they feel that by doing so they will reduce or avert their susceptibility and the severity of the disease, (Rosenstock, 1966). However, individuals may not always act rationally.

### **5.24.4. Perceived danger**

The participants' perceived danger of having BC and not knowing seemed to outweigh that of finding something untoward. Participants reported that they would rather know than not know. That if they find out early that they have BC,

then something could be done about it, (P20f, P2m). They reported that this is better than finding out very late when the consequences could be very fatal. Fear of getting cancer outweighed the taboo and squeamishness (chapter 5) for most of the participants causing them to complete the test. Some of the reasons for the perceived dangers include family history, recent 'bad health', and old age, lack of symptoms (particularly if it is in the family), fatality and fear of other more invasive procedures such as colonoscopy as mentioned earlier. One of the participants completed the test because she does not want to carry a colostomy bag as illustrated below.

P20f: Knowledge of not any personal experience. And I always knew I didn't ever want to carry a bag (laughs). Yea I had a social worker friend who worked in a hospital and she used to get very upset because part of her job was to tell people who have colostomies how this is good. That colostomy is good but it's not. Cliff Richard had a colostomy but he could have his clothes designed specifically, you know and get special stuff.

Doing the FOBt to avert colonoscopy suggests that this participant does not fully understand that the FOBt is not a conclusive test. This raises a question about the influence of literacy on participation, (i.e. those who have limited literacy might misinterpret health information or even miss out). I explored this further during data collection but the study participants reported finding the information and the procedure easy to understand. Although participant's social/education status was not acknowledged in this study, most of the participants acknowledged to being retired from all kinds of public service work. Perhaps, future research might explore the influence of literacy on participation.

#### **5.24.5. Altruism**

Awareness (Chapter 6) seemed to have awakened the altruistic tendencies in some study participants. This was an interesting facilitator for some of the participants. They seemed to feel a sense of duty to help in beating cancer and that by taking part they are helping in different ways such as helping with research. One of the participants diagnosed with BC in between screening tests wants to help as a result of his past experience and as a survivor. Another participant felt that by taking part in the screening money will be saved for the NHS as he felt that preventative measures are more cost effective. Another feels that by taking part his family will benefit as he wants to spend more time with his family. Another participant feels that taking the test at home will take

strains off NHS waiting times and that 'it must be important otherwise they wouldn't send it'. Below are some of the quotes that illustrate altruistic behaviour.

P23f: I think so and it takes the strain off hospitals and clinics and saves NHS times. I think it's perfect for people to do it um...to help themselves, it's self-help. So I didn't have a problem with it.

P26f: Um...I think because it's offered, and cost a lot of money for the NHS to do all these things...um...and also for my own health I suppose.....basically, for my interest. And secondly surely everyone is interested in beating cancer. And um, if you can play a little part by completing the test, that's fine'.

P18f: No I didn't have any second thoughts. I think it is a good idea. It seems sensible for people to care for health .... And this is one of way that the public could save lives. Because it is gonna show any early indication of problems that can be rectified probably. So to ignore it would be silly, I think.

This sense of obligation to family members and to the government was not a single reason in itself for taking part in the screening, but an additional reason among others. This finding may not resonate with healthcare systems where people paid for their health care. The sense of moral obligation to carry out 'responsible health behaviours' such as screening in order to save limited public resources may be true in free health care systems such as the NHS. This could result to feelings of compulsion or pressure to act responsibly. However, the NHSBCSP does not put pressure on people; it is delivered under the principle of informed choice service. The participants in the current study seemed not to feel pressured in any way, rather saw it as an opportunity and a choice they had to make.

### **5.3. Summary of chapter 5**

This chapter presented some of the social concepts that emerged from data within the social context of the participants. In an attempt to narrate/describe their experiences, participants were unconsciously contextualising their behaviour and beliefs in terms of age, gender, attitudes and wider socio-cultural contexts. These factors acted as facilitators or potential barriers to participation and may highlight deeper processes involved and wider influencing factors which will be discussed in more depth in chapter 8. Cancer and defecation seemed to remain taboos among the participants and are more likely to be barriers than facilitators. It emerged that people do not want to talk about these

things. However, it seemed that more people are beginning to talk about it particularly with the publicity of BC through the screening invitation; many people seem to be overcoming these taboos, though still faced with embarrassment. There also emerged a correlation between old age, disease and mortality. There was a general perception that as people get older they are more likely to have one disease or the other such as cancer which could lead to death. Burying the head in the sand came out as a potential coping mechanism for some people as many tend to think if I don't know it would not happen to me.

There is the possibility that traditional male gender role could still stand in the way of many men in assessing healthcare. However, findings from this study suggest that the trend may be changing from what has been reported in previous literature, (Blaxter, 1990; Marks, 2005). This perhaps could be as a result of change in public health strategies through health promotion, awareness campaigns and celebrity culture in the 21<sup>st</sup> century. Health messages are now easily accessible from different sources. They could even be found in public toilets. Therefore men may be becoming more informed.

Finally, people have become more aware that the absence of pain does not mean absence of disease and that burying the head in the sand is not necessary. The following chapter will continue with the results. It will look at the major category of awareness along with the accompanying sub-categories.

## Chapter 6

### Awareness: major category 2

#### 6.1. Chapter overview

This chapter focuses on the second major category, 'awareness'. The chapter presents participants' knowledge and understanding of BC and the screening programme from the participants' perspectives. This includes their knowledge prior to and after screening invitation, how they make sense of the information provided in the screening pack and how these influence their decision towards the screening test. Here awareness means having some knowledge, whether formal or informal about something.

An exploration of participants' awareness of BC and the screening programme prior to screening invitation revealed that many were aware of BC and other cancers. An interesting finding is that most of the participants were not aware of the screening programme prior to receiving screening invitation as can be seen from the quotes:

P24f: No I don't think I knew there was a screening system. Um...I have always been anxious that there should be a screening system. (Because of family history of BC)

P12f: The only thing previous knowledge I had was that my grandfather apparently died of BC. This is about years and years ago. But that is the only thing; I don't know anything else about it.

P14f: Not until I got the um....the kit. Well you get the letter to say would you like to participate in it you know. I mean .... I.....

P5m: No, I have no knowledge of it (screening) at all. So, I was just in the dark really.

P21f: Um....no I don't think I did. I don't well I probably might have heard of it but I didn't know what was involved anyway. So no basically I didn't know about it.

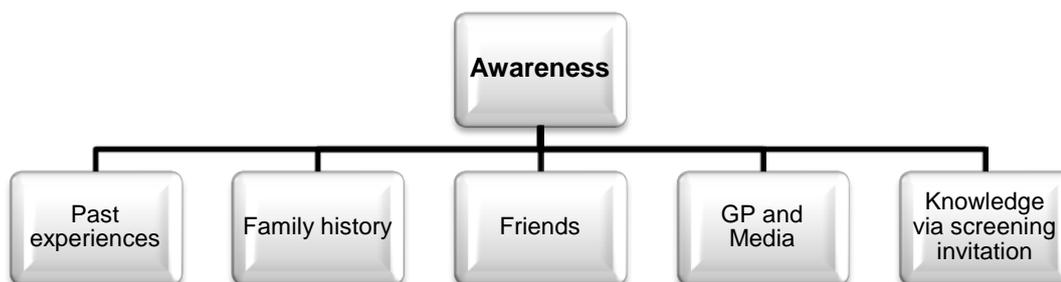
This suggests that in order to improve perception and knowledge of an intervention like screening, a lot more needs to be done in terms of raising awareness. Indeed people cannot take part in what they do not know about, they need information that will help them to make informed decisions and

choices. Few of the participants indicated that they do not normally seek out information:

P7m: I have done, no I have not sort out information particularly, I do not particularly seek out information, but I have been aware and have read articles in the newspapers, magazines and things like that.

This could mean that under normal circumstance people are less likely to seek information about a disease unless something happened (cues to action). Awareness emerged as an important facilitating factor (cue for action) for the uptake of the BC screening programme. Participants' awareness of BC and the screening programme prior to screening invitation were identified as having come from mainly past personal experiences, family history and friends. A few of the participants worked in healthcare settings and so were also aware from place of work. Only very few said they got their health information from the GP or the media. These sources of awareness (figure 6.1) will be discussed in turn below.

**Figure 6.1: Awareness**



## 6.2. Past personal experiences

Personal awareness and knowledge of BC and the screening programme seemed to have greatly come from peoples' past experiences of bowel problems, undergoing other bowel investigations, diagnosis of other cancers and work life as illustrated in the quotes:

P17m: No apart from ..... I've been to hospital. No, oh... I have heard about cancer as I said I went to hospital for this test. I had symptoms..... I had ...um... painful stomach and I lost weight. That's where it started. Yes but I mean it's different from the kit. I had the camera.

P6f: I might have read about it when I was on my treatment for ovarian cancer, my focus was on ovarian cancer, you know so I wouldn't be bothered about BC. I'm a bit discreet. I think it says second biggest killer or not sure about that; so no knowledge of it..... Since I had my cancer I will read everything. But no you know people well think if there's breast cancer.....you know what's gonna happen to you, you know your hair is fallen off from the chemo treatment dead on you know. It's just horrible. So as I said now if I just read the newspapers and I see someone's um..... especially like ovarian cancer, I'll read it straight away, I'll read all of it um....., see if it was BC I probably wouldn't show that much interest. You t know what I mean?

P14f: Well as I was saying before that I have got diverticular thing, which means...., so I had the camera and everything, in the bowel. So I didn't know about it but I kept a watch because they explained about you know...BC. And knew the BC was the cancer if caught quick and everything, good you could get rid. But um... when my first one (screening kit) came, I would have never ever have thought to say no I don't want it, because any test that can eliminate or get rid of or you get it quick enough, you don't know you've got it, um.. you are quite ....well I will take any test just to see if you are ok or you have to have another look or ....um.... but I mean I suppose I knew as much as anybody. But I didn't go into it or anything like that.

P23f: Um.....yes, yes I did. Yes I did. I know because I worked in hospital. I worked in hospital.

Two of the participants were health workers who through education and work knew about BC and screening. As illustrated in the quotes, it seems that people would take more notice when they have experienced a disease and the effects than when they feel that they have no cause for concern. This was also evident from the previous chapter where men's perspective is seen to be changing as a result of old age and fear of illness and mortality. However, a bad experience could have a 'knock on' effect in some circumstances. For example, one of the participants who had a bad experience of colonoscopy does not want to go through it again as the quote below suggests. What she did not seem to realise is that the FOBt is not diagnostic and that a positive FOBt could indicate the need for another colonoscopy.

P16f: I thought it's gonna check to have it done at home, send it in and they check it and let you know whether you are alright or not. I think it is good because I got the letter and it said that everything was fine, no problems or whatever. Cause I had to go to hospital.....it was 2 years ago....and I had what do you call it, endoscopy, it's painful because the nurse she put the anaesthetic in the wrong vein, she did not do it properly and it was very painful. But um, it was checked it was all clear.....yes as long as you don't give me endoscopy

P21f: Yes, alright, the same procedure. Actually endoscopy, I suppose it must be very painful; well they can control it. I suppose it must be very painful if you have got a blockage and they can't get up to.....I have had an endoscopy one or two times down into my stomach, that's worst I think that's worst (Chuckles)

The two quotes above indicate that endoscopy is perceived as a painful procedure and experience by these participants. Interestingly, it seemed as if some participants completed the FOBt (in addition to other perceived benefits) in order to avert the pain of endoscopy; possibly not realising that FOBt is not a conclusive test but could lead to colonoscopy. These findings continue to indicate there is a need for increased awareness so that people would know and 'nip things in the bud', (P2m) before it is too late as one of the participants put it. Increased awareness could also help people to make more informed choice. Nevertheless, most of the past experiences acted as facilitating factors for uptake of the FOBt in the present study. However, misconception of averting colonoscopy by completing FOBt was one of the few disconfirming cases in the findings as other participants appeared to know that FOBt is not 100% sensitive, (P18f below).

P18f:.....It is to see if your bowels are healthy or not, um... as to whether you've got any signs of bowel problems, yea within the .....you know....no. I understand that it can be a bit ... um hit and miss can't it? Sometimes it shows something, I believe you retest don't you? If there is a suspicion of a problem and if that happens maybe on the second test it may show up something then you will be given an appointment to investigate it properly.

This last quote suggests that the consequence of proper investigation after a positive FOBt offers reassurance that the perceived fatal disease, BC can be treated if caught early. Therefore some people seem to be willing to complete the test to keep their mind at rest knowing that there is treatment as P2m reported below.

P2m: .....If there something to find out, it is better someone tells us, a lot of men about BC and that, if they've got or think they've got it, they are frightened like I said I was frightened, but I could they say I will sort it out for you. I think a lot of people are frightened in case there is something wrong and that's where the problems starts, but me if I have it and have it operated on or whatever and it means I spend more time with kids and wife. We've been married thirty one years.

The knowledge that BC could be treated was a facilitator in the last quote. However, there may be other cases where this might not be a facilitator. For example a scenario where treatment has not helped might act as a barrier for uptake. People with such experience can lose confidence in the FOBt and therefore not complete it. However, this was not reported in the current study.

### 6.3. Family History

Having a family member diagnosed with BC, survived BC or even died of BC played a huge part in the choices that people make regarding participation and was a major influence for uptake. Having a blood-related family member diagnosed with an illness which could be genetic seemed to generate extra fear for the participants. The participants felt that they were at a higher risk (perceived danger) where there is such a family history. Death appears to generate a lot of fear in people causing them to complete the screening as they do not want to go through what their father or grandfather went through. Success of early diagnosis (perceived benefit) also has the same positive impact on uptake as fear but from a different perspective. The participants now tend to feel that it is better to know at early stage when a lot could be done for them than when it is too late. Fear of getting cancer outweighed the cultural taboo and squeamishness for most of the participants causing them to complete the BCSP as illustrated in the quotes below:

P21f: 'Well I think to avoid having cancer of the bowel like my father you know. And you know you sometimes think if you've got, are you not better not knowing you know, but it's silly because it gets to an advanced stage, it can spread like it did with dad. And he had no.....I don't ....you....what cancer was a word; you see all those years cancer was a word that wasn't used a lot'.

P24f: 'Um....No. Um in a sense I probably would at this point....should say to you why nothing would put me off it because it....this is what colours my reactions to it and that is that my relation had BC nearly two decades ago and he was diagnosed very early and he has been fine ever since. But from the time he had BC, I have always been anxious that there should be opportunities for people and people should be made aware of the fact that BC can go undiagnosed and can be fatal and that people have to try to um...get rid of their inhibitions and be relaxed about the fact that if people wish.....people will offer it....if you are offered an opportunity to have some kind of BC screening then you should take it every time because otherwise you could be somebody who would develop it and not know it and the result could be fatal'

P2m: ... I mean my mum and dad they had cancer um but not that cancer um and I've heard some old friends having it but you never think this could have happened at your front door. Well I suppose that's a bit worrying. It's like you don't know, you don't know.

P3m: A little because my brother -in-law had some experience, he had done the test that identified some precancerous cells, and he had an operation. So um...and um the age I was, I was expecting the test material to come through the post at some point and I was always happy to undertake it.

A pattern could be observed in the quotes showing that participants have taken part in the screening programme as a result of family history and so were more

easily convinced when they received the invitation. A lot of contemplation and deliberation went on in the first two quotes above about whether to complete the FOBt or not. Possibly, if not because of family history, many would not have taken the test. Therefore other people (non-responders) who may not have had these experiences may not necessarily pay attention to the FOBt invitation artefacts. Therefore, there seems to be the need for a more effective way of raising awareness in addition to the screening test invitations. The quote above from P24f suggests that the taboos over bowel motions and cancer could negatively influence uptake in screening. However, it could be inferred from the quotes that the awareness of BC and its detrimental effects; benefit of early diagnosis and dangers of late diagnosis were strong facilitators for uptake for these participants. Awareness seems to be gradually demystifying the taboos and perceptions surrounding bowel issues and cancer. This pivotal role of awareness on the other two major categories is well illustrated in the 'awareness-led behaviour model' (figure 4.8), the product of this study.

#### **6.4. Friends**

Awareness of BC and the screening programme also came from friends. Some of the participants reported becoming aware of BC through their friends who have been diagnosed with or died from bowel and other cancers. Some participants also became aware of the screening programme through friends who have completed the test as illustrated below:

P12f: Um no. no wait a minute, there was a friend of ours, they had said they had um...these screening things as well and they were asking if we had it, they're about the same age. And um, I said oh not yet. But it did come along eventually and we did it.

P10m: I would ask for it... because I believe in.... if I see, I think everybody when you at a certain age you start to think, have I got cancer? A friend of mine was given two months to live the other day. You he's...he was in a home he has cancer of the throat but he fully cleared then he had some problems, and he wasn't very well

P2m: Not about BC because I know friends, I mean my mum and dad they had cancer um but not that cancer um and I've heard some old friends having it but you never think this could happened at your front\_door. Well I suppose that's a bit worrying. It's like you don't know, you don't know. I'm getting old and changing my mind that's why I rely on the family and the kids to keep us on the go.

The influence of a friend and an age mate convinced P12f and her spouse to take the FOBt. This shows the significance of friends' influence on one another and how this could be a way of raising awareness. An intriguing question would be the opposite: what if the friend did not like the test? What would have been the reaction of P12f and her spouse about the FOBt or the friends of P13f below if she had a negative perception of the test? P13f reported that she has a lot of friends she socialises regularly with. In this circle of friends, they talk about anything and that was where she heard about the screening. This lady reported that she now talks to other people about the screening programme as illustrated below.

P13f: Yes, I had heard, yes.....I am not aware of a lot of publicity. I certainly wasn't at the time. I think it is more talked about now.....I mean I always talk about it to friends because I think it is very, very important. But there was a lot of misconception. So I felt .....to bring things into the open , the more that can be done for screening; for things which particularly for things that people don't actually like talking about it....

One of the participants reported that after talking to a friend, the friend requested the kit. The friend was diagnosed with BC as a result. This friend was eventually treated and is doing well. These incidents suggest that 'word of mouth' is potentially a significant way for increasing awareness but should be approached with caution as its influence could be in opposite directions, (discussed further in chapter 8).

## **6.5. Media and General Practitioners**

Only two people reported having heard of BC through the media. This participant has seen the national awareness and early diagnosis campaign on the television (quote below). One of the participants noted that the campaign did not mention the screening programme and wondered why. The other participant was not sure where he had heard about BC. He said it must have been at the doctor's because that is where he gets most of his information from.

P15f: Yes, yes ... um .... I mean it is publicised on the television and yes I knew about BC yes, yea. It (TV campaign) mention the test, I think you should promote that (FOBt) alongside that bit about going to the doctors.

P5m: Um....I must have done at some degree from the doctor or something like that, you know, that's where most of my information come from. But I have short memory, short term, that's terrible. You know I can't remember who told us before they sent the letter to us.

The above two quotes suggest another two vital sources of information for people. However, as could be seen later in chapter 7, when GP involvement was theoretically sampled, there was a lot of disagreement over this source of information and service. Awareness seems to come from past experiences and a combination of other sources as this chapter illustrates and as could also be seen below from participant 18f interview extract.

P18f: I've heard off other people that actually used the kit themselves. So obviously um... when it came along I wasn't surprised. So yea I had heard quite over a number of years about this kit test.

P18f: Um ... my brother had a bowel problem as well. Also um it seems quite appropriate to use it. It is to see if your bowels are healthy or not, um... as to whether you've got any signs of bowel problems, yea within the ....you know....no. I understand that it can be a bit ... um hit and miss can't it? Sometimes it shows something, I believe you retest don't you? If there is a suspicion of a problem and if that happens maybe on the second test it may show up something then you will be given an appointment to investigate it properly.

## **6.6. Knowledge through screening invitation**

Another significant source of awareness in addition to the previous sources, (6.2, 6.3, 6.4 and 6.5) was the BC screening invitation pack, (FOBt kit). It emerged that many people may have heard about BC and a small number about the screening programme but the information seemed inadequate to engender active participation. The BC screening kit comes with information on facts about BC and the screening programme; to provide better understanding and instruction on how to complete the test and to facilitate informed decision. This seemed to have been a very good decision aid and education tool in improving peoples' knowledge and perception of the BC screening programme.

Prior to receiving FOBt test kit, BC awareness seemed to be related to the fatality of the disease. BC also appeared to be one of the taboo subjects that people feel uncomfortable talking about. Perhaps, this may be because of its association with death and bowel motions (another taboo subjects). The invitation to participate in the BC screening programme seemed to have enlightened people causing many to take part in the screening and indirectly lifting some of the socio-cultural barriers relating to BC and practicality issues (practicality issues is presented in chapter 7). The following quotes illustrate

lack of awareness of FOBt prior to receiving the invitation pack and the impact of the same.

P14f: Not until I got the um....the kit. Well you get the letter to say would you like to participate in it you know. I mean .... I..... (Participant was not aware of FOBt until she received the test kit).

P13f: Yes. I had heard yes. I'm not aware of a lot of publicity. I certainly wasn't at the time. I think it is more talked about now. I mean I always talk about it (FOBt) to friends because I think it is very, very important.

P24f: My understanding of the stool test kit was that um....by providing the sample stool, they were able to um... to check the stools to see whether there were ...I think whether there was any blood in it or um... an abnormality in the stool which could indicate the presence of BC. I understood and ....even if you are clear on the stool test it doesn't necessarily mean that you haven't got BC.

P15f: Um ... well my understanding is that they just test different parts of the ... your sample, I don't know, I suppose they are looking for .....some kind of indication.

P22m: It is testing for BC. Oh yes yea, yea. Well it does explain to you that...it does say that it does not mean by completing the test you will not get BC because obviously who knows in the future. Just a precautionary method, isn't it really, to see if there is any early signs.

Those who have taken part in the screening felt that the screening invitation was an education tool in raising their awareness. Many participants reported becoming more aware of BC and screening through the screening invitation. Some even seem to have become advocates of FOBt by talking to their friends about it (P13f & P14f quotes above). However, some argued that non-responders must know about the test since the invitation is sent to everyone in the age group.

'I don't know. Um ... I don't know...it's not a thing talked about. I don't know if people realise that you can just do..., well they must do because they get the kit, so they must know'.

The participants seem to know more facts than they knew prior to being invited to take part, for example, as a result of the FOBt information pack, participants seemed to know more about the FOBt, BC signs and symptoms and the asymptomatic nature of BC. Most of the participants also understood that the test is not 100% accurate:

P24f: My understanding of the stool test kit was that um....by providing the sample stool, they were able to um... to check the stools to see whether there were ...I think whether there was any blood in it or um... an abnormality in the

stool which could indicate the presence of BC. I understood and ....even if you are clear on the stool test it doesn't necessarily mean that you haven't got BC.

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P22m: It is testing for BC. Oh yes yea, yea. Well it does explain to you that...it does say that it does not mean by completing the test you will not get BC because obviously who knows in the future. Just a precautionary method, isn't it really, to see if there is any early signs.

The quotes seem to illustrate that participants are becoming aware of the 'pros and cons' of the screening which is helpful for making informed decision (section 2.6). Even though the FOB test is not diagnostic and not 100% accurate, the participants seem to be pleased with it. They reported that knowing that there is a test which could aid early detection of a potentially fatal disease is good. Therefore, this perceived benefit seem to be a significant influencing factor on their decision making process, which triggered uptake by these participants.

Nevertheless, one of the participants felt that once is enough; that once he is 'clear' with one test he is covered for the next ten years as illustrated in the first quote below. The test was then further explained to the gentleman. Information leaflets were also given to him. However, misconception of once being enough has not prevented him from completing subsequent screening. Another participant reported getting 'mixed up' with information. She reported that she is not the one for reading instructions and has not read the information that came with the pack properly as illustrated in the second quote. Another male participant thinks that the FOBt is an accurate test as could also be seen in the last quote.

P7m: I don't know how, um... regular it needs to be, as I understand if it comes out clear then there's a very good chance it's going to stay clear. Well at my age... I am 70... If it is clear then you've got a good chance of going for the next ten years without any problems but just the same and quite happy to do it as regularly as um necessary. Um...I can do it once a year, every two years, and five years, whatever.....I'll continue to do it as long as it's there to be done.

P15f: Now that's what I wasn't sure about. I got a little bit mixed up about it, I probably hadn't read it properly, you know.....Yes 3 different times. I will read it more specifically. Sometimes you say oh yes I've got to do the test and you .... You know but that's me. It's nothing to do with how it's presented or the information booklet something like that. As I say I don't like feeling forms and stuff like that.

P3m: Um....no because I felt it was an important thing to do, from what I read and what I have heard it is a very good test and it does you know some times I have read about prostate cancer and sometimes it creates false truth sort of thing I think. Whereas this one (FOBt) I think all the evidence I have sort of see it's a very accurate test and it does catch things very early um... so I felt that it was certainly worthwhile doing it. I wouldn't have not done it because it was a bit ... you know....

Intriguingly, the underlined sentences in quotes P7m and P3m indicate again some of the few disconfirming cases that stood out from analysis. It suggests that the provision of information is never linear and does not guarantee knowledge. People may have literacy issues understanding information leaflets and therefore may misunderstand or misinterpret the intended message. Providing information may not necessarily lead to participation due to peculiar individual contexts, priorities and practical issues associated with tests as will be discussed in chapter 7. Nevertheless, knowledge and awareness, the focus of this chapter seemed to have enlightened peoples' perceptions of benefit of screening and dangers of BC/late diagnosis. It has also enhanced individuals' altruistic tendencies. These will be described below and discussed in more details in chapter 8.

## **6.7. Summary of chapter 6**

In summary, prior to screening invitation, participants' awareness seemed to mainly come from past experiences of personal problem, family history and friend or knowing someone who was diagnosed or died of cancer. However, these past experiences seemed to have different effects on different people. As discussed in chapter 5, past experience particularly non personal experience might make people to 'bury their head in the sand' like the Ostrich as result of fear. This might happen where experience involved a bad report. For example if someone died despite the early diagnosis and treatment. Other people might think there is no point going through all the trouble if they will die eventually. However, where the experience has been negative (diagnosed with BC) but the outcome was positive, (successful treatment) the opposite might be the case. In the current study, these experiences tend to have been negative but with positive outcome as a result of the FOBt. Some of the participants reported finding out about the screening through friends or family whose lives have been potentially saved by the BSCP. These people have gone ahead to complete the

test and have in turn encouraged their friends and family in the age group to do the same. This is as a result of the perceived danger and perceived benefit of late diagnosis and prompt treatment respectively.

Past experiences of having bowels problems, family history, altruism and knowing someone who has had an experience all seem to be significant reasons for most of the study participants and made them keen if not anxious to undertake the screening programme. However, the core source of formal or informed knowledge seems to be the screening invitation pack, which seems to have widened the scope of knowledge, potentially aiding informed decision and even made some advocates of the screening test. Nevertheless, few of the participants seemed not to have completely understood the information as a result of different factors. This however, has not affected their uptake. The third major emergent category in the participation decision making journey 'practicalities/practicalising' which includes further facilitators and potential barriers to uptake will be discussed in the next chapter.

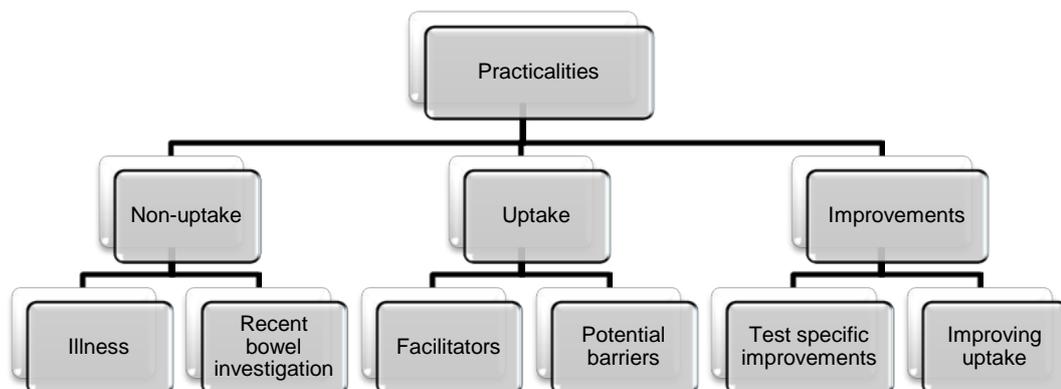
# Chapter 7

## Practicalities of FOBt – major category 3

### 7.1. Chapter overview

Having overcome some of the societal perceptions (chapter 5) that could have hindered screening uptake through knowledge and awareness (Chapter 6), most of the participants made the decision to complete screening in the first round and subsequent rounds of the screening programme. This chapter focuses on the third major category 'practicalities'. This includes reported participants' experiences and perceptions of the practical issues encountered in relation to the FOBt; and how these influenced their decisions to complete/not complete the FOBt. Study participants were 'practicalising' their participation experience and decision making journey. These practical issues, (figure 7.1) also seemed to be very influential to FOBt uptake. The influence tends to lean more towards potential barriers than motivators.

**Figure 7.1: Practicalities**



Interestingly, despite the potential barriers, participants still completed the tests and said they will continue to complete the screening as long as it is on offer. Some participants said that they would ask for the kit when they pass the age limit of 75. All the participants seem very positive about the screening programme. Most participants said they would recommend it. They seem to suggest that seventy is not particularly old in this era where people are living

much longer. Perhaps this is as a result of the perceived benefits and dangers which seemed to have been evident in the previous two chapters. However, one participant reported doing anything that is on offer, saying that it (FOBt) must be important otherwise they would not have sent it.

Twenty-four out of the twenty-six study participants completed the BC screening test in the first round while 2 of the subjects did not but have gone ahead to complete them in the subsequent rounds. Figure 7.1 shows the emergent possible practical factors (facilitators and potential barriers) to participation. These will be discussed in turn from participants' perspectives with reference to interview narratives.

## **7.2. Non-uptake (Illness and recent bowel investigation)**

The reasons for non-uptake for the two subjects who did not complete FOBt in the first round were illness and recent bowel investigation. One of the subjects could not complete the screening the first time as he reported being 'under the weather' when the screening kit arrived (see quote below). However, he has completed the screening twice now:

P2m: Um...once I think, the first time when it happened I was a bit under the weather so to speak. I never took much notice um but the second time which was the BC thing the sticks and the coloured chart and that and I sent that off, that is really the first time, because the first time I was under the weather, I don't mind anything about that.

The second participant could not complete it the first time because he has had a recent bowel investigation (colonoscopy) and his doctors advised that he did not have to complete the test. He has since then completed subsequent invitations:

P3m: No um.....um, my wife did. I didn't because I have..... had some sort of bowel difficulties and the doctor had sent me to a colonoscopy and they said it was not necessary to do the test but a couple of years after that because obviously they had a good look in the bowel and it was ok.

The quote (P2m) above exemplifies the influence of competing health issues as a possible barrier to participation in screening. The second quote shows that it is not relevant to undertake the FOBt after colonoscopy; after all colonoscopy is the preferred diagnostic test for bowel cancer. Although these two reasons for non-uptake seem to be straightforward in the cases of P2m and P3m, it may not always be as clear cut for other non-responders of FOBt. It is likely that more

competing and conflicting issues abound for non-uptake given the complex and dynamic nature of human beings. Therefore, non-responders' reasons can only be known through further research specifically targeted at them.

### 7.3. Uptake

Another outcome of FOBt invitation was uptake. The reasons for uptake seemed more or less similar for all the participants. In a broad sense, the participants seemed to have completed the screening for preventative reasons as a result of the following: perceived benefits, perceived danger, altruism, fear of more invasive procedures and opportunity (chapter 5 and 6). I have grouped the practical issues relating nature of screening test into facilitators and potential barriers; though there may still be some cross-cutting of some of the factors.

#### 7.31. Facilitators

The FOBt participation decision making seemed not an easy task for participants. A lot of contemplation appeared to be going on in their minds. The findings suggest some competing factors in this process for example socio cultural contexts, (chapter 5) and lack of awareness, (chapter 6). However, there emerged some positive influences (figure 7.2) that helped people make the decision to participate in the screening programme. These are discussed in turn.

**Figure 7.2: Facilitators (positive influences)**



### 7.31.1. Venue of test

Venue of the screening test emerged as a significant factor. Participants seemed to feel that such things like bowel movement should be kept personal and private. This appeared to make them feel more comfortable with the test. One of the ladies wished that cervical smear tests could be done at home too where no one else can see them. Only very few seemed indifferent about the venue. One of the ladies said she would not find it impossible but rather difficult doing the FOBt in the hospital or at the doctors. All participants reported that home is ideal as illustrated in the following quotes:

P5m: 'Yes. You couldn't get it easier. You know who wants to go to a hospital for things like that or going to pathology with sample, (Chuckles), you know what I mean. It's done and dusted. You couldn't get it any easier. Whoever thought about it did a good job'.

P1m: Doing it in the privacy of your own bathroom, um... I suppose you.... it could have some people might have found embarrassing but not in my case. Again I just.....it was a necessary thing that should be done, so on that basis it did not bother me personally. It had to be done. There is no problem

P13f: 'No, I... you see I personally would find it harder, I wouldn't find it impossible but I would find it harder to go to the Doctor's to or .... You talk about smear test, I didn't like doing that and if I could have done that at home, I would have done it alright. So this is the sort of thing really, you know, you don't like to show your bits to strangers. And if you can do it yourself, it's totally pain free and you just, as I say I can't understand why they don't. I really don't. It's just as simple as that'.

P4f: It is, well like I said I wouldn't bother (about venue), but I think it's a very good idea, 'cause some people haven't got cars or transport. They feel safer in their own home. You know, more comfortable.

P3m: I will feel that's a personal choice, I will rather do it myself at home. I'll feel maybe a little bit embarrassed going to hospital and having a nurse, you know, it's not that bad, it's more difficult to arrange. I guess other people might feel more comfortable about that um ..... I think if you are doing it over series of day which you need to do I think to arrange that will be very problematic I would have thought you know, not an easy.....logistically I think it is not an easy thing to do you know. So the whole thing in a sense is simpler you know but um.....maybe there is an alternative but I just think it's not an easy thing to arrange, yea

There was no better way of illustrating the convenience of completing FOBt at home than the participants' narratives above. Intriguingly, references were made to why home is ideal such as the simplicity of the test which the people seemed to feel does not require going to hospital, no associated costs (transport and pain); most significant reference pointed towards the taboo

nature of this subject. The embarrassing nature of the test was the most cited reason why it is ideal to be done at home; after all, 'no one likes to show their bits to strangers' (P13f). Again the logistics of sample collection over few days still put home as the ideal venue. If home is ideal, why is uptake of FOBt still low? Perhaps, potential barriers (7.32) might offer some insight.

### **7.31.2. Information leaflet**

The FOBt instruction leaflet was identified as a facilitator in completing the test and served as an education tool because a lot of the participants had no prior awareness of the screening test. People reported that the information leaflet was straightforward, self-explanatory, told you exactly what to do, simple enough, pictorial, very short, well set out, clear, well explained and easy to understand as illustrated below.

P11m: No, no... it was very simple in itself. All you had to do was read the letter, read the instructions and it was easy enough to do. Well once I opened it and read it was pretty self-explanatory and I just followed the instruction basically. And it was simple enough to read and simple to do you know.

P13f: No. I just kept wondering how I would do it until I read the hints. Once I had read that I found it so easy.

P20f: I thought it was really good because it was pictorial as well as verbal so you know you have to be pretty stupid not to understand that.

As seen in the above quote, the screening invitation and associated information leaflet were important 'cues to action', (Rosenstock, 1966; Glanz et al., 2002; 2005). The screening invitation acted as a prompt and guide for people to participate in the screening. However, not much is known about the impact of the information leaflet on non-responders particularly people with literacy challenges. Although P13f felt that the instruction would be easy enough for everyone, not every study participant found the information leaflet easy to understand. There was confusion about the number of days to collect the sample and the number of samples to collect. This highlights difficulties with understanding the FOB test procedures. There were also situations where some did not understand the procedure well and had to read the information twice. This difficulty is illustrated in the following quote.

P17m: Then I was working it out how to do it and that was the worst part.....Um...I think I didn't understand that it doesn't have to be a three consecutive days, I don't think that was very clear, because it doesn't have to

be, does it? No. What I mean, you know I always do it 3 consecutive days, I think that's how it's meant to be. No I thought I can't do that.

Another participant expressed concern for people with literacy issue:

P21f: Yes, I didn't find it too difficult whether....well you don't know really who they are sent to but anybody that struggled; I am always conscious that our son, although he's got his own business, it's marvellous how he's got on. He was quite strictly dyslexic and um...he still....I mean he uses computer in his own business, I don't know what he will do without computers really. To read something is a real effort for him. Now whether people like that you know I don't know he is not older.....Oh yea. I think he would be pretty sensible but it will be an effort I think, to read it especially when you are trying to make sure of what you are doing. Otherwise I think for people with normal intelligence or even below ...I think it's quite straightforward

The NHS seemed to have made the information easy to understand by presenting it in simple language as well as in pictorial form as noted by participants. This study highlights that those who read the instructions seemed to be confident completing the test and also know more facts about the test. For example they seemed to know that the screening test is not 100% accurate. On the other hand it was found that those who reported not reading the instructions well seemed to have some misconceptions about accuracy of result. For example, one of the male participants thought that completing the test once is enough for the next ten years as mentioned in section 6.6. Another thought that the test is 100% accurate. Some of them asked for more explanation about the screening test. Explanation and information leaflet were given to them at the end of each of their interviews. In the long run, these participants all completed the test anyway. There seemed to be no doubt that the information leaflet helped many but how far the information leaflet played a role in the choices eventually made could be a case for further research.

### **7.31.3. Cost of doing the test**

Practicality in terms of costs (financial and non-financial) of the test seemed to play a role of facilitating participation decision making for most people. Study participants reported the good things about the screening test as being pain-free, no travelling involved and not much time involved. Some reported scepticism to tests that could cause pain. Majority of the people seem to find the screening test simple and easy to do. Other participants seemed to feel that since it was on offer and does not costs anything, it is better to take advantage. Some participants reported that because there was no financial cost to bear,

they were more prepared to complete the test, (P20f below). However, one of the male participants said that financial cost would not have been an issue for him as he gets himself checked up any time he feels there is something wrong even if he had to pay privately, (P7m). Another participant perceives cost in terms of her time and said it does not take much time and yet the reward is great:

P20f: You know it took a little bit of extra time; but only what? 3 days or whatever so you know no big deal. Um...the gain you got, ok I mean it was a little bit fiddly, but what you learn because you did it was so invaluable and wonderful to know that you don't have to worry about that.

P5m: I think it is well done, there is no going to the hospital, and you do it in your own home, your own convenience, big words there. The um....it is simple easy to do. You just stick it in the post. So you are not inconvenienced at all.

P15f: Nothing, no, no as I say the way I have explained it's not sort of thing we bare our bodies to other people. Doing something like that in the privacy of your own home, it's nothing.

P7m: ...done an examination privately, which has been very expensive and I'm quite happy with that and ...

P20f acknowledged the cost in terms of time (3 days) but maintained that the benefit of completing the FOBt is invaluable. Although perceived benefit seemed a strong motivator for most people, each individual seemed to have other atypical motivators. For example, body parts (see section 5.2) was an issue for P15f and knowing that she did not have to 'bare her body' to others seemed to have helped in the decision she made. Also P5m may have found travelling an issue. Nevertheless, this study indicates that factors influencing participation are complex and do not work in isolation but are interactional.

#### **7.31.4. Self-efficacy**

Self-efficacy refers to one's perception of their ability to carry out a task. This could be acquired through past experience of doing the same task or similar task. Most of the participants seem to feel very confident about completing the test and reported that they will continue to complete it as long as the opportunity is there. Most of the ladies have been involved in other screening programmes (e.g. cervical and breast), so found the bowel screening alright. However, some of the men reported that they found the screening difficult the first time but had to do it because 'it is a necessary thing to do', (P1m). Nevertheless, some of

the men reported not being 'put off' initially but found completing the second time as much easier because they seemed to have got the 'hang of it'.

P26f: No. well I think once you've done it once and certainly when you've done it twice I mean you are so used to it then.

P24f: No, not really. Um....I have gone for a mammogram test every three years and I think now I'm going to have to ask because now I'm over 70, you have to ask if you are over 70. And um....when I was asked to write comment in the book after having my mammogram, each time I ....until I'd had a BC screening test, I would write 'I think this is a very good programme, I wish there would be something similar for BC' (Laughs).

P20f: so having ....having had the breast cancer screening which I thought was good, and to think there was such an easy little kit that I hadn't known about where they were screening other, I thought that was really good. Yea, yea excellent...

P15f: Um ... nothing. It didn't bother me that you had to sort of scrape and put.....I think to be honest as a woman, if you've had babies and you know you just, you seem to lose your dignity as you go for cervical screening so you don't really and they you have your breast swashed with the other ...you know.....

This suggests that previous participation and self-efficacy could foster future participation. However, it may also depend on the experience of the phenomenon. Those who did not find the test easy the first time might be put off the second time. Therefore, future research may be carried out to understand factors that made some people to decline test second time after initial participation. This could help in improving service and uptake of screening. Interestingly, the indication that previous participation potentially fosters future one seemed to mainly come from ladies who naturally have gone through more screening than men as a result of their gender (see chapter 5). Men reported feelings of embarrassment as the quote below indicates.

P17m: Well the more people talk about things like that, the more common it gets, and people understand it more. Like as I said the first time I was embarrassed but after it didn't bother me at all.

The quote also indicates that men are seemingly getting more used to screening which is in the third round now.

#### **7.31.5. Significant others**

The encouragement from significant others seemed to play a vital role in participants' decisions. Seeing or hearing about others who have done the test

was a boost for many. Some reported family member encouraging them to do the test. I observed that most of the participants live with their spouses who are also in the age group for the screening programme and this enhances such encouragement. A lady reported of how her husband could not be bothered with the test and she had to nag him until he eventually completed his own (see section 5.23, quote P20f). However, there was a lady who reported that her husband is still adamant not to do it. This lady said she could not understand why he would not do the test despite being educated and understands the importance of screening. I also observed that a lot of the encouragement seemed to come from the ladies as illustrated in chapter 5. Nevertheless, one of the ladies reported that it was her husband that encouraged her as illustrated below.

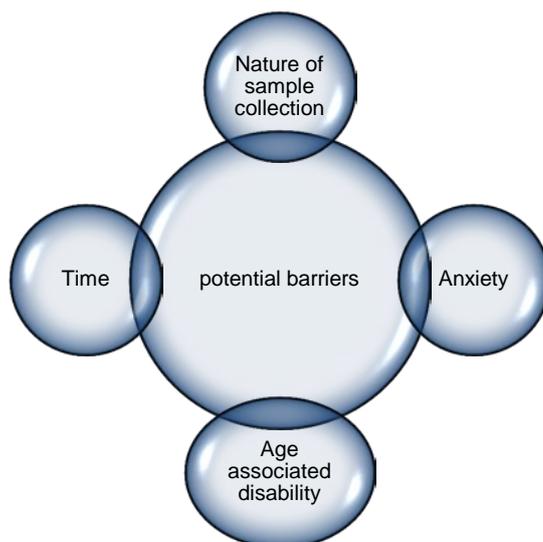
P12f: I will do it, yes. Because actually my husband he talked to us and said you should do it you know. And I think if I have to do it again, it's something that has to be done. You've got to find out you know.

The seemingly intriguing part of the 'the significant other' as a facilitator for some of the participants was that they want to spend more time with their spouse and children. They are fearful of dying before their time and so they take every necessary measure that helps, of which screening seem to be part of.

### **7.32. Potential Barriers**

Potential barriers are factors competing with participation and influencing the decision making process in opposite direction (figure 7.3). These have been labelled 'potential' barriers because though they were there, these factors did not seem to have stopped current study participants from completing the screening test. However, the potential barriers may have stopped others who are not in this study sample.

**Figure 7.3: Potential barriers**



### **7.32.1 Nature of sample collection**

Sample collection was generally viewed as unpleasant. People did not seem to like the nature of the FOB as described in these words: squeamish, embarrassing, unpleasant, not the nicest thing to do, yucky, unhygienic, messy, fiddly, un-dignifying, awkward and off putting:

P11m: I must admit ... when you are collecting the sample, it is a little bit off putting, but it's just a minor thing. It's something you need to do to complete the test. So I don't see any other way of doing it. So it was fine.

P21f: Well I thought at first it was a bit yucky, (Laughs). But um...well I left it like everybody just left it a few days I think if I can remember.

P12f: I think it was a bit embarrassing at first. But I thought well, it's gonna do good so just do it and that's it, you know.

P1m: No regrets, happy I did it, and the experience of doing it wasn't too unpleasant...wasn't too unpleasant. It wasn't pleasant as I said you just do it in the privacy of your toilet but it wasn't unpleasant..... Doing it in the privacy of your own bathroom, um... I suppose you.... it could have some... people might have found embarrassing but not in my case. Again I just....it was a necessary thing that should be done, so on that basis it did not bother me personally. It had to be done. There is no problem.

P24f: .... a little bit messy, not messy but no it won't put me off.....I was happy with it. I was happy ....in a sense it is a bit of a messy process but you do it in the privacy of your own home and in that respect, um...once you know, once you smeared your stick and everything you, they provide you with everything and if you can ....you are happy to accept the fact that yes this is um...a very useful thing to accept because it could be the difference between life and death. I can do it in my private; nobody else has to see what's happening. I think it is a good way of doing it really.

These quotes indicate that people find dealing with stool disgusting which could have been a hindrance. However, in this study, men seemed to particularly find it most unpleasant (see section 5.23). Women reported that it was unpleasant but having changed baby nappies they found it easier to deal with.

### **7.32.2. Anxiety**

As already mentioned in section 5.22, fear seemed to be a potential barrier for taking part in the screening programme. The anxiety of finding underlying problems filled participants with indecision and contemplation on whether to complete the test or not. As people seem to believe that with old age, (5.22) the likelihood that something might be found increases, (see quote below). It seemed to take older people longer to decide whether to participate or not. Majority of study participants seemed to suggest that due to the knowledge that earlier diagnosis means early treatment which can lead to better chance of survival, they had to complete the screening test:

P2m: 'I suppose the first time I heard about it I was frightened in a way in case they find out something wrong. If there something to find out is better someone tells us, a lot of men about BC and that, if they've got or think they've got it, they are frightened like I said I was frightened, but I could they say I will sort it out for you. I think a lot of people are frightened in case there is something wrong and that's where the problems starts, but me if I have it and have it operated on or whatever and it means I spend more time with kids and wife. We've been married thirty one years.'

What else could you do, it's really the only way you can do it. Yea, it was ok with me. I had no problem with it. I thought if it's got to be done, it's got to be done.....for peace of mind yes hopefully to get the all clear and I defy anyone to say they are not worried when they do the test and send it away and wait for that letter coming back.

P21f: ...But um...well I left it like everybody just left it a few days I think if I can remember.

Nevertheless, like other potential barriers anxiety was not a complete hindrance for current study participants.

### **7.32.3. Disability**

Age associated disability was highlighted as a potential barrier to FOBt. Two study participants who were not able to collect the sample by themselves as a result of physical difficulties reported being assisted by their family members. Other participants raised concern for disabled people:

P16f: ... or maybe they can't stretch to the thing (stool) by themselves, or they are too old and nobody to help them. And they are too shy and embarrassed to ask somebody to help them. I mean my own daughter, I mean I wouldn't ask my son, I.....ask my daughter to help me. And she is a nurse any way.

This raises the concern that those who may have nobody to help them could miss out from the FOBt. However, the NHSBCSP has a helpline for those who may encounter any difficulties or have any queries to telephone the BC screening nurses or the hub. Therefore, people were encouraged to use this facility if they have any problems.

#### **7.32.4. Time**

Time was another constraint that emerged which could have hindered some participants. The test kits are sent out around a person's birthday which may have implications for those who plan special holidays to mark their birthday. One participant reported that the screening test always came at a bad time when she is away on routine family holiday.

P26f: Yes I know that but it comes when I am away, that's my problem. I think my test comes January or February, early February. I'm just never here then, but as long as it doesn't matter if I don't do it straight away. I'll just do it when I come back from holiday, that's fine. It comes after the birthday every time.....it gets done eventually because there is so much post after 3 months holiday.

On the other hand, some people seem to have time reporting that they are retired and so have time to do these sorts of tests which people who are still working might not have:

P21m: Why they don't, yea I'm retired. Sometimes I think that possibly with people.....I know obviously younger people are working but I think sometimes people if they are still working at 60, 65 sort of, working full time they would probably just go...oh I can't be bothered with this sort of thing you know. Often times especially women that probably have family you know.

In summary, as a result of the awareness of the perceived benefits of screening and dangers of BC particularly late diagnosis, these potential barriers did not stop the participants from completing the screening. The acknowledgement of these issues by the participants shows how strong the barriers could be; particularly the nature of sample collection which could compete in the participation decision making process. It also emerged that taking part in the screening has had some effects on the participants themselves and their perceptions of the FOBt. These will be discussed in the following section.

## **7.4. Suggested improvements**

The impact of participating in the FOBt on those who completed the tests was many folds. The experience did not only improve awareness and led to uptake but as a result of the challenges through this lived experience led to suggestions for improving FOBt kit and uptake. Completing the screening appeared to have resulted to both positive and negative outcomes, although the positives were more apparent. The positive impact of screening seems to create a continuous positive counter effect on the socio-cultural perceptions and potential barriers. This simply means that social contexts (age, gender, cultural beliefs and perceptions) which people carried with them prior to screening invitation were demystified through knowledge and awareness of BC and FOBt. The practicalities, (nature of sample collection, cost and time) were also overcome through physical completion of the FOBt. These have led to continued participation in the programme for the study participants. A major negative impact from the data seemed to be around the issue of false hope about the accuracy and timing of the screening test. There is the likelihood that misunderstanding of test might cause some people not to complete the screening in the future. However, this secondary non-uptake may no longer necessarily be as a result of cultural perceptions but other factors such false hope created by the screening test.

### **7.41. Improving perception and uptake**

All participants felt positive about the FOBt and suggested that there should be more awareness so that others could take part. Participants seemed to have many ideas and suggestions on how to improve perceptions and uptake. They also suggested some improvements in relation to the kit and could not think of any other way of providing sample other than from going to toilet. Almost all felt that the screening kit is very simple and straightforward to use but major issues and worries seem to be collection problem around how to capture the sample before it falls into the toilet. Suggestions for improvement are presented below and will be discussed in more depth in chapter 8.

### 7.41.1. Word of mouth

It was felt that the best way to improve perception is by telling others about the screening especially success stories. There seemed to be the notion that people tend to take action when they hear or know of someone who has had the experience as illustrated below.

P18f: I mean, obviously a lot of it is word of mouth, isn't it? I talk to people about it; I have just done this test and if anybody says to me 'oh I didn't bother' I will say but why, you know it's for your own health you know. Um... I always listen to word of mouth, its better, you know pass on. I just think some people just can't be bothered. I mean I don't like going through smears when I was but I used to go because that was for my benefit. ....I think if people realised just how simple it is they'll just..... It is messy you know they think what they are dealing with. I mean I've done that once and I know there is nothing to it. But I think the way to hear about anything is word of mouth. Just to pass word of mouth. I don't know if you can do that, it's not much good, is it? Just for people just sort of me to tell people about it and tell them, for people to realise. I think if the whole thing is spoken more about openly, you know.

P13f: Yes ... (laughs), yes anything that creates awareness. Because some people, I found that some people live in a very small world. And unless they know anybody that has something wrong with them or as I said they heard from the doctors, they don't seem to know about it.....

Word of mouth can be a strong way of improving perception and uptake of FOBt. However, it can depend on the source and the willingness of people to talk about this embarrassing subject (see section 7.32) which has been masked with a lot of taboo (chapter 5).

### 7.41.2. Health centres

Participants suggested raising awareness via GP surgeries, chemist shops and blood donor centres. There seemed to be a consensus about displaying posters at the GP but divided opinion about getting the GP involved with the actual test:

P13f: Well I think it could start at the GP, GP surgeries with posters.....

P4f: No. they (GP) don't unless you have a problem, then they will talk to you. They just haven't got the time. If you are going for another reason they haven't got the time. You've only got 10 minutes per appointment. So they haven't got the time either way, unless they have a night where they can call a conference, no not a conference but giving out information like this

The argument was that GPs are already too busy and adding FOBt to their workload will put more strain on their services. This argument seems to align itself with findings from the BC screening pilot evaluation study in which a

number of GPs expressed fear over the adverse impact the BC screening could have on their services such as their services being over stretched, (Jepson et al., 2005). However, in a later study the GPs who were involved in carrying out the pilot screening before screening was rolled out noted that workload has not been overstretched as they feared, (Woodrow et al., 2006). Perhaps, adequate payment of GPs for extra work generated by the FOBt as suggested by GPs may boost their involvement, (Jepson et al., 2005). Maybe this is the time to renegotiate/reconsider whether GPs could help in enhancing uptake which has remained below target.

Nevertheless, other research participants felt that getting the GP involved could boost confidence as people tend to trust their doctors more. Many of the participants reported that they get most of their information from the GP surgery; as such it would make sense if the GP surgery is involved rather than the programme coming from unfamiliar source, (quote P4f)

P4f: If it's coming from their own GP surgery, they might feel more confident but um.... information coming from outside of the surgery some people might just say oh yes and put it in the bin.....but if it is from their medical centre, then they would probably be more confident and trust it more, you know

P5m: Not a problem. Right, you know, it's the sort of thing you don't really, it doesn't matter who it comes from as long as it's efficient and works well. I don't think it will make any difference getting it through your GP. They will probably ask you to take it back to the office that's another.....um...for most old people it's a bus trip, for me that's driving the car, I still don't like going down, you know,

P1m: ...but if you don't go to the doctor's you won't see the advert on the walls at the doctors, you know and the screening tests at the doctors.

Others seemed not to mind about where FOBt comes from as long as it is effective, (P5m above) but worried about how to get the sample to the hub. However, there was also concern over some people missing out if FOBt becomes GP based as some argued that not many people visit the doctors unless they are ill. Some suggested GP could sign the invitation letters that get sent out as a way of enhancing people's confidence in the test and getting them to take part:

P7m: It would not make any difference to me. Um, I don't know if it will make any difference to anybody else. The fact that it comes from the NHS and it comes from the Queen Elizabeth Hospital, or it comes from the doctor your surgery, I don't think it makes any difference. You might be able to work out a

way of taking the kit and putting into an envelope with a covering letter that appears to come from the doctor's, your own doctor. You could cross both bridges with the same, tackle the issue with the same envelope rather than sending it from a central point, it could appear to come from your doctors but I would rather not have him involved really. Because it is the resource; taking time and effort that the doctor can use in other ways. Um....um if it could be done on his behalf so that he could sign one page and then you just copy them, that sort of thing. You send them out; he doesn't have to do anything. He would probably say, I'll sign that, you've given me a letter, I like the letter, and I'll sign it. Now it can go off in your letter with my name on it. That might be better.

This suggestion and prior confidence boosting via GP involvement are not surprising as some studies reported improvement in uptake as a result of GP engagement. For example, in the UK, Hewitson et al., (2011) reported that BC screening uptake improved as a result of GP personalised screening invitation; similarly in Australia and Italy, GP invitation letters improved uptake, (Cole et al., 2002; Federici et al., 2006). Adherence to other types of screening has been increased as result of GP involvement, (Mann et al., 2009).

A few of the participants suggested incorporating BC screening into routine GP health checks. However, in researcher's opinion incorporating FOBt in health checks either as physical test or screening information may add to an already information- packed appointment and needs to be approached with care.

### **7.41.3. Media (health campaigns)**

Media could also be a good medium for creating awareness. The use of television to improve perception and awareness and using celebrities who have positive stories about the FOBt were suggested by participants.

P22m: I can't think of any other way to get at people other than the media; papers, television advertisements.

Some suggested incorporating BC screening in soap line citing the example of Jade Goody who died of cervical cancer though not a success story. It was argued that using such story will actually put fear/shock to the people and make them take the test.:

P24f: um... I think when high profile you know if celebrities get um...linked to a particular campaign, you will find that sometimes will encourage other people not to be so.....um prudish..... but if celebrities could, can come along and support campaigns um the people are more willing, I think to go 'oh, oh, oh yes'. Like the Jade Goody one, yes, exactly yes...was tragic because she died.

Um...I wouldn't want to say that a celebrity has to die. But nevertheless if people who have had BC and who are celebrities could come out and say 'well I had it X years ago and I'm ok but that was because I was caught early'.

P1m: ..... I suppose to get directly to majority of the male population is TV advertising, advertise on the TV, because um.....I would say 99% of men especially say advertise on television and sometimes they would react to that..... But to shock men, to shock people into realising that it will or could happen to them...

The above quotes also illustrate support for using both positive and fear messages which the researcher feels should be carefully planned for ethical reasons. Furthermore, the FOBt invitation artefact was generally felt as a useful tool for improving perception and uptake. There were divided views over radio adverts, newspapers and leaflets. Many people reported that leaflets are often treated as junk and not a lot of people listen to the radio these days:

P11m: television, yea. I think most people just get a letter and leaflets and they just say oh more junk and put it in the bin. Not too many listen and pay attention to the radio..... But Television people sit and pay attention.

P10m: Some people don't buy papers, um because they say I'll get it off the television off the news at 6 o'clock.

P12f: ... I think a lot of people watch the television.... Um I think the television and radio. I know we listen to a lot of radio and television. I don't think a lot of people will read the leaflet...they'll just put it in the bin...

P15f: Television. I think the television is a good medium to actually, you know to let people know about BC. Um... and perhaps you know like say it is a simple test, this could save your life. You know ...um...

P9m: Oh.... Something to do with getting paid, if they are paid to do it, there will be so many who will do it then probably.... Maybe TV commercial.... but if it comes on there (points at his TV) in the middle of Coronation Street they might take notice of it.

Participants felt people in their age group, (60-74) watch TV. The impact of TV messages in changing health behaviour needs to be well articulated while considering its use. These divided opinions about the best type of media to use to get to people poses a challenging task for policy makers. Perhaps, varied and flexible methods of raising awareness are therefore needed. However, a few of the participants seem to think that screening programme does not need any improvement:

P18f: I can't really think of anything that they could do to improve it. It is not a very pleasant thing to do. I can't see any how they can make it any nicer. Can they? (laughs) It is straightforward, simple.

Only one participant (quote P9m above) felt that paying people to do the test might boost uptake. However, using this method has its disadvantages which could jeopardise the aim of the programme.

## **Test specific improvements**

### **7.41.4. Sample collection**

Mode of sample collection appeared to be a significant potential barrier in FOBt. The stool sample needs to be captured before it touches the toilet; thus the difficulty working out how to capture the sample was a major practical challenge for almost all the participants. For example a female participant, (P20f) uses a plastic bowl to collect the sample. However, the disposal of the stool after taking the required amount poses health and safety questions around infection control in relation to the washing and storage of the plastic container. Another lady suggested a one off sample rather than two samples from each of the 3 different bowel motions resulting in a total of six. Her suggestion is to help those who may not like the idea of faeces remaining in the house to take part.

P20f: ...Making it clear how you can get your sample, so that like my plastic bowl problem, you know that you could have done it unto a tissue.....um....I suppose may be. You know possibly make suggestions to people as to how they can capture the sample. You know the manufacturing of toilets; um...the way toilets are made, there is no way to inspect your bowel movement. It's flushed away quickly. In the old days, people used to look at their bowel movements more (both laughs) you know it's true

P3m: I think it's quite difficult to do. If you have to have probably some kind of stool sample, I don't know how else you could collect it and it's really just the collection. The kind of the way the material is; that is difficult I cannot see how else you might do that, you know but on your own it is not one of the easiest things to do.

The major concern was related to capturing the stool sample before it touches the water. Participants reported a lot of their friends and relatives declining the FOBt as result of collection difficulty. They suggested that if the sample collection procedure was improved, these relatives would be more likely to do the test. As a result of practicality issues and the suggestions of the participants, the researcher also suggests that the screening (FOBt) kit needs improvement in order to meet people's needs. The World Health Organisation advocates that screening should be acceptable to the population which it is aimed at, (table 2.2). However, more evidence may be needed to buttress this

need. Perhaps, a systematic review of studies on faecal sample collection issues or a larger quantitative study (to obtain representative sample of people) is needed to reinforce the findings of the current research.

#### **7.41.5. Hand protection (gloves)**

Another practical issue related to sample collection was hand protection. Some of the participants suggested providing gloves in the screening pack. Some ladies reported using cling film or own gloves to cover their hands. Another participant suggested the use of bottle/vials or pots instead of cardboard (but worried about increase in cost). However, most participants felt that people should not be put off because there were no gloves:

P19f: Well, it was ok but I just found that the thing is fiddly to use, you know. Um I felt really you should have rubber gloves on or something. You know to protect your hands I can't remember seeing any gloves. I think I used some cling wrap on my hand but other people might not think about that. ....People should not be put off....an important test.

Even without gloves, some people showed motivation to complete the FOBt by using other means of hand protection. They were not deterred by lack of gloves in the pack. However, people who do not have this kind of strong volitional control may be discouraged.

#### **7.41.6. Age and frequency of test**

There were suggestions about lowering the age limit for the screening and increasing the frequency of the screening mainly as a result of perceived threat of BC. This appeared to come from those who have had past experience of different cancers; those diagnosed in between tests; those whose relative had been diagnosed and those who have lost someone to cancer:

P1m: Just that it should be more regular. Ideally 6 months or a year.....again it is because of my particular situation. I had cancer in between the tests, yea.

P24f: Yes you see my husband was....he was 55 when he got it um so....no I just wondered whether, I just wondered whether the lower age might be reduced a bit but um....if you um....I think it would be important and I don't know now whether this is happening.....whether they now send it out to people as soon they are 60.

This again illustrates the influence of perceived threat on people's behaviour towards screening as suggested earlier by other participants.

## 7.5. Summary of chapter 7

Chapters 5, 6 and 7 have presented the three major categories of factors that could affect participation and uptake of bowel cancer screening along with the subcategories. It emerged that social contexts around taboo, demography, perceptions and beliefs could play a big part in people's behaviours and decision towards the FOBt. The impact of societal perceptions could be either positive or negative, but seemed to be mostly negative for the bowel screening which the participants seemed to agree could be as a result of the nature of the topic. However, awareness through past experiences, family history, work related, friends and the BCSP invitation seemed to also have influence on participants' behaviour towards participation in the screening. Data analysis revealed limited awareness of the FOBt prior to receiving invitation letter, but seemed to be greatly improved by reading the information in the pack. It seemed to strongly emerge from this study that education and awareness could have major effect in counteracting long held perceptions and attitudes created by the societal contexts and other potential barriers to screening. Awareness through screening invitation appeared to have influenced people to choose to take action and complete the screening test; this came as a result of the perceived danger and benefits. The participants in this study all seem to feel that the benefit of completing the screening outweighs any embarrassment or discomfort.

From the small sample (26 participants), there appeared to be no significant difference in the attitude/behaviour of men and women towards the BC screening; both seem to feel very positive about the test. However, men seemed more likely to find it more unpleasant. The long held perception of the traditional male gender role seemed to lessen as the men got older. A number of influencing factors emerged as either facilitators or potential barriers to the uptake. Fear seems to be a potential barrier to uptake as well as a significant facilitator. The fear of finding something untoward appeared strong among the participants. However, the fear of having BC and not knowing seemed significant enough for uptake due to the asymptomatic nature of BC. This could be related back to awareness; the participants appeared to have come to know that BC if caught early could be treated and think that it will be 'silly' not to do the test. Participating in the BC screening which is in the third round now could

have a lasting impact on the participants and the prevailing cultural barriers. All interviewed participants felt more confident and knowledgeable about the screening having taken part. For example some reported that they encourage others to take part, and that they themselves will continue to complete the test every two years. The question to be pondered upon is the extent to which previous uptake leads to subsequent uptakes in screening, (to be discussed further in the next chapter). Having lived the experience of the bowel screening, the participants have also suggested ways of improving perception and uptake of the BC screening programme. The discussion of the key findings follows in the next chapter.

## Chapter 8

### Discussion of key study findings

The aim of this study was to explore the factors that influence participation in the NHSBCSP. This has been addressed through developing the ‘awareness-led behaviour’ model. The study was informed by drawing on literature from relevant national and global public health policies and evidence-based interventions which covers a range of disciplines and theoretical perspectives: sociology; economics and also from health psychology focusing on behaviour model and theories. The appraisal of research literature, (chapter 2) on factors influencing uptake of NHSBCSP indicated limited literature in the UK particularly in the NEYH, which could be attributed to the relatively newness of the programme. Nevertheless, many studies were found in America and other countries operating in totally different organisational and socio-cultural contexts.

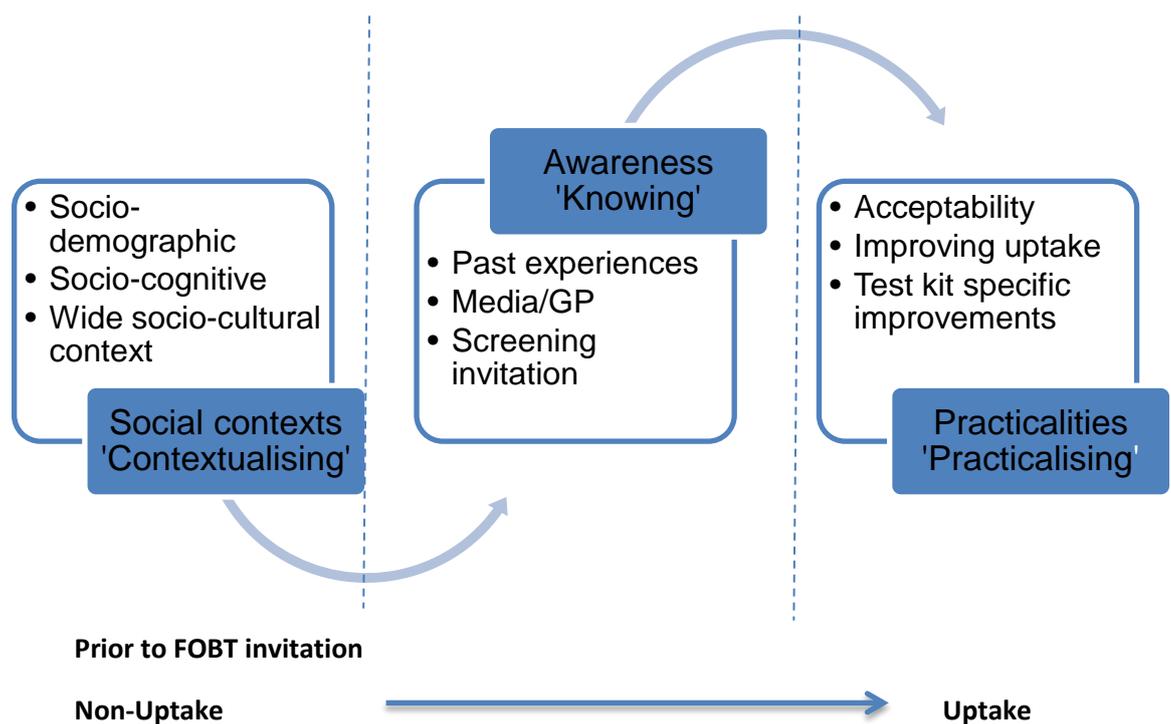
The paucity of research evidence demonstrated the need for a qualitative study to explore the factors influencing participation and uptake of FOBt from those who have been invited to take part. The philosophical and methodological stances underpinning this study have been detailed in chapters 3 and 4. Using a GT methodology ensures that the study findings were grounded in the data rather than from existing literature and theoretical frameworks. The findings were outlined in chapters 5, 6 and 7 corresponding to each of the three emergent major categories (‘contextualising’ ‘knowing’ and ‘practicalising’). Figure 4.7 presented three high level concepts depicting a tentative process of participation decision making. This illustrated the significant role of awareness on both social contexts and practicalities; and the perceived benefit and acceptability of FOBt, thus contributing to meeting the study aims and objectives.

#### 8.1. Chapter Overview

This chapter provides a discussion of the key study findings. It begins by presenting again the summary of the findings (Figure 8.1) and study objectives

in order to determine the extent to which the stated objectives have been achieved and form a basis for discussion. The discussion will be approached in three sections depicting each tentative process involved in the decision making – ‘contextualising’, ‘knowing’ and ‘practicalising’- the components of the ‘awareness-led behaviour model’. The processes encapsulate the personal and wider social influences on participation, sources and role of knowledge and awareness, the practicalities associated with completing FOBt and ways of increasing awareness. These will be located and discussed within wider empirical and theoretical literature from relevant subject areas. Critical reflections on the methodological procedures are also provided. The chapter ends with a summary. Chapter 9 concludes this thesis by highlighting the various implications of the findings for theory, policy, practice, education and research.

**Figure 8.1: Summary of key findings**



The study objectives were: 1. To develop an understanding of peoples’ experiences and knowledge regarding BC and the screening programme; 2. To explore peoples’ understanding of the information provided/gathered regarding the screening and how this influences their decision to participate or not; and 3. To describe the similarities and differences in how different groups of people (for example, men and women) perceive BC screening (FOBt). The ‘social

contexts' largely addressed the first, third and parts of the second objectives; the 'Knowing' addressed the second part of the first objective and the second objective; while 'practicalities' addressed all three objectives. These demonstrate the inter-related nature and interaction of the three elements of this study model.

## **Section one**

### **8.2. 'Contextualising'**

The first objective of this study was to develop an understanding of peoples' experience and knowledge regarding BC and the screening programme, (FOBT). The current study findings suggest that social factors such as demography, cognition and culture are among the social factors affecting participation and uptake of the BC screening. Social context was identified as the antecedent to people's experience regarding BC and the FOBT. An individual's understanding and interpretation of health and their health behaviour is not only influenced by personal social factors such as demography and cognition but are also rooted in the wider socio-cultural contexts in which the individual lives out their life in a particular point in time and space, (Nettleton, 1995; Nolen-Hoeksema et al., 2009; Gleithman, et al., 2011, Nettleton, 2013). It has been noted that even though all people eat, cultures vary in what, how, where and when, (Gleithman et al., 2011).

There is the need for understanding health, health beliefs and practices as context bound and socially embedded. This is as a result of the shift from a biomedical definition of health (disease context) to a sociological definition. Sociological definitions emphasise health as a product of social and behavioural factors which sometimes seem to place more responsibility on people for their own health. Current public health policies advocate a modification of life style encouraging people to adopt healthy life styles. However, it has been suggested that the emphasis on life style in isolation of social context is somewhat a fallacy, (Nettleton, 1995; Marks, 2005). Nettleton reiterated that behaviours which affect health most times carry other meanings outside the health domain. The findings of this study buttress these points; the words bowel and cancer

brings different personal, social and cultural meaning to different people that sometimes have very little to do with the biomedical model. These social factors need to be appreciated in planning of health interventions.

## **8.21. Socio demographic context**

### **Perceptions associated with old age**

In the present study, old age emerged as one of the 'dangerous' positions that predisposes people for the majority of diseases not just BC. Generally, old age appeared to be one of the wider societal beliefs/perceptions for the risk of developing BC leading to many questions such as those asked by Leventhal, (1984) to aid better understanding of perceptions of aging and illness:

1. Is there an age when people begin to feel or see themselves as becoming old and when is this time?
2. Does the feeling of old age mean long life and is it dependent on external clues such as wrinkles, children leaving home, retirement and how one is addressed by others?
3. Are there also internal cues to being old such as tiredness and presence of ailments?

Although, the above questions were asked many years ago, they still seem very relevant today as they can help health professionals understand the association between aging and illness when older patients present for medical help. This is because a patient's description and understanding of symptoms could be quite different from a medical explanation and could alter judgements about prevention and treatment, (Leventhal, 1984). For example, aches and pains could be simply seen by the lay person as part of growing old, while it could be a sign for a potential serious health problem. Current study participants seemed to associate being retired; not being able to do what they use to do and being a grandparent with growing old. However, most of the participants reported feeling younger 'at heart' than their chronological age. Within their mind they feel young but on the outside as a result of biology and social representation they are growing old. Leventhal's, (1981) parallel processing model depicts that inner and outer environments affect how experiences and behaviours are constructed which in turn affects coping mechanism, (Leventhal,

1984). In the current study, it seems that people have accepted old age from the age of 60 (researchers opinion) as a result of environmental and contextual factors. For example, retirement occurs age at age 60, BC is associated with old age and so is the age of getting invited for screening. There were also reported internal personal issues signalling old age for study participants such as prevailing medical problems and chronic illness which were not experienced at young age.

The above perceptions of old age seemed to influence individual's participation in FOBt in the current study. This resonates with findings from previous studies, (Seeff et al., 2004; Subramanian et al., 2004; Kim et al., 2005; Weller et al 2006; 2007; Holt et al., 2009). Current study participants also associated aging with mortality. Ageing thus led to the fear of being predisposed to cancer, which prior to FOBt invitation, people felt may be a 'death sentence'. It was assumed by some participants that any screening could lead to finding underlying problems. Most people seemed to find making a decision to participate in the screening a challenging one. There was reported reluctance as a result of fear, (see section 5.22). This is in line with the findings from previous studies (Busch, 2003; Chapple et al., 2008; Holt et al 2009). Similar influences (fear and pain) were also found for breast cancer, (Ahmadian & Abu, 2012). Although Chapple et al., (2008) noted that feeling healthy was one of the reasons people might decline screening; in the current study people seemed to understand the asymptomatic nature of BC illustrating that feeling healthy may not necessary mean an absence of disease. This indicates that either those perceptions have changed generally or they have changed in this small group, possibly as a result of the screening information they received.

Unfortunately, age is one of the risk factors that are not modifiable, (Flight et al., 2004) in addition to hereditary and family history, and personal history of colorectal problems, (Gazelle et al., 2000). In line with Barry, (2002), the understanding of the asymptomatic nature of BC appeared to have led to increased perception of susceptibility. Therefore, increased perception of susceptibility may have led to subsequent uptake as the participants were all over 60 years old. This is illustrated in the 'awareness-led behaviour' model, (figure 4.8) and is supported by the health belief model, (Rosenstock, 1974) which suggests that people are more likely to make positive behaviour change if

they feel susceptible to a condition and that making the change will reduce the risk, (chapter 2). It was also found that as a result of perceived susceptibility with age coupled with other predisposing factors, there was a preference for more regular FOBt rather than biennially. This preference resonates with the recommendation of Winawer, et al., (2003) for more regular bowel screening. However, other practical factors may make this challenging, for example, organisational factors such as screening systems and guidelines which vary from country to country.

Elsewhere, Mereen & Smith, (2010) reported the belief that cancer is an incurable disease. However, this was not the case in the present study, almost all the participants felt that their age (over 60 years) makes them more susceptible and more likely to develop cancer; and not that it is incurable. They felt that screening could actually be an opportunity to keep things under check. So, fear of cancer associated with old age was a trigger for uptake.

## **Gender**

Gender is a widely recognised determinant of health which can lead to inequalities as a result of biological and societal make up, (Nettleton, 1995; Marks, 2005; Loadsman, 2013). It has also been suggested as one of the factors that could influence uptake of healthcare services not just BC screening, (Lloyd et al., 2001; Coen, et al., 2013; Loadsman, 2013) which is socio-culturally located, (Connell, 2005; Mac an Ghail & Haywood, 2007) as was also found in the current study. Therefore, gender needs to be taken into consideration while planning and developing health care services. Unfortunately, it has been suggested that the male gender has been neglected by the NHS possibly ignoring the equality act 2006, even though there are clear differences in the way men and women behave and in their predisposition to diseases, (Wilkins et al., 2008; Nettleton, 2013). Most male participants in the current study seemed to be in agreement with earlier suggestion of neglect as some of them reported that men have been marginalised in screening programmes and would like to see more preventative health services for men.

It has been argued that observed differences may not necessarily be explained by gender but also on particular career and life choices, (Galdas, et al., 2005; 2007). However, Loadsman, (2013) noted that men's use of health services is

relatively less in comparison with women. Men's poor health help seeking and presentation with primary health care staff was found to be correlated with mortality, (Blaxter, 1990; Van Roosbroeck et al., 2012). It has been suggested by sociologists that the major barrier to accessing and using health services could be associated with the traditional forms and values of masculinity which place specific expected behaviours/roles on men, (Marks, 2005). These include dominant masculine norms such as stoicism and emotional suppression; compliance to patriarchal masculine characteristics such as independence, self-reliance, ordinance and superiority; and embarrassment discussing disease associated with male reproductive organs (Loadsman, 2013). Nevertheless, these notions are in dissonance with 'the awareness-led behaviour' model and the health belief models which proposes that people will take action when they realise that they are vulnerable; the condition is serious and that the action will help them to avoid the condition or minimise the adverse effects, (Rosenstock, 1974). The 'ALB' model (figure 4.8) suggests perception of susceptibility as an important facilitator for men's participation in the FOBt.

Unexpectedly, although limited by participant numbers from each gender (16 women and 10 men); the current study showed no major difference in how men perceive BC and the FOBt in comparison with the women. However, men seemed to find completing the kit more awkward than women. This mirrors the findings from Vart, (2010) study on gender differences in perception of the FOBt. Vart reported that men have lower fear, high fatalistic belief of BC and low self-confidence in completing the kit. A major pitfall in Vart, (2010) study is the method of participant recruitment during BC publicity event. The limitation here is that the study may only attract those passer-byes who are enthusiastic and more aware of BC. People, who dislike the idea of screening or for other reasons may not approach the event.

Women's self-confidence in the current study seemed to be as a result of previous experience of other screening programmes as was also noted by (Price et al., 2010; Van Roosbroeck, et al., 2012) which has led to self- efficacy, (Bandura, 1998; Nutbeam & Harris 2004). Bandura, (1998) model assumes that the confidence in one's ability to carry out a task could influence ones behaviour towards the task. One of the ways to acquire self-efficacy could be via repeated performance of the same task or similar task. Women, having been involved in

other cancer screening such as breast and cervical screenings may have become accustomed to screening unlike men, who are perhaps being included in the first of its kind routine screening. However, men in the current study may have also gained self-efficacy as majority of the male participants reported to have completed the FOB test at least once. This compares with McGregor & Bryant, (2005) cohort study of Canadian men and women, which reported that the commonest predictor of FOBt for men was past recent uptake of the PSA, (prostate-specific antigen) and education attainment. McGregor & Bryant also noted that previous pap test, mammogram, employment status and educational attainment were strong predictors for women. However, unlike this study, McGregor et al used a questionnaire study which can only show trends in behaviours rather than within individual personal context.

In the present study, both gender seemed to believe that they have strong control over their health and seemed determined to do everything within their ability to promote and protect it. Although this behaviour could be linked to voluntary opt in approach used in participant recruitment for this study meaning mainly that people who tend to look after their health may have been recruited. It could also simply be summarised by the locus of control theory which suggests that when people have strong internal locus of control, they are more likely to engage in health promotional behaviours (Myers et al., 1994). In the UK, nevertheless, uptake of bowel FOBt has remained consistently higher in women, (Weller et al., 2007; Steele et al., 2010; Von Wagner et al., 2011).

There have also been inconsistencies on reported male uptake and attitudes towards the FOBt. Similar to the findings of the current study, (Weitzman et al., 2001) reported that male gender with high social class and family history of a disease was associated with compliance to screening while in contrast poor uptake rate has been reported for men and minority ethnic groups, (Alexander & Weller, 2003; Weller et al., 2006; 2007; Holt et al, 2009). Perhaps the method of study, location, health care systems and target population may have played a part in these discrepancies. For example, Holt et al., (2009) found that African-American men were least likely to undertake BC screening because of cultural beliefs. These men associate subsequent diagnostic tests such as sigmoidoscopy with homosexuality and were not willing to engage with screening.

Interestingly and in contrast to aforementioned evidence, men in the current study seemed positive about screening and suggest that traditional male gender expectations had nothing to do with caring for health, but rather attributed behaviour to life-cycle necessity or an age 'thing'. They suggested that everyone, no matter their gender cares less about health at a young age but cares more as old age sets in. It appeared from the current study that the new trend in men's attitudes may be related to underlying bowel problems or the age limit for FOBt which suggest that they are susceptible. This is well illustrated in the first and second components (age and past medical history) of this study model, (figure 4.8).

## **8.22. Socio-cognitive contexts**

### **Perceptions and attitudes**

A number of socio-cognitive/psychosocial concepts emerged from the present study among factors that could influence participation in the BC screening programme. These included; embarrassment, ostrich syndrome (denial), pain and altruism. Similar to the current study, one of the most reported reasons for reluctance in cancer screening is embarrassment; perhaps this could be attributed to the nature of the screening programmes and with very private nature of body parts, (Chapple et al., 2008; Youngman, 2010). Indeed current study participants reported feelings of embarrassment while talking or dealing with private body parts. This seemed to suggest that body parts have been socially represented as one of the taboo subjects in the society as will be discussed later in in this section.

Illness beliefs emerge and change in daily social interaction, (Nettleton, 1995; Marks, 2005). Social representation theory is used by psychologists to gain a better understanding of the nature and interactions of social beliefs, (Marks, 2005). The theory is concerned with broader societal systems and how these systems shape an individual's interpretations of their world. The perception of the degree of risk has consequential effect on how people react to and tolerate health threats. For example, where risk is heightened or over rated, repressive intervention is more likely to be favoured particularly where a disease is characterised as a lifestyle disease. It is assumed that individuals have a control and choice over their lifestyles. A practical example was the picture of the AIDS

disease, (Pollack, 1992). The appearance given to AIDS sufferers (skinny and next to grave) heightened the perception of the risk at individual and societal level. This seems to suggest that the adoption of a healthy lifestyle means improvement in health while a risky life style could be detrimental to health as always seemed to be portrayed in society particularly through the media.

Likewise in this study, perceptions around threat of BC, one's proneness, benefit of and barriers to action, ability and self-confidence, and cues to actions also emerged among the socio-cognitive factors that influence uptake of the FOBt. Even though the current study did not set out to explore the association between the health belief model and participation in screening, the aforementioned socio-cognitive factors seemed to be well located within the constructs of the psychological theory of the health belief model and linked closely with the 'awareness-led behaviour' model social contexts. The health belief model, (HBM) constructs include perceived susceptibility, threat, severity, benefit, barriers, self-efficacy and cues to action, (Rosenstock, 1974; Stretcher & Rosenstock, 1997; Janz et al., 2003).

**Perceived susceptibility:** Perception of the likelihood of developing BC was a significant facilitator for completing the FOBt for current study participants in line with this HBM construct. The construct proposes that the likelihood of adopting target behaviour in the absence of obvious signs and symptoms increases with increased perception of susceptibility, (Rosenstock, 1974; Stretcher & Rosenstock, 1997; Rosenstock, 2005). However, this may not always be the case for some individuals who feel that they are not at risk of a problem. For example studies on college students have shown that perceived susceptibility does not always lead to healthier behaviour as suggested by the HBM, (Lewis et al., 1997; Courtenay, 1998; Lamanna, 2004). Furthermore, Chapple et al., (2008) noted that past experience of knowing someone who has suffered from cancer may not only be a motivating factor but could also become a barrier to screening. Thus attitudes to screening could be influenced by either positive or negative past experiences. A person whose relative died from cancer after many treatments may not completely believe that screening could prevent adverse effect. However, according to Stretcher & Rosenstock, (1997) perceived susceptibility and seriousness combined together could lead to perceived threat where there is a real risk. This means that when people feel

that there is real chance of developing serious illness, behaviour often changes, (Forsyth & Goetsch, 1997; Weinkunat et al., 2003; Mullens et al., 2004). This is supported by the first and second component of the 'awareness-led' behaviour model, showing that study participants, that as a result of their age, family history and past medical experiences they are more susceptible to developing BC. They therefore made the decision to carry out the FOBt.

**Perceived benefit:** In accordance with the constructs of the HBM, current study participants believed they were susceptible to BC. In line with the current study, Robb et al., (2004) also found that family history increased perception of risk. Though it has been reported elsewhere that the implications of family history may not be well understood by those with low level of education, (Jepson et al., 2000) the potential implication of family history and adverse consequences of BC seemed to be well understood in the current study. The current findings indicate that screening was seen to be beneficial in moderating/cushioning the susceptibility and the seriousness of BC. Perhaps, this may be seen as a 'protection effect' rather than 'tempting fate', (van Wolferen et al., 2013). Protection effect reminds people that the precautionary actions they have taken make them think that the likelihood of a related risk is less while tempting fate effect reminds people that inaction exposes them to related negative outcome, (van Wolferen et al., 2013). The effect of perceived benefit in this study is also well supported by the exchange theory which suggests that people adopt new behaviour if it will benefit them in exchange, (Kotler & Lee, 2002). Therefore the FOBt was deemed a beneficial venture in exchange for associated personal costs.

**Perceived severity:** As mentioned earlier in chapter 2, this construct suggests that a person's perception of the threat posed by an illness will trigger an action to avoid or reduce the threat, (Strecher & Rosenstock, 1997). It could be argued that a person's perception of the condition depends on knowledge of condition in question and the importance a person attaches to it as illustrated in the 'awareness-led' behaviour model. This could imply that low importance could lead to low perception of threat and lack of action and vice versa. However, in the current study, there seemed to be high perception of severity which facilitated uptake. For example people with family history and past experiences and BC survivors (see section 8.3) due to perceived threat of recurrence of the

cancer all felt that BC is a serious condition. This supports the argument that perception of severity depends partly on level of knowledge of a given condition. Nevertheless, as seen earlier in the case of increased susceptibility, perceived threat may not always lead to change of behaviour, (Gerba et al., 1996; Hanson & Benedict, 2002).

As illustrated in the 'awareness-led behaviour' model, there may be other mediating variables such as practicalities (section 8.4 & figure 4.8). The HBM also suggested that behaviour in relation to severity could be influenced by some modifying variables, such as past experience and education status. Past experience could modify behaviour in two opposite ways. Firstly, it has been suggested that the experience of having a disease could increase the perception of the risk, (Weinkunat et al., 2003; Frank et al., 2004; Mullens et al., 2004). On the other hand, having the disease quickly treated could also lower the perception of the seriousness.

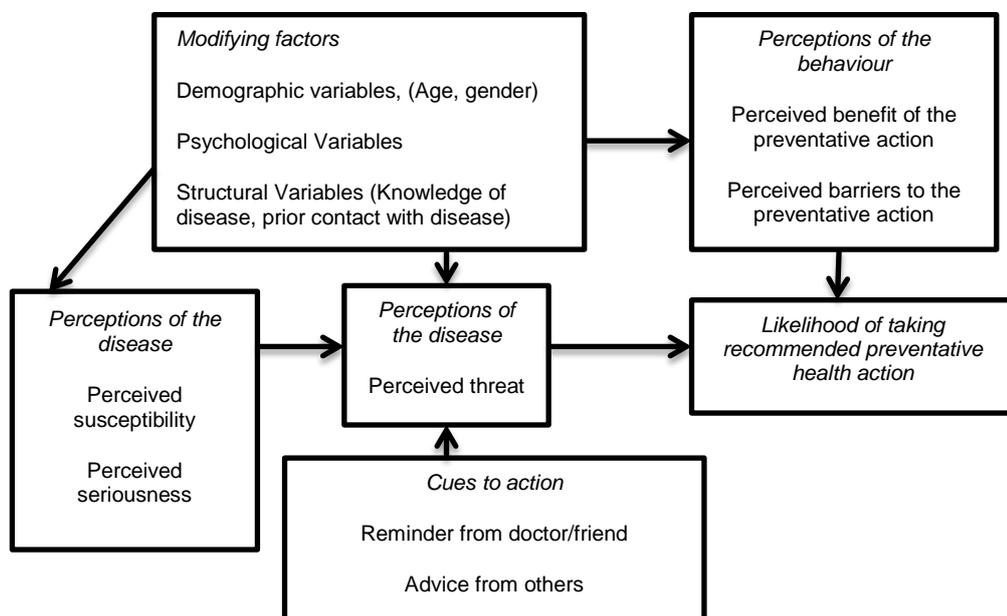
**Perceived barrier:** Behaviour change can be a challenging task; adopting a new behaviour requires a lot of determination and effort, (Janz & Becker, 1984). According to Janz & Becker (1984), a person's perception and evaluation of the hindrances may be a significant influence on behaviour change. In the current study, participants reported many perceived barriers but felt that the benefits outweighed barriers. Similar to the findings of this study, fear, embarrassment and inconvenience were among the numerous reported hindrances that could affect uptake of breast cancer self-examination, (Umeh & Rogan-Gibson, 2001) and pap test for cervical cancer, (Byrd et al., 2004). Fear and pain have also been reported for cervical screening particularly among those who have never done it before, (Burack & Meyer, 1997).

**Cues to action and self-efficacy:** The invitation to participate in the screening was a major cue for action and helped enhance the self-efficacy, (Bandura, 1986; 1997; 2004) needed to complete the FOBt in this study. It has been noted that behaviour can be influenced by interpersonal and environmental factors, (Bandura, 1997; Glanz et al., 2002) and self-efficacy. The interpersonal factors include a person's knowledge of a task and the ability to carry out the task, (Bandura, 1986; Mailbach & Cotton, 1995). In relation to self-efficacy social cognitive theory, (SCT) suggests that self-efficacy is the primary focal

determining factor for behaviour change because of its direct and indirect effect through its influence on other determinants, (Bandura, 2004). Bandura suggested that those with higher efficacy have higher outcomes than those with low efficacy. However, SCT has failed to recognise that knowledge is not the only prerequisite to a change of behaviour. People may decide to adopt a new behaviour for many other reasons. For example people may choose to exercise and eat healthily to lose weight simply because they want to look more attractive rather than for any health gains.

In the present study, cues to action and self-efficacy were both influential in facilitating uptake of the FOBt for the study participants. However, other people who have self-efficacy but are squeamish about bowel issues may be less likely to take the FOBt. Similarly, Wallace's, (2002) study of exercise and osteoporosis in women found that those who do not normally do weight bearing exercise have a low perceived self-efficacy over their ability to exercise even when exercise could prevent the disease. In this case exercise becomes a barrier as a result of lack of self-efficacy. The diagram below shows the HBM constructs and the relationships with the modifying variables cues to action and self-efficacy. The diagram shows that self-efficacy; cues to action and modifying variables influence how one perceives seriousness, susceptibility, benefits and barrier, (Adapted from Rosenstock, 1974). The outcome of the influences can determine subsequent behaviour.

**Figure 8.2: Relationship of HBM with modifying variables**



In relation to environmental factors, an influence may be the availability of resources in the person's immediate environment. Similar to MacFayden et al., (1998) cited in Hasting, (2007, pg. 28), current study has shown that environmental influence directly came from a person's immediate family, friends, colleagues, peer group and indirectly from the wider societal context. These environmental factors might act as triggers or cues to action as exemplified in this study in sections 6.3 and 6.4 where the influences of family and friends are shown. Action could then be completed as a result of self-efficacy. However, self-efficacy and cues to action may not be enough to affect the positive behaviour. As identified from the findings of this study and illustrated in the 'awareness-led behaviour' model, the constructs of the HBM do not work in isolation but could be influenced by other socio-psychological, socio-demographic and environmental variables, (Nettleton, 1995; Janz et al., 2002; Marks, 2005). For example age or education status can influence perceptions (of susceptibility, seriousness, benefits and barriers), which may then indirectly affect behaviour. For example, Wagner et al, (2009) noted that literacy has a direct impact on information seeking and is associated with self-efficacy.

### **Altruism**

Altruism emerged as part of the 'contextualising' component in the decision making process illustrated in the 'awareness-led behaviour' model. Altruism has been defined as 'regard for others as a principle of action' (Walker, 2004, p129); an 'unselfish concern for the welfare of others', (Otto & Bolle, 2011, p558); and as 'taking the interest of the other as one's own', (Scott & Seglow, 2007, pg2). From a sociological point of view, altruism has been described as putting the interest of others above one's own interest, (Nettleton, 1995). Walker suggests that charity, (which she defined as the love of others and giving to those in need) is a derivative of altruism traceable to the biblical principle of 'love your neighbour as you love yourself'. This psychosocial and perhaps moral concept shows that personal perceived benefit was not the only reason for participation in BC screening, but that it was also undertaken for the benefit of others, (family and wider community) and for the NHS. Out of concern and moral obligation regarding how one's family will cope if one dies from cancer, and wanting to spend more time with family, it was deemed responsible health behaviour to take part in the BC screening. Scott & Seglow, (2007)

argued that altruism is an element of moral idea which could raise dilemmas. For example, an organ donor who does not wish his organ to be given to person of different race or religion is trying to be altruistic but may be seen as a racist. Altruistic behaviour was manifested in three different forms in current research:

1. People seemed to perform some tasks because they do not want to let others (family and friends) down. For example, there were worries over what family members would do and how they will cope if one dies. So they completed the FOBt as a step towards making sure the family time together is protected.

2. There was also altruistic behaviour in the wider context. This study has indicated a collective sense of ownership in solving a national problem. For some, there appeared to be an obligatory sense of duty 'everyone is interested in beating cancer, so completing the FOBt is my own way of contributing'. Participating in the screening was seen as playing one's own part towards achieving this wider societal goal.

3. Saving the NHS money: People felt that they would be wasting NHS limited resources (money used in producing and posting the screening kit) if they did not complete the test. It also emerged that if people took part in the screening, they felt it would help to cut NHS waiting times, as prevention was perceived to be better than cure. They may have recognised that the fund used in preventative measure would be far less than that used for treatment of a disease. This could be compared with the findings of d'Agincourt-Canning, (2006) genetic testing for hereditary breast and ovarian cancer. Even though the altruistic belief may be modifiable by other factors, it was felt a 'good citizenship' to take part in the screening.

This sense of 'obligation' considered as saving (scarce resource) money for the NHS, cutting waiting times and help in beating cancer is also comparable to previous studies among the reasons for taking part in screening tests (Chapple et al., 2002; d'Agincourt-Canning, 2006; Chapple et al., 2008). Chapple et al., (2008) qualitative study in the south of England highlighted the notion of 'good citizen' as a predictor for screening uptake. However, at that time, the screening programme was at an infancy stage and had not reached many parts of the UK. The current study undertaken in a different location and during the

third round of screening adds to/strengthens the evidence for this evolving reason for participation in the BC screening. In addition to saving the NHS money as identified by Chapple et al., (2008), the current study adds a new dimension of 'cutting waiting times in hospitals and beating cancer'. It was felt that taking part in screening is playing one's part in the fight against cancer.

However, 'civic obligation' was not a single reason in itself but an additional reason among others and may not resonate with healthcare systems where people pay for health services. The current study agrees with Chapple et al., (2008) that this evolving trend might be as result of socialised healthcare system. Perhaps, people have become socialised through mass media health campaigns, of the meaning and importance of responsible health behaviours. This in effect may result to feelings of compulsion or pressure to act rationally/responsibly. Stott & Pill (1990) advocate that people should not be put under this kind of pressure; screening should be an informed choice service. However, the participants in the current study seemed not to feel pressured in any way, rather they saw it as a choice that they had to make.

Historically, altruistic behaviour may be an evolutionary (biological view) trait seen in human interaction ranging from food sharing, cooperative hunting and participation in warfare, (Walker, 2004; Bernhard et al., 2006). It appears to be a group social value that constrains selfish behaviour. Bernhard et al., (2006) suggest that altruistic behaviour is mediated by parochial instincts - preference for favouring one's own social group members such as race, local community and work colleagues. However, Sober & Wilson, (1998) distinguished between two types of altruism, which places earlier analogy as an evolutionary altruism and a second type as psychological altruism. They suggested that in evolutionary altruism, feelings and thoughts on behaviour are not taken into account as events are largely to do with actions that affect survival while psychological (moral) altruism is more concerned with beliefs and motives. The individual analyses actions and consequences before actually carrying it out. This dichotomy indicates there is a gap between these two ideas of altruism; and leaves the question of the how possible it might be to bridge the gap (or balance) between the two. Counter arguments may arise, but current study findings suggest that it will be difficult to bridge a gap between evolutionary and moral altruism.

The idea that emerged from current study indicates that individuals felt that protecting themselves could also lead to protecting and helping others (family, NHS and wide society). This could imply that the motive is not exclusively for the benefit of others but could be for 'ulterior purpose' of protecting oneself, (Konstan, 2000). This last sentence, adds to many arguments relating to the motives behind altruistic behaviour. It has been argued that 'egoism' or 'warm glow' (egocentric theories) largely play a part, (Becker, 1974; Andreoni, 1990, 2001). Egoism or warm glow refers to 'feeling good', 'self-confidence', and 'preservation of ego' factors that are achieved by doing well to others. Therefore motive for altruism is multidimensional. Other studies have also reported the association of altruism with emotional benefits, (Dunn et al., 2008; Konow & Earley, 2008; Reyniers & Bhalla, 2013; Aknin et al., 2010). However, Khalil, (2004) suggested that the primary motivator for altruistic action is the enhancement of welfare and suggests that it would be 'sentimental foolishness' to just act on warm glow. This indicates that ego/warm glow could be a social motivator but may be secondary or a by-product, (Khalil, 2004). Therefore, this could imply that there is no such thing as pure altruism, but people do things for anticipated utility which they can also derive from the action, (social or material gains). The prevailing argument could be summarised by the following quote from a well-known economist, Smith, (1969) theory of moral sentiments cited in Piliavin & Charng, (1990, p.27):

How selfish so ever man be supposed, there are evidently some principles in his nature, which interest him in the fortune of others, and render their happiness necessary to him, though he deserves nothing from it, except the pleasure of seeing it' (Piliavin & Charng 1990; Smith & Hanley, 2010).

Piliavin, (1990), thus provides a succinct summary by suggesting that from whatever perspective (biological, sociological, psychological, economic and political views) altruistic actions is scrutinised, there will always be an underlying 'ulterior self-motives'. The current study findings resonate with Piliavin, (1990) above as this study seem to suggest that the 'bottom line' for completing FOBT was for health protection and peace of mind for study participants. The next section focuses on the socio-cultural context affecting participation behaviour.

### **8.23. Socio cultural contexts**

Current study findings suggest that BC is surrounded by many socio cultural perceptions and beliefs which could affect uptake of screening services in different ways, either as motivators or possible barriers. BC seems to be among the societal taboo subjects such as death which are generally not openly talked about. BC screening appears to have attracted 'double taboo' because of the two words 'bowel' and 'cancer'. Cancer seemed to be associated with fear and death while bowel was also embraced with embarrassment. However, the taboo surrounding bowels may be changing given the wide publicity through the screening programme.

#### **Taboos around cancer and bowel motions**

Taboo can be defined as a group of socially constructed and sanctioned negative norms which prohibit certain actions, (Kuhn, 1987; Shoemaker & Tetlock, 2012). In the current study, there appeared to be a general consensus from participants that cancer and bowel motions are taboo subjects which are not generally and openly talked about. These findings supports Allen, (2008) and Haslam, (2012) who noted that death, bowel motions and sex are also among the societal taboos. The findings of the current study are similar to Thomas et al., (2005) focus group study of black and minority ethnic (BME) group; which found cancer to be associated with taboo and superstition. Unlike the current study, Thomas and colleagues study also identified superstitious beliefs, such as the belief that cancer was a punishment for sexual promiscuity. However, the study involved people from different races with diverse languages and religions. BME groups may have quite specific beliefs which may be stronger than those of the general population and there may be methodological issues in grouping such diverse people together. Elsewhere, cancer was also perceived to be associated with homosexuality; a perception that indicates inaccurate medical information, (Holt et al., 2009). Again this is an example of how the socio-cultural environment could shape and be shaped by individual's perception and behaviour; this is the core concept of the social cognitive theory of behaviour, (Bandura, 1986; Macdowall et al., 2006). Awareness campaigns have been identified as a suitable medium for dismissing taboos, (Kuhn, 1987) as will be discussed later in this chapter.

In the current study, more than anything cancer attracted a lot of fear and worry as it is often perceived as fatal. This has led to denial as suggested by some participants 'what I do not know will not happen to me'; heads are therefore rather 'buried in the sand' like an ostrich. This finding is not surprising as denial has been an extensively investigated and discussed subject in different theoretical trends over time, originating from psychoanalytical theory, (Freud, 1937) and cognitive psychology (coping and stress model), (Rabinowitz & Peirson, 2006; Vos & De Haes, 2007). This may be because of its clinical relevance. Hence, the psychoanalytical theory and cognitive psychology define denial as a normal adaptive strategy to temporarily protect oneself against overwhelming feelings and events, (Horowitz, 1983; Dorpat, 1985; Horowitz, 1988). In other words, 'it is an avoidance strategy with adaptive properties', (Vos & De Haes, 2007). However, Rabinowitz & Peirson, (2006) noted that denial can become a dysfunctional response and detrimental when it causes delays in seeking help and treatment particularly for conditions which could become malignant. Some of the current study participants appeared to initially show signs of denial. However, decided to take part in the screening after they have had time to process the information about the FOBt. They then felt that it was better to know than not know, so that something could be done about it earlier if there is a problem, (cancer). Unfortunately, no one who refused to undertake FOBt participated in this study and accessing this group would enhance understanding of non-participation and potentially including denial

Although the study participants appeared to understand that BC could be treated if detected early and confident that screening is a means of ensuring that. They also seemed confident and able to complete the FOBt but they seem to continue to be fearful of all cancers; which the lay public and perhaps society in general appeared to have labelled the most threatening of all diseases. This seems to indicate that culture/society plays a significant role in the concept of denial. Vos & De Haes, (2006) reported that denial is not related to cancer type and gender but noted that the elderly were more likely to deny and men more likely in the terminal phase of cancer. It is also interesting to note that screening seemed to be another way of coping (or 'therapeutic mechanism') with fear and worry associated with cancer in the current study. There seem to be a growing unwillingness to accept the earlier notion that cancer means a

death sentence; the notion of cancer as a taboo subject seems to be gradually changing as participants reported talking more about cancer now than in the past.

### **Taboos around bowel motions**

Toilet taboos strongly exist in UK, it has been reported as part of 'Britishness', (Anonymous, 2000). Swain, (2011) noted the far-reaching and repressive discussion around bowel issues as a result of the taboos imposed on anal products through families and culture (civilisation). Toilet taboo begins the moment a child is being toilet trained; also demanded by the society. It is conveyed to the child by the mother that 'poo' is dirty and unacceptable through the mother's verbal and nonverbal language. Armed with this notion, the child devalues all that has to do with the bowel, (Swain, 2011) at the expense of his/her own instincts. Ironically, Swain, (2011) acknowledged that while certain societal taboos could encourage psychological and emotional development, some taboos can restrict and stifle individualisation process (personal identity). To break taboos can therefore in some ways be seen as liberating for the individual. The findings of the current study support both sides of Swain's argument (encouraging versus restricting individualisation) as could be seen from the current study model (Figure 4.8). On the restrictive side, the explanatory model, illustrates that societal norms (toilet taboo) veiled many study participants from discussions around BC screening; many even reported losing a family member as a result of personal and private nature of the bowel and lack of wish to discuss such issues, (P8f, section 5.21). On an encouraging note through awareness, the screening programme may have offered people the freedom to break what Swain termed the 'most virulent taboo – the forbidden self' leading to the decision to engage in the screening. This means that people have become more aware and do not seem to care about societal taboo placed on bowel issues rather they care more about the personal benefits screening can offer. Mass media campaign has been advocated for breaking these cultural barriers, (Stones, 2005). The world toilet organisation holds annual world toilet day with campaigns such as 'Pee or Poo, break the Taboo' to raise awareness of the need to talk more about bowel matters.

In this study, bowel motions and body parts seemed to be associated with embarrassment and seen as a taboo subject as discussed above as also reported by (Thomas, 2001; Stones, 2005). People were equally embarrassed while talking about their experiences of the screening programme but approached the topic with sense of humour rather than fear as in the case of cancer. This finding resonates with the toilet psychology and notions of cultural taboos (Haslam, 2012). Haslam noted that bowel movement is a universal part of human experience which been masked with taboo as people always want to hide their bodily waste. This was evident in the 2010 survey where the British people ranked the invention of toilet flushing as the 9<sup>th</sup> greatest invention (Haslam, 2012). It is not surprising given that this invention helps people achieve their goal of concealing their bodily wastes. Haslam hopes that this mask will one day be lifted in the same way as taboos surrounding sex and death have been unravelled. This may assist in more effective treatment and cure for diseases which people are reluctant to talk about.

Similar findings of embarrassment as a barrier for screening uptake in BC have been reported, (Janz et al., 2003; Chapple et al., 2008; Holt et al., 2009); prostate cancer, (Conde et al., 2011); cervical cancer, (Youngman, 2005), and breast cancer, (Price et al., 2010). Holt et al, (2009) found that African American men were reluctant about the FOBt as a result of the myth surrounding the type of procedure involved. For them the embarrassment of handling faeces was bad enough but the thought of endoscopy was worse. They tend to relate the procedure to sexual encounter and felt that agreeing to such procedure might make them look like homosexuals as mentioned earlier. However, in the current study this socio cultural issue did not seem to hinder participation. Perhaps, it may have hindered non-responders; and a limitation of the current study is a lack of non-responders who have continued to decline participation in BC screening. Future work may need to be undertaken to find out whether cultural issues such as taboo are major reasons for non-participation.

Nevertheless, there appeared to be general positive attitude from the current study which resulted in uptake despite initial reported reluctance because of taboo, denial and embarrassment. It is possible that embarrassment may have been mediated by other socio-cognitive factors – perceived threat, susceptibility, benefits, cues to action and self-efficacy (Rosenstock, 1974;

Bandura, 2004), as discussed earlier in section 8.22 and illustrated in the study model, (figure 4.7, 4.8). Positive attitude has been found across health behaviour theories to be an important predictor of health behaviour. Positive attitude as a predictor of uptake was also reported by (McCaffery et al., 2003; Subramanian et al., 2004; Ellis et al., 2007; Taskila, et al., 2009). A systematic review by Subramanian et al (2004) identified positive attitude towards screening as a primary influencing factor for uptake. There is no doubt that attitude could influence behaviours; however, what influences that attitude is usually unclear or given less attention. The current study found that a variety of factors such as knowledge (see next section below) could affect attitudes and intentions. Therefore increased knowledge combined with strong positive attitude could perhaps lead to stronger intention and subsequent action. Nevertheless, attitude has been viewed as proximal indicator while knowledge as a distal predictor by socio-cognitive theories such as the health belief model, (Rosenstock, 1974) and the theory of planned behaviour, (Ajzen, 2002), (section 2.10). However, measurement of knowledge is a challenging task and the degree to which knowledge is measured can be difficult to establish. As the epistemological and ontological stance (chapter 3) of the researcher indicate, truth is relative and knowledge is socially constructed, both depending on the social, cognitive, and environmental contexts which can be quite complex. Therefore, it may only be possible to approximately measure knowledge relative to specific time and context. Quantitative measures are often overly simplistic while qualitative measures limit generalizability, so a mixed approach might be needed for a more comprehensive understanding which is always going to be socially and historically located. Therefore, there is never a perfect answer.

## **Section Two**

### **8.3. 'Knowing'**

As illustrated in this study model, knowledge and awareness were very important influences on decision making and participation. The study findings suggest limited knowledge of BC and the FOBt as a significant factor which could potentially limit the uptake of the FOBt; and better knowledge as a potential factor for improving participation and uptake. It appeared that

knowledge was very poor prior to invitation particularly for the FOBt, but improved with the screening information received in the invitation letter. This may be because some participants reported not generally seeking information unless something triggers them. Prior to the invitation, major sources of awareness included past experiences from past medical history, family history, significant others- friends and family members; and work-related but in very limited detail (discussed in turn below). Only two people mentioned the GP and television as sources of awareness. Awareness was limited but not exclusive to the threat posed by BC (death) and the signs and symptoms. Perhaps this explains the fear and fatality that are generally associated with cancer. However, these perceptions appeared to be gradually fading away through informed knowledge via the screening invitation information leading the current study participants to complete the FOBt as illustrated in the 'awareness-led behaviour' model.

### **8.31. Past experiences**

Past experiences played significant role in participants' understanding, interpretations and decisions regarding diseases, screening and treatments. Family history and past personal medical experiences were among the facilitators for uptake of FOBt in the current study. It has been noted that people's narration of their illness experiences is woven into their biographies and reflects the person's experience of life, (Kleinman, 1988; Nettleton, 1995). Both authors advocate an understanding of people's illness behaviour and action. According to Nettleton, illness behaviour means the way a person behaves as a result of their symptoms while illness action is how a person interprets and makes sense of their illness. In other words, it is their 'social construction' of illness.

People who have family history of any cancer particularly where it involved death felt the FOBt was a good intervention. One of the participants felt her father would have lived longer if there was screening in those days. In addition, other participants who have survived BC as a result of screening fit nicely into Nettleton's ideology and thanked 'God' for the screening programme – also indicating additional influence of other belief system such as religion, (Nettleton, 1995; 2013). Furthermore, some study participants who had recent bowel

problems and investigations, felt after the experience and anxiety of the recent health scare, that the FOBt was a good way of keeping their mind at rest. Perhaps having some past experience is a positive influence. Possible future research might explore the relationship between lack of past experience and participation in BC screening. The extent of knowledge of risks associated with having a family history has been found to be poor, (Rubin et al., 2009). The current study however suggests that family history increases awareness and knowledge of risks and therefore uptake in screening programme.

These actions and behaviours are also shaped by the belief, cultural and historical contexts in their environment and need to be understood within the wider interpretative process of 'narrative reconstruction' (Williams, 2004). In the current study, the interplay between biographies (8.21) and cultural beliefs (8.23) was evident. Even though cultural beliefs (for example, taboos about cancer, death and bowel motions) affected the people's perception of BC and screening services, the power of personal experience and the impact of illness on a participant's life superseded cultural perceptions particularly where there was fatality; also survival as a result of screening and subsequent treatment. Meillier et al., (1997) purported that past experience is among the major cues for action activating change in health behaviour. However, this may not be the same for those who have no past experience of BC.

Study findings showed that some people were aware of the BC screening due to having other BC screening tests such as colonoscopy. People were also aware of other cancers and BC but in less detail. This is comparable with the findings from other studies in the UK, (Youngman, 2005; Robb et al., 2008; Taskila et al., 2009; Meeren & Smith, 2010). Robb and colleague's, (2008) survey and Youngman's, (2005) focus group studies focused on the minority ethnic group and noted poorer knowledge in this group than their white counterparts. However, the two studies looked at different methods of cancer screening; flexible sigmoidoscopy and breast/cervical cancer screening respectively. Therefore, the current study has made a different contribution by throwing more light on the knowledge of the white British population (who predominantly made up the interview sample, about 92%) regarding the FOBt. Knowledge was poor in the current study, as was also reported by (Chapple et

al., 2008; Taskila et al., 2009; Conde et al., 2011). This stresses the need for an improvement in knowledge.

As noted in this study, most of the participants reported that their knowledge of the disease has improved greatly and has helped in their participation decision. This is similar to the findings of Koo et al., (2010) which showed that knowledge and media could predict intention for uptake with higher intention coming from knowledge. However, Koo and colleagues' study was a survey and did not highlight whether the improved knowledge contributed to uptake decision. Moreover and in contrast it has been argued that positive attitude and/or knowledge does not necessarily translate to acceptability and behaviour change, (Ellis et al., 2007; Jepson et al., 2007). Unlike the present study Ellis et al only measured perceptions of acceptability rather than actual participation using questionnaires (quantitative approach) which could yield a different result as found by the current study. In contrast to Ellis et al., (2007), the current study employed a qualitative approach in the exploration of actual experience which provides a clearer picture of what is going on for the participants suggesting informed knowledge via FOBt invitation artefacts as strong facilitator for uptake. However, this might not present the views of the low literate individual and people whom English is not their first language as the entire study participants seemed to exhibit good literacy levels. Influence of significant others was another source of 'knowing' which could facilitate uptake of FOBt.

### **8.32. Influence of significant others**

Study findings suggest that the family and friends significantly influenced participation. People whose friends had completed the test acknowledged that this was a motivating factor for them. Others reported being encouraged by their spouse. This resonates with Guessous, et al., (2010) and Meiser et al., (2007) who noted that being married was a positive influencing factor for uptake as a result of the encouragement provided to each other. However, being married may not necessarily always influence uptake or positive attitudes to the FOBt. Other personal factors such as emotional, (fear, worry, embarrassment and squeamish) issues may outweigh the effect of significant others. For example, one of the current study participants reported that her spouse has refused the FOBt despite her encouragement as he dislikes the thought of handling poo and

having poo in the house despite knowing how important screening is. This again highlights the strengths of certain taboos which in this case seemed to outweigh the positive influence of the significant other.

### **8.33. FOBt invitation**

FOBt invitation artefacts emerged as good awareness tool and facilitator for uptake. The information leaflet acted as a facilitator for both improved knowledge and self-efficacy for carrying out the test. This is a clear example of the interaction of the decision making variables within the 'ALBM', with better knowledge heightening perception of self-efficacy. Only one participant reported telephoning the screening help line to ask for more clarification. This finding was similar to the findings of a randomised control trial in the South of England, (Hewitson et al., 2011) and other studies, (Miller et al., 2005; Stokamer et al., 2005) which also reported FOBt invitation as a facilitator for uptake. However, it could be argued that information leaflets may only benefit those who are literate as Senore et al., (2010) found that those with higher education relied more on the enclosed information leaflet for the participation decisions than those with lower literacy level who found more confidence in healthcare practitioner help in addition to the leaflet. Elsewhere, low literacy was reported to pose more barriers to FOBt, (Peterson et al., 2007). In the current study, few participants raised concerns about people with literacy issues; the ability to read/understand and carry out the screening test. This was another indication of altruistic tendencies.

Further exploration of this concern among the participants suggested that the literacy level of the test literature was low enough for the understanding of those with low literacy. Smith et al., (2008) also reported that information leaflets meant to be a decision aid for patients can be intimidating and frightening for people with low reading skills. However, irrespective of literacy level, there may still be difficulties associated with information leaflets, perhaps as result of negative attitudes in relation to information seeking. Evidence has suggested that adults with low literacy levels are less likely to read health information materials such as leaflets and booklets, (Smith et al., 2008; Von Wagner et al., 2009; Smith et al, 2010). Von Wagner et al (2009) UK study using test of functional health literacy in adults (TOFHLA) found literacy to have a direct

impact on information seeking and was associated with self-efficacy. This could be challenging during the planning and development of health promotion information for health as most health education programmes rely on printed materials. There was no association between literacy and awareness of BC. However, Wagner and colleagues have not taken into account the influence of factors such as psychosocial and socio-cognitive factors. The current study did not take into account participants' education status. This was not deemed necessary as the study was one of the first in this region (NEYH) and mainly sought to establish general reasons for participation/nonparticipation. Perhaps, future research may be needed to explore this parameter/dimension further.

Furthermore, studies have also suggested that social deprivation is associated with poor literacy and could pose barriers to screening, (Gannon & Dowling, 2008; Weller & Campbell, 2009; Meeren & Smith, 2010). Unlike these studies, the current study done in the North East, Yorkshire and Humber; an area reported to be among the socially deprived areas of the UK, (ONS, 2013) seems to suggest otherwise – although this would need to be 'tested out' by further study which paid particular attention to deprivation indicators for those participating in the FOBt. Perhaps, the contrast in current study with aforementioned studies might be due to the fact that personally, study participants are not socially deprived even though they live in socially deprived area. As was observed during data collection, it seemed that majority of the participants live in the more affluent parts of the region, only very few seemed to live in council owned houses (A measure of social deprivation) but tend to have had good working life and are now retired. However, people who may be described as socially deprived may have been excluded from the study as it appears that people who are enthusiastic and literate are usually the ones seeking health information as mentioned earlier and are more likely to engage in research activities. Therefore, this is a limitation of the current study.

Minority ethnic groups may have also been excluded as a result of language barrier, (Weller & Campbell, 2009; Meeren & Smith 2010), perhaps the use of multi-linguistic invitation letter and interpreter may have been a strategy to get them involved in this study. However, efforts have been made in the NHS to present health information in easier to read and understand format (including pictorial form) and in different languages. However, McAvoy & Raza, (1988)

noted that these efforts by the NHS alone might not help in the minority ethnic group. McAvoy & Raza suggested that information given and explained by a healthcare professional might be more beneficial in reaching those with lower social status. Therefore, perhaps healthcare professionals might also be a strategy for recruiting in future studies. This study also suggests that although improved literacy facilitates uptake of FOBt, other test practicality issues (next section) might interact with its influence in facilitating or hindering uptake.

## **Section 3**

### **8.4. 'Practicalising'**

The last component of the 'awareness-led behaviour model' is 'practicalising'. Having got through some of the social context issues, 'contextualising' in the FOBt decision making journey through the process of 'knowing', study participants were faced with the practical issues associated with carrying out the FOBt – they seemed to 'practicalise' the feasibilities of completing the FOBt as result of their lived experiences. The practical issues played an important role in the decisions they later made. 'Awareness-led behaviour' model (figure 4.8) shows that practical issues were more likely to be a hindrance to carrying out screening test than a facilitator. The nature of the FOBt (to do with faecal matter) emerged as a major practical issue in the current study. However, other mediating factors such as family history and informed knowledge seemed to have helped to overcome (modify) the negative feelings. The test was found to be easy to do once people got over the initial feelings through the aid of the instruction leaflet, although there were very few reported difficulties in understanding the procedures. Assistance in collecting stool sample was very useful for those who could not manage themselves. Other facilitating practical issues were venue of test and cost. As a result of the practical issues encountered while completing the FOBt, study participants have suggested ways of improving the test and its uptake. These are also discussed in this section.

#### **8.41. Nature of the FOBt**

The nature of the FOBt as a potential barrier and reluctance to screening has also been highlighted by other studies, (O'Sullivan, & Orbell, 2004; Ellis et al., 2007). Comparable to the current study, Ellis et al., (2007) explored acceptability of three different FOBt sample collection methods, (swab, pot and cardboard) and found that despite positive interests in FOBt, acceptability was still an issue and varied. The cardboard was the least preferred method out of the three. Women preferred the use of 'sample pot' while men preferred the cardboard type. In the current study, the FOBt was associated with general feelings of disgust, unpleasantness, 'yucky', not the easiest thing to do, messy and unhygienic just to mention a few. These findings indicate that previous experience may not necessarily lead to acceptability. For example, a person may have had a negative past experience of completing a test which puts them off. Sociocultural issues such as taboo as discussed in section 8.23 may also play a part. Also, a person's perceptions in relation to socio cognitive contexts in the 'awareness-led behaviour model' and the HBM constructs, (Rosenstock, 2005) such as perceived susceptibility, severity, benefit, barrier, self-efficacy and cues to action (chapter 2) may influence their decision. For example where perceptions of susceptibility, threat, benefit is low with increased barriers and no cues for action; an individual may not take action. In other words, if a person feels that he/she is not prone to developing cancer perhaps with no family history and 'feeling healthy', they may not feel the need for screening.

The major practical barrier to participation in the FOBt arising from current study seems to be issues around sample collection such as how to capture sample before it falls into the toilet. This raises an important policy and practice issues for the NHS of the need for improvement in the sample collection method currently used for the FOBt if improvement in acceptability is to be achieved. On a general note, Khalid et al., (2011) systematic review indicated that studies comparing screening methods showed higher participation rates for less invasive methods. Also studies comparing invitation methods showed higher participation rates with general practitioner involvement, a more personalized recruitment approach, and reduction of barriers that discourage participation, (Khalid et al., 2011). The current study coheres with Khalid et al., (2011) as

most participants felt after comparing FOBt with colonoscopy that the former is less invasive' so preferred the FOBt.

#### **8.42. Interventions to improve participation**

As a result of the lived experiences of study participants and practicality issues they encountered while completing the FOBt, many suggestions for ways of improving the screening awareness and uptake test emerged. The suggestions include word of mouth, health centres/GPs, posters, media (TV, newspapers and magazines), health checks and pension forms and use of incentives. These suggestions could have service and policy implications as they seemed to provide a first-hand evaluation of the FOBt from service user perspective (consumer insight). The suggestions could help in the planning and implementation of future interventions aimed at improving participation and uptake. This is because tailoring interventions to what works well would be better than implementation of ones based on what policy makers feel would work.

##### **Word of mouth**

Word of mouth, (WOM) emerged as a significant way of raising awareness. Study participants reported getting most of their information through WOM. WOM is an informal mode of communication which has significant effect on consumer behaviour and attitude, (Brown & Reingen, 1987; Lim & Chung, 2011). Davies et al., (1979), acknowledged that media is undoubtedly a valuable mechanism for creating awareness of goods and services. However, when it comes to buying decision making in purchasing products, consumers tend to rely more on WOM. WOM could be more effective than other forms of advertising as result of its trustworthiness. Katz & Lazarsfeld, (1955), cited in Harrison-Walker, (2001) reported WOM to be potentially seven times more effective than newspaper and magazine advertisement, four times more than personal selling and two times as effective as radio in brand switch. It is also potentially nine times as effective as advertisements aimed at changing negative perceptions into positive, (Hesket, 1997). These are based on the fact that a satisfied customer could reach many more customers more quickly.

The approach to WOM seems rather too simplistic; attention seems to focus on the positives (favourableness). Negative (unfavourableness) effects can also arise from an unsatisfied customer. Lately, customer reviews in online shopping seem to be the closest to WOM and helps future buyer when making buying decisions (researcher's observation). Both positive and negative WOM could help in the evaluation of products and services. Lim & Chung, (2011) experiment on the impact of WOM suggested that positive WOM could be used to evaluate credence attributes of an unfamiliar brand. This could help manufactures in knowing what buyers think of their products. WOM seemed to be valued by study participants and has helped many in their decisions in participating in the FOBt. WOM was largely positive for the participants. The importance of word of mouth cannot be overestimated; however, it may be a factor for future debate/research: the quality of information given/received and degree to which word of mouth add to informed knowledge.

## **Media**

Media emerged as one of the strong ways of increasing awareness and uptake in the current study. Media acts as a conduit of medical ideas to the public, (Marks, 2005). And seem to have become a major channel of communication and information giving in the contemporary society. Thus, media could be used to subvert some of the social cultural perceptions about BC and FOBt. However, there were varied opinion on type of media, how best to use the media and what type of messages to be conveyed. Television (TV) appeared to be a popular choice over newspapers, magazines, posters, leaflets, and radio. People preferred TV because it is right there in people's faces and could reach wider audience in small amount of time. However, limitations of using the mass media have been cited (Cho & Salmon, 2007); ethical dilemmas may also arise regarding the use of media to raise awareness.

Firstly, media health campaigns notably do not last for very long on a continuous basis and are low-cost and small-scale in nature as a result of high cost when compared to commercial campaigns. This implies that once the campaigns and attention wear off, the initial increase in uptake may reduce, (Van Roosbroeck et al., 2012). Secondly, mass media interventions meant to serve one segment of the society could in reality cause harm to the non-target

segment. For example the use of fear appeal could cause emotional harm to the unintended audience. However, most media interventions as part of social marketing activities are based on utilitarian perspective, relativism and theories of justice, (French & Blair-Stevens, 2005).

On the utilitarian angle it is alright to implement an intervention if the intervention serves 'the greatest good to the greatest number of people'. Therefore social marketing seems to identify with the public health paradox which prioritises social welfare over individual satisfaction. However, the advertising standards authority has advocated that even when an intervention is deemed good for a larger number of the target population but causes psychological harm to the non-target audience, this renders the intervention unethical. Attention should not focus largely on participation but on informed participation and a balance struck between respecting individual autonomy and the goal of achieving greater public health effectiveness, (Rimer et al., 2004). Nevertheless, a higher scale mass campaign may hold the key for increasing public awareness and a possible high uptake rate of the FOBt as suggested by the current study findings and illustrated in the study model.

Thirdly, mass media campaigns may not necessarily cause positive behaviour change. Unintended effects may also occur such as 'boomerang' and 'desensitisation', (Cho & Salmon, 2007). 'Boomerang' occurs when a health communication message creates a reaction that is the opposite of the intended response of the persuasion message while 'desensitisation' occurs when the public become apathetic as a result of continual exposure to messages about a health risk may over a long time. People may become used to media campaigns that they 'switch off'. During the data collection, some participants noted that some of their friends and families would not look at or listen to anything to do with BC screening.

Fear messages were raised as ways of shocking people, however, it was suggested that this may cause distress as it can frighten people. The gentle use of positive life experiences and the use negative (to shock people) experiences whether in the TV drama or as a commercial/campaign, were seen to be the way forward. However, there may be ethical issues associated with either method. The promotion of only beneficial aspects of an intervention could have

ethical issues. It is deemed necessary that promotion information should not only provide benefits but also the risks associated to aid informed decision making (IDM), (Rimer et al., 2004; Jackson et al., 2008).

Variations on favoured information choice have also been reported in other studies, (Austoker, 1999; Woodrow et al., 2008). In line with the current study, Woodrow et al. reported that positive messages may be favoured for helping people to decide and argued that providing risk information may cause distress and deter people. In contrast, (Trevena et al., 2008; Smith et al., 2010) suggest that detailed absolute risk and benefit information could be used at home by all including those with low literacy to effectively increase informed choice. Even though full information needs to be provided, (Austoker, 1999) the extent of balanced information on risk and benefit is not very clear, (Briss et al., 2004). Elsewhere, Edwards et al, (2003) reported that communicating individualised risk in any form (written, verbal and visual) is associated with increased uptake of screening tests, (Edwards et al., 2003; 2013). However, Edwards et al, (2003) review was limited by small number of studies predominantly on mammography and may not be generalisable to FOBt.

It has also been argued that people do not pay too much attention on risk but rather tend to consider efficacy, (Cockbun et al., 1995; Chamot & Perneger, 2001). Moreover people with low literacy may not understand the concept of informed choice, (Janz et al., 2003). So, provision of balanced information may cause more distress and decreased uptake if risks are promoted while framing benefits in the most positive light may be judged as manipulative, (Sarfati et al., 1998). In line with Janz et al., (2003) the researcher advocates tailoring interventions to education and literacy levels of the target population. This can be achieved through an exploration of understanding and jointly identifying optimal communication methods (verbal and written) to support/facilitate decision making. However, the feasibilities of interventions need to be carefully considered in the midst of limited resources as they can be very expensive to run and may not be practical.

## Health centres/GP

General Practitioner involvement emerged as one of the possible ways of improving information giving, perception and uptake of FOBt in the current study. Evidence from a randomised control trial, (Hewitson et al., 2011) and other studies (Szczepura et al., 2003; Klabunde et al., 2007; Myers et al., 2007) has also identified GP input as one of the significant factors that could influence uptake. Myers et al., (2007) reported that GP involvement increases the uptake of FOBt. However, in the UK GPs are not currently involved in the implementation and running of NHSBCSP. There were varying degrees of views for GP involvement from the current study. Some of the participants reported that they would take more notice if some information or services come through their GP; others seemed indifferent. Some of the participants suggested that GPs are too busy to get involved in the programme when the time could be used for more serious patient issues. It was generally agreed that GPs could get involved by advertising the programme in the surgery in form of leaflets, posters, incorporate in health checks or better still have the usual invitation letter endorsed by the GP.

It was widely felt that more trust is given to personal GP than from strange sources. This is comparable with the findings from two randomised controlled trials, (Hewitson et al., 2011; Van Roosbroeck et al., 2012) on the effects of GP endorsed letter and patient enhanced leaflet to improve participation in BC screening. The Hewitson trial reported a potential increase of 10%, relatively a 20% improvement on the current outcome. Both trials reported more uptake rates from invitation leaflets than through GPs. However, trial outcome was measured with the return of screening kits within short time interval, (20 weeks for Hewitson trial). This could limit the findings; as RCTs in health promotion are usually limited by short term follow up, which may increase the chances of missing late adopters. The reasons for this increase is however unclear, unlike the current study which explored reasons for uptake from patients own perspective. Moreover, ethical issues may arise in RCTs when one group or arm of the trial is treated differently from the other arm particularly when they are randomly selected. Also there may be issues of internal validity if the basis for selection is lost.

In contrast, the current research adopted a bottom-up approach to explore what might work from participants lived experiences and perceptions. However, effectiveness of GP involvement depends on the general practitioner's attitude (amount of interest) and willingness to participate in the screening programme, (Federici et al., 2005; 2006; Damery et al., 2010). A UK survey (Damery et al., 2010) showed that GPs have a positive attitude towards the NHSBCSP. However, this study was based on GP self-reported attitude which could be different from actual behaviour as attitudes do not always guarantee behaviour. There could also be issues of over reporting.

It has also been reported by previous studies in other countries (Cole et al., 2007; Senore et al., 2010; Zajac et al., 2010) that healthcare practitioner endorsement is a significant facilitator for completing the FOBt. However, in current study, the varied opinions in GP involvement particularly the indifferent attitude about where the test kit comes from, some participants reported that is an important test with a lot of benefits so did not care where it came from; perhaps throws more light on the fact that the decision making process is not a straightforward journey but a complex interaction of many factors. Here, the socio cognitive concepts (Bandura, 2004; Rosenstock, 2005) seem to be playing more important role than the trust on GPs. Nevertheless, others agreed that information coming from personal GPs are trusted more than from strangers and suggested that GP could sign the invitations before sending them out to people as this might help non-responders who might have more trust in their GPs to participate in the FOBt.

There may be need for a further qualitative study to find out what ways the GPs in the UK would want to get involved based on the patient preferences emerging from current study. This need is further strengthened by the varying differences in the beliefs, perceptions, and practices of GPs which could be attributed to GP training, health care system, existence of appropriate and adequate practice guidelines, and ethnicity, (Subramanian et al., 2004; Tong et al., 2004; Turner et al., 2006; Damery et al., 2010). There are also differences in national healthcare systems and the findings from other countries may not be applicable in the UK.

The next section presents the rigour and quality issues relating to the current study.

## **8.5. Rigour and quality**

Reflexivity is widely encouraged as best practice in qualitative research and an important tool for enhancing the quality of research, (Holloway & Freshwater, 2007). Here, I provide a critical and transparent account of the research process which relates to my position and personal values which could have potentially influenced the process of data collection, analysis and interpretation, (Machin, 2009; Polit & Beck, 2010; Walker et al., 2013). In order to demonstrate rigour and to justify the relevance otherwise credibility, (Patton, 1999; 2002) of my findings, this section provides a critical appraisal of my methodology followed by reflections on the methods. This reflexive account began in chapter 4.

Many arguments and contention about validity of qualitative inquiry such as GT arise due to the predominantly non-objectivist position of qualitative researchers, (Seale, 1999). The symbolic social interaction of the researcher and the research subjects during the interviews and the researcher's personal and professional influence, (Gabrielle et al., 2008) during analysis and interpretations could all influence the study thereby questioning the credibility of the findings and should be accounted for. Reflexivity is rarely used in quantitative research as result of its positivist objective philosophical stances. According to Burns & Grove, (2005) the data collection process in quantitative research involves an objective and systematic use of numbers to gather information about a phenomenon and every care is taken to minimise bias as the researcher assumes objective and external observer position, (akin to bracketing). This helps to ensure the validity of the study while Ryan & Golden, (2006) argue that the rigid control mechanisms such as described by Burns & Gove, (2005) above underpinning the validity of quantitative inquiries could be undermined by introducing reflexivity in quantitative research as objectivity is the core principle guiding quantitative researchers.

Furthermore, the relevance and nature of knowledge generated through qualitative research and the criteria for measuring qualitative research have

been subjects of debate among authors, (Hoepfl, 1997; Mays & Pope, 2000) and many criteria abound, (Lincoln & Guba, 1985; Charmaz, 2011). According to Bryman, (2008), attempts have been made by some authors to apply the quantitative concepts of reliability and validity to qualitative research but they are inapplicable as result of assumption of the feasibility of a single absolute reality in quantitative approach, (realism) which is to be discovered, (Guba & Lincoln, 1994). Qualitative researches assume multiple accounts of reality; and the credibility of each account determines its acceptance by others, (Bryman, 2008). However, it is imperative that there is a means through which qualitative research should be evaluated. Criteria have been developed to aid the appraisal of the quality of qualitative study such as Lincoln & Guba criteria, (Seale, 1999; Bryman, 2008). Lincoln & Guba, (1985) recommended trustworthiness as alternative benchmark for evaluating the quality of qualitative studies with each aspect of trustworthiness paralleling each aspect of quantitative research benchmark. These are illustrated in table 8.1. The appreciation and implementation of the quality criteria is anticipated to enhance the quality of the study.

**Table 8.1 Quality criteria**

<b>Quantitative (positivist)</b>	<b>Qualitative (Naturalistic)</b>
<b>Internal validity – how confidently has the independent variable caused the variation in the dependent variable (believability)</b>	Credibility
<b>External validity - is it generalizable beyond the specific context? Will the findings apply to other contexts</b>	Transferability
<b>Reliability – likelihood of results applying at other times (repeatable)</b>	Dependability
<b>Objectivity – degree of researcher influence</b>	Confirmability

Seale, (1999) advises that the quality of an inquiry is not automatically determined by imposing the above criteria, rather they should sensitise researchers to quality issues that need to be addressed in their particular research.

**Credibility:** is akin to internal validity in quantitative research which considers the extent to which causal propositions are true in a particular setting, (Seale, 1999). The credibility and plausibility, (Hammersley, 1992; Hutchinson & Wilson, 2001) of this study is increased from the views of the participants as they (participants' views) form the basis of the emergent theory. The description of the factors influencing participation and uptake of the FOBt by the study participants provides diverse insight about the wider target audience (60-74 year olds) and not necessarily to generate directly generalizable explanations, (Strauss & Corbin, 1990). Hammersley, (1992) also recommended relevance as a criterion for qualitative research. Relevance indicates the importance of the study and its contribution to knowledge in its substantive field, (Bryman, 2008). The relativist stance adopted in the current study purports multiple constructions of reality and knowledge that are context and time based and in continuous evolution. This context base was evident in this study finding and illustrated in the 'awareness-led behaviour' model. Relativist stance could subject the findings of the study as being of no use in contributing to knowledge if no one position assumes legitimacy over another.

On the other hand, I could not adopt a realist position, which ignores how researchers construct and interpret findings but assumes the findings as a true independent reality. Even though there are multiple realities about a social phenomenon, relativism recognises the context and time bound of the social world. The social world is influenced by political, historical and cultural contexts which are bound to change over time. Therefore, the findings of an inquiry underpinned by relativist stance are of paramount importance at the particular local environment, time and context; and contribute to knowledge. In addition they could provide insight for future reference.

**Transferability:** Transferability parallels with external validity in positivist research. This is the extent to which findings could be generalised to different contexts or settings, (Bryman, 2008). As a result of the subjective nature of qualitative research, the findings cannot be generalised but could be transferable to similar context in terms of population, time and background, (Johnson, 1997). This is because the findings are the interpretation of the opinions and lived experience of those invited for the NHSBCSP who live in the NEYH regions and may not be generalised to other locations elsewhere due to

differences in culture and social systems, time and contexts. The characteristics of the participants may also be typical to the regions. However, the use of GT strengthens the findings in a number of ways.

Firstly, the aim of GT is to explore the views and experiences of individuals on a given phenomenon and the views are useful for representing different viewpoints on the factors influencing uptake of the FOBt. Furthermore, GT focuses on the generation of substantive theory rather than stopping at rich descriptions, (Glaser & Strauss 1967; Glaser, 1978). Therefore, strength of GT is the advancement of everyday empirical knowledge to a conceptual level, which can translate into a practice development tool (Bryant, 2007). The use of concepts aids shared understanding. The theory generated using the grounded theory approach could be used to offer coherent explanation of similar phenomenon in practice which could aid the development of appropriate interventions to improve wellbeing. Nevertheless, grounded theory is still grounded in the data and remains true to the data through systematic and rigorous techniques such as coding, memoing and field notes congruent with GT approach. This indicates that hypothesis could be developed from GT and tested in other contexts; others could arrive at similar conclusions using the same data. In order to aid transferability of my findings by others, it was deemed good practice to provide detailed information about the study participants, context, data collection and analysis in chapter 4 whilst maintaining anonymity and confidentiality.

The sample size of this study, (16 women and 10 men) may expose it to being criticized as being unrepresentative of all the target population invited for screening in the NEYH regions. However, according to (Lincoln & Guba, 1985), the likelihood of gathering multiple realities in a naturalist paradigm could be better achieved through selective sampling. Moreover, as mentioned earlier in chapter 4, credibility of a study does not depend on sample size but more on the richness of the data collected, the depth rather than the breadth as in quantitative approaches.

**Dependability:** is the extent to which results are true to data. A major strength of this study is the use of theoretical sampling of data and maximum spread in study participants which aided adequate rich data collection that helped to

address the aims and objectives; and findings which are strengthened by research and empirical evidence. The constant comparative technique which involved concurrent data collection and analysis enabled me to maintain theoretical sensitivity. Theoretical sensitivity enhances the confidence that the results are true to the data. According to Patton, (1990), the trustworthiness of qualitative is also judged on the ability of the researcher to make appropriate judgements in the field and sensitivity to data. Keeping record of all the stages of the research process, the iterative process, memo writing, field notes, and interview transcripts (Appendix 12) all served as audit trail which enabled me to remain open and sensitive to the data, (see chapter 4). I was able to monitor the influence I could have on the process and sift this from participant voices. This was achieved by the verbatim transcription of interviews, use of Nvivo and mind genius soft wares, in vivo codes and direct quotes from participant's words which Johnson, (1997) suggests enhances dependability.

**Confirmability:** The last criterion by Lincoln & Guba, (1985) for judging qualitative research addresses the extent of researcher's influence and theoretical predisposition on the study. This is akin to objectivity in positivist research. Keeping an audit trail and providing a self-reflexive critical methodological account of the research process has helped enhance confirmability of the current study. According to Seale, (1999) it is not possible for qualitative researchers to remain neutral in the interpretation of the finding. However, grounded theory techniques such as line-by-line coding aided by Nvivo, constant comparative analysis, theoretical sampling and participant validation at interviews ensured that the emergent theory remained true to the data, (chapter 4). Comparing data for differences and similarities and negative cases and discussion with peers and supervisors helped to keep my influence under check in this study.

Despite, the limitations in credibility of qualitative research, this study has provided one of the initial insights on factors affecting participation on the NHSBCSP in the NEYH and has helped the participants to express their constructions of social context, knowing and practicalities relating to BC screening using the FOBt. The next section continues with reflection on the methods of this study.

## 8.6. Strengths and limitations of the study

### Reflection on sampling

My sampling approach to this study has been detailed in chapter 4. However, specific sampling issues particularly those that arose during data collection and analysis and which may pose a threat to the credibility of the study will be revisited. Initially, I set out to explore reason for uptake/non-uptake of FOBt in the first round of the screening programme. One limitation of the current study is the very few, (two participants) of non-responders in the sample. The two may not necessarily be classified as non-responders as they have completed subsequent screening invitations at the time of this study. This limited the findings from the perspectives of the continued non-responders. This group could have given first hand insight on reasons for non-uptake. There was no sample attrition in the final 26 individuals who opted into the study after the initial effort to contact the 40 people who opted in initially. The 26 participants were very happy to be interviewed and all said that they have enjoyed the process. It may be argued that the method of recruitment used may only attract those who are most enthusiastic about the phenomenon under study. I did not encounter any difficulty in building a good rapport with participants from telephone contact (negotiating interview) to actual interview. However, there were very minor issues during interviews in relation to background noise as already highlighted in chapter 4.

The sampling issue may have been rectified by theoretical sampling of non-responders which was difficult due to time and resource constraints on the study. It would also involve fresh application for ethical approval in order for me to redesign an appropriate sampling strategy likely to get non-responders. I believe that the recruitment technique minimised any potential risk of cohesion. Nevertheless, the study participants did share information on their initial reluctance and what might have stopped them from taking part which has led to the understanding of the determinants (both motivators and barriers) of uptake that could help in the planning and implementation of appropriate strategies for improving perception and uptake of the FOBt. I made every effort to make sure that the data is theoretically collected by constant comparison which also enhances the study credibility. It is the suggestion of this study that future study

could focus on non-responders by reviewing recruitment strategy which may have jeopardised the recruitment of this group in the current study. Future recruitment targeting this group may be more successful through their GP practices that have direct contact with non-responders than through the screening hub. A major strength and contribution of this study is that, it is among the first studies in the NEYH regions exploring participation and uptake of the FOBt.

Secondly, there was lack of minority ethnic groups. An initial objective was to also explore the experiences of ethnic minorities; however, it was difficult to recruit this group. This could possibly be as a result of the recruitment method and/or language barrier. Recruitment of participants was done through the screening hub via the central register of attendees and non-attendees of FOBt. This was to maintain confidentiality as per ethics. The hub tried to gain maximum variation in the sample by looking at, among other things areas with higher concentration of minority ethnic group from available statistics and map of the region. But none from the minority ethnic group opted into the study.

In addition, sampling excluded those who do not understand and/or speak English due to limited resources. By offering the use of interpreters, people who might have language barriers but are interested in the study may have come forward. As a result of the difficulty in obtaining variations in the sample, data collection continued even when theoretical saturation was reached in order to see whether there will be additional non-responders or ethnic minority. Therefore, future study may be needed to find out whether the minority group experiences/influencing factors differ from their white counter part that have been the focus in the present study.

### **Ethical issues**

Similar to sampling issues, ethical considerations involved in the conduct of this study were detailed in chapter 4. These include how research participants were recruited, whether and how consent was obtained, confidentiality of the information, data protection and management, any potential harm to participants and how these will be dealt with. As research interferes with participant's life there are bound to be ethical issues. I have based this study on

the ethical principle of 'benevolence' which means doing good and causing no harm. As mentioned in chapter 4, the first step was obtaining ethical approval from appropriate bodies which helped in seeing the study from a neutral standpoint and making necessary adjustment to enhance benevolence.

The second step involved making sure participants voluntarily made informed decision to be interviewed without coercion. I made efforts to ensure that participants made informed choice by provision of decision aids such as information sheet, consent forms, reply slip and telephone numbers should they wish to make further clarifications before the decision to take part in the study or not. The information included the purpose of the study, methods, intended possible uses and their involvement. In addition the telephone contact to arrange interview dates and verbal discussion of the information sheet and consent before commencement of interviews also provided the opportunity for participants to ask further questions knowing that they are free to withdraw at any time with no consequences. I always made sure during the interview that participants are still willing to continue. This is because consent is not just about obtaining a signature from participants but also an on-going processes, (Reed & Payton, (1996). This also provided further opportunity to build a good rapport.

In addition, I was conscious of confidentiality making sure that all possible personal identification and data were anonymised as discussed in chapter 4. On hindsight, there was no significant untoward ethical incident arising from the study. However, one of the participants who was undergoing treatment for another cancer (only made aware at the point of interview), whom I thought it might be distressing for her to be interviewed insisted in taking part. Another was diagnosed in between test and was also happy to be interviewed; both participants seemed alright and positive about the FOBt during the interview.

### **Reflections on data collection**

Data collection took the form of one-to-one semi-structured interviews. I decided to adopt this method as a result of the topic under study which might be embarrassing to some individuals. It was deemed a good technique because participants were free to share the positives and negatives, personal and

intimate issues regarding their decision to participate in the FOBt without worrying about the presence of others; which can be an issue in a focus group. The interview guide helped the participants to guide the process, raising and discussing issues which are of priority to them. I was initially nervous as I have not previously carried out a formal and systematic interview like this before. Being a nurse, I have taken history at the point of admission and care from patients so I felt I would be fine once I get started. The first interview was not as scary as I had thought. Interviews went well and took a conversational style as I progressed. I did not need to consult my guide as I grew in confidence. I tried to make the interview as informal as possible.

Firstly, my dress code was semi-formal, in between formal and casual. Knowing that participants are at home and so may be wearing comfortable home clothes, so I did not want to appear too formal. This was to operate from the same level as them and to maintain appropriate researcher/participant relationship. Secondly, I tried to avoid the use of technical terms/jargon. For example, the use of the word 'participation' was viewed as a big word. A particular participant acknowledged what a big word to use at this time of the day whenever she mentioned the word; 'taking part' was the preferred alternative. Thirdly, I addressed the participants by their title and surname as a mark of respect unless otherwise stated. As I felt uncomfortable referring to them by first names given the culture I was brought up in, it is a mark of disrespect and being overly personal to refer to older people by their first names. The participants in this study were all older than I am. Being older they shared a lot of experiences and personal issues which further enhanced the research relationship and the depth of data collected. It is a mark of trust and it felt good to know that participants would share personal issues with me. I noticed that those interviews that include life stories and experiences lasted longer and had richer information than others. The participants tried to make me understand their experience of the FOBt as a result of being younger and had no experience of the test particularly on topics such as past family history and practicalities of completing the FOBt. I felt that participants represented themselves and their thoughts; I had confidence that the participants gave honest information.

Data analysis occurred concurrently with collection. In order to gather rich information on the topic of study which assisted the development of a grounded

theory, there was a constant verification of participants' views during data collection. I constantly paraphrased participants' words to verify that I had captured their intended view point. I also sought more clarification by asking further questions to enable me understand their social interactions, understanding and interpretation of meaning relating to the topic of study and factors that influence these. I enjoyed writing field notes, research diaries, and memos after every interview and constantly revisited the transcripts. The audio recordings were listened to innumerable times to make sure that my interpretations remain as close to the data as possible.

I undertook all the interviews being the chief investigator. Also the use of multiple interviewers could introduce potential bias. Interviews were conducted in participants' homes and audio recorded to ensure that participants views were correctly captured. Poland, (2002) advised that data is analysed for what participants said and how it was said; seeing through the eyes of the participants, (Bryman, 2008; Gubrium, 2012). Therefore, the recorded interviews were transcribed verbatim, though tedious and time consuming. The concurrent collection, coding and analysis (constant comparison) made the process even more time consuming. The constant comparison enabled nuance interpretation of data that ensured the emerging hypothesis reflected the views and experiences of the study participants which was able to address the study objectives. The use of Nvivo and mind genius software was very useful during the coding process. The management of data was made a lot easier by these. I specifically used the software to organise, sort and manage the data. They did not take over my judgements.

### **Reflections on data analysis**

A major challenge in qualitative research is the amount of data generated from interviews which could be quite overwhelming. I conducted 26 interviews in total and therefore had large number of transcripts, research diaries and field notes. One advantage of employing grounded theory is the early onset of data analysis as a result of concurrent data collection and analysis. This means that as data is being collected, it is transcribed and provisionally analysed before the next interview. This was very helpful in dealing with accumulated transcripts to code,

though inevitable at times. I allowed ample length of time between interviews to make sure the previous interview is provisionally analysed before the next one.

I had considered at the commencement of the study the use of software to aid managing the data. Having no previous experience, I booked myself onto the Nvivo training programme. I also did a self-directed online tutorial on mind genius. Although arguments abound, (Becker, 1993; Hutchinson & Wilson, 2001) over the use of software in analysing qualitative research (chapter 4), Corbin & Strauss, (2008) acknowledge that software makes the tedious job of sifting, taking to bits and sorting through the data a lot easier. I agree with Corbin & Strauss, (2008) as I felt that the use of Nvivo enhanced adeptness and audit trail of the process of analysis thereby increasing rigour. I disagree that the use of software such as Nvivo could necessarily inhibit researcher's sensitivity to the data. However, as I progressed in the open coding stage (line-by-line coding), the amount of codes were too many and I began to lack concentration and comprehension of all the too many codes. I needed something much easier to manage the fragmented pieces of data, in line with Yates, (2003). Yates warns that qualitative data could become de-contextualised and fragmented from coding. Over conceptualisation could also arise, (Glaser, 2002). At this stage I decided to use the mind genius. Mind genius provided a one-stop pictorial representation of the data. It helped me to get to the conceptual level of data analysis (axial and selective coding) identifying key emerging concepts rather than individual accounts.

I also developed a participant trajectory (see table 4.4) for each participant which provided me with all individual experiences and aided analysis across participants. This led to provisional emergent categories which later pulled together to aid theory formation. It is a challenging task trying to make sure that all individual experiences are reflected in the provisional emergent category and so I cannot claim that this was so. I agree with Corbin & Strauss, (2008) that as a researcher, I am a translator of research participants' words and actions which may never be completely interpreted as participants would like it to be. However, I feel that inductive-deductive reasoning employed during the analysis has helped me to address the aims and objectives of this study through the substantive explanatory model developed. The next section reflects on health behaviour theories.

## Reflections on behaviour theories

As identified in chapter 2 and touched upon in this chapter, a number of health behaviour theories have been developed and used to understand, explain and even predict health related behaviours. Throughout this discussion chapter, I have tried to demonstrate ways this study has tried to address the gaps in evidence as outlined in chapter 2. This section extends the discussion of the findings by outlining its contribution to existing theories of health behaviour.

The current study sought to explore possible factors which could affect people's decision regarding completing the FOBt using the kit supplied. Bearing in mind that people are complex and dynamic beings; and factors influencing their behaviour could be multifaceted, I decided against underpinning the study within any particular behaviour theory. Locating the study within a particular theory from onset would hinder and limit the findings. Rather, based on my philosophical, ontological and epistemological stances (chapter 3), I adopted a qualitative methodology appropriate to explore the different reasons for uptake from various dimensions. I felt that grounded theory is robust and dynamic to uncover these dimensions and has been able to address the objectives. Therefore, the current study model has provided a more flexible and dynamic way of exploring and understanding factors that can influence peoples' behaviour unlike some health behaviour theories. For example, the theory of planned behaviour and stages of change model are based on rigid quantitative approaches, (i.e. Likert scales and questionnaires).

The findings of this study suggest most of the factors influencing decision to participate in the FOBt fit within the health belief model, (HBM) except altruism, (doing things for the sake of others). Altruism was an interesting novel finding which seemed scarce in existing health behaviour theories from literature appraisal (chapter 2) and this was also acknowledged by Chapel et al., (2008). The findings of this study help to fill this gap by providing rich descriptions of the influence of altruism on uptake, (sections 6.6 & 8.22). However, appraisal of health behaviour theories was only limited to most commonly used theories and therefore not exhaustive. The emergence of altruism as a potential influence on participation in FOBt therefore reinforces that health behaviour can often carry meanings outside the health realm. This was also acknowledged by Nettleton,

(1995). Nevertheless, as mentioned in section 6.6, altruism was not a single reason in its self for participating in screening rather an additional modifying reason among others.

Majority of the commonly used health behaviour theories are focused on individual behaviours (Painter et al., 2008) such as the health behaviour model, (section 2.10) particularly cognitive aspects albeit the influence of the wider physical and sociocultural environment. The awareness-led behaviour model locates people within their individual and wider social cultural context. Some health behaviour theories are also largely underpinned by the assumption of rational behaviour, even though people may not always act rationally, (Rothchild, 1999). Therefore, there is the need to apply theories that pass beyond individual level to impact health behaviour issues in communities. Perhaps, the starting point could be to refine and expand current theories to capture some of the other factors influencing behaviour such as altruistic tendencies that emerged from the current study. Current study model, the Awareness-led behaviour' model in addition to cognitive factors influencing behaviour has also highlighted the influence of the wider socio cultural influences such as taboos and traditional male gender role on behaviour.

As mentioned in chapter 4, human behaviour is a complex concept that may not be understood from one model alone. The HBM only provides the personal psychological dimensions as predictors of behaviour, (Rosenstock, 1974; 2005). Human beings do not exist in isolation and are bound to influence and be influenced by their social and physical environment, (reciprocal determinism) such as family, environment, friends and work life, (Bandura, 1986). Reciprocal determinism implies the triad simultaneous interaction of a person, a person's behaviour and the environment; the constant influence of these three components on one another, (Glanz et al., 2002), (see section 2.10 for more discussion on Bandura and socio cognitive theory). This study has thus provided further influences of participation in FOBt, (Figure 4.7). Some of these factors seemed to agree with the social cognitive theory, (SCT), (Bandura, 1986; Baranowski, et al., 2002; Bandura, 2004), (see section 2.10). Thus adding to the platform and dynamism from which affective interventions could be designed, implemented and evaluated.

Stages of change theory, (Prochaska & Diclemente, 1983) locate people on a change continuum, posing a risk of leaving out those who are on or below the pre-contemplation stage. It does not explain how people move across the stages. The stages of change theory focus on an individual without evaluating the role of structural and environmental issues on the individual's ability to enact behaviour change, (Bandura, 2004). Each of the stages on the change continuum of stages of change theory may not be suitable for characterizing every population. In addition, the relationship between stages is not always clear because the theory presents a descriptive rather than a causative explanation of behaviour. Perhaps incorporating aspects of other theories at the appropriate stage would strengthen the stages of change model and give insight into the causative influences on behaviour (Prochaska, 1994). The 'awareness-led behaviour' model proposed in the current study has thus provided clearer tentative explanation of behaviour and the factors likely to cause the behaviours; thus enabling a better understanding of how behaviour change happens. For example, the study model has reinforced the pivotal role of knowledge and awareness on social contexts/practicalities in bringing about positive behaviour change.

Furthermore, in relation to participation, the theory of participatory democracy argues that the experience of participation could leave the individual psychologically better equipped to undertake future participation, (Moote et al., 1997). This appeared to be true experience of the study participants who reported that once they had completed the FOBt the first time, they were confident and comfortable with it the next time, this reinforces self-efficacy construct of behaviour theories. However, the level of confidence varied among individuals who took part in the FOBt. Employing Arnstein's ladder of participation (Figure 2.3) locates people at the lowest rung of the ladder, with no input in policy and practice decisions. Whilst not having involved the current study participants in the study design or implementation, I feel that this study has been valuable in representing the voice of the people who are experts in their health and decision making regarding improvements in the planning, delivery and evaluation of the FOBt. Also, the current study acts to bring participants closer to the desirable rung on the participation ladder. I believe that the findings of this study add to existing behaviour change theory by the

complex nature of the awareness-led behaviour model. It is anticipated that current study may inform and affect policy and practice.

## **8.7. Summary of chapter 8**

During this discussion and comparison of the study findings with previous literature; differences, similarities, limitations and inconsistencies among different studies were noted. They were attributable to study methods, mode of screening, location of study, mode of sample recruitment; method of data collection and analysis, ethnicity and health care systems. This justified the need for the present study, as these earlier studies may not be generalisable to the NEYH. In addition, the aforementioned issues justify the need for locating lived experiences within individuals' social and environmental context. An important factor that is more likely to lead to effectively tailoring interventions to needs of the particular population rather than over generalisation which could yield no benefit as a result of different social, geographic and health systems context discussed in this section. This study has made a contribution by exploring and representing the voices and lived experiences of the people specifically in the NEYH (but which could form the basis of other larger studies) that could help in providing interventions responsive to the needs of those in the NEYH and may help to inform interventions in other geographical areas. Applicability of the findings to other settings is made easier by the higher level concepts developed in awareness-led behaviour model, (figures 4.7& 4.8).

In summary, the study findings suggest that factors influencing participation in the NHS BC screening using the FOBt are complex, multidimensional and context based as shown in the summary of findings (figure 4.7). They are socially, psychologically, geographically and economically situated in time and space. Many health behaviour models have been formulated in trying to unpick health behaviours. The current study model demonstrates that participation and uptake of the BC screening could be influenced by social contexts, knowledge/awareness and practicalities associated with completing the FOBt. A combination of the factors lead to the likelihood of uptake of FOBt and vice versa as illustrated in the model, (Figure 4.8). There was no significant difference in how both genders perceived BC screening. However, an evolving concept 'altruism' also emerged which does not seem to be addressed in the

commonly used health behaviour theories. The participation decision making process seemed to involve the interaction of one or more combination of these variables. Societal perceptions such as taboo seem to act as a potential barrier and the nature of the test itself could be off putting. Knowledge and awareness emerged as significant variable that could subvert the barriers which could lead to improved uptake. Knowledge came from past experience and other sources and was an important facilitator for uptake. Therefore, this increases the need for effective strategies that could raise awareness and subsequent uptake if the screening target (60% of the invited population) is to be attained.

Reflections on rigor and quality, strengths and limitations and health behaviour theories were also presented. The next and final chapter of this thesis will present the implications of the current study beginning with an examination of the implications for social marketing in raising awareness, uptake and participation before presenting other implications and concluding remarks

## Chapter 9

### Study implications and conclusions

#### 9.1. Introduction

A number of potential policy and practice implications emerged from the findings of this study. In practical terms, policy and practice are interwoven. Therefore, it will be challenging to separate the two in reporting the implications. Thus the two will be discussed together in this section. The findings revealed that social contexts, knowledge and awareness, and practicalities of completing the FOBt can all affect decision to participate or not in the bowel screening test acting either as barriers or facilitators. A number of suggestions arose from study participants on how awareness could be raised and practicality issues improved in order to improve uptake which has remained low despite the NHS effort to minimise the morbidity, mortality and other costs arising from BC. The appraisal of literature in chapter 2, report of findings in chapter 5, 6 & 7 and the discussion of findings in chapter 8 indicated that education and awareness are important tools in raising cognisance, demystifying many of the social barriers and addressing some of the practicality issues associated with completing the FOBt. This chapter examines potential study implications for policy, practice, education and research.

#### 9.2. Policy and practice implications

My intention was to generate knowledge and add to the existing evidence base that will aid improvement in the NHSBCSP and alleviate barriers for participants. A number of potential barriers were identified in this study preventing people from completing the FOBt. In addition, knowledge and awareness were very limited prior to being invited. Informal awareness largely came from past medical experience, family history, friends and work life. Therefore policy makers and practitioners should take appropriate steps to minimise these barriers. The current study suggests that the awareness of BC and the screening programme could be greatly improved via the FOBt invitation artefacts enclosed in the screening kit.

The study, therefore suggests that future policy should channel more attention to education and awareness; GP involvement in the FOBt is also to be considered. It is a consensus in this study that people trust their GPs and information coming from personal doctor more than those from an unfamiliar source. Study participants suggested the endorsement of GPs name and signature on the invitation letter. Therefore, an exploration of GP experience and how they could be involved in the delivery of the FOBt might be an appropriate starting point. GPs could act as an additional resource for the screening programme. Opportunities for collecting kits at the GP practice may be useful and also the inclusion of the FOBt in the health check questionnaire.

A major practical barrier to participation in the FOBt arising from current study seems to be issues around sample collection. This raises an important policy and practice issues for the NHS of the need for improvement in the sample collection method currently used for the FOBt if improvement in acceptability and uptake are to be achieved. Two issues arose from the participants. Firstly, there was confusion on how to collect the stool samples. Study participants suggested provision of succinct explanation for sample collection. Different people were not sure on number of samples, number of motions and days they are meant to collect the sample. Another problem raised was how to capture the sample before it gets to the toilet water. Service providers, such as the BC screening nurses can support service users by providing additional education on amount of samples to be collected and duration and making it clearer how to capture the stool samples.

Secondly, there were issues with the kit itself and storage of collected sample. It was pointed out that the kit is too fiddly and unhygienic. In terms of storage, it may be highly beneficial to explore one sample collection pot rather than a card board of samples collected over few days as currently used. A remodelling of the collection kit may need to be considered to deal with practicality of collection. The current study suggests that current FOBt kit needs to be re-evaluated. At the moment service users are left to work out how best to capture the sample. Issues arose in the study where people have used plastic bowls at home which raises infection control questions regarding cleaning and disposal of the bowls. The current study suggests a new FOBt kit which will include a biodegradable stool capturing tool/device and spatula which will be put over the

toilet seat and sat over. These will be flushed down once sample has been taken. I anticipate that this will lift most of the barriers for responders and non-responders and increase compliance in the FOBt.

### **9.3. Suggestions for improving uptake of the FOBt**

The awareness-led behaviour model has illustrated the role of awareness as a mechanism for improving positive behaviour change (completing FOBt) and for maintenance of such (future uptake). This highlights the continued need for raising awareness to improve knowledge and sustained uptake of the FOBt. External motivators such as appropriate public education campaigns; informal support groups and worst case scenario government policies are needed. Social marketing currently seem to be among public health interventions to raise awareness and influence voluntary positive behaviour, maintenance of the behaviour, and prevention of negative behaviour initiation, (Maibach et al., 2002). Therefore, the researcher recommends social marketing as possible systematic strategy to be considered for improving uptake.

Social marketing in general is the systematic application of marketing, alongside other concepts and techniques to achieve specific behavioural goals for a social good, (Hasting, 2007). SM for health is focused on improving health and wellbeing, removing barriers and reducing health inequality in the population, (French & Blair-Stevens, 2005; Hasting, 2007).

As a result of the need to put people at the centre of public health after all 'it is their health' and to save public funds that otherwise will be used in managing preventable ill health that the department of health white paper 'it is our health' called for a national social marketing strategy for health and the most recent document 'Changing behaviour, improving outcomes: a new social marketing strategy for public health', (DH, 2011). The economic advantage of preventing chronic ill health is of high importance as efficiency and cost saving becomes high on government agenda. SM could save £190 million for every single per cent improvement in health outcomes, (French & Mayo, 2006). In addition, it could save families £700 million and lower employer cost by £110 million. The social value of SM could significantly reduce premature death and disability (French & Mayo, 2006) and achieve the maximum attainable shift in public

health, (Wanless, 2004). However, for interventions to be successful, they have to be tailored to the needs of the people. There has to be a shared decision making between the policy makers, practitioners and service users in reaching agreement on how best to meet the needs of the service users and not just what the policy makers think would work. This will foster community participation and active involvement in policy making on issues affecting the individuals, (McHunu, 2009).

SM intervention begins with an understanding of factors that influence behaviour such as knowledge, environmental, family, religion and self-efficacy, (consumer insight). This study has helped in providing consumer insights as part of shared decision making that may help policy makers to rightfully tailor interventions. The finding has particularly raised the voices of service users; highlighting the practical challenges encountered while trying to complete the FOBt and ways of alleviating these issues from service user perspective. The emergent barriers to FOBt uptake such as fear, embarrassment, ostrich syndrome, taboos and practical issues could be modified by affective social marketing intervention through the application of appropriate marketing mix. Marketing mix is an important tool used in social marketing in achieving its objectives. The four 'Ps' is an example of marketing mix consisting of price, product, place and promotion, (Kotler et al., 2002).

Having gathered some insights from the current study and some lens from behaviour theory on factors which could influence participation and uptake of FOBt and behaviour respectively, this study suggests stirring the four, 'Ps' in the appropriate directions. The key fundamental principle of SM includes target behaviour change, target audience segmentation and marketing mix. The market is already segmented in terms of age (60-74 year olds) and no significant difference in the genders arising from the study but this needs to be further explored in future studies. Maibach et al., (2002) recommends that marketing programmes should offer attractive bundle of benefits, at an acceptable cost, at the time and place, when or where target market members will be most open to the offer; inform and persuade target market members that the offer is in their best interests. The role and the process of the four 'Ps' will be considered in turn.

**Product:**

This study suggests that there is already a perception of attractive benefits and convenient time and place for the product, (FOBt). However, more work needs to be done around acceptable cost and informing and persuasion levels. There needs to be a careful consideration of the type of messages to use. Two options arose from the study; the use of fear appeals and gentle positive messages. A further option to be considered is the use of deductive frameworks, (Kotler & Andreasen, 1996; Andreasen & Kotler, 2008) which the two options suggested by participants sits well within; the rational, emotional and moral frameworks. According to Kotler & Andreasen, (1996) rational messages pass on information that conveys benefits of a service and is aimed at serving audience self-interest. Emotional message are aimed at stirring up positive/negative emotions, (joy, pride, humour, love, fear, guilt, shame) in order to enact target behaviour change while moral messages sensitise people to what is the right or wrong behaviour. However, this framework may portray social marketing as a manipulative process that preys on peoples' cognition and of questionable ethical stand. Kotler & Andreasen suggest that when there is too much fear, people tend to ignore the messages.

**Price:**

Having made some of the target population to acknowledge and voluntarily accept the benefits of the FOBt, (Product). It is important to sustain the behaviour change and to get many more of the target population who are not already taking part to consider the product. At this stage of the process the aim of any social marketing intervention is to identify and ensure that the cost/price (physical, social and emotional) is minimal. The most significant identified perceived price/cost seems to be the practicality of completing the FOBt. This means in a nut shell, 'how to capture the sample'. Hence, the need for better and alternative ways of collecting stool sample in order to minimise this cost. According to Mailbach et al., (2002) price reduction leads to an increase in sales, increased sales volume at a low profit margin allows the total level of profit to remain constant.

**Place:**

Place is the distribution channel which in commercial marketing is often considered the most important element of the marketing mix. Making the product easily accessible and convenient and in front of the target population is paramount. This study suggests that this has been a successful element of the FOBt. All study participants felt that home was the ideal place for that 'sort of thing'. It was felt that not much was required of them. This is because the test arrives through 'your front door, you do the test and post it back; they (NHS BC screening services) cannot get it any easier'. But then, why are others not participating in the test, is it that straightforward?; even though it has been suggested that increased access interventions offering ready and easy access increases uptake, (Cohen et al., 1999). Perhaps, others outside this study may not wish to carry out the test at home and/or by themselves. This might need to be investigated further.

**Promotion:**

Perhaps inadequate promotion may be among the factors that prevent people from taking the FOBt. Target population cannot voluntarily change their behaviour if they are not aware of the benefits of a product, the reasonable associated cost and the availability which is convenience of their own homes. Promotion (awareness) was identified in the current study as an area needing more attention. Awareness was quite low prior to FOBt invitation and increased with participation. This indicates that the creation of more awareness should be an important integral element of any social marketing intervention to improve uptake of FOBt. 'Promotion involves education and is often mistaken to be synonymous with the whole idea of SM concept' (Maibach et al., 2002 in Glanz et al., 2002 pg. 447).

Promotion could be done in a number of ways such as word of mouth, entertainment media, advertising, the internet, emails, direct mails and public relations. The careful and systematic use of all the appropriate elements of SM in an appropriate mix is likely to yield a better outcome than using them as stand-alone measures. In relation to the FOBt, this may also require the combined effort of appropriate stake holders such as the service users, the

national bowel cancer screening programme (NBCSP), the GPs, media, the FOBt manufacturer, the screening hub and the QUARC. The NBCSP and the hub are already providing support within their control. GPs, entertainment industries, and sales force may be the next to consider if uptake is to be increased as suggested by the findings.

In summary, the ultimate goal of SM is to influence positive individual behaviour change. Therefore the target client and their perspectives should be at the centre of any SM intervention. For an effective influence, there is the need for a timely exchange that fosters increase in benefit and reduction in barriers than already available choices, (Maibach et al., 2002). Maibach and colleagues suggested that individual behaviour could be directly or indirectly changed by changing the environment in relation to benefits and barriers and by changing the culture with respect to expectations and norms. Given the findings of current study, this last statement could only be achieved if the product is right, and more individuals become more aware of it through the right promotion and at a reasonably reduced cost. On-going research is therefore needed to develop theoretical framework to underpin health education interventions, programmes and campaigns that draw on this research evidence. The next sections present the remaining implications of the study.

#### **9.4. Suggestions for further research**

Evidence is always desired by policy makers to enable constructive recommendation of interventions to service commissioners and practitioners. This study has highlighted the need for research in a number of areas. Firstly, as outlined in the previous section, practicalities associated with completing FOBt appeared to be a major barrier in participation and uptake. As suggested above, a revaluation and redesign of the screening kit may need to be undertaken. This study therefore suggests a systematic review of literature or a large quantitative study on the influence of practicalities of FOBt on its uptake. If this is conclusive, a trial and evaluation of a new kit is deemed necessary. A pre and post evaluation will measure output and impact of the new kit on screening.

Many of the study participants also described some reasons given by their friends and families for not responding to the screening programme. The majority of these reasons include the nature and practicality of the FOBt. Those family and friends were not part of this study. Therefore, it is pertinent to focus a future study on the extent to which test practicality problems affect uptake of FOBt in non-responders.

Secondly, a rather interesting finding which seemed scarce in the most commonly used health behaviour theories emerging from this study but gradually evolving in research literature is the association of altruism and health behaviour. None of the theories seemed to recognise the influence of being a good citizen and other altruistic dimensions on people's behaviour. Discussions abound in psychological literature on the concept of altruism, but not much in research literature of its influence on participation in screening programmes. It emerged from this study that altruism could also influence perception and subsequent behaviour. Given the small sample, (26 participants) on-going research will be valuable to explore on a much bigger scale the correlation between altruism and participation in screening.

Thirdly, a limitation of this study is the absence of minority ethnic group and those who have continuously declined completing the FOBt which is in the third round presently. It will be important to explore these two groups to understand the reasons for non-attendance. Particularly among minority ethnic group which studies have continuously reported low uptake. UK is a multi-racial country, therefore if the burden of BC on public health is to be brought under check, this group need to be accounted for. This will help in planning and developing appropriate tailored intervention to improve uptake among the minority group.

Furthermore, the study findings suggest that social context, knowledge and practicalities all influence participation and uptake of FOBt in different ways either positively or negatively, with knowledge affecting in the most positive ways by acting on social context and practicalities. Therefore, it will be interesting for future research to test the product of this study 'awareness-led behaviour model' in other areas of screening, region, with other groups of service users such as the non-responders and minority ethnic group. It is

anticipated that repeating this research with other service user group could generate important findings for better targeted services.

## **9.5. Contributions to knowledge and Conclusions**

This study makes original contribution to knowledge in several ways: conceptual, practical, methodological and educational. At the conceptual level, factors influencing participation and uptake of the NHSBCSP using the FOBt are presented in the tentative explanatory model developed from this study which also adds to existing health belief theories. Participation and uptake could be influenced by social contexts, knowledge and practicalities associated with the screening test. The abstract of preliminary findings of this study has been published in the Lancet, (Azodo, Steven and Geddes, 2012, Appendix 1) and a full paper is being prepared for publication. Power points and posters have also been presented at seminars and conferences, (some of these are presented in appendix 1). The explanatory model (awareness-led behaviour) could be tried out in practice to explain similar phenomenon in the same context and could also provide insight in different context. Social cultural context, poor knowledge and practicalities of test largely emerged as potential barriers to uptake. Therefore at a practical level, these will help in developing appropriate interventions to address these; the study has suggested social marketing as a valuable approach.

At a methodological level, the use of grounded theory offers a unique contribution to knowledge by approaching participation from a qualitative stance which provided in-depth and rich explanations from participant's perspective and an explanatory model still grounded in the data in ways in which quantitative stance may not have allowed.

Finally at educational level, it is anticipated that this study will be of significant benefit to students and researchers. It will be a reference point for future academic and research purposes.

### **Concluding remarks**

My aim for undertaking this study was to understand factors influencing individual participation and uptake of the NHSBCSP from the perspective of

those who have been invited to take part in the screening programme. Thereby gaining insight in the following:

- Peoples' experience and knowledge regarding BC and the screening programme
- Peoples' understanding of the information provided /gathered regarding the screening and how this influences their decision to participate or not
- The similarities and differences in how different groups of people (for example, men and women) perceive BC screening programme (FOBt)

The key findings (section 8.22) clearly suggest that BC was perceived to be a serious health condition and screening as an effective way of preventing or reducing adverse effects of BC. The invitation artefacts were perceived to give effective cues to action and act as an education tool which facilitated self-efficacy. There also emerged perceived barriers. However, these barriers could be modified by effective social marketing. There was no significance gender difference. A major challenge which still remains unresolved is the practicality of completing the FOBt. Even though there was a unanimous positive attitude towards the FOBt asserting its importance, there is still a general feeling of disgust about the nature and method of sample collection. This has led to suggestions of how awareness could be promoted and the FOBT kit improved.

I identified that there were not many qualitative research studies in UK, particularly in the NEYH regions where there seemed to be apparently no published research on the factors influencing participation and uptake of the FOBt at the commencement of this study. The majority of available studies only explored trends in uptake without accompanying reasons for such trends. This study has shed some light on the experiences of participants and represented their voices. I believe that taking part in this study has helped the participants to share their experiences and has helped to enhance my qualitative research skills. It has been a challenging, well worth and fulfilling experience for me.

An outcome of this study is the 'awareness-led behaviour' model (Figure 4.8) which explains that health screening decision making is primarily a complex phenomenon which could be influenced by three concepts: Firstly, social contexts - socio-demographic, socio cognitive and wider socio cultural contexts.

Secondly, knowledge and awareness were recognised as potential mechanisms of 'knowing' positively affecting the other concepts thereby causing participation and uptake. Effort is therefore needed to improve knowledge and awareness. Thirdly, practicalities of completing the FOBt kit adversely affects uptake leading to either uptake or non-uptake depending on the strength of facilitators and barriers and other modifying variables.

In order to have impact on regional and national policy and practice, the study findings will be reported to the quality assurance reference centre for cancer screening (QUARC) and also disseminated to appropriate stakeholders. The findings will also be shared across the academic community, (Northumbria university research link, academic journals, conferences and seminars). This is anticipated to elicit and inform future studies.

Finally, it is hoped that the recommendations of this study will help researchers, practitioners and policy makers in planning and implementation of appropriate service user-tailored interventions (e.g. social marketing and improvements in the screening kit), which will increase participation and uptake of the NHSBCSP and thereby help in reducing the mortality, morbidity and other costs associated with BC.

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# Appendices

## Appendix 1: Research Outputs

### 1a. Published abstract, The Lancet Nov 2012

Title: Participation in Bowel cancer screening: An exploration of the processes involved

Ijeoma P. Azodo, Alison Steven, Lesley Geddes

#### Abstract

**Background:** Bowel cancer is the third most common cancer and the second major cause of cancer deaths in the UK. Research suggests that the risk of death from bowel cancer can be reduced by 16% through regular screening. An initial scientific literature review shows little research in this area. Previous studies identify non-attendance and low uptake as a major challenge and suggest that these factors could be affected by literacy level, fear, and anxiety. However, many of these studies were undertaken in other locations and countries, limiting replication or generalisation in the UK. There is therefore a need for qualitative investigation into the reasons and motives for low uptake. We explored reasons for participation and non-participation in the NHS bowel cancer screening programme, which requires participants to undertake a faecal occult blood test. We aimed to develop an understanding of behaviour regarding bowel cancer and the screening process; explore how people make sense of information gathered and how this influences their decisions; and describe similarities and differences regarding different groups' perceptions of bowel cancer screening.

**Methods:** Qualitative research methods are used to unpick participants' sense-making processes. A grounded theory approach has allowed the development and understanding of how participants form meanings and make decisions dependent on factors such as culture and sex. 26 participants were recruited through the bowel cancer screening hub in accordance with ethics approval. Participants were those who completed the faecal occult blood test (with negative result) and those who declined during the first round of the programme. Data were obtained with semi structured, face-to-face interviews and were analysed with grounded theory techniques. Analysis was done by organisation of data into codes, themes, and categories by Nvivo and Mind Genius software. Interviewer bias was minimised by use of credibility strategies such as member checking, reflexivity, and peer review.

**Findings:** Data analysis showed participants' low awareness of the faecal occult blood test before they received the invitation for screening. Awareness of bowel cancer was mainly through past experience or family history or was work-related. Data suggested that demography and cultural issues such as age, sex, taboo, attitudes, altruism, so-called ostrich syndrome, and stoicism can affect behaviour and decisions. Knowledge and awareness were identified as factors in breaking some of the cultural barriers affecting uptake. Main reasons for uptake were health protection or peace of mind. All participants viewed

screening positively and will continue with screening. Men seemed very keen to participate in screening and seemed as mindful of their health as were women. Possible reasons to decline the invitation included “if I don’t know it won’t happen to me”, “taboo subject”, “method of stool sample collection”, “fear”, and “messy and not pleasant”. Limitations of our study included the small number of people who declined screening: only two declined in the first round, but have completed subsequent screening. Several practical issues have been identified that will inform service provision—e.g., improvement of the invitation letter and information about sample collection.

**Interpretation:** We expect the output of this research to inform future practice and policy implementation towards increased awareness, improved perception and uptake of screening, and service improvement that could lead to a substantial reduction in bowel cancer deaths. The findings will also be drawn on to explore the role of social marketing in improving perception and uptake of the bowel cancer screening programme.

**Funding:** Northumbria University at Newcastle upon Tyne in conjunction with North East, Yorkshire and Humber Quality Assurance Reference Centre for Cancer Screening (NEYHQARC).

**Contributors:**

IPA contributed to the literature search, study design, data collection, data analysis, data interpretation, and writing. AS and LG were involved in conceptualisation and development of the design of the study, and contributed (reviewed and corrected) to the writing.

**Conflicts of interest:**

We declare that we have no conflicts of interest.

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**1b. The Lancet poster at Public Health Science Conference: A national conference dedicated to new research in public health; organised by the Lancet in conjunction with the Royal Society of Medicine, London School of Hygiene and Tropical Medicine and the National Heart Forum**

# Participation in Bowel Cancer Screening: An exploration of the processes



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber

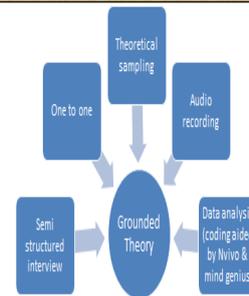


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## Abstract

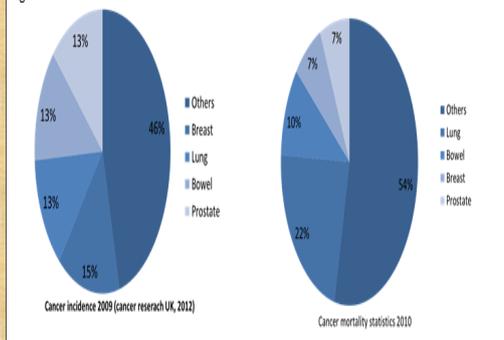
This research study explored reasons for uptake and non-uptake of the NHS Faecal Occult Blood test (FOBT) in the North East, Yorkshire and the Humber among those who were invited for screening. The research employed Grounded Theory approach. Twenty-six research participants were recruited through the Bowel Cancer screening hub in accordance with ethical approval that was obtained. Data was collected using semi-structured, face-to-face interviews. Data analysis involved using Grounded theory techniques of coding with the aid of Nvivo and Mind genius software.

## Methods

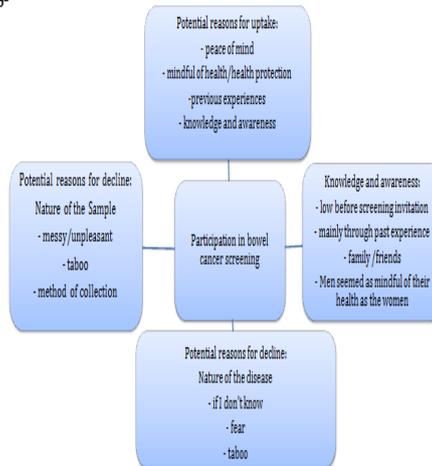


## Introduction

- Bowel Cancer is the third most common cancer and the second major cause of cancer deaths in the UK
- Research indicates the risk of dying from bowel cancer can be reduced by 16% through regular screening
- Initial literature review shows little research in this area. Previous studies identify non-attendance and low uptake as a major challenge and suggest that these factors could be affected by literacy level, fear, and anxiety.
- However, many of these studies were undertaken in other locations and countries, limiting replication or generalisation to the North East, Yorkshire and Humber area.
- There is therefore a need for qualitative investigation into the reasons for low uptake in the specified region.



## Findings



## Aims & Objectives

### Aim

•This study explores reasons for participation and non-participation in the NHS Bowel Cancer Screening Programme that requires participants to undertake the Faecal Occult Blood test.

### Objectives

- To Develop an understanding of behaviour regarding Bowel Cancer and the screening process
- To explore how people make sense of information gathered and how this influences their decisions
- To Describe similarities/differences regarding different groups perceptions of bowel cancer screening

**Conclusion:** Demography and cultural issues such as gender, taboo, attitudes, ostrich syndrome and stoicism seems to affect behaviours and decisions

## Interpretation

- Several practical issues have been identified that is likely to inform service provision e.g. invitation letter and information regarding sample collection.
- It is expected that the output of this research will inform future practice and policy implementation towards increased awareness, improved perception and uptake of screening, and service improvement that could lead to a substantial reduction in bowel cancer deaths.
- The findings will also be drawn on to explore the role of Social marketing in improving perception and uptake of the Bowel cancer screening programme.

Funding: This research is sponsored by the Northumbria University in conjunction with the NHS North East, Yorkshire and Humber Quality Assurance reference centre for cancer screening, (NEVQARC, contact Dr Keith Faulkner).

**1.1a. Centre for Translational Research in Public Health (FUSE) conference, (July 2012)**



**Research Title:**

**Participation in Bowel Cancer Screening: exploring the processes involved and the potential role of Social Marketing as an approach for improving perception and uptake.**

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The research is sponsored by the Northumbria University in conjunction with the North East Yorkshire and the Humber Quality Assurance Reference Centre for Cancer Screening.

**Background and objectives:** Bowel Cancer is the third most common cancer and the second major cause of cancer deaths in the UK (Cancer Research, UK, 2006). Research has shown that the risk of dying from Bowel cancer can be reduced by 16% through regular bowel screening, (Cochrane Database of Systematic Reviews, 2006). There seems to be limited research and work in this area while undertaking literature review.

This an on-going PhD study exploring reasons for participation and non-participation in the NHS Bowel Cancer Screening Programme that requires participants to undertake the Faecal Occult Blood test.

The Objectives are to:

- Develop an understanding of behaviour regarding Bowel Cancer and the screening process
- Explore how people make sense of information gathered and how this influences their decision
- Describe the similarities/differences on how different groups perceive bowel cancer screening e.g. men and women; and

- Investigate ways SM could be used to improve perception and uptake.

**Methods and design:** Qualitative research methodology is being used to unpick the 'sense making' process, (Dervin,1992) as it allows the researcher to gain/discover an inner experience of population sample and develop an understanding of how they form meanings and make decisions depending on different factors such as culture and gender using Grounded Theory approach. 26 participants were recruited through the Bowel Cancer screening HUB in accordance with ethical approval. Invited participants were those who completed the Faecal Occult Blood test (with negative result) and those who declined during the first round of the programme. Data was collected using semi-structured, face-to-face interviews. Data is currently being analysed using Grounded theory techniques. This involves organising data into codes, themes and categories using Nvivo software.

**Preliminary findings:**

- Limited knowledge of bowel cancer and the screening process (improving with FOBt invitations)
- Reasons for completing the test included: health protection/peace of mind
- All participants thought screening was good idea and will continue with screening
- Male participants seem very keen to participate in screening and mindful of their general health
- Reasons for declining included: 'if I don't know it won't happen to me' 'taboo subject' 'method of stool sample collection' 'messy and not pleasant'
- However the study is limited absence of people who declined screening, only two declined in the first round but have complete subsequent screening.

**Conclusions and implications:** The findings will be drawn upon to explore the role of Social marketing in improving perception and uptake of the screening programme.



## Participation in Bowel Cancer Screening: exploring the processes involved and the potential role of Social Marketing as an approach to increasing future participation.

Prisca I. Azodo PhD Student; Dr Alison Steven; Lesley Geddes.  
(School of Health Community and education studies)



### Abstract/Summary

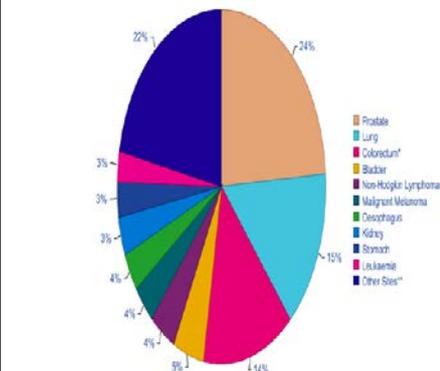
This is an on-going PhD research exploring reasons for uptake and non-uptake of the NHS Faecal Occult Blood test, using Grounded Theory approach.

Research participants were recruited through the Bowel Cancer screening HUB in accordance with ethics. Data has been collected using semi-structured, face-to-face interviews. Data is currently being analysed using the using Grounded theory techniques of coding with the aid of Nvivo software.

Subsequent to data analysis, the findings of the research will be drawn upon to explore the role of Social marketing as an approach to improving perception and uptake of the screening programme.

### Introduction

- Bowel Cancer (BC) is the 3<sup>rd</sup> most common Cancer in men and women
- And the second major cause of cancer deaths in the UK
- Early detection through screening saves life and reduces bowel cancer death by 16%



(The ten most com

### Aims/objectives

This research aims to investigate the factors that influence participation and non participation; and to explore the potential role of Social Marketing (SM) in improving screening uptake.

The main objectives are: to develop an understanding of behaviour regarding Bowel Cancer and the screening process; explore how people make sense of information gathered and how this influences their decision; describe the similarities/differences on how different groups perceive bowel cancer screening e.g. men and women and investigate ways SM could be used to improve perception and increase uptake.

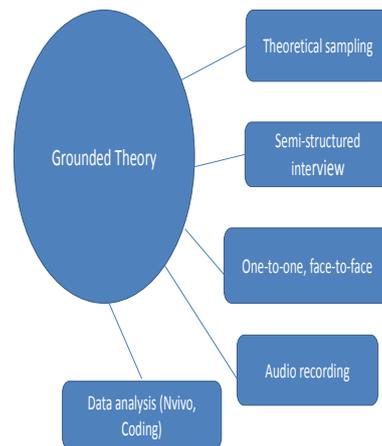
### Social Marketing

Social Marketing in general is the systematic application of marketing alongside other concepts and techniques, to achieve specific behavioural goals for a social good, (Hasting, 2007). Social Marketing for health is focused on improving health and wellbeing, removing barriers and reducing inequality in the population, (French & Blair-Stevens, 2005).

### Social Marketing

Social Marketing in general is the systematic application of marketing alongside other concepts and techniques, to achieve specific behavioural goals for a social good, (Hasting, 2007). Social Marketing for health is focused on improving health and wellbeing, removing barriers and reducing inequality in the population, (French & Blair-Stevens, 2005).

### Methods and Methodology



### Discussion

Data collection just completed

Initial highlights from data collection as data not yet analysed:

- Limited knowledge of bowel cancer and the screening (improving with FOBT invitations)
- Reasons for completing the test included: health protection/peace of mind
- All participants thought screening is a good idea and will continue with screening
- Most of the male participants seem very keen to participate in screening and are more mindful of their general health than when they were younger.
- Reasons for declining the screening test included: Ill health, recent bowel investigation, 'if I don't know it won't happen to me' 'taboo subject' 'method of stool sample collection' 'messy and not pleasant'
- However the study is limited by a very small number of people who declined the screening in the first round.

### And?

The findings will be drawn upon to explore the role of social marketing in improving perception and uptake of the screening programme.

This research is sponsored by the Northumbria University in conjunction with the NHS Quality Assurance reference centre for cancer Screening.

**1.2a. Faculty of Health and Life Sciences conference abstract and University wide conference**

<b>Name: Azodo, Ijeoma P.</b>
<b>Presentation / Poster</b>
<b>Doctorate Title:</b> <b>Participation in Bowel Cancer Screening: Exploring the processes involved and the potential role of Social marketing as an approach for improving perception and uptake</b>
<b>Year of Programme: 3rd</b>
<b>Supervision team:</b> <ul style="list-style-type: none"><li>• Principal Supervisor: Dr Alison Steven</li><li>• Second Supervisor: Mrs Lesley Geddes</li></ul>
<b>Department: Public Health and Wellbeing</b>
<b>Contact Email Address: ijeoma.azodo@northumbria.ac.uk</b>
<b>Title:</b> Participating in bowel cancer screening: the why's and the why not's Bowel cancer is the third most common cancer and second major cause of cancer deaths in the UK. Research suggests that the risk of death from bowel cancer can be reduced by 16% through regular screening. However, uptake remains low. This study explored reasons for uptake and non-uptake of the NHS Faecal Occult Blood test (FOBT) in the North East, Yorkshire and the Humber among those who were invited for screening.  This study employed Grounded Theory, a qualitative research approach. Twenty-six research participants were recruited through the Bowel Cancer screening hub in accordance with ethical approval. Data was collected using semi-structured, face-to-face interviews. Data analysis involved using Grounded theory techniques with the aid of Nvivo and Mind genius software.  Data analysis showed low awareness of the faecal occult blood test prior to screening invitations. Awareness of bowel cancer seemed to be mainly

through past experience, family history or work-related. Data suggested that awareness, practicalities of FOBt and social contexts such as culture, age, gender, taboo, attitudes, altruism, and 'ostrich syndrome' could affect behaviour and decisions. Knowledge and awareness were identified as key factors that could break the barriers to uptake. Main reasons for uptake seemed to be health protection. All participants viewed screening positively.

The findings of this study will be drawn upon to explore the role of social marketing in improving perception and uptake of the FOBt. It is anticipated that the output of this research will inform future practice and policy implementation towards increased awareness, improved perception and uptake of screening, and service improvement that could lead to a substantial reduction in bowel cancer deaths.

**Key Words (up to five):** Bowel cancer, colorectal, Screening, Grounded theory, Participation

**External Agencies: NHS North East, Yorkshire and the Humber Quality Assurance Reference Centre for Cancer Screening, (NEYHQUARC)**

## 1.2b. Faculty of Health and Life Sciences poster

# Participation in Bowel Cancer Screening: the why's and the why not's



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber



northumbria  
UNIVERSITY

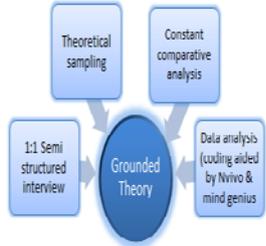
Hjeoma P Azodo, ([hjeoma.azodo@northumbria.ac.uk](mailto:hjeoma.azodo@northumbria.ac.uk)); Alison Steven; Lesley Geddes, Faculty of Health and Life Sciences, Northumbria University

---

### Abstract

This research explored reasons for participation and non-participation in the NHS bowel cancer screening programme (NHSBCSP) using the faecal occult blood test (FOBT) in the North East, Yorkshire and the Humber among those who were invited for screening. The research employed grounded theory approach. Twenty-six research participants were recruited through the bowel cancer screening hub in accordance with ethical approval that was obtained. Data was collected using 1:1 semi-structured interviews and analysed using grounded theory techniques of coding with the aid of nvivo and mind genius software. Results indicate that participation could be influenced by social context, knowledge and screening practicalities.

### Methods

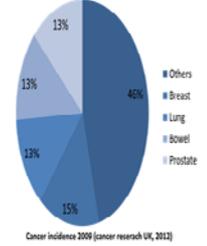


The diagram shows 'Grounded Theory' at the center, surrounded by four boxes: 'Theoretical sampling', 'Constant comparative analysis', 'Data analysis (coding aided by Nvivo & mind genius)', and '1:1 Semi structured interview'.

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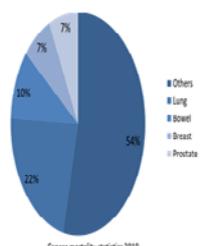
### Introduction

- Bowel Cancer is the third most common cancer in men and women and the second major cause of cancer deaths in the UK
- Research indicates the risk of dying from bowel cancer can be reduced by 16% through regular screening
- Initial literature review shows little research in this area. Previous studies identify non-attendance and low uptake as a major challenge and suggest that these factors could be affected by literacy level, fear, and anxiety.
- However, many of these studies were undertaken in other locations and countries, limiting replication or generalisation to the North East, Yorkshire and Humber area.
- There is therefore a need for qualitative investigation into the reasons for low uptake in the specified region.



Cancer incidence 2009 (cancer research UK, 2012)

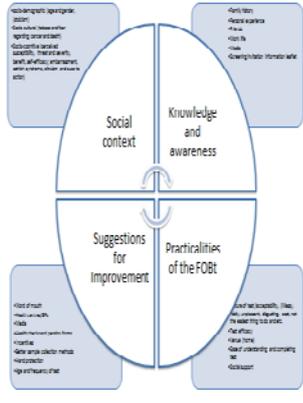
Cancer Type	Percentage
Others	46%
Breast	13%
Lung	13%
Bowel	13%
Prostate	15%



Cancer mortality statistics 2010

Cancer Type	Percentage
Others	54%
Lung	7%
Bowel	10%
Breast	22%
Prostate	7%

### Findings



The diagram shows a central circle divided into four quadrants: 'Social context', 'Knowledge and awareness', 'Suggestions for Improvement', and 'Practicalities of the FOBT'. Each quadrant is surrounded by text boxes containing specific findings related to that category.

Factors influencing participation and uptake of NHSBCSP

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### Aims & Objectives

#### Aim

- This study explores reasons for participation and non-participation in the NHS Bowel Cancer Screening Programme that requires participants to undertake the Faecal Occult Blood test.

#### Objectives

- To Develop an understanding of behaviour regarding Bowel Cancer and the screening process
- To explore how people make sense of information gathered and how this influences their decisions
- To Describe similarities/differences regarding different groups perceptions of bowel cancer screening

### Conclusion

Personal and wider social contexts; knowledge and awareness; and screening test practicalities and improvements could affect behaviour and decision making in bowel cancer screening using the FOBT

### Study implications

- Several practical issues have been identified that is likely to inform service provision e.g. invitation letter and information regarding sample collection.
- It is expected that the output of this research will inform future practice and policy implementation towards increased awareness, improved participation and uptake of screening, and service improvement that could lead to a substantial reduction in bowel cancer deaths.
- The findings will also be drawn on to explore the role of Social marketing in improving perception and uptake of the Bowel cancer screening programme.

Funding: This research is sponsored by the Northumbria University in conjunction with the NHS North East, Yorkshire and Humber Quality Assurance reference centre for cancer screening, (NEYQARC, contact Dr Keith Faulkner).

## Appendix 2: Initial project approval



Professor Kathleen McCourt FRCN  
Dean

This matter is being dealt with by:

Research and Enterprise Office  
School of Health, Community & Education Studies  
Room H007  
Coach Lane Campus East  
Newcastle upon Tyne  
NE7 7XA

Tel: 0191 215 6276  
Fax: 0191 215 6083

E-mail: [susan2.davies@northumbria.ac.uk](mailto:susan2.davies@northumbria.ac.uk)

Prisca Azodo  
7 Gidside Court  
Whickham  
Newcastle Upon Tyne  
NE11 9PT

19 April 2011

Dear Prisca

I write to inform you that the School's Research Committee has considered and approved your application for Initial Project Approval (IPA) and I can confirm to you that you are now fully registered for the degree of PhD on a full time basis, with effect from 1 November 2009.

**Your required submission date is 1 October 2013**

**Please note** that before submission there is a key milestone which you are required to meet; this is the submission of your application for your Mid-Point Progression (MPP), which should be submitted to the School Research Office **by no later than 1 May 2012**.

Once you have submitted your thesis the University aims to hold your oral examination within two months of the submission of your thesis.

If you require any further information or assistance please do not hesitate to contact me.

Yours sincerely

A handwritten signature in black ink, appearing to be "CC", written over a horizontal line.

Dr Colin Chandler  
Director of Postgraduate Research

Cc Alison Steven, Principal Supervisor

## Appendix 3: University ethics sub-committee approval

2



Professor Kathleen McCourt FRCN  
Dean

This matter is being dealt with by:  
Research and Enterprise Office  
School of Health, Community & Education Studies  
Room H007  
Coach Lane Campus East  
Newcastle upon Tyne  
NE7 7XA  
Tel: 0191 215 6701  
Fax: 0191 215 6083  
E-mail: [julie.blackwell@northumbria.ac.uk](mailto:julie.blackwell@northumbria.ac.uk)

Prisca Azodo  
7 Gibside Court  
Whickham  
Gateshead  
NE11 9PT

7 June 2011

Dear Prisca

### School of HCES Research Ethics Sub Committee

**Title: Participation in bowel cancer screening: exploring the processes involved and the potential role of social marketing as an approach to increasing future participation**

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent CRB and occupational health clearance if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:  
<http://www.northumbria.ac.uk/researchandconsultancy/sa/ethgov/policies/?view=Standard>

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- Research Ethics Committee (REC). [They will require a copy of this letter plus the ethics panel comments and your response to those comments]. If your research is subject to external REC approval, a 'favourable opinion' must be obtained prior to commencing your research. You must notify the University of the date of that favourable opinion.

Both the University and NRES strongly advise that the supervisor accompany the student when attending an external REC.

All researchers must also notify this office of the following:

- Commencement of the study;
- Actual completion date of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

A handwritten signature in black ink, appearing to read "C. Clarke".

Professor Charlotte Clarke  
Associate Dean (Research)

*Vice-Chancellor*  
Professor Andrew Wathey

Northumbria University is the trading name of the University of Northumbria at Newcastle

## Appendix 4: NHS research ethics committee, (REC) approval



### **National Research Ethics Service** NRES Committee North East - County Durham & Tees Valley

Room 002  
TEDCO Business Centre  
Viking Industrial Park  
Rolling Mill Road  
Jarrow  
Tyne & Wear  
NE32 3DT

Telephone: 0191 428 3566  
Facsimile: 0191 428 3432

19 October 2011

Mrs Prisca, I Azodo  
7 Gibside Court  
Whickham  
Gateshead  
NE11 9PT

Dear Mrs Azodo

**Study title:** Participation in Bowel Cancer Screening Programme:  
exploring the processes involved and the potential role  
of Social Marketing as an approach to increasing future  
participation.

**REC reference:** 11/NE/0230

Thank you for your letter of 28 September 2011, responding to the Committee's request for further information on the above research and submitting revised documentation

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

#### **Confirmation of ethical opinion**

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

#### **Ethical review of research sites**

##### **NHS sites**

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

#### **Conditions of the favourable opinion**

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

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

This Research Ethics Committee is an advisory committee to the North East Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

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

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

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

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

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

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

#### Approved documents

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

Document	Version	Date
Covering Letter		
Evidence of insurance or indemnity		16 June 2011
Investigator CV		14 July 2011
Letter from Sponsor		14 June 2011
Letter of invitation to participant	1	19 July 2011
Other: Supervisor's CV - Alison Steven		14 July 2011
Other: Contact details for summary of results	1	19 July 2011
Other: Interview schedule	1	19 July 2011
Other: Letter responding to points raised in provisional opinion letter		27 September 2011
Other: Letter from Mr Ian Ward, Hub Manager, BCSP North East Programme Hub		
Participant Consent Form	2	28 September 2011
Participant Information Sheet	2	28 September 2011
Protocol	1	19 July 2011
REC application	IRAS 3.2	22 July 2011
Referees or other scientific critique report		07 June 2011
Response to Request for Further Information		28 September 2011

#### Statement of compliance

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

#### After ethical review

##### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed

This Research Ethics Committee is an advisory committee to North East Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

guidance on reporting requirements for studies with a favourable opinion, including:

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

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

Feedback

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

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

<b>11/NE/0230</b>	<b>Please quote this number on all correspondence</b>
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With the Committee's best wishes for the success of this project

Yours sincerely

*J Brown*

*PP* **Dr A MacSween  
Chair**

Email: joan.brown@sotw.nhs.uk

Enclosures: "After ethical review – guidance for researchers" SL-AR2

Copy to: *Ms Donna Smith, Northumbria University, Ellison Building, Newcastle upon Tyne, NE1 8ST*

*R&D Office, Queen Elizabeth Hospital, Sheriff Hill, Gateshead, Tyne & Wear, NE9 6SX.*

This Research Ethics Committee is an advisory committee to North East Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

## Appendix 5: NHS research and development department, (R&D) approval

25th October 2011

Mrs Prisca Azodo  
7 Gibside Court  
Whickham  
Gateshead  
NE11 9PT

Dear Mrs Azodo

**Our Ref:** 766/11 (please quote on all future correspondence)  
**Project Title:** Participation in Bowel Cancer Screening Programmes  
**Ethics Ref:** 11/NE/0230

Further to my letter of 19th August 2011, I understand that you have now received a favourable ethical opinion from NRES Committee - North East - County Durham & Tees Valley dated 19th October 2011.

### Opinion

On behalf of the Committee, I am pleased to confirm that this project has now been fully validated to take place within Gateshead Health NHS Foundation Trust. Validation of this project lasts for the period covered by County Durham & Tees Valley favourable opinion.

### Sponsorship

It is understood that Northumbria University has agreed to act as sponsor for this study.

### Research Governance

Please find enclosed a Research Governance Agreement which you should complete, sign and return to Mrs Alison Harvey, Governance, Research & Development Manager.

The Research & Development Department regularly monitor / audit research activity within the Trust to ensure compliance with the Research Governance Framework (Department of Health, 2<sup>nd</sup> Version, 2005).

You are therefore required to notify the Research & Development Department of:-

- The actual start and completion dates for the study
- Any significant changes or substantial amendments to the study
- Any decisions made by Research Ethics Committee which affect the study
- Extensions, suspension or abandonment of the study
- Details of study findings, publications and presentations

A Progress Report will be sent to you on an annual basis which should be completed and returned to the Research & Development Department. A copy of your Annual Progress Report to Ethics is acceptable (if applicable).

The Researcher should be aware that information about his / her research activity is sent to Divisional Managers on a quarterly basis and may also be incorporated into the Trust's Annual Research Report.

I wish you well with this study.

Yours sincerely



**Dr A Thomas**  
**Chairman: Research & Development Committee**

cc: Mrs A Harvey, Governance, R & D Manager, Gateshead Health NHS Foundation Trust

## Appendix 6: Letter of invitation



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber  
Ground Floor  
North East Strategic Health Authority  
Waterfront 4  
Goldcrest Way  
Newburn Riverside  
Newcastle upon Tyne  
NE15 8NY

Tel: 0191 210 6595 [www.neyhqarc.nhs.uk](http://www.neyhqarc.nhs.uk)

25<sup>th</sup> November, 2011

Dear Sir/Madam,

**Research: Participation in the First round of the North East Yorkshire and Humber  
Bowel Cancer Screening Programme. Ref. 11/NE/0230**

Northumbria University Newcastle upon Tyne in conjunction with the North East Yorkshire and Humber Quality Assurance Reference Centre for bowel cancer screening is currently looking at people's participation in the first round of the Bowel Cancer Screening Program (the home test kit). In order to complete this research we are working with Prisca Azodo, a postgraduate research student at the Northumbria University Newcastle Upon Tyne.

The research aims to explore two things:

1. The factors (the reasons why people took part) that made some people to take part in the first round of the home test kit and the things that stopped others from taking part from the Bowel Cancer Screening Programme (the home test kit).
2. Explore how social marketing could be used to improve awareness and increase participation for early diagnosis and effective treatment of bowel cancer

We would like to invite you to take part in this research study. The health authority is very interested to hear your views. This is why you and other people from the North East, Yorkshire and Humber who completed and those who did not complete the home test kit during the first round 2007-2008 are being invited to give your views as part of this research study.

There is information attached to this letter to give you more details. Reading this will help you to decide whether you would like to participate in this research study or not. If you need further information or have any question before making your decision please contact the researcher, Prisca Azodo, using the contact details on the information sheet.

*Dr Keith Faulkner  
Regional Director of QA (Screening)*

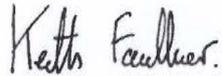
The North East, Yorkshire and The Humber Quality Assurance Reference Centre is accountable to North East Strategic Health Authority

This initial letter and information has been sent to you by the North East, Yorkshire and Humber Quality Assurance Reference Centre for Cancer Screening. No personal details have been passed on to any third parties. The researchers can only contact you using the information you supply on the reply slip.

If you would like to take part in this research, please complete the reply slip attached and return in the prepaid envelope to the researcher, Prisca.

Thank you for your support

Yours sincerely,



**Dr Keith Faulkner**  
**Regional Director of QA (Screening)**

## Appendix 7: Study information sheet



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber

### Information Sheet for Participants

We would like to invite you to take part in our research study which is about participation in bowel cancer screening. We have provided this information sheet to help you understand why the research is being done and what it will involve for you before you decide whether to take part or not. This would take about ten minutes to read. We would like you to read the information carefully and discuss it with other people if you wish. You are very welcome to speak to Prisca Azodo, the researcher, if you would like additional explanations or more information.

#### **What is the study about?**

The purpose of this research is to explore the factors that make some people take part in the bowel cancer screening programme and the factors that lead to others not taking part. The research also aims to explore/investigate ways of increasing awareness and getting more people to take part in the bowel cancer screening programme. This would help reduce the number of deaths from bowel cancer.

The research is being organised and funded by the University of Northumbria in conjunction with the North East, Yorkshire and the Humber Quality Assurance Reference Centre for Bowel Cancer Screening.

#### **Why have I been asked to take part in the research?**

Both people who completed the first round of the home test kit during 2007-2008 and also some of those who did not complete it have been invited to give their views as part of this research project.

#### **What am I being asked to do?**

If you would like to take part in this study, please complete the reply slip and return to Prisca using the prepaid reply envelope provided.

Prisca will then contact you to arrange a time and a mutually convenient venue for an informal interview. The recording will be anonymous.

The interview will last a maximum of 1 ½ hours.

The interview will take place at a venue of your choice. It could be in a local private meeting room arranged with the researcher or at your home. If the interview is not held at home, any travelling expense incurred to get to the interview venue will be fully reimbursed.

At the interview the researcher will first review this information sheet with you and answer any questions you may have. The researcher will then ask you to sign the consent form if you are happy to continue to take part in the research.

The researcher will then ask you some questions regarding your thoughts and views about the bowel cancer screening programme (the home test kit) and your participation in the programme.

The interview will be tape recorded with your permission. This is to help the researcher to correctly remember information. The interview recording will be anonymous.

**What happens if I do not want to participate?**

Participation is completely voluntary. It is entirely up to you to decide if you would like to take part.

**What would happen if I agree and then change my mind?**

You are under no obligation to take part and if you do decide to take part, you are free to withdraw at any time if you change your mind without giving a reason. However, the data collected from the interview will still be used in the research with all personal identifiable information removed. It will not be possible to withdraw the data at this stage. Not taking part or withdrawing at any stage will not affect any future screening or standard of care you receive.

**Will my participation in the research be kept confidential?**

Yes, your taking part in the study will be kept confidential, only the research team will know about your participation in the research.

**What will happen to the information that is gathered at the interview?**

All the information collected will be kept confidential. After the interview the researcher will type up the conversation with your name and any other identifiable information removed. Only the research team will have access to this information. The information from all of the people interviewed will then be analysed and used to complete the final report. Any direct quotations or comments that are used in the final report or any subsequent publications or presentations will be anonymised. Names and details of participants will not appear in any printed document. The tapes will be stored securely in a locked cabinet at the Northumbria University and destroyed a year after the end of the research. The transcripts will be kept for three years and then destroyed.

**What will happen to all the information collected for the research and how will the research report be disseminated?**

All the information collected will be looked at and analysed in order to identify participants' common and uncommon thoughts and views about the home test kit. These will then be used to produce a final report.

The final report will be presented to the North East Yorkshire and the Humber Quality Assurance Reference Centre for bowel cancer screening and the Northumbria University. This final report will form part of the researchers PhD degree.

A summary of the research finding will be sent to all the participants and the full report can be requested by the participants after the final report has been produced. Findings may also be used in subsequent publications and presentations scientific meetings and conferences.

**Who do I contact if I want to ask more questions about the study?**

You are very free to contact the researcher, Prisca Azodo, if you need further information.

Prisca Azodo  
Room H005, School of Health Education and community studies  
Coach Lane, East Campus  
Northumbria University, Newcastle upon Tyne,  
NE7 7X. Telephone Number: 07948569256

**If you are unhappy or have any concerns about this study please contact**

Dr Alison Steven  
School of Health, Community and Education Studies  
Northumbria University, Coach Lane campus  
Newcastle upon Tyne  
NE7 7XA  
01912156483

Or

Mrs Lesley Geddes  
School of Health, Community and Education Studies  
Northumbria University, Coach Lane Campus  
Newcastle upon Tyne  
NE7 7XA

## Appendix 8: Reply slip



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber

### Reply Slip

Please tick the right box that applies to you and return the slip in the prepaid envelope provided, thank you.

**Yes I would like to take part. I would like to be contacted by the researcher. My contact telephone number is.....**

**No I do not want to take part.**

---

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## Appendix 9: Informed consent form



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber

### CONSENT FORM

**Research Title:** Participation in Bowel Cancer Screening Programmes: exploring the processes involved and the potential role of Social Marketing as an approach to increasing future participation.

**Research Aims:**

To explore the complex processes involved in participation in bowel cancer screening programme

To explore the potential role of Social Marketing in improving perceptions of bowel screening that may influence screening uptake.

**Researcher: Prisca I. Azodo**

	Yes (please tick)	No (please tick)
I have read and understand the Information Sheet dated - _____ (Version 1) and have had the opportunity to ask questions which have been answered to my satisfaction.		
I understand that I do not have to take part. If I do take part I may withdraw at any time, without giving a reason. This will not affect my treatment/education/care in any way.		
I agree to participate in an interview. I understand that the interview will be recorded. I give permission to the researcher to have access to this information for analysis.		
I understand that the information I have given in this study may be used in the future as part of further work on this subject. I understand that it will not be possible to identify me from this information and no further contact will be made with me.		
I understand that my taking part in the study and the content of the interview will be kept <b>confidential</b> . My name and details will be kept confidential and will not appear in any printed documents. Where direct quotations are used in reports they will be <b>anonymised</b>		

The North East, Yorkshire and The Humber Quality Assurance Reference Centre is accountable to North East Strategic Health Authority



# Appendix 10: Summary of result form



Quality Assurance Reference Centre  
North East, Yorkshire and The Humber

## CONTACT DETAILS FOR SUMMARY OF RESULTS

I would prefer to receive the results by (please tick one)

Post

Email

Postal address.....  
.....  
.....  
.....  
.....  
.....  
.....  
.....

Email .....

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## Appendix 11: Interview guide

### Interview guide

#### **Always record the interview number and demographics**

The interview will follow a semi-structured format which means that research may not follow specific questions but the list below will serve as a guide.

**First, Introduction: Introduce myself and confirm that I am at the right place and speaking to the right participant.**

**Thank them for agreeing to be interviewed. Explain what I will be doing**  
**Re: Go through the information sheet and consent form, audio recording, clarify any issues. Get them to sign the consent form and then begin the interview.**

**Reaffirm that there is no right or wrong answers, that we are only interested in your views and thoughts about the home test kit.**

- Knowledge of BC and the screening programme before receiving the FOBt (home test kit) invitation

General understanding, experience, awareness and perception of BC (e.g. incidence and symptoms, etc.) and the screening programme.

What is their understanding and knowledge of the home test kit?

- Did they attempt to complete the test?

What was their feeling about completing the test, did they consider doing the test? When did they complete the test?

- Understanding of the procedure for completing the test?

Was the explanation/information easy to understand? (How easy or difficult) was the procedure? What would have made it better/easier?

- Why they chose to/not to complete the test or did halfway but not return completed kit.

What was the main thing that put them off?

What made (motivation) them decide to do the test/ (or not do the test)

How would they explain the experience of completing the test?

Any regrets or happy with it

Would they or did they complete the second round

- What would have increased their likelihood of completing the test?

What would make them to do the test in the future?

- What way do they feel the screening process could be improved/ uptake could be increased?

What improvements would they like to see in the screening programme re information about the screening the kit, the kit itself, (re: home or hospital setting/ surgery) any general suggestion on how the screening could be improved to make it more acceptable.

Closure of interview: Is there any question you would like to ask or issues to clarify? Thank them for participation in this study.

## Appendix 12: Interview transcript

P7m

Interview 7 (3/2/12) P7m 70-74

R: So now that we have signed the consent form and you are still happy to be interviewed....

P7m: Yes

R: My first question is really, did you know anything about bowel cancer or the screening before you received the test kit

P7m: Yes, yes I have two cousins who um...suffered from bowel cancer. And um so um.... I was aware of that. So I was aware that there was a tendency for bowel cancer in the family.

R: Other than that, other than your cousins having bowel cancer, what other ways have you come to know about it.....?

P7m: I have done, no I have not sort out information particularly, I do not particularly seek out information, but I have been aware and have read articles in the newspapers, magazines and things like that.

R: ok, so it wasn't the first time

P7m: No, no.

R: Ok, how many times have you completed the test now?

P7m: About 3, I think.

R: about 3, ok and you've done the 3 of them.

P7m: Yea

R: Ok um..., what were your feelings about completing the test (FOBT)

P7m: oh not at all, I mean I, it struck me that this was a necessary thing. It is a very useful thing to do. The fact that you can do a screening for that potential condition seems to me to be a very good way of monitoring and of preventing serious effects. So you might as well take advantage of, in fact it's a good thing to take advantage of that service that is offered. Um and so I was very happy to do it.

R: There are so many people who don't do the test

P7m: Well I think it's um... it might be embarrassing for people. It's one thing doing a blood test; it's another thing doing a faecal test. And I think that um... people may be a bit squeamish about it. And I think that's silly. It's a test that has a potential to save your life and it doesn't matter how easy or how difficult or unpleasant and or how.... If you can have the test done that's great.

R: Inside the kit, there is an instruction booklet, a leaflet that explains the procedures of how to complete the test. How did you find the information?

P7m: I ... I ... it's some time since I did it so I can't really recall the details of the instruction booklet. But um....I didn't find it difficult. It wasn't...I mean there are always better ways of doing things I think, but that seems to me to be perfectly straightforward. I didn't have any trouble with it.

R: that's ok. How did you find the test?

P7m: Oh very easy. It's simple, I .... No problems at al.

R: yea. If you look at the test, was there anything that may have put you off doing it?

P7m: No I don't think so. Um, I didn't feel um at all negative about it. Very positive about it and as far as the application goes and actually doing the test I didn't find any problems at all with it. Um ...I am surprised.... It sounds as if there might be a big problem from your side, from the way you .... and the way the NHS sees it. Are you getting a bad response?

R: There is a poor response; about 50% of the people that are invited actually take up the test.

P7m: I can't really help with that because I am very positive about it. It is very easy to do and if you say I've got another one in the bag, I'll do it no problem. I mean my wife didn't have any problems with it. She was quite positive about it. She was fine.

R: What improvements would you like to see in the screening programme?

P7m: In terms of..... well in terms of the application, doing it.....?

R: yes in terms of every aspect of the test; the venue.....

P7m: I don't know how, um... regular it needs to be, as I understand if it comes out clear then there's a very good chance it's going to stay clear. Well at my age... I am 70... If it is clear then you've got a good chance of going for the next ten years without any problems but just the same and quite happy to do it as regularly as um necessary. Um...I can do it once a year, every two years, and five years, whatever

R: It's once every two years

P7m: I'll continue to do it as long as it's there to be done

R: what about the venue? What do you think about the venue?

P7m: Oh much more convenient to do it at home than it is to do it anywhere else. I always had problems giving samples in hospitals... doctors so I will much prefer to do it at home anyway. It's much more convenient, you know you are not stuck to any ....time or .....It will be much more embarrassing doing it elsewhere. So, no I don't think there is a problem there.

R: what ways do you think that the message could be conveyed to people for it to get more attention?

P7m: I think maybe television advert might be a way of doing it. Um, I don't know how..... I wouldn't design the advert. But um....it might be difficult. I think that you have to get across the message that there is nothing shameful or messy or undesirable about it. Use a positive thing to get the message across to people. I think the television is a way of doing that, you can show ordinary people or you can show celebrities even; People that people know. Um, and they'll do it, I've done it. Um....I think it's a great thing to do. Get people to say positive things about it. Um I will certainly go for that. Giving people leaflet and things are not um....it's a passive way of getting the message across. They have to want to read it; they have to want to take the message on it on board in order to get the message. Put it in front of people, cinema advertising, television advertising or they .....it confronts them when they are in a position to take on board the message. Then it's more likely to get across than give somebody a leaflet and say this is about bowel cancer and people might say ...oh I don't want to know about that and throw it away. But... When they've been watching Coronation Street and it's there, you can't avoid it; well you can avoid it if you get up and go away. Most people wouldn't do that. It's to put the message in front of people when they in a position that they can't escape if you like.

R: Right, thank you very much. Is there anything else you wish to add or ....general opinion about the whole thing.

P7m: Really I just, the only thing I will say is thank goodness you are doing this; thank goodness the NHS is doing it. I don't mean that as a criticism, I mean it's a great thing to do that test, test of all kind. Because I think preventive medicine is far more effective before the event than after and yea preventive medicine is something that I think we've tended to um.. not to do very well. I mean the medicals have tended to be there in my view in response to demand and I much prefer to see more of a corrective getting out there and doing it as you are doing. And the anti-smoking message and the anti-drinking messages and the anti-obesity messages, I think they are great things to do. Um, not for the nice

and healthy which obviously is the best. You can't get it any more important than that, but you save so much money.

R: Saves life

P7m: It saves also lives. I can't imagine what the counter argument is for not doing it. I think it's great. I very much support it. It is something I'm very pleased to ... to cooperate with. You know to help with and do whatever I can with it in all sorts of ways. I will like to see a bit more on prostate cancer. There are a lot on breast cancer and that is very vital. Um...prostate cancer doesn't get that kind of press. It doesn't get the same sort of um... impact and, I'd always had an issue with um with my GP, about that and.... I remember once well on more than one occasion, I've been in to see my GP and said I would like a well man clinic, I'll like to be able to come and talk to people about issues and have tests done um for ..um preventive purposes; I want to know what my cholesterol is, I want to know PSA reading is and I want to know what my blood count is and test results are. Um because I am responsible for my body and um I regard you as helping me to do it. It's not your problem; you are helping me to solve whatever problem I've got. I do think it's up to me to do it. But the response I've had certainly in the past not so much now but certainly in the past have been 'oh we don't do that, come to us when something is gone wrong and we will try and fix it' I mean those aren't the exact word, but that's the attitude. I mean... I think the first time I went, I saw the practice nurse, and um... I said I've come to....um....if you do a well man clinic, she said oh we used to, we don't do it anymore, so what is it that you want; um... what's wrong? I think she said, I said nothing wrong, I just want to, want to oh.... You want tests; what kind of tests do you want? I said any sort of test you would give to a 60years old man. It was when I just retired. Well I thought clean sheet, start afresh. {R: Yea}. I can find out what your results are, your medical and she said 'what type of tests do you want?' and I said it's really up to you to tell me what sort of tests you think are appropriate for somebody, a man 60 years old. She... well what sort of test do you want? I said something like PSA, cholesterol, and blood pressure and she said we can do blood pressure, we can do PSA, and we can do what anything else you want. I said you tell me 'cause I haven't got the medical knowledge I haven't got the experience. And things are changing now in this ten, twelve years things have changed. And I very much appreciate that. Um while it's still not a regular thing in my practice to do that, I have been able to get the information; I think I've been able to get the necessary information. I have done an examination privately, which has been very expensive and I'm quite happy with that and I'll like the NHS doing much more of that because I don't know whether my practice is typical or not. But I would like to think that there would be somewhere where preventive testing can be done. And done on a regular basis. We inject babies for diphtheria, and things that's standard, you get to certain age, you get injection for measles

R: Every four weeks after the baby is 2months old for 3times then you wait till you reach the next milestone

P7m: Yea, and I think bringing things down things down to us as a regular routine, I think routine procedure if you like is good, is a good thing. And may be if bowel cancer testing was put across as a routine, everybody does it and it happens when you are ..... Unless there are other reasons for doing it, it happens on a regular basis when you are getting to the age of 50 and it will happen every five years or whatever.

R: It is like that. It is regular from the age of 60 to 75years olds every two years.

P7m: is it?

R: When you are between 60 and 75 you will get the kit through your door every two years no matter where you live in England.

P7m: I didn't know that.

R: yes

P7m: oh right. Oh it's happening {laughs...} that's good.

R: so it's every two years you are going to get called back, not called back but you know it comes through the post.

P7m: Good, because it gets put into people's mind that this is a routine thing that ought to be done. I mean I'm sure hundred years ago when people were is more than that in the genre when people develop this small pox. People thought that was horrifying in the old days they stick a needle in with cow pox. I don't want to know that's awful, that's

R: Cow Pox, What is that?

P7m: it was Genre, the man who invented inoculation. And he noted, this was in the 17<sup>th</sup>, it was a bit over 200years ago. He noticed that milk maids didn't get small pox. Um people, those who milk cows didn't get small pox and small pox was a huge problem ravaging the population at the time. And he noticed that they didn't get it. And he investigated and realised that the cow's got a version of small pox which was called cow pox, and because the girls have been exposed to the cows, the bovine version, of small pox they built up antibodies

R: immunity

P7m: Immunity, and he didn't know that at the time but they built up an immunity to um....small pox, they'd had a milder form of the same condition in the form of cow pox and cow pox is not fatal, it wasn't anything that cause any

damage because they developed the antibodies they were able to fight off small pox. He realised there was some kind of connection between the two and so he injected a small boy with the puss from um a cow pox, and saw he didn't get small pox. And um I don't know exactly how it was done and he discovered that. Strangely enough and that then became more and more common practice.

R: OK

P7m: And it was quite significant apparently, it was the fact that small pox no longer became a major spurge, a major problem within the community. It reduced church attendance because people said well if I'm not going to get small pox, I don't need to go to church because I'm not going to die. They used to have to go to church to make sure or try and make sure you didn't die like they used to, now that I'm not going to get it, I don't need to go to church. They simply put that down to the fall in church attendance was due to the small pox inoculation. Yes.

R: well, thank you very much

P7m: well I don't know if this has been helpful

R: Yes, it has been of help. You've been really helpful.

R: what do you think about the GPs getting involved with this screening?

P7m: Um,

R: I mean GP surgeries, do they talk about it?

P7m: um, I think they are a lot better now than they used to be um in my surgery. And ... and I think probably there are more younger practitioners in now than there used to be. Um and I think that um, yea I'm really, reasonably happy with the situation. But I would like to think that if medical profession was more corrective in the sense although from what you've said they are. We are doing it every two years. And it is happening.

R: What I meant was like from the GP surgery, It (FOBT) doesn't have anything to do with the GP surgery at the moment. It comes from the queen Elizabeth Hospital Bowel Cancer Screening HUB and goes back there. If comes from the GP, what do think about that?

P7m: It would not make any difference to me. Um, I don't know if it will make any difference to anybody else. The fact that it comes from the NHS and it comes from the Queen Elizabeth Hospital, or it comes from the doctor your surgery, I don't think it makes any difference. You might be able to work out a way of taking the kit and putting into an envelope with a covering letter that appears to come from the doctor's, your own doctor. You could cross both

bridges with the same tackle the issue with the same envelope rather sending it from a central point, it could appear to come from your doctors but I would rather not have him involved really. Because it is the resource; taking time and effort that the doctor can use in other ways. Um....um if it could be done on his bum...so that he could sign one page and then you just copy them, that sort of thing. You send them out; he doesn't have to do anything. He would probably say, I'll sign that, you've given me a letter, I like the letter, and I'll sign it. Now it can go off your letter with my name on it. That might be better.

R: Ok

P7m: But I'm not fussy, personally, I don't care, I'll do it any way.

R: Thank you very much, that is just it. Thanks

P7m: Not all, pleasure.