EXPLORING SERVICE USER AND PRACTITIONER PERSPECTIVES OF USING CANCER RISK ASSESSMENT TOOLS IN PRIMARY CARE CONSULTATIONS

Joseph Noble Azomboliga Akanuwe

A thesis submitted in partial fulfilment of the requirements of the University of Lincoln for the degree of Doctor of Philosophy (PhD)

May 2018

TABLE OF CONTENTS

TABLES, FIGURES AND BOXES

Tables

FIGURES

BOXES

ACKNOWLEDGEMENTS

Professor Niro Siriwardena has been the ideal primary supervisor for this project. His patience, understanding and constructive criticisms have contributed to the completion of this work. I am equally grateful to my second and third supervisors, Dr Sharon Black and Professor Sara Owen who patiently and wholeheartedly offered their support for the completion of this project. I appreciate the contribution of Dr Karen Windle, who was one of my supervisors at the initial stage of this study.

I reserve a special place for all the staff of the Community and Health Research Centre (CaHRU). Thanks to our Postgraduate Research Administrator, Mrs Susan Bowler for her support in the management of this project. I appreciate the support of the staff at the finance department in relation to the payment of my tuition fees. I am grateful to Mrs Jasmit Kaur Phull, a supporter of the University of Lincoln, who offered a £100 funding to support my research. I appreciate the grant offered by CaHRU as a contribution towards the payment of my second-year tuition fees.

I thank all the service users and practitioners who participated in this research. Thanks to Miss Janice Wiseman (research Manager), Miss Katy Ward at the Lincoln Community Health Services Trust, and Dr Jo Middlemass at CaHRU for their role in the recruitment of practitioners for this study. I am grateful to the Healthier Ageing Patient and Public Involvement (HaPPI) group at CaHRU, who helped with the recruitment of service users.

I thank Prof Robert Yennah, Dr Gideon Azumah, Dr Ravindra Pathiratne, Mr and Mrs Amankwah, and all those who helped me to realise my dream. Finally, three special people, stuck by my side at a time I felt the rest of the world was against me. They are my wife, Lilian Akanuwe and my sons, Raphael Akanuwe and Emmanuel Akanuwe, for their love and the sacrifice of their comfort to see me through this work. I thank my wife’s parents, Mr and Mrs Quarranttey for praying and encouraging me to complete this course.

ABSTRACT

Introduction: Cancer risk assessment tools are novel tools that combine risk factors and symptoms to predict an individual's risk of developing cancer. Little is known about the views of service users and primary care practitioners on how cancer risk assessment tools should be used in primary care. Following a scoping review of the literature, the qualitative study explored perspectives of service users and primary care practitioners about how best cancer risk information can be communicated to patients during primary care consultations. The study also explored the enablers (facilitators) and barriers to the implementation of cancer risk assessment tools from the perspectives of both service users and practitioners.

Methods: The scoping review followed the framework proposed by Arksey and O'Malley for conducting scoping reviews. The scoping review resulted in the statement of two research questions: (i) How best can cancer risk information be communicated to patients? (ii) What do service users and practitioners perceive as enablers and barriers to the implementation of cancer risk assessment tools in primary care?

The next phase was the qualitative study, which involved the use of individual and focus group interviews with service users recruited from the public and primary care practitioners (GPs and nurses) recruited from general practices in Lincolnshire, a large rural county in the East of England. The qualitative data were transcribed verbatim and analysed using the framework approach.

Results: Thirty-six participants (19 service users and 17 primary care practitioners) were interviewed before practitioners used cancer risk assessment tools in patient consultations. Some of the practitioner participants were interviewed again after they had used the tools in patient consultations.

Participants suggested ways to best communicate cancer risk information to patients in primary care consultations. Before using the tools with patients, participants emphasised the importance of: tailoring visual representation of risk; being open and honest; informing and involving patients in use of cancer risk assessment tools; and providing time for listening, explaining and reassuring in the context of a professional approach. After using the tools in patient consultations, primary care practitioners maintained these perceptions. These findings add to our knowledge and understanding of how best to communicate cancer risk information to patients when using cancer risk assessment tools in general practice consultations.

Before using the tools with patients, both service users and practitioners agreed on the following as potential enablers to the implementation of cancer risk assessment tools: aiding decision making; improving speed and processes of diagnosis and treatment of cancer; identifying and raising awareness for modifying health risk behaviours; and personalising care. After using the tools, primary care practitioners mentioned ‘ease of use’ in addition to the enablers already cited.

Barriers to the uptake of cancer risk assessment tools were also identified by participants, which included: the additional time required; worry and anxiety generated by referral for investigations; the potential for over-referral; practitioner scepticism about using the new tools; and the need for evidence of effectiveness before introducing cancer risk assessment tools in general practice consultations. These barriers were perceived before the use of the tools. After using the tools, practitioners identified the following barriers in addition to those already mentioned: the need to integrate the tools into general practice IT systems; the need to involve secondary care specialists (consultants) in the implementation of the tools; and the need for training of practitioners on how to use cancer risk assessment tools in patient consultations.

Conclusion: Ways to best communicate cancer risk information during patient consultations were identified in this study, adding to existing knowledge. Enablers and barriers to the implementation of cancer risk assessment tools were also identified by participants in this study.

DECLARATION

I declare that this thesis and the work presented in it is based on my own original research with the guidance of my PhD supervisors. No portion of this thesis has been submitted for another degree or qualification of this institution or any other institute of learning. Where I have consulted the published work of others, this has been clearly attributed. Where I have quoted from the work of others, the source has been given, and I have acknowledged all main sources of help. Apart from these, this thesis is entirely my own work.

Name: Joseph N.A Akanuwe
Date: May 2018

PUBLICATIONS AND CONFERENCE PRESENTATIONS

Publications

A paper based on the qualitative phase of this study was submitted to the British Journal of General Practice (BJGP). Following receipt of feedback, this paper is now being revised for resubmission. A second paper based on the scoping literature review is also being drafted for submission to a suitable journal. The titles of these two papers are stated below:

- Akanuwe, J., Siriwardena, N., Black, S. & Owen S (2017) Service user and practitioner perspectives of cancer risk assessment tools in primary care consultations.
- Akanuwe J., Siriwardena, N., Black, S., Owen, S. (2017) A scoping review for evidence of the availability and use of cancer risk assessment tools for symptomatic patients in primary care.

Conference presentations

I delivered oral and poster presentations at several conferences as listed below. Copies of the abstracts submitted and accepted for these presentations are added to the Appendices (see Appendices 1.1 - 1.5).

- Akanuwe, J., Siriwardena, N., Black, S., Owen, S. (2017) Exploring service user and practitioner perspectives of using cancer risk prediction tools in primary care GP consultations. In: Society for Academic Primary Care (SAPC) ASM Conference, 12-14 July 2017, University of Warwick.
- Akanuwe, J., Siriwardena, N., Black, S., Owen, S. (2017) A systematic scoping review of the use of cancer risk assessment tools for early detection of cancer risk in primary care. In: Society for Academic Primary Care (SAPC) Regional Conference, 21 March 2017, Lincoln.
- Akanuwe, J., Siriwardena, N., Black, S., Owen, S. (2017) Informing use of QCancer in the primary care consultation - perspectives of service

users and practitioners. In: Cancer Research UK Early Diagnosis Conference 2017, 23-24th February 2017, London.

- Akanuwe, J., Siriwardena, N., Black, S., Owen, S. (2016) Exploring service user and practitioner perspectives of QCancer use in primary care consultations. In: College of Social Science Research Conference 2016, 4th July 2016, University of Lincoln.
- Akanuwe, J. (2016) Service user and practitioner perspectives of QCancer use in primary care consultations. In: Health and Social Care Research Forum 2016, 20th April 2016, University of Lincoln.
- Akanuwe, J., Siriwardena, N., Black, S., Owen, S. (2016) Exploring service user and practitioner perspectives of QCancer use in primary care consultations. In: Trent Regional SAPC Spring Meeting, 15 March 2016, Leicester.
- Akanuwe, J., Siriwardena, N., Black, S., Owen, S. (2016) Service user and practitioner perspectives of QCancer use in primary care consultations [workshop]. In: GP Educators Conference, 14 January 2016.

DEDICATION

This work is dedicated to my parents, Mr and Mrs Akanuwe who taught me never to give up on my dreams. I also dedicate this work to my late elder brother Mr James Akanuwe, who cared for me so much and sent me to school, but like our father, he did not live long enough to see the fruit of his labour. James, I have done what you always wanted me to do. You may now rest in peace.

ABBREVIATIONS

AUROC: Area Under the Receiver Operating Characteristic curve

BMJ: British Medical Journal

CVD: Cardiovascular disease

CaHRU: Community and Health Research Unit

CCGs: Clinical Commissioning Groups

CRATs: Cancer Risk Assessment Tools

CFIR: Consolidated Framework for Implementation Research

DOI: Diffusion of Innovations

DBS: Disclosure and Barring Service

eCDS tool: Electronic Cancer Decision Support tool

EMIS: Egton Medical Information Systems

GBD: Global Burden of Disease

GPs: General Practitioners

HaPPI group: Healthier Ageing Patient and Public Involvement group

IT: Information Technology

LCHS: Lincolnshire Community Health Services NHS Trust

NHS: National Health Service (UK)

NPSA: National Patient Safety Agency

NRES: National Research Ethics Service

NAEDI: National Awareness and Early Diagnosis Initiative

NPV: Negative Predictive Value

NPT: Normalisation Process Theory

ONS: Office of National Statistics

PPV: Positive Predictive Value

PYLL: Potential Years of Life Lost

RAT: Risk Assessment Tool (cancer risk assessment tool) also called Hamilton Risk Assessment tool

UK: United Kingdom

WHO: World Health Organisation

GLOSSARY OF TERMS

Acceptability: The extent to which those for whom the test is designed agree to be tested.

Cancer: A disease caused by an uncontrolled division of abnormal cells in a part of the body.

EMIS Web: Formerly referred to as Egton Medical Information Systems. EMIS Web currently supplies electronic patient record systems and software for use in many primary care organisations (general practices) in England.

General practice consultations: A meeting with between a patient and a primary care professional working in general practice, such as a licensed general practitioner (GP), GP specialist trainee, or nurse practitioner with the purpose of seeking advice and treatment.

General practice: A general practice provides person centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities.

General practitioner: A medical doctor who treats acute and chronic illnesses and provides preventive care and health education to patients.

Negative predictive value: the extent to which subjects are free of the disease in those that give a negative test result.

Primary care: Health care provided in the community for people making an initial approach to a medical practitioner or clinic for advice or treatment.

Practice Nurses: General practice nurses are registered nurses employed by, or whose services are retained by a general practice.

Positive predictive value: the extent to which subjects have the disease in those that give a positive test result.

QCancer: QCancer is a cancer risk prediction (or assessment) tool that works out the risk of a patient having a current yet undiagnosed cancer, or developing a cancer within two years taking account of their risk factors and current symptoms. It does not give a diagnosis of cancer, but a risk.

Risk Assessment Tool (Hamilton risk assessment tool): The Risk Assessment Tool (RAT) is based a series of case-control studies which identified symptoms of common cancers that are presented to primary care and quantified the risk of cancer associated with them.

Service user: A service user generally refers to anyone who is a patient or other user of health and / or social services.

SystmOne: A pioneering clinical system which fully supports a 'one patient, one record' model of healthcare. With SystmOne, clinicians can access a single source of information, detailing a patient's contact with the health service across a lifetime.

Sensitivity: The effectiveness of a test in detecting a cancer in those who have the disease.

Specificity: The extent to which a test gives negative results in those that are free of the disease.

Vision+: This is a management and practice protocol tool for the Quality and Outcomes Framework (QOF) information. It includes real-time alerts for additional QOF points, practice-based protocols and a simple but powerful recall and reporting facility.

CHAPTER 1 BACKGROUND TO THE RESEARCH

1.1 Summary of the chapter

This chapter covers the background information to the research and is separated into the following sections:

- The problem of cancer in a global context (Section 1.2)
- The problem of cancer in the United Kingdom (UK) (Section 1.3)
- Developments to tackle late diagnosis of cancer in the UK (Section 1.4)
- Direction of travel of cancer risk prediction tools (Section 1.5)
- Outline of the thesis (Section 1.6)

1.2 The problem of cancer in a global context

Cancer is one of the leading causes of morbidity worldwide, with approximately 14 million new cases in 2012 (Ferlay et al., 2013). The number of new cases of cancer is expected to rise by about 70% over the next two decades (WHO Media centre, 2017). Globally, cancer is the second leading cause of death; it was responsible for 8.8 million deaths in 2015, with the most common causes of cancer death attributable to cancers of the lung (1.69 million deaths), liver (788 000 deaths), colon-rectum (774 000 deaths), stomach (754 000 deaths) and breast [571 000 deaths] (WHO Media centre, 2017).

Around one third of deaths from cancer are due to five leading behavioural and dietary risks: high body mass index, low fruit and vegetable intake, lack of physical activity, tobacco and alcohol use. Tobacco use is the most important risk factor for cancer, and it is responsible for approximately 22% of cancer deaths (Global Burden of Disease [GBD] 2015 Risk Factors Collaborators, 2016). It is estimated that between 30–50% of cancers can be prevented by avoiding risk factors and implementing existing evidence-based prevention strategies (WHO Media Centre, 2017).

The cancer burden can also be reduced through early detection of cancer and effective management of patients who develop cancer, since late-stage presentation and inaccessible diagnosis and treatment of cancer are common. Indeed, many cancers nowadays have a high chance of cure if diagnosed early and treated adequately.

Some of the most common cancer types, such as breast, cervical, oral and colorectal cancers have high cure rates when detected early and treated appropriately (WHO Media Centre, 2017). Similarly, other cancer types, even when cancerous cells have travelled to other areas of the body (i.e metastasised), such as testicular seminoma or leukaemia and lymphomas in children, can have high cure rates if appropriate treatment is provided (WHO Media Centre, 2017). Despite these possibilities to prevent or treat and cure cancer, the problem of cancer persists in many countries including the United Kingdom.

1.3 The problem of cancer in the UK

Cancer is one of the biggest health problems in the UK with one in two people potentially developing some form of cancer in their lifetime (Ahmad et al., 2015). Consequently, cancer is a major cause of premature mortality in the UK and accounts for over one in four of all deaths (NICE, 2015).

However, mortality rates have been falling since the early 1990s. Thus, the proportion of people in the UK who get cancer but do not die from the disease has increased by about 70% over the past 20 years (Macmillan Cancer Support, 2015). People now live nearly ten times longer after their cancer diagnosis compared to the past 40 years. There are now an estimated 2.5 million people living with cancer in the UK, and this is projected to reach 4 million by the year 2030 (Macmillan Cancer Support, 2015).

Despite these improvements in mortality and survival rates of cancer, there are still concerns that, in the UK, cancer mortality remains high compared to other countries in Europe (Ferlay, 2010; Department of Health, 2011; Office for National Statistics, 2012). A recent study involving 29 European countries found that survival rates for almost all common cancers were worse in the UK than the overall European average (De Angelis et al., 2014). The poor survival rates are related to late diagnosis of cancer, as it is estimated that about 7500 to 10000 lives are lost annually due to late diagnosis in the UK (Department of Health, 2011; Office for National Statistics, 2012).

Late diagnosis of cancer in the UK is due to late presentation by patients (Allgar & Neal, 2005) or non-recognition by primary care general practitioners (GPs) or a combination of the two (Bowen, 2002; Koyi et al., 2002). This can result in delays in primary care processes of investigation and referral, leading to late diagnosis of cancer (Neal, 2009; Al-Azri, 2016). Recent developments to tackle late diagnosis of cancer in the UK are discussed below.

1.4 Developments to tackle late diagnosis of cancer in the UK

As part of measures to tackle late diagnosis of cancer, the National Awareness and Early Diagnosis Initiative (NAEDI) policy was introduced by the Department of Health (DH, 2007). One aim of this policy relevant to this study was to promote awareness among the public and healthcare professionals in recognising and detecting early signs and symptoms of cancer. Another was to encourage people with symptoms to seek early advice. The NAEDI policy also aimed to support primary care professionals to contribute to effective referral and diagnosis of cancer.

A national audit of primary care was developed to identify the support that would help GPs to identify potential cancers earlier. These initiatives have helped to improve access to diagnostic technologies and urgent referral pathways for suspected cancer (DH, 2007). The efforts to improve early diagnosis of cancer have also contributed to an increased interest in the use of technology-based interventions such as cancer risk assessment tools to aid early detection of cancer risk in symptomatic individuals presenting to primary care (e.g Hamilton, 2009; Hippisley-Cox & Coupland, 2011; Hippisley-Cox &

Coupland, 2012; Hippisley-Cox & Coupland, 2013). The direction of travel of these cancer risk assessment tools is considered below.

1.5 Direction of travel of cancer risk assessment tools

It is recognised that cancer risk assessment tools could potentially help to improve patient outcomes through early detection of cancer risk, diagnosis and treatment (National Cancer Institute, 2010). Some of the cancer risk assessments tools, especially the recently developed symptom-based tools, are in the public domain, and both patients and clinicians can access them from the internet. Patients can potentially use these tools to learn about their risk of cancer. While this may appear helpful, some people might inaccurately understand or interpret their risk information (Zikmund-Fisher et al., 2007; Brown et al., 2011). Consequently, primary care practitioners may be best suited to use these risk assessment tools, appropriately interpreting the resulting risk and then communicating this to the patient (Usher-Smith et al., 2017). The general practitioner would then conduct a consultation with the patient when referring them for further investigation of symptoms suspicious of cancer (Banks et al., 2014).

A fundamental problem is the uncertainty in the evidence about the use of cancer risk assessment tools for symptomatic individuals in primary care (Usher-Smith et al., 2015; Williams et al., 2016). For example, it is unclear how these tools should be used and how risks should be communicated to maximise benefits and minimise harms such as anxiety and false reassurance. A starting point for this thesis was a scoping review which explored the evidence relating to the use of cancer risk assessment tools in primary care settings, which is presented in Chapter 2 of this thesis. The outline of the thesis is presented in Section 1.6 below.

1.6 Outline of the thesis

This thesis is organised into seven chapters. Chapter One presents the background to the research. The problem of cancer globally and the context of the UK is highlighted. Efforts to improve early diagnosis of cancer, such as the NAEDI policy and the increased interest in the development and use of cancer risk assessment tools in symptomatic individuals, are discussed here. Finally, the uncertainty in evidence about the use of these cancer risk assessment tools in primary care and the need to explore the evidence using a scoping literature review approach is stated in this chapter.

Chapter Two presents a scoping literature review that explores the evidence around use of cancer risk assessment tools available for symptomatic individuals in primary care. The methodological approach for the scoping review is based on the framework recommended by Arksey and O'Malley (2005). The analysis of the evidence extracted from included studies is presented as the results. These results are discussed in relation to the available literature, and research questions for further qualitative exploration are established in this chapter.

Chapter Three deals with the conceptual background literature that explains the key concepts relating to this research. The chapter outlines the policy, structure and functions of UK primary care, highlighting the 'gatekeeping' function of general practitioners when referring patients to secondary care specialists. The cancer risk assessment tools of interest (those for symptomatic individuals in primary care), the effects of risk assessment or prediction on communicating risk to individuals and the relevant communication and implementation theoretical frameworks are also discussed in this chapter.

The methodology (including the philosophical stance of pragmatism and the approach to the qualitative research) is presented in Chapter Four. The methods including the use of individual and focus group interviews to collect qualitative data from service users and primary care practitioners, and the use of the framework approach for data analysis, are detailed in this chapter.

The results from individual interviews with service users and focus group interviews with practitioners are presented in Chapter Five. In line with the research questions, this chapter suggests ways to better communicate the cancer risk information to patients as perceived by participants. This adds to our knowledge about how best to communicate cancer risk information to a patient during a general practice consultation.

The perceptions of participants about the enablers and barriers to use or implementation of cancer risk assessment tools are also reported, supporting the existing evidence on enablers (or facilitators) and barriers to their implementation in primary care. In this chapter, the perspectives of participants are presented in two parts. In the first part, the perspectives of service users and primary care practitioners expressed before they have used the tools are presented, comparing the views of each. The second part of the results details the perspectives of primary care practitioners after they have had an opportunity to use the tools in patient consultations.

In Chapter Six, the key and original findings are highlighted. The overall results are then discussed in relation to the existing literature and the relevant theoretical frameworks.

The overall conclusion to the research is presented in Chapter Seven. A recap of the key steps or points from each of the chapters is outlined here. Also, highlighted in this concluding chapter are: the developments in the area since this research was commenced and completed; a personal reflection of the researcher; and next steps going forward.

1.7 Conclusion of the chapter

This chapter has covered the background information to the research. A discussion of key issues such as the problem of late diagnosis and the high mortality from cancer in the UK points to the need for better cancer diagnosis. From the evidence discussed in this background chapter, how cancer risk assessment tools for early detection of cancer risk in primary care should be used and communicated is unclear.

Hence, there is a need to scope the literature for evidence of the types of cancer risk assessment tools available for symptomatic individuals in primary care and the use of these tools including the benefits and barriers to implementation.

CHAPTER 2 SCOPING LITERATURE REVIEW

2.1 Summary of the chapter

The aim of the scoping review was to explore evidence on cancer risk assessment tools available in primary care, and the benefits (facilitators/enablers) and barriers to implementation of these tools.

After analysing 43 included studies, this review found that the use of cancer risk assessment tools for symptomatic individuals has some benefits such as a potential to improve cancer survival through early detection of risk, leading to timely investigation, diagnosis and treatment.

Despite the benefits, the review found concerns about potential barriers to implementation of the tools. These barriers include concerns about: how to make the tools accessible to clinicians, where to set the threshold for action, and how to communicate cancer risk information to patients.

Based on the findings from this review, it was proposed that the uncertainty about how best to communicate cancer risk information to patients would merit further exploration. Also, since evidence of the benefits (enablers or facilitators) and barriers to implementation are limited to a few studies, it would be useful to add to the existing evidence by exploring these further. Therefore, the research questions* arising from the scoping review were:

- What are the perceptions of patients (or service users) and practitioners about how best cancer risk information can be communicated to patients during general practice consultation?
- What do service users and practitioners perceive as enablers (or facilitators) and barriers to the implementation of cancer risk assessment tools?

*The research questions were initially formulated around QCancer. Following comments and recommendations received from my PhD examiners, and after careful consideration, the QCancer component was replaced with ‘cancer risk assessment tools for symptomatic individuals’ since the thesis refers more widely to cancer risk assessment tools.

2.2 Key points

The key points in the scoping review include:

- The scoping review sought to explore for evidence of cancer risk assessment tools available in primary care, and the benefits (enablers/facilitators) and barriers to the use of these tools.
- The review was informed by Arksey and O'Malley's 2005 framework recommended for scoping reviews.
- 43 studies were included in the review and analysed for evidence to address the review question.
- The review found evidence of some cancer risk assessment tools designed for detecting cancer risk in symptomatic individuals.
- The benefits of using cancer risk assessment tools were also identified from the literature.
- The review also found barriers to the implementation of cancer risk assessment tools.
- Based on the findings two research questions are stated (as in Section 2.1 above).

2.3 Background to the review

Using the methodological framework outlined by Arksey and O'Malley (2005), this chapter presents a systematic scoping review that explores the evidence available on the use of cancer risk assessment tools to support early detection of cancer risk in primary care settings.

Scoping reviews are usually conducted to map the key concepts underpinning a research area and the main sources and types of evidence available (Mays et al., 2001). In the view of Mays and colleagues, scoping reviews can be undertaken as stand-alone projects, for example, in complex areas of study or areas that have not been comprehensively reviewed. Hence, scoping reviews usually involve a comprehensive coverage of the available literature, although the depth of information extracted from studies may also depend on the reasons for conducting the scoping review (Arksey & O’Malley, 2005). Arksey and O’Malley (2005) outlined four reasons for conducting a scoping literature review:

- To examine the extent, range and nature of evidence without describing the research findings in detail
- To identify whether a full systematic review is feasible or relevant.
- To summarise and disseminate research findings by describing in more detail the findings and range of research areas of study, which could be useful to policy makers, practitioners and consumers who might otherwise lack time or resources to undertake such work (Antman et al., 1992)
- To identify research gaps in the existing evidence.

Arksey & O’Malley (2005) suggest that the four reasons stated above can further be grouped into two main reasons for conducting scoping reviews. The first two reasons suggest that a scoping review might be viewed as one part of an ongoing process of review, with the aim of conducting a full systematic review. The third and fourth, however, suggest a scoping review can lead to the dissemination of research findings including the identification of gaps for further research.

The aim of this scoping review was to explore the evidence on cancer risk assessment tools available for symptomatic patients in primary care, the use of the tools (including the benefits and barriers to implementation) and to identify research gaps for further exploration.

While pursuing the aim of this review, it was noted that, unlike systematic reviews, scoping reviews do not usually involve a quality assessment component and they do not usually seek to determine whether the findings of studies are robust or generalisable (Arksey & O’Malley, 2005). Therefore, while quality assessment of the evidence was not performed in this scoping review, it should be noted that the identification of research gaps depends to some extent on the quality of the studies identified in the scoping review.

Nonetheless, the framework outlined by Arksey & O'Malley (2005), and adopted for this scoping review, is in line with the principles of systematic reviews. That is, the methods used throughout the different stages of the review were rigorous and transparent (Mays et al., 2001). In addition, the process of the scoping review was documented in sufficient detail to enable the study to be replicated by others who wish to do so. This explicit approach increases the reliability of the findings, and seeks to address concerns about the methodological rigour of the scoping review (Mays et al., 2001). The methodological framework that guided the conduct of this scoping review is presented in Section 2.4.

2.4 Methodological framework

The methodological framework adopted for this scoping review was developed by researchers at the University of York (Arksey & O'Malley, 2005) and has been used by other researchers subsequently (Brien et al., 2010; Davis et al., 2009; Levac et al., 2010; Daudt et al., 2013; Pham et al., 2014). This framework suggests five stages including: identification of the research question; identification of relevant studies; study selection; charting the data; and collating, summarising and reporting results of the review. A sixth stage, which is optional, involves consultation with stakeholders to ensure comprehensive inclusion of all relevant material (Arksey & O'Malley, 2005). Consultation in this case was limited to one of the project academic supervisors (a general practitioner in the study area). The following sections describe the stages which guided the process of this scoping review.

2.4.1 Identification of the review question for the scoping review

In developing the research question, all aspects of the research area were considered to generate a breadth of coverage (Arksey & O'Malley, 2005). Therefore, in line with the review aim stated above, the question for this scoping review was stated broadly as: what is the evidence on: cancer risk assessment tools available for symptomatic individuals in primary care, and use of these tools (including the benefits and barriers to implementation)?

2.4.2 Identification of relevant studies

A scoping review needs to be as comprehensive as possible to identify all relevant literature suitable for answering the research question (Arksey & O'Malley, 2005; Brien et al., 2010; Levac et al., 2010). To ensure coverage of most current and relevant literature around cancer risk assessment tools for symptomatic individuals in primary care, it was decided that it would be appropriate to include only studies published from 2005 (prior to development of cancer risk assessment tools) to the date of presentation of the thesis (2017). Similarly, studies reported in languages other than the English language were excluded because of the cost and time involved in translating such studies into English. These considerations guided the development of the following list of inclusion criteria for the selection of relevant studies.

2.4.2.1 Inclusion criteria

To be considered relevant to this scoping review, studies were included if:

- They were conducted within the period 2005 - 2017
- They were conducted in primary care settings such as general practices
- The studies were reported in the English language
- The study participants were adults
- Study participants were patients or service users or practitioners or clinicians or general practitioners
- The studies were about cancer risk assessment tools for symptomatic people (and not asymptomatic people).

Studies that did not meet the above inclusion criteria were excluded. While the inclusion criteria were adopted for practical reasons, potentially relevant studies, such as those published in languages other than the English language, might have been excluded.

Having specified the inclusion criteria, the next step in this scoping review involved searching for available literature through electronic databases, reference lists of published papers and personal records of researchers or experts for relevant papers not captured by the search, especially records of studies that had not yet been published.

2.4.2.2 Electronic databases

For the electronic database search, a search strategy was designed which involved the development of search terms and search limits. The search terms were a combination of free text or phrases of five key search terms (see Table 1 below).

Search strategy

Using the search terms in Table 1 below, electronic databases (Medline, Cumulative Index to Nursing & Allied Health Literature (CINAHL), Scopus, Cochrane Database of Systematic Reviews (CDSR), Science Direct and Psych-INFO) were searched. These search terms also guided a search for relevant published or grey literature in the academic websites of researchers or experts in the field of early diagnosis or detection of cancer risk. Details of the search strategy including the databases, search terms, search limits and the results generated from the search are presented in Table 1.

Table 1 Search terms, limits/expanders and number of results for databases searched

No of searches	Key search terms /queries	Results						Limiters/ expanders
		Medline	CINAHL	Scopus	Cochrane	Science direct	Psych-INFO	
S1	Existing cancer risk assess* tools (Cancer risk assess* tool* OR model*) AND (early diagnosis OR early detect* OR symptomatic patient*) AND (primary care OR general pract* OR family pract*)	96	1638	115	2	372	3397	-Full Text; Published Date: 20050101-20171231; English Language; Research Article; Human; Language: English; Age Groups: All Adult **-Search modes:** Boolean/Phrase
S2	Cancer risk assess* tool* use (Cancer risk assess* tool* OR model*) AND (symptomatic patient* OR clinician* or general Pract*) AND (benefit OR impact*)	119	2093	20	15	162	2462	Full Text; Published Date: 20050101-20171231; English Language; Research Article; Human; Language: English; Age Groups: All Adult **Search modes:** Boolean/Phrase
S3	Cancer risk assess* tool* use (Cancer risk assess* tool* OR model*) AND (symptomatic patient* OR service user* clinicians OR general Pract*) AND barrier*	11	672	39	20	114	1327	Full Text; Published Date: 20050101-20171231; English Language; Research Article; Human; Language: English; Age Groups: All Adult **Search modes** - Boolean/Phrase

S4	Communication of cancer risk (Cancer risk assess* tool* OR model*) AND (symptomatic patient* OR service user* OR clinicians or general pract*) AND (communicat* OR interact* OR discuss*)	416	3131	105	0	3	7733	Full Text; Published Date: 20050101-20171231; English Language; Research Article; Human; Language: English; Age Groups: All Adult **Search modes** - Boolean/Phrase
S5	Outcome of cancer risk assess* tool* use (Cancer risk assess* tool* OR model*) AND (early refer* OR investigat* OR diagnosis*) AND (symptomatic patient*) AND (primary care OR general pract* OR)	92	535	54	25	2	19	Full Text; Published Date: 20050101-20171231; English Language; Research Article; Human; Language: English; Age Groups: All Adult **Search modes** - Boolean/Phrase
S6	S1 AND S2 AND S3 AND S4 AND S5	302	105	23	10	5	4	
Number of studies considered by database		302	105	23	10	5	4	
Total number of studies considered		449 + 22 (from citations & other sources =471						

2.4.2.3 Reference lists and citation search

To ensure all relevant studies were identified, the reference lists of studies found through the electronic database searches were checked. This helped to identify several relevant studies. A citation search was also done by using Google Scholar and the University of Lincoln search engine to track relevant references that were cited in the studies identified from the electronic databases.

2.4.2.4 Academic websites of researchers (experts) in the field

Existing networks and organisations can provide potentially relevant information (Arksey & O’Malley, 2005). Hence, the websites of existing network of researchers and organisations, which are within the public domain, were searched as listed in Table 2.

These websites were targeted for searches because they had the potential to contain relevant studies. Several relevant studies were identified from the websites of individual researchers and organisations involved in cancer research, but most of these studies were also found through the electronic database search.

Table 2 Websites of existing network of researchers searched for relevant literature

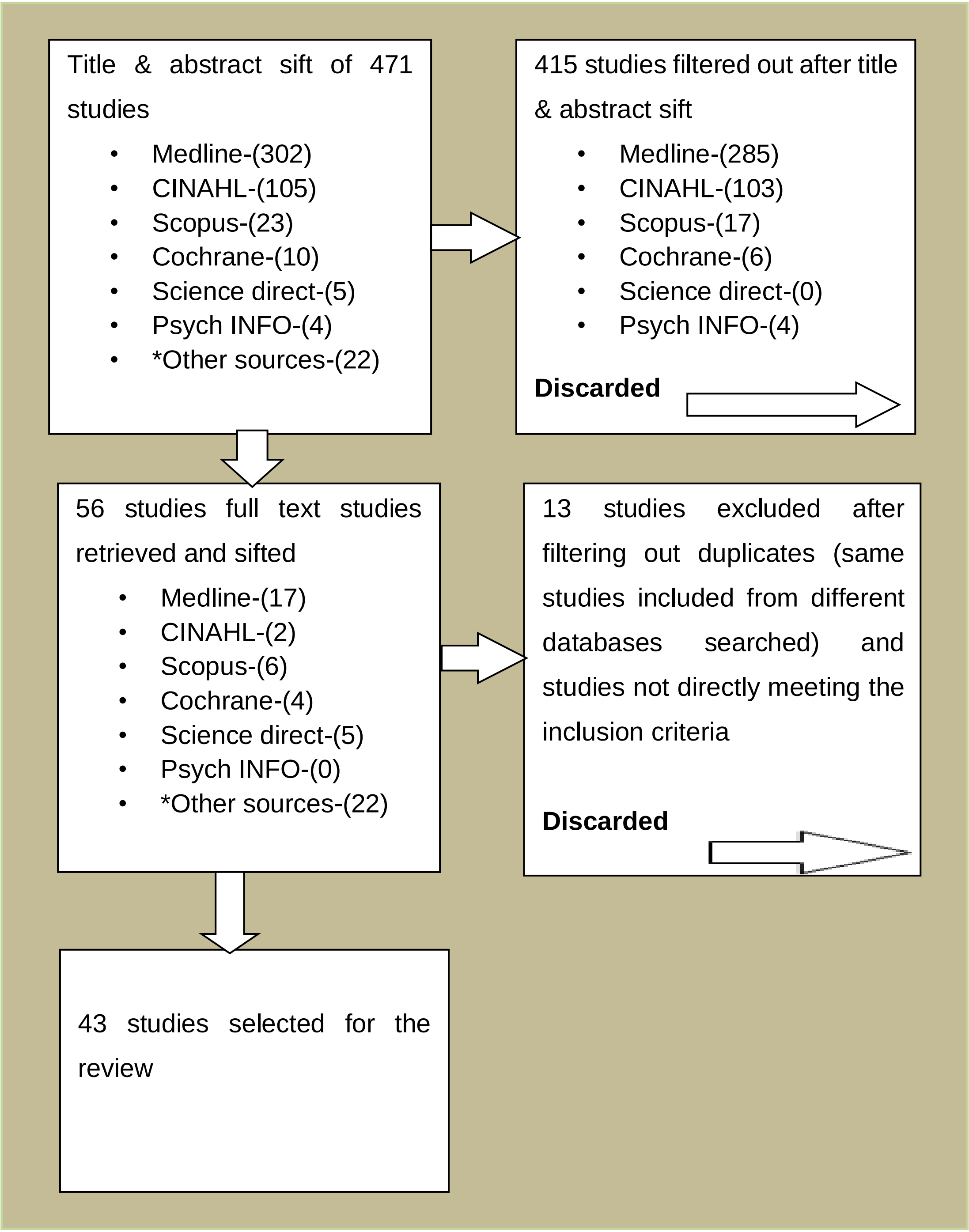
Organisation	Website	Researcher of interest
Cancer research UK	http://www.cancerresearchuk.org/	
Macmillan Support, UK	http://www.macmillan.org.uk/	
Nuffield Department of primary care, University of Oxford	http://www.phc.ox.ac.uk/	
Division of Epidemiology and Public Health	http://www.nottingham.ac.uk/medicine/about/eph/people/index.aspx	Prof. J. Hippisley-Cox Prof. C. Coupland
Division of primary care, University of Nottingham	http://www.nottingham.ac.uk/medicine/about/eph/people/index.aspx	Prof. Hippisley-Cox Prof. C. Coupland
Centre for Statistics in Medicine, University of Oxford	http://www.csm.ox.ac.uk/about	Prof D. Altman Prof. G Collins
Department of Public Health and Primary care	http://www.phpc.cam.ac.uk/people/pcu-group	Dr F. Walter
Research records at School of Medicine, Pharmacy and Health, University of Durham	https://www.dur.ac.uk/school.health/	Prof G. Rubin
Medical School, University of Exeter	http://medicine.exeter.ac.uk/about/profiles/index.php?web_id=Willie_Hamilton	Prof. W. Hamilton
Leeds Institute of Health Sciences	https://medhealth.leeds.ac.uk/profile/600/1689/richard_neal/1	Prof Richard Neal

Many studies were generated from the search which needed to be examined before being included in the review. The references generated from the search in this review were managed with RefWorks, a bibliographic management software available to staff and students of the University of Lincoln.

2.4.3 Study selection

The search for evidence for this scoping literature review yielded several potentially relevant studies. These included studies from electronic databases and studies from the relevant websites of existing network of researchers and organisations. Applying the inclusion criteria described under identification of studies stated above, all the studies were examined by title, abstract and full text and studies that met the inclusion criteria were selected. A flow chart of the study selection process is presented in Figure 1.

Figure 1 Steps in the study selection process



*Number of studies is in brackets [()]. *Other sources: Websites of existing networks/cancer researchers*

2.4.4 Charting the data

In line with the recommended framework (Arksey & O’Malley, 2005) adopted for this scoping review, the charting process was multi-staged and involved the extraction of information from individual studies. Scoping reviews usually include a mixture of general information about the study, such as the study population, type of intervention, outcome measures, the study design and the results (Arksey & O’Malley, 2005; Brien et al., 2010; Davis et al., 2009; Levac et al., 2010). This scoping review included similar information extracted from the selected studies: the author(s), year of publication, sample size, study setting or location, study design, outcome measures and results. These details were extracted and tabulated (see Tables 3 to 7).

Table 3 Details studies (the QCancer series) for cancer risk assessment tools available for symptomatic individuals in primary care

No	Author, date & title	Design	Sample size & setting	Data collection	Outcome measure	Results
1	**Hippisley-Cox & Coupland (2011)** Identifying patients with suspected lung cancer in PC: derivation & validation	Cohort study	-Patients aged 30-84 years in 375 practices for development and 189 for validation -In UK	Data from QResearch database	Incident diagnosis of lung cancer in the next 2 years	The algorithm has good discrimination & could potentially be used to identify those at highest risk of lung cancer
2	**Hippisley-Cox & Coupland (2011)** Identifying patients with suspected gastro-oesophageal cancer in PC: Derivation & validation	Cohort study	-Patients aged 30-84 years in 375 general practices for development and 189 for validation -In UK	Data from QResearch	Incident diagnosis of gastro-oesophageal cancer in the next 2 years	The algorithm has good performance and could be used to help identify those at highest risk of gastro-oesophageal cancer
3	**Hippisley-Cox & Coupland (2012)** Identifying patients with suspected renal tract cancer in primary care (PC): derivation & validation	Cohort study	-All patients aged 30-84 years in 375 general practices for development and 189 for validation -In UK	Data from QResearch database	Incident diagnosis of renal tract cancer in the next 2 years	The algorithm has good discrimination and calibration and could potentially be used to identify those at highest risk of renal tract cancer
4	**Hippisley-Cox & Coupland (2012)** Identifying women with suspected ovarian cancer in PC: Derivation & validation	Cohort study	-Women aged 30-84 in 375 general practices for development and 189 for validation -In UK	Data from QResearch database	Incident diagnosis of ovarian cancer in the next two years	The algorithm explained 57.6% of the variation. The 10% of women with the highest predicted risks contained 63% of all ovarian cancers diagnosed over the next two years
5	**Hippisley-Cox & Coupland (2012)** Identifying patients with suspected colorectal cancer in PC: Derivation & validation	Cohort study	-All patients aged 30-84 years in 375 general practices for the development & 189 for validation -In UK	Data from QResearch database	Incident diagnosis of colorectal cancer in the next 2 years	The algorithm has good discrimination and calibration and could potentially be used to help identify those at highest risk of current colorectal cancer
6	**Hippisley-Cox & Coupland (2012**) Identifying patients with suspected pancreatic cancer in PC: Derivation & validation	Cohort study	-All patients aged 30-84 years in 375 general practices for development and 189 for validation -In UK	Data from QResearch database	Incident diagnosis of pancreatic cancer in the next 2 years	The algorithm has good discrimination and calibration and could potentially be used to help identify those at highest risk of pancreatic cancer
7	**Hippisley-Cox & Coupland (2013)** Symptoms and risk factors to identify women with suspected cancer in PC: derivation and validation of an algorithm	Cohort study	-Women patients aged 25 - 89 years in general practices -In UK	Data from QResearch database	Incident diagnosis of cancer in women (lung, colorectal, gastro-oesophageal, pancreatic, renal, blood etc)	The receiver operator characteristic (ROC) statistics were lung (0.91), colorectal (0.89), gastro-oesophageal (0.90), pancreas (0.87), ovary (0.84), renal (0.90), breast (0.88), blood (0.79), uterus (0.91), cervix (0.73), other cancer (0.82). 10% of females with highest risks had 54% of all cancers diagnosed over 2 years

8	**Hippisley-Cox & Coupland (2013)** Symptoms and risk factors to identify men with suspected cancer in PC: derivation and validation of an algorithm	Cohort study	-Male patients aged 25 - 89 years in general practices -In UK	Data from QResearch database	Incident diagnosis of cancer in men (lung, colorectal, gastro-oesophageal, pancreatic, renal, blood, prostate, testicular etc.)	The 10% of males with the highest risks contained 59% of all cancers diagnosed over 2 years. The algorithm has good discrimination and could be used to identify those at highest risk of cancer to facilitate more timely referral and investigation.
9	Collins & Altman (2012) Identifying patients with undetected colorectal cancer: independent validation of QCancer	Cohort study	All patients in general practices in THIN database -In UK	Data from THIN database	Incident diagnosis of colorectal cancer during the 2 years after study	Very good discrimination with an area under the receive operator characteristic (AUROC) curve of 0.92 (women) and 0.91 (men). Well calibrated across all tenths of risk & over all age ranges with predicted risks closely matching observed risks
10	Collins & Altman (2013) Identifying patients with undetected renal tract cancer in PC: Independent validation of QCancer (Renal)	Cohort study	Patients in general practices in THIN database -In UK	Data THIN database	Incident diagnosis of bladder, kidney, ureter or urethra cancers	-Had very good discrimination with AUROC curve of 0.92 and 0.95 for women and men respectively -Well calibrated across all tenths of risk and over all age ranges with predicted risks closely matching observed risks
11	Collins & Altman (2012) Identifying patients with undetected gastro-oesophageal cancer in primary care: External validation of QCancer- (Gastro-Oesophageal)	Cohort study	Patients in general practices in THIN database –In UK	Data THIN database	Incident diagnosis of gastro-oesophageal cancer	-Demonstrated good performance. Had very good discrimination with c-statistics of 0.93 & 0.94 for women and men. QCancer - (Gastro-Oesophageal) was well calibrated across all tenths of risk & over all age ranges with predicted risks closely matching observed risks. Explained 74.4% and 75.6% of the variation in men and women respectively
12	Collins & Altman (2013) Identifying women with undetected ovarian cancer: independent and external validation of QCancer® (Ovarian) prediction model	Cohort study	Patients in general practices in THIN database – In UK	Data THIN database	Incident diagnosis of ovarian cancer	Had very good discrimination with an AUROC curve of 0.86 & explained 59.9% of the variation. 10% of women with the highest predicted risks included 64% of all ovarian cancer diagnoses over the next 2 years
13	Collins & Altman (2013) Identifying patients with undetected pancreatic cancer in primary care: an independent & external validation of QCancer	Cohort study	Patients in general practices in THIN database – In UK	Data THIN database	Incident diagnosis of pancreatic cancer	Had very good discrimination, with AUROC curve of 0.89 and 0.92 for females and males respectively. QCancer (Pancreas) explained 60% and 67% of the variation in females and males respectively. QCancer (Pancreas) over-predicted risk in both females and males, notably in older patients

Table 4 Details studies (the RATs series) for cancer risk assessment tools available for symptomatic individuals in primary care

No	Author, date & title	Design	Sample size & setting	Data collection	Outcome measure	Results
1	Hamilton (2009) The CAPER studies: five case-control studies for identifying and quantifying the risk of cancer in symptomatic primary care (PC) patients	Case-control studies	Review of 5 studies in Primary care -In UK	Searched GP records	Identifying and quantifying risk of cancer for symptoms and primary care investigations	Symptoms matched previous series from secondary care, though the risks of cancer, expressed as positive predictive values were lower
2	Marshall et al. (2011) The diagnostic performance of scoring systems to identify symptomatic colorectal cancer compared to current referral guidance	Case-control study	Patients with suspected colorectal cancer in primary care databases -In UK	From Electronic primary care databases	-Diagnosis of colorectal cancer -Derivation of algorithm	Both multivariable symptom scoring systems performed significantly better than NICE referral. Areas under the curve were: BB 0.92 (95% CI 0.91 to 0.94); CAPER 0.91 (95% CI 0.89 to 0.93)
3	Shephard et al. (2012) Clinical features of bladder cancer in primary care	Case-control study	4915 patients aged ≥40 years, diagnosed with bladder cancer Jan 2000 to December 2009, and 21 718 - age, sex, & practice-matched controls- UK	Electronic medical records (GPRD)	Association between clinical features and bladder cancer	Seven features were independently associated with bladder cancer, with the most being visible haematuria, odds ratio 34 (95% confidence interval [CI] = 29 to 41) with a positive predictive value for visible haematuria in patients aged ≥60 years was PPV of 2.6% (95% CI = 2.2 to 3.2)
4	Stapley et al. (2012) The risk of pancreatic cancer in symptomatic patients in primary care: a large case–control study	Case-control study	3635 cases aged ≥40 years and 16 459 controls -In UK	General Practice Research Database	Quantified risk of pancreatic cancer for features in primary care	9 features were associated with pancreatic cancer. Positive predictive values for patients aged X60 were o1%, apart from jaundice at 22% (95% CI 14, 52), though several pairs of symptoms had PPVs >1%.
5	Shephard et al. (2013) Clinical features of kidney cancer in primary care: a case-control study using primary care records	Case control study	3149 patients aged ≥40 years, with kidney cancer between 2000 & 2009, & 14091 age, sex & practice matched controls -In UK	General Practice Research Database records	Association between clinical features & kidney cancer	Fifteen features were independently associated with kidney cancer: visible haematuria, odds ratio 37 (95% CI = 28 to 49) being the commonest and most powerful single predictor of kidney cancer, with positive predictive value for visible haematuria in patients aged ≥60 years was 1.0% (95% CI = 0.8 to 1.3)
6	Dommett et al. (2013) Risk of childhood cancer with symptoms in primary care: a population-based case-control study	Case-control study	1267 children aged 0–14 years diagnosed with childhood cancer was matched to 15 318 controls	General Practice Research Database records	Clinical features associated with	12 symptoms were associated with PPVs of ≥0.04%, which represents a greater than tenfold increase in prior probability. The 6 symptoms with the highest PPVs were pallor head and neck masses, masses elsewhere

			-In UK		subsequent diagnosis of cancer	lymphadenopathy, symptoms/signs of abnormal movement, and bruising
7	Walker & Hamilton (2013) Risk of uterine cancer in symptomatic women in primary care: case–control study using electronic records	Case-control study	2732 women aged ≥40 years with uterine cancer between 2000 & 2009, & 9537 age-, sex- & practice-matched controls	General Practice Research Database records	Clinical features associated with uterine cancer	9 features were significantly associated with uterine cancer, and these features are important for diagnosis of uterine cancer, particularly postmenopausal bleeding. The PPV of uterine cancer with postmenopausal bleeding was 4%, and was higher in women with multiple or repeated symptoms
8	Stapley et al. (2013) The risk of oesophago-gastric cancer in symptomatic patients in primary care: a large case–control study using electronic records	Case-control study	7471 cases and 32 877 controls were studied -In UK	General Practice Research Database records	Identified & quantified features of oesophago-gastric cancer	16 features independently associated with oesophagogastric cancer (all Po0.001): dysphagia; reflux; abdominal pain; epigastric pain; dyspepsia; nausea and/or vomiting; constipation; chest pain; weight loss; thrombocytosis; low haemoglobin; low MCV; high inflammatory markers; raised hepatic enzymes; high white cell count; & high cholesterol. The only PPV 45% in patients ≥55 years was for dysphagia. In patients > 55 years, all PPVs were >1%.
9	Walker et al. (2014) Risk of breast cancer in symptomatic women in primary care: a case–control study using electronic records	Case-control study	3994 women aged ≥40 years with breast cancer between 2000 & 2009, & 16 873 age-, sex-, & practice-matched -In UK	CPRD patient records	Clinical features associated with breast cancer	Four features were significantly associated with breast cancer: breast lump (odds ratio [OR] 110; 95% CI = I88 to150), breast pain (OR = 4.2; 95% CI = 3.0 to 6.0), nipple retraction (OR = 26; 95% CI = 10 to 64), nipple discharge (OR = 19; 95% CI = 8.6 to 41): all P-values <0.01. The PPV of breast cancer with a breast lump was 4.8% in women aged 40–49 years, rising to 48% in women aged >70 years. PPVs were lower in women who also reported breast pain
10	Hamilton et al. (2014) The risk of cancer in primary care patients with hypercalcaemia: a cohort study using electronic records	Case-control study	Patients aged ≥40 years (54 267) had calcium, with control participants from a previous study -In UK	General Practice Research Database	Association between calcium and cancer	Hypercalcaemia was strongly associated with cancer, especially in males: OR 2.92, 95% CI 2.17–3.93, P¼o0.001; positive predictive value (PPV) 11.5%; females: OR 1.86, 95% CI 1.39–2.50, Po0.001: PPV 4.1%
11	**Price, et al. (2014)** Non-visible versus visible haematuria and bladder cancer risk: a study of electronic records in primary care.	A case–control study.	4915 patients (aged ≥40 years) diagnosed with bladder cancer between Jan 2000 and Dec 2009 matched to 21 718 controls for age, sex, and practice -In UK	CPRD patient data	Association between non-visible, visible haematuria and bladder cancer	Non-visible haematuria was independently associated with bladder cancer. The PPV of non-visible haematuria was 1.6% (95% CI = 1.2 to 2.1) in those aged ≥60 years and 0.8% (95% CI = 0.1 to 5.6) in 40–59-year-olds. The PPV of visible haematuria was 2.8% (95% CI = 2.5 to 3.1) and 1.2% (95% CI = 0.6 to 2.3) for the same age groups respectively, lower than those calculated using coded data alone.

Table 4 Details of studies (the RATs series) for cancer risk assessment tools available for symptomatic individuals in primary care

No	Author, date & title	Design	Sample size & setting	Data collection	Outcome measure	Results
12	Hamilton et al. (2015) Clinical features of metastatic cancer in primary care: a case–control study using medical records	Case-control study	162 cases, 152 cancer controls, and 145 healthy controls -In UK	Medical records	Association between clinical features & metastatic cancer	Groin pain was uncommon, but strongly associated with (16 [10%] cases and 1 [1%] cancer control, as was pleural disease (9 [6%] cases & 1 [1%] cancer control, but fairly common occurrence of non-specific symptoms (vomiting and loss of appetite) is important and may explain delays in diagnosis of metastases
13	**Shephard et al. (2015)** Quantifying the risk of non-Hodgkin lymphoma (NHL) in symptomatic primary care patients aged ≥ 40 years	Case-control study	4362 patients aged ≥ 40 years, with NHL between 2000 and 2009, & 19 468 age, sex, and general practice-matched controls -In UK	CPRD patient records	Association between clinical features and NHL	Unexplained lymphadenopathy (OR) 263 (95% CI = 133 to 519) had a PPV of 13% for NHL in patients ≥60 years, and produces a very high risk of NHL in primary care this group of patients
14	**Grewal & Hamilton (2015)** Ovarian cancer prediction: development of a scoring system for primary care	Case-control study	212 women with ovarian cancer & 1060 age, sex- and practice-matched controls -In UK	data from a case-control study	The ROC curve value	-Scoring system could potentially direct general practitioners to appropriate investigations for ovarian cancer based on symptoms. The area under the ROC curve was 0.883 (95% CI 0.853-0.912). -The chosen cut-off had a sensitivity of 72.6% & a specificity of 91.3%.
15	Shephard et al. (2015) Quantifying the risk of Hodgkin lymphoma in symptomatic primary care patients aged ≥ 40 years: a case–control study	Case-control study	283 patients aged ≥40 years, diagnosed with HL between 2000 & 2009, & 1237 age, sex, & general practice-matched participants -In UK	CPRD patient records	Association between clinical features & HL	-Lymphadenopathy (OR 280, 95% CI = 25 to 3100), has a positive predictive value (PPV) of 5.6% for HL in patients aged ≥60 years -i.e lymphadenopathy is the clinical feature with the highest risk of HL in primary care and warrants urgent investigation
16	Shephard et al. (2015) Quantifying risk of multiple myeloma from symptoms reported in primary care **patients: a** large case-control study	Case-control study	2703 patients aged ≥40 years, diagnosed with myeloma between 2000 and 2009, & 12 157 age, sex, & general practice-matched controls -In UK	GPRD primary care electronic records	-Association of clinical features with myeloma - Positive predictive values (PPVs)	-Hypercalcaemia and leucopenia are particularly important abnormalities, and coupled with symptoms, strongly suggest myeloma - Sixteen features were independently associated with myeloma, with hypercalcaemia - odds ratio 11.4 (95% CI = 7.1 to 18)
17	**Schmidt-Hansen et al. (2015**) Symptomatic diagnosis of cancer of the	A systematic review	6 studies with 159 938 patients were included	Searched MEDLINE, PreMEDLINE, EMBASE, the	Quantified the risk of brain/CNS cancer in symptomatic	All the individual and combined symptoms of brain tumours had low PPVs of less than 0.39%, apart from new-onset epilepsy.

	brain and central nervous system in primary care: a systematic review		-In UK	Cochrane Library, Web of Science, ISI Proceedings & PsychINFO	patients presenting in primary care	This gives a diagnostic problem, as brain tumours have all the expected features seen with cancer diagnostic delay, with high proportions presenting as an emergency and having had multiple primary care consultations before referral
18	Williams et al. (2016) Risk prediction models for colorectal cancer in people with symptoms: a systematic review	A systematic review	18 papers describing 15 risk models were included -In UK	Searched Medline and EMBASE	Systematically identify & compare the performance of models that predict the risk of primary CRC among symptomatic individuals	9 studies were developed in primary care populations and 6 in secondary care. Four had good discrimination (AUROC > 0.8) in external validation studies, & sensitivity & specificity ranged from 0.25 and 0.99 to 0.99 and 0.46 depending on the cut-off chosen
19	Schmidt-Hansen et al. (2016) Symptoms of pancreatic cancer in primary care: A systematic review	A systematic review	8 studies with 3,438,363 patients included -In UK	Searched MEDLINE, PreMEDLINE, EMBASE, the Cochrane Library, Web of Science, ISI Proceedings & PsychINFO	Symptoms indicative of pancreatic cancer	-The only high-risk feature of pancreatic cancer in primary care was jaundice, and this clearly warrants investigation. The PPV of jaundice was more than 4.1% in patients 40 years or older and increased with age, although only 30% of patients reported jaundice
20	**Shephard et al. (2016)** Symptoms of adult chronic and acute leukaemia before diagnosis: large primary care case-control studies using electronic records	Case-control study	- cases diagnosed between 2000 and 2009, 4655 aged ≥40 years -14 103 eligible controls -In UK	CPRD patient records	Identified symptom profiles of chronic and acute leukaemia in adults in primary care	-10 symptoms were independently associated with CL, the three strongest being: lymphadenopathy; weight loss; and bruising. No individual symptom or combination of symptoms had a PPV >1%
21	Walker & Hamilton (2017) Risk of cervical cancer in symptomatic women aged ≥40 in primary care: A case–control study using electronic records	Case-control study	1,006 women aged ≥40 years diagnosed with cervical cancer and 4,992 age-, sex-and practice-matched controls -In UK	Clinical Practice Research Datalink	Clinical features associated with cervical cancer	7 symptoms & 2 abnormal investigations were associated with cervical cancer: All *p* < .005. The PPV of cervical cancer in women aged ≥55 with post-menopausal bleeding was 4.6% (2.5, 8.3)
22	Merriel et al. (2016) Association between unexplained hypoalbuminaemia and new cancer diagnoses in UK primary care patients	A cohort study	100 122 participants who had at least one albumin test result were followed	A large a UK database of adult primary care patients	The association between hypoalbuminaemia and a new diagnosis of cancer is yet unknown.	Hypoalbuminaemia was associated with an increased risk of subsequent cancer diagnosis within 12 months (odds ratio [OR]: 2.29; 95% confidence interval [CI]: 2.15-2.43), although this association was smaller in magnitude after controlling for other conditions known to affect albumin levels (OR: 1.29; 95% CI: 1.12-1.49).

Table 5 Details of other studies for cancer risk assessment tools available for symptomatic individuals in primary care

No	Author, date & title	Design	Sample size & setting	Data collection method	Outcome measure	Results
1	**Grewal et al. (2013)** Ovarian cancer prediction: development of a scoring system for primary care (PC)	Case-control study	212 women with ovarian cancer and 1060 age, sex and practice-matched controls in 39 general practices in Exeter -In UK	Secondary data from a case-control study	The ROC curve value for ovarian cancer prediction	Has a highly acceptable ROC value of 0.883 (95% CI 0.853–0.912). Using a - 4-point cut-off, the scoring system has a specificity of 91.32% and sensitivity of 72.64%. The scoring system could potentially direct general practitioners to appropriate investigations for ovarian cancer on the basis of symptoms and save a substantial number of unnecessary ultrasound scans
2	Iyen-Omofoman et al. (2012) Using socio-demographic and early clinical features in general practice to identify people with lung cancer earlier	Case control	12 074 cases of lung cancer and 120 731 controls in a large general practice database -In UK	A large general practice database	Prediction of lung cancer	-Socio-demographic features (age, sex, S-E status) and smoking history were independently associated with lung cancer -4 to 12 months before diagnosis, symptom (cough, haemoptysis, dyspnoea, weight loss, lower respiratory tract infections, non-specific chest infections, chest pain, hoarseness, upper respiratory tract infections and chronic obstructive pulmonary disease were independently predictive of lung cancer -On validation, the model performed well with an area under the ROC curve of 0.88.
3	Toftegaard et al. (2016) Development of an algorithm to identify urgent referrals for suspected cancer from the Danish Primary Care Referral Database	Cohort	-417 GP clinics with 831 GPs and ~8,000 new cancer patients annually -In Denmark	Analysis of data from a primary care referral database	Identification of urgent cancer referral from general practice	The algorithm had a sensitivity of 0.939 (95% [CI]: 0.905–0.963) & a specificity of 0.937 (95% CI: 0.925–0.963) compared to the gold standard, with positive and negative predictive values of 69.8% (95% CI: 65.0-74.3) & 99.0% (95% CI: 98.4-99.4), respectively, which increased to 83.6% (95% CI: 78.7–87.7) & the specificity to 97.3% (95% CI: 96.4–98.0) for populations without earlier cancer diagnosis.

Table 6 Details of studies for benefits of using cancer risk assessment tools for symptomatic individuals in primary care

No	Author, date & title	Design	Sample size & setting	Data collection method	Outcome measure	Results
1	**Khan (2009)** Implementation of a diagnostic tool for symptomatic colorectal cancer in primary care: a feasibility study	A feasibility study (trial)	122 patients with bowel related symptoms in 25 general practices in five regions -In UK	Three audits assessed recruitment success, compliance with the assessment tool & clinical outcomes	GP compliance with completing the CAPER score	-4 patients diagnosed with colorectal cancer; all met the referral criteria for the CAPER score; but only 3 met the NICE referral criteria. Assessment tool compliance was low
2	**Hamilton et al. (2013)** Evaluation of risk assessment tools for suspected cancer in general practice: A cohort study	Cohort study with nested qualitative study	614 GPs from 165 practices were provided with RATs -In UK	In-depth interviews were conducted with 34 individuals (11 project managers and 23 GPs)	Number of RATs used, and subsequent cancer investigations and diagnoses	-Compared with preceding 6 months, there were 292 more chest X-rays, 104 extra 2-week chest clinic appointments, & 47 additional diagnoses of lung cancer. -Colorectal cancer: 304 more 2-week referrals, 270 more colonoscopies& 10 more cancers identified
3	**Green et al. (2015**) Exploring GPs' experiences of using diagnostic tools for cancer: a qualitative study in PC	Qualitative study to explore GPs' experiences of incorporating the RATs for lung and bowel cancers into their clinical practice	11 project managers who implemented the study and 23 GPs In UK	semi-structured interviews over the telephone	GPs' experiences of incorporating the RATs	-RAT helped GP's referral decision & lung & colorectal cancer symptom recognition. -Embedding of clinical decision support tools achievable if used with clinical judgement - GPs' use of the RATs increased diagnostic activity and led to additional cancer diagnoses
4	**Chiang et al. (2015)** Implementing a QCancer risk tool into general practice consultations	Exploratory 'action design'- using simulated consultations	15 General practitioners -In Australia	Semi-structured interviews based on the normalisation process theory	Explored issues relating to implementation of the tool	-Potentially useful for patients with complex histories - Useful resources that can help GPs with early detection of cancer
5	**Dikomitis et al. (2015)** Embedding electronic decision-support (eCDS) tools for suspected cancer in PC	Qualitative study for views of GPs (GPs) who piloted (Ecds	23 GPs who piloted the eCDS -In UK	Telephone interviews	Whether GPs able to integrate the eCDS (tools) into their everyday practice	-eCDS tools are useful for detecting cancer risk. -The tools could raise awareness about cancer

Table 7 Details of studies for barriers/challenges to implementation of cancer risk assessment tools for symptomatic individuals in primary care

No	Author, date & title	Design	Sample size & setting	Data collection	Outcome measure	Results
1	**Chiang et al. (2015)** Implementing a QCancer risk tool into general practice consultations	Exploratory 'action design'- using simulated consultations	15 General practitioners -In Australia	Semi-structured interviews based on the normalisation process theory	Explored issues relating to implementation of the tool	-Inconsistency in the interpretation of symptoms, -Difficulty in introducing the tool into primary care consultation -Uncertainty about where to set the threshold -Uncertainty about how best to communicate cancer risk to patients
2	Dikomitis et al. (2015) Embedding electronic decision-support (eCDS) tools for suspected cancer in primary care	Qualitative study for views of GPs (GPs) who piloted (eCDS	23 GPs who piloted the eCDS -In UK	Telephone interviews	Whether GPs able to integrate the eCDS (tools) into their everyday practice	Potential for 'prompt fatigue
3	**Green et al. (2015)** Exploring GPs' experiences of using diagnostic tools for cancer: a qualitative study in primary care	Qualitative to explore GPs' experiences of using the RAT for lung & bowel cancers in clinical practice & to identify constraints & facilitators to disseminate the tool	11 project managers who implemented the study and 23 GPs -In UK	semi-structured interviews over the telephone	GPs' experiences of incorporating the RATs	-Extra time requirement -Potential for alarming patients -Potential burden especially on secondary care resources -Challenge of integrating the tools into general practice IT systems

2.4.5 Collating, summarising and reporting the results

In the first stage of summarising and reporting the data, the study type and study setting or location of included studies were summarised using tables (see Tables 8 and 9 below). Details of the sample sizes of studies were also summarised as stated below.

Table 8 Type of study

Study type	**No**
Mixed (quantitative & qualitative)	2
Cohort	15
Case control	20
Qualitative	2
Systematic reviews	3
Others/feasibility study (trial)	1
Total	43

Table 9 Study setting/location

Study setting/location	**No**
UK	41
Denmark	1
Australia	1
Total	43

2.4.5.1 Study sample size

The sample sizes for the studies identified and included in the review are indicated in Tables 3 – 7. Participants in most of the studies were practitioners and/or patients depending on the type of study. Eighteen (18) years was the minimum cut off age in line with the inclusion criteria for this scoping review. This resulted in the exclusion of studies with participants who were less than 18 years of age, although one RATs study (Dommett et al., 2013) about the risk of childhood cancer (children aged 0-14 years) was included (just to demonstrate awareness of existence of RAT for children) (see Table 4). In the second stage of summarising and reporting the evidence, the evidence from 41 included studies (Tables 3 – 7) was examined, analysed and organised thematically as the results.

2.5 Results

The results from the 43 included studies were analysed and the evidence organised into two main themes. The first theme was about evidence on cancer risk assessment tools available for symptomatic patients in primary care (38 studies including 13 QCancer series papers, 22 RATs series papers and 3 others). The second theme related to evidence on the use of the tools (8 studies) including the benefits (5 studies) and barriers (3) to use. These are presented in detail below.

2.5.1 Evidence on cancer risk assessment tools available for symptomatic individuals in primary care

From the evidence gathered in this scoping review, tools that predict the risk of cancer in individuals with symptoms are developed for a range of cancers in primary care in the United Kingdom. The two popular tools are the Hamilton risk assessment tool (RAT) initially developed from case-control studies in primary care (Hamilton, 2009) and the QCancer series developed using data from QResearch, a primary care electronic research database (e.g Hippisley-Cox & Coupland, 2013).

The Risk Assessment Tool (RAT) was initially developed from the Cancer Prediction in Exeter (CAPER) studies (five case-control studies) for identifying the risk of symptomatic patients having colorectal and lung cancers (Hamilton, 2009). There are now RATs for a range of cancers including: leukaemia (Shephard et al., 2016); oesophago-gastric (Stapley et al., 2013), ovarian (Grewal et al., 2013), kidney (Shephard et al., 2013), bladder (Shephard et al., 2012), pancreas (Stapley et al., 2012), breast (Walker et al., 2014), cervical (Walker & Hamilton, 2017), uterine (Walker eta al., 2013), brain (Schmidt-

Hansen et al., 2015), childhood (Dommett et al., 2013), metastatic (Hamilton et al., 2015a), Hodgkin's lymphoma (Shephard et al., 2015), non-Hodgkin's lymphoma (Shephard et al., 2015), multiple myeloma (Shephard et al., 2015). Other symptom-based RATs include risk of cancer in people with hypercalcaemia (Hamilton et al., 2014), low albumin (Merriel et al., 2016) and haematuria (Price et al., 2014) have also been published.

The QCancer series also included a range of cancers: lung (Hippisley-Cox & Coupland, 2011), gastro-oesophageal (Hippisley-Cox & Coupland, 2011), colorectal (Hippisley-Cox & Coupland, 2012), renal tract (Hippisley-Cox & Coupland, 2012; ovarian (Hippisley-Cox & Coupland, 2012), pancreatic (Hippisley-Cox & Coupland, 2012), suspected cancer in women (Hippisley-Cox & Coupland, 2012), and suspected cancer in men (Hippisley-Cox & Coupland, 2013).

The RAT provides risk estimates for patients with single symptoms of possible cancer, pairs of symptoms and repeat attendances with the same symptoms (e.g. Hamilton, 2009; Shephard et al., 2016; Stapley et al., 2013; Grewal et al., 2013; Shephard et al., 2013; Shephard et al., 2012; Stapley et al., 2012; Walker et al., 2014; Walker & Hamilton, 2017; Walker et al., 2013; Schmidt-Hansen et al., 2015; Dommett et al., 2013; Shephard et al., 2015a; Shephard et al., 2015b; Shephard et al., 2015c; Hamilton et al., 2014).

In contrast to the RATs, the earlier QCancer series of tools are designed for symptomatic patients who might have an existing but undiagnosed cancer by estimating an absolute risk of any cancer with a breakdown of type of cancer based on both risk factors and symptoms suggestive of cancer already present (e.g Hippisley-Cox & Coupland, 2013). A more recent QCancer series (e.g. Hippisley-Cox & Coupland, 2015) can be used to estimate a 10-year risk of cancer in asymptomatic individuals.

Three other relevant risk assessment tools for symptomatic patients include: a scoring system developed for ovarian cancer prediction in primary care (Grewal et al., 2013); a tool that combines sociodemographic and early clinical features to identify people with lung cancer in primary care (Iyen-Omofoman et al., 2012) and an algorithm developed from the Danish Primary Care Referral Database to identify urgent referrals for suspected cancer in Denmark (Toftegaard et al., 2016), but may be useful in other countries.

An independent validation for many of the risk assessment tools for symptomatic individuals using data from separate populations has been done - for example, the QCancer risk assessment series of tools (e.g. Collins & Altman, 2012; Collins & Altman, 2013) and the RATs (Marshall et al., 2011). These studies suggest the tools have good discrimination with Area Under the Receiver Operating Characteristic Curves (AUROCs) between 0.79 and 0.95, and sensitivities of 46.0 - 61.3 with a specificity of 95% (Collins & Altman, 2012; Collins & Altman, 2013; Marshall et al., 2011) as noted by Usher-Smith et al. (2015).

Similarly, a systematic review of risk prediction models for colorectal cancer in people with symptoms presenting to both primary and secondary care suggests the risk models had good discrimination (AUROC > 0.8) in external validation studies, with sensitivity and specificity ranging from 0.25 and 0.99 to 0.99 and 0.46 (Williams et al., 2016). One exception relates to the RATs for brain tumour for which all the individual and combined symptoms of brain tumours had low PPVs of less than 0.39%, apart from new-onset epilepsy, thus making diagnosis for brain cancer problematic, as brain tumours have all the expected features seen with cancer diagnostic delay (Schmidt-Hansen et al., 2015).

To aid understanding, the statistical terms of AUROC, Sensitivity, Specificity and PPV mentioned here are defined in Box 1 below.

Box 1 Definition of AUROC, PPV, Sensitivity and Specificity

- Area Under the Receiver Operating Characteristic (AUROC): The AUROC is used to measure the accuracy of a test, that is, how well the test separates the group being tested into those with and without the disease of interest. Thus, an area of 1 represents a perfect test; an area of 0.5 represents a worthless test.
- Sensitivity: Sensitivity refers to the ability of a test to detect an individual with disease as positive. A highly sensitive test means that there are few false negative results, with fewer cases of disease missed.
- Specificity: The specificity of a test is its ability to detect an individual who does not have a disease as negative.
- Positive Predictive Value (PPV) and Negative Predictive Value (NPV): The PPV and NPV describe the performance of a diagnostic test. That is, PPV and NPV are the proportions of positive and negative results in diagnostic tests that are true positive and true negative results, respectively.

The evidence on the use of the tools in primary care is presented in Section 2.5.2 below.

2.5.2 Evidence on use of cancer risk assessment tools for symptomatic individuals in primary care including benefits and barriers to use

The evidence generated from studies about the implementation of cancer risk assessment tools for symptomatic individual in primary care included evidence on benefits of use and barriers to implementation.

2.5.2.1 Benefits of using cancer risk assessment tools

This review found evidence from an evaluation study which suggests that the RATs helped clinicians to confirm a need for investigation (Hamilton et al., 2013). The tools allowed for reassurance when investigation was not needed (Hamilton et al., 2013). Similarly, in an exploration of GPs' experiences of using diagnostic tools for cancer, participants perceived the RAT as beneficial in helping GPs to recognise symptoms of lung and colorectal cancers, and to confirm referral decisions (Green et al., 2015). However, Green and colleagues noted that the implementation of clinical decision support tools was more likely to be achieved when the tools were perceived to support rather than supersede clinical judgement (Green et al., 2015).

This review also found evidence that a cancer risk assessment tool like QCancer can be useful for patients with complex histories (Chiang et al., 2015), although GPs were less likely to use a cancer risk assessment tool if they did not perceive cancer as a likely diagnosis (Chiang et al., 2015). This finding contrasted with the findings of Dikomitis and colleagues in the Macmillan eCDS pilot study (Dikomitis et al., 2012). In that qualitative study of GPs' experiences of electronic decision-support tools for suspected cancer in primary care, Dikomitis and colleagues found electronic decision-support tools were useful resources that could help GPs with early detection of cancer as well as raise awareness about cancer, although there was a potential for 'prompt fatigue', where frequent or multiple prompts led to a greater likelihood of them being ignored (Dikomitis et al., 2015). As noted by Chiang and colleagues, the contrasting evidence between Dikomitis and colleagues and Chiang and colleagues may be due to the sustained efforts in the UK to raise awareness about early cancer diagnosis (Chiang et al., 2015).

Further evidence of the benefits of using cancer risk assessment tools relate to increased referral and diagnosis. An evaluation of the use of a cancer risk assessment tool for suspected cancer in general practice revealed that, compared with the preceding 6 months, there were 292 more chest X-rays, 104 extra 2-week chest clinic appointments, and 47 additional diagnoses of lung cancer (Hamilton et al., 2013). For suspected colorectal cancer, there were 304 more 2-week referrals, 270 more colonoscopies, and 10 more cancers identified (Hamilton et al., 2013). Overall, there was an increase in referral and diagnosis of cancer (Khan et al., 2009; Hamilton et al., 2013). Similarly, an exploration of GPs' experiences of using a diagnostic tool for cancer detection, revealed that GPs' use of the RAT increased diagnostic activity and led to additional cancer diagnoses (Green et al., 2015). The next section deals with the barriers to implementation of the tools.

2.5.2.2 Barriers to implementation of the tools

While the cancer risk assessment tools designed for symptomatic patients have a beneficial potential, this review has found that there can be some barriers to the implementation of these tools in primary care.

One challenge is about making the tools easy to access by primary care clinicians. Evidence from the QCancer study in Australia suggests there was inconsistency in the interpretation of symptoms, and that practitioners had trouble in introducing the tool into the primary care consultation (Chiang et al., 2015).

Other barriers include uncertainty about where to set the threshold for action (Chiang et al., 2015) and how best to communicate cancer risk to patients (Chiang et al., 2015). Other studies have identified further barriers including: extra time requirement, potential for alarming patients, potential burden especially on secondary care resources, the challenge of integrating the tools into general practice IT systems to ease use (Green et al., 2015) and a potential for ‘prompt fatigue’ (Dikomitis et al., 2015).

In summary, this scoping review found no evidence of randomised controlled trials (RCTs) relating to the implementation of cancer risk assessment tools for symptomatic individuals in primary care. The evidence mentioned here is limited to the non- RCT feasibility studies (Hamilton et al., 2003; Green et al., 2015; Dikomitis et al., 2015; Chiang et al., 2015), as opposed to studies based on a widespread implementation of the tools. These findings are discussed further in Section 2.6 below.

2.6 Discussion

The aim of this scoping review was to explore the literature for evidence relating to cancer risk assessment tools available in primary care for symptomatic individuals, the use of these tools including the benefits and barriers to their implementation.

Using the methodological framework outlined by Arksey & O'Malley (2005), this scoping review explored the literature and identified studies relevant to the research question. These studies were examined and analysed. The findings suggest that most of the literature referred to two cancer risk assessment tools, designed for symptomatic individuals in primary care.

While these tools are currently not widely implemented, they have potential to aid earlier diagnosis of cancer through early detection of cancer risk in symptomatic individuals when used in primary care patient consultations. In particular, findings from feasibility studies involving the use of the RAT (Khan, 2009; Hamilton et al., 2013; Green et al., 2015), the electronic cancer decision support tools (eCDS) in the UK (Dikomitis et al., 2015), and the QCancer tool in Australia (Chiang et al., 2015) suggest the tools may have benefits including improvement in the number of referrals for cancer investigations and diagnoses (Hamilton et al., 2013; Green et al., 2015). To maximise these benefits, these tools may need to be used in combination with the clinical judgement of practitioners when deciding about a patient's cancer risk (Chiang et al., 2015). This is in line with the new NICE guidelines for cancer which support clinicians' use of their clinical judgement, freeing them from having to make patients fit guidelines (Hamilton, 2015b).

Despite the potential benefits reported by the feasibility studies, there are concerns about barriers to the use of the tools. These include how to make the tools available to clinicians (Chiang et al., 2015), uncertainty about the threshold for action to be taken (Chiang et al., 2015) and how best to communicate cancer risk information to patients (Chiang et al., 2015). Other barriers relate to extra time requirement, potential for causing alarm to patients, potential burden on resources, the challenge of integrating the tools into general practice workflow (Green et al., 2015), and a potential for 'prompt fatigue (Dikomitis et al., 2015) when using the tools in primary care consultations. These findings are similar to those from previous studies on barriers to the use of cardiovascular disease risk predicting tools, which include: lack of time, poor knowledge or understanding of the tools and poor computer software (Van Steenkiste et al., 2004; Muller-Riemenschneider et al., 2010).

Regarding making the tools accessible to practitioners, recent developments suggest that the tools have been integrated into general practice IT systems through a collaboration between Macmillan Cancer Support, Cancer Research UK and individual experts in this area (Macmillan Cancer Support, 2015). Despite this development, there may still be a need to support practitioners further on how to access the integrated tools on their computers.

The uncertainty about the threshold for referral is an important challenge, but current developments suggest that the threshold for referral currently stands at 2% (Macmillan Cancer Support, 2015). It is worth noting that, while a threshold of 2% or even less may help to identify more patients for investigations or referral for diagnosis, this greater sensitivity is balanced by reduced specificity, where a lower threshold can lead to over-investigation, over-diagnosis and unnecessary harmful treatment (Usher-Smith et al., 2015). To complicate matters further, clinicians are expected to use the tools to support their clinical judgement in deciding what to do with a patient's risk, rather than relying solely on the threshold for intervention.

The uncertainty around how best to communicate risk information when using the tools with patients is an important challenge to the use of the tools. The format in which risk information is presented is important, as this can affect both clinicians' use of the tool and patients' understanding and perception of the risk information (Usher-Smith et al., 2015). For example, findings from the QCancer simulated study with GPs suggest a preference for traffic-light colour coding of risks (red, amber and green) with secondary access to the numeric risks, if needed, rather than absolute numeric risks or being presented with diagnostic guidance as the primary output (Chiang et al., 2015).

Lessons about how best risk information can be presented to patients can be learnt from the area of cardiovascular disease. Research in this area suggests that numerical presentation of risk as opposed to simple risk categories and time-frames of 10 years lead to more accurate risk perceptions (Waldron et al., 2011; Usher-Smith et al., 2015). On the other hand, presenting relative risk reductions helps to increase acceptance of treatment and ‘heart age’ may increase intention to change behaviour (Waldron et al., 2011). In the absence of further research, it remains unclear whether this evidence will apply to the communication of cancer risk information to patients, as noted in a recent review (Usher-Smith et al., 2015).

In the face of the barriers identified, there is a need for evidence on facilitators or enablers to the implementation of the tools. These will merit further research exploration. In the context of policy, the implications of the findings from this scoping review are discussed further in Section 2.6.1 below.

2.6.1 Policy context

The findings about the benefits of using cancer risk prediction tools for symptomatic individuals in primary care support the objectives of the National Awareness and Early Diagnosis initiative (NAEDI), particularly in relation to early detection of cancer in primary care. The tools have potential to prompt investigations, referral for diagnosis, treatment and improvement in quality of life. Existing evidence suggests that earlier diagnosis efforts may benefit patients by helping to improve earlier staged diagnosis, survival and quality of life in different cancers (Neal et al., 2015).

There have been efforts to integrate the tools into the general practice IT systems to facilitate general practice clinicians’ access to the tools (Macmillan Cancer Support, 2015), but there may still be a need for training or education on how to access the tools from the general practice IT system, as well as how to communicate the risk to patients.

The potential benefit of the tools in helping to alert practitioners to a possible cancer risk during a patient consultation suggests a policy need for the Department of Health to integrate the tools with the existing NICE guidelines. This will enable practitioners to combine clinical judgment with the use of cancer risk assessment tools and NICE guidelines. Integrating the tools into general practice consultation may imply the need to review the current 10-minute patient-practitioner consultation time. The issues presented and discussed in this chapter are concluded in Section 2.7 below.

2.7 Conclusion of the chapter

This review found that cancer risk assessment tools for symptomatic individuals have the potential to improve cancer survival through early detection of risk, and timely investigation, diagnosis and treatment. Despite the potential benefits of the tools, there are concerns about barriers to the implementation of the tools including how to make the tools accessible to clinicians, where to set the threshold for action and how to communicate cancer risk information to patients.

The uncertainty about how best to communicate cancer risk information to patients requires further research exploration. Given that the evidence on the barriers to implementation are limited to a few studies, it will also be useful to explore further the barriers to implementing cancer risk assessment tools in symptomatic individuals presenting to primary care. In addition, in the face of barriers, it will be useful to explore the enablers (facilitators) to implementation of the tools. Therefore, there is a need to use appropriate research methods to explore the following research questions:

- What are the perceptions of patients (or service users) and practitioners about how best cancer risk information can be communicated to patients during general practice consultations?
- What do service users and practitioners perceive as barriers and enablers (facilitators) to the implementation of cancer risk assessment tools?

To appropriately address the above research questions, it is important to review the conceptual background literature to understand the relevant concepts around risk, risk prediction models or tools, risk communication and related risk communication theory. Chapter Three follows next with the conceptual background literature.

CHAPTER 3 CONCEPTUAL BACKGROUND LITERATURE REVIEW

3.1 Summary of the chapter

This chapter discusses the key ideas underpinning the research, specifically policy and practice relating to primary care and issues concerning early detection of risk. It covers risk prediction models, highlighting cancer risk assessment tools for symptomatic individuals and their psychological impact when communicating risk information with individual service users. There is a more general discussion on risk communication. Relevant theories informing the research including a risk communication framework and an implementation theoretical framework are discussed.

3.2 Key points

The key points noted in this chapter include:

- Primary care policy, structure and function highlighting policies for early diagnosis of cancer
- Risk prediction models
- Cancer risk assessment tools for symptomatic individuals in primary care
- Effects of cancer risk assessment
- Communicating cancer risk information
- Theoretical frameworks informing the research including a risk communication framework and an implementation theoretical framework.

3.3 Primary care policy, structure and functions

Primary care is usually the first point of contact that service users have with a health care professional, often a general practitioner (GP), when they have an illness, injury or symptoms that are new to them. The National Health Service (NHS) provides both primary and specialist health care which is free at the point of delivery (Roland, 2012). In primary care, GPs are responsible for registered populations of patients, often working in groups of self-employed doctors working as partners in a partnership arrangement. To support their work GPs often employ non-partner (salaried) GPs, nurses and ancillary staff (Roland, 2012).

Recent reforms include a wide range of national quality improvement initiatives and a pay-for-performance scheme, the Quality and Outcomes Framework, that accounts for around 25% of family practitioners' income (Gillam & Siriwardena, 2011). The four countries of the UK differ in some important aspects of health care organisation, but generally in the United Kingdom patients can access primary care services through their local general practice, community pharmacy, optometrist or dental surgery.

Services are usually provided free-of-charge through the NHS, and patients do not usually have direct access to specialists or consultants in secondary care, as this is controlled by GPs (Royal Commission on the NHS Chapter 7, 1979), which is referred to as ‘gatekeeping’. Critics have called for this ‘gatekeeping’ policy to be revisited to accommodate the government’s aim of modernising the NHS and giving patients more choice (Greenfield et al., 2016). Such calls are yet to materialise, because any relaxation of the gatekeeping policy needs to be evaluated to ensure the clinical and non-clinical benefits outweigh the costs (Greenfield et al., 2016).

The functions or activities of GPs, community pharmacists and other primary care service providers include primary or secondary prevention. Primary prevention entails avoidance of disease through measures including immunisation and smoking cessation. Primary care practitioners also provide secondary and tertiary prevention, that is, prevention of recurrent disease and long-term complications respectively, through providing support for people with long term conditions.

Overall, the evidence suggests important services provided by primary care include: comprehensive and accessible first point of contact care for all members of a community; continuous person and family focussed care with opportunities for choice; effective and systematic management of chronic or long-term diseases; and referral to and coordination of outpatient and inpatient specialist care as and when appropriate.

The primary care function of referral to and coordination of specialist care is important for this research, as it relates to early detection of cancer risk and referral for investigations and early diagnosis. The policy relating to early diagnosis of cancer is discussed below.

3.3.1 Early diagnosis of cancer policy

From a broad perspective, the World Health Organisation (WHO) recognises that early diagnosis of cancer can increase the chances for successful treatment by focusing on detecting symptomatic patients as early as possible (WHO, 2017). The WHO also regard early diagnosis as an important public health strategy in all settings, as it can help to improve cancer outcomes by providing care at the earliest possible stage (WHO, 2017).

Specifically, in the UK, evidence suggests that cancer patients in England have more advanced disease by the time they are diagnosed (Coleman et al., 2011; De Angelis et al., 2014) compared with patients using other healthcare systems in Europe (DH, 2007). To reduce the gap between England and the rest of Europe, the Department of Health introduced several policy actions to improve early diagnosis, which together is estimated would help save about 5000 lives a year (DH, 2011). Relevant among these policy actions was the introduction of National Awareness and Early Diagnosis Initiative (NAEDI) policy which had several aims (DH, 2007): increasing awareness among the public and healthcare professionals to recognise and detect early signs and symptoms of cancer; encouraging people with symptoms to seek early advice, and supporting primary care professionals to contribute to effective referral and diagnosis of cancer.

A national audit of primary care was also developed to identify the support that would help GPs to identify potential cancers earlier. These initiatives supported primary care services by improving access to diagnostic technologies and urgent referral pathways for suspected cancer (DH, 2007). These diagnostic technologies relate most importantly to risk prediction models. Relevant risk prediction models that may be used in primary care general practice settings to aid early detection of risk are discussed below.

3.4 Risk prediction models

Risk has been described as the possibility of losing something of value, such as physical and emotional health and well-being (Kungwani, 2014). Risk has also been described as an intentional interaction with uncertainty (Cline, 2005). Uncertainty here refers to a potential, unpredictable, and uncontrollable outcome (Cline, 2005).

A risk prediction model is designed to predict the probability of a condition occurring among individuals or groups, using a combination of known factors (Usher-Smith et al., 2015). Risk prediction or assessment tools represent how risk prediction models are implemented in clinical practice (Usher-Smith et al., 2015). Examples of risk prediction tools include the: Cardiovascular Disease (CVD) risk prediction tools such as the Framingham Equation (Wilson et al., 1998; D'Agostino et al., 2008) and QRisk (Hippisley-Cox et al., 2008); osteoporosis (fracture) risk assessment tools such as the FRAX (Kanis & WHO Scientific Group, 2008) and QFracture (Hippisley-Cox & Coupland, 2009; Hippisley-Cox & Coupland, 2012); diabetes risk assessment tools such as the Diabetes UK ‘Know your risk’ tool and QDiabetes (Hippisley-Cox and Coupland, 2011); kidney failure risk assessment tool [QKidney] (Hippisley-Cox and Coupland, 2010); and cancer risk prediction tools such as the Hamilton Risk Assessment Tool [RAT] (Hamilton, 2009), QCancer (Hippisley-Cox & Coupland, 2011; Hippisley-Cox & Coupland, 2012; Hippisley-Cox & Coupland, 2013) and the Electronic Clinical Decision Support (eCDS) tools (Green et al., 2015; Macmillan Cancer Support, 2015), which are the focus of this research.

There are also the National Institute for Health and Care Excellence (NICE) guidelines, which are not risk assessment (or prediction) tools, but are used to support clinical decision-making in primary care consultations. Several NICE guidelines are available to patients and health professionals to support early detection of risk and diagnosis of a range of conditions including cancer, diabetes and cardiovascular disease. For example, the NICE guidance for the early detection and treatment of cancer advises primary care practitioners to request specific blood tests for patients with symptoms suggestive of certain cancers (DH, 2011).

Regarding the use of risk assessment tools there are several challenges, which are particularly the case with cancer risk assessment tools, in setting thresholds for investigation and specialist referral. To improve early diagnosis of cancer, and to avoid missing individuals with cancer, a low threshold might be set for further assessment of symptomatic patients. Although a low threshold risk may increase case selection for screening, preventive measures and investigation for suspected cancer, this might also increase the risk of over-investigation, over-diagnosis and potentially unnecessary or harmful procedures (Usher-Smith et al., 2015).

There are other common challenges to using these risk assessment tools and communicating the risk generated to patients. For example, evidence about challenges relating to the use of CVD risk prediction tools include: lack of time, poor knowledge or understanding of the tools, the perception that clinical judgement is as good as or better than risk tools, uncertainty about how to account for risk factors perceived to be important but not included in the tools and poor computer software (Van Steenkiste et al., 2004; Müller-Riemenschneider et al., 2010). Similarly, in the use of cancer risk assessment tools particularly for symptomatic individuals, there may be challenges of how to make the tools accessible or available to clinicians, while presenting the risk information in a format that can easily be understood by practitioners and patients (Usher-Smith et al., 2015). For example, one study found that when using a risk assessment tool, GPs were inconsistent in their interpretation of symptoms, had trouble introducing the tool into the consultation process, or were sometimes reluctant to use the tools for fear of alarming or frightening patients if the risk information was presented too explicitly (Chiang et al., 2015).

Furthermore, in communicating risk, the format in which risk information is presented is an important aspect of risk assessment tools. The format affects both clinicians' use of the tool and patients' understanding and perception of risk. Evidence from the study cited above, which involved GPs and simulated consultations using QCancer (a cancer risk assessment tool), suggested that GPs may prefer traffic-light colour coding of risks (red, amber and green) with secondary access to the numeric risks, rather than being presented with absolute numeric risks or diagnostic guidance (Chiang et al., 2015).

Similarly, in terms of how best to present risk information to patients, evidence from CVD risk assessment suggests that numerical presentation of risk rather than simple risk categories, and timeframes <10 years lead to more accurate risk perceptions (Waldron et al., 2011; Usher-Smith et al., 2015). On the other hand, presenting relative risk reductions maximises acceptance of treatment and ‘heart age' appears to increase intention to change behaviour (Waldron et al., 2011). Since cancer risk assessment tools for symptomatic individuals are the focus of this study, a further discussion of these are detailed below.

3.5 Cancer risk assessment tools for symptomatic individuals in primary care

As mentioned earlier, cancer risk assessment tools are novel tools that have been developed to identify and quantify cancer risk in people with initial symptoms to aid early detection of cancer in primary care. These include the Risk Assessment Tool [RAT] (Hamilton, 2009) and QCancer (Hippisley-Cox & Coupland, 2011; Hippisley-Cox & Coupland, 2012; Hippisley-Cox & Coupland, 2013). The RAT, which was initially developed as a desktop tool, but now available in electronic version, was initially used for assessing risk of colorectal and lung cancers (Hamilton, 2009), but now covers several cancers. The desktop version of the RAT tables is printed on a mouse mat or a desk easel, and contains the risk values for each symptom in isolation, and repeat attendances at the general practice with the same symptom and in combination with one other symptom.

The QCancer tool provides specific risks of different cancers according to combinations of baseline risk factors: age, body mass index (BMI), smoking, family history and alcohol, current symptoms and specific clinical conditions (Hippisley-Cox & Coupland, 2012). QCancer predicts the risk for a broad range of more than 10 different types of cancer as listed in Box 2.

Box 2 List of QCancer predicting cancers

- Colorectal cancer
- Gastro-oesophageal cancer
- Pancreatic cancer
- Blood cancers
- Lung cancer
- Renal track cancer
- Testicular cancer
- Breast cancer
- Uterine cancer
- Ovarian cancer
- Cervical cancer
- Other cancers (including some rare cancers)

Many of these cancers such as colorectal, gastro-oesophageal, lung, haematological, renal, pancreatic and ovarian cancers, often present with vague and overlapping symptoms. The symptoms included in the QCancer calculator are those symptoms which the patient has been sufficiently concerned about and has decided to consult a GP. Two calculators, one for women and another for men, have been developed (Hippisley-Cox & Coupland, 2013). The QCancer calculators for men and women may be used in two main ways in primary care: within a doctor-patient consultation and in a batch processing mode.

Within a doctor-patient consultation, QCancer can be used to calculate the absolute risk of symptomatic patients either having or developing a currently undiagnosed cancer within two years. This can be done by entering all the data required directly into the QCancer calculator or by using QCancer integrated into the clinical computer system. Many of the variables needed for the calculation are already recorded in the patient’s underlying electronic medical record whilst others can be entered during the consultation. The results from the calculation can be shared with the patient and further investigations or referral can be considered between the patient and practitioner.

When using QCancer in a ‘batch processing’ mode, the calculation is performed automatically with data already in the electronic medical record. A risk profile for each patient is generated, which can be stored in the medical record or an ancillary table and can then be used to sort patients per their overall cancer risk or risk of an individual type of cancer. Below is an illustration of how QCancer estimates cancer risk based on the risk factors and symptoms presented by a patient.

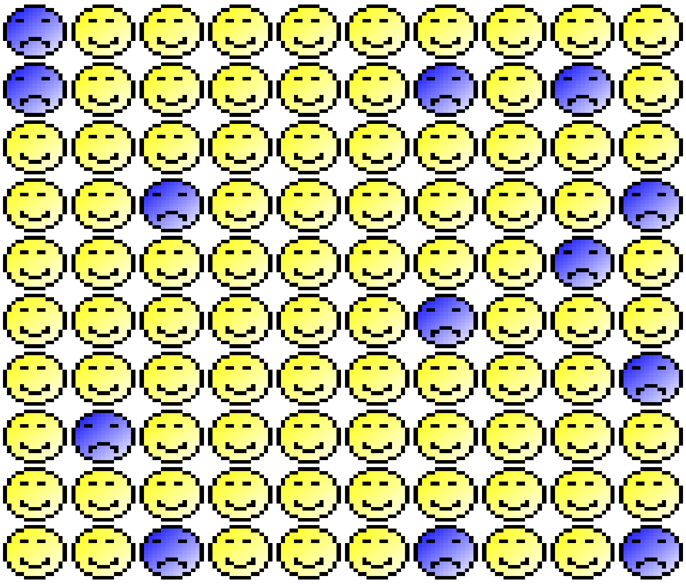
An illustration of how the QCancer tool estimates cancer risk
Imagine:

- A 55-year old woman (height 172 cm, weight 85kg)
- Living in Lincoln (postcode - LN6 7TS)
- Moderate smoker 10-19 cigarettes/day
- Abdominal pain, abdominal swelling, indigestion
- What is her risk of developing cancer in the next 2 years?
- How does this compare with a typical person of the same age and sex without symptoms?

By entering the above patient data in the QCancer calculator, the following data will be generated as represented in Figure 2 below:

Figure 2 Vignette (example) of QCancer risk scores

- No cancer 86.83% represented by the yellow smiley faces
- Any cancer 13.17% represented by the blue sad faces



Estimates for the individual cancers

- Ovarian 9.16%
- Other 1.46%
- Colorectal 0.58%
- Pancreatic 0.55%
- Gastro-oesophageal 0.43%
- Lung 0.41%
- Breast 0.24%
- Renal tract 0.11%
- Blood 0.11%
- Cervical 0.09%
- Uterine 0.04%

Your QCancer® score	13.17%
The score of a typical person with the same age and sex[*]	0.79%
Relative risk[**]	16.7

The QCancer model has been internally validated in terms of finding the cancers it was designed to predict. In other words, the developers of QCancer (Hippisley-Cox & Coupland, 2011; Hippisley-Cox & Coupland, 2012; Hippisley-Cox & Coupland, 2013) tested it using rigorous statistical techniques with general practice patient data from QResearch, a large primary care database. The QCancer tool has also been independently tested using a database different from the database used for the development of the tool, and found to accurately predict a range of cancers (Collins & Altman, 2012; Collins

& Altman, 2013). Box 3 below presents details of the RAT and QCancer tools (Usher-Smith et al., 2015).

Box 3 Details of the RATs and QCancer series risk prediction tools for symptomatic individuals

The Risk Assessment Tools	• Designed to be used in symptomatic populations presenting to primary care. • Developed from case–control studies in primary care. • So far, tools for 14 separate cancer sites have been published (colorectal, oesophageal, lung, ovarian, kidney, bladder, pancreas, breast, uterine, brain, prostate, Hodgkin lymphoma, non-Hodgkin lymphoma and multiple myeloma). • Provide risk estimates for patients with single symptoms of possible cancer, pairs of symptoms and repeat attendances with the same symptoms
The QCancer series	• Hybrid models that can be used both in symptomatic and asymptomatic populations. • Developed in the QRESEARCH database, a large database comprising over 12 million anonymised health records from 602 general practices throughout the United Kingdom using the EMIS (Egton Medical Information Systems) computer system. • Six models have been published for symptomatic populations (for colorectal, gastro-oesophageal, lung, renal, pancreatic and ovarian cancer), plus models predicting risk for multiple cancers for males and females. • Provide estimates of absolute risk of any cancer with a breakdown of type of cancer based on both risk factors such as age, gender and family history, which increase the likelihood of cancer, and risk markers such as haemoptysis or weight loss, which are features, usually symptoms, suggesting that cancer is already present. • Available on line at www.qcancer.org.

Adopted and modified from: Usher-Smith et al., 2015

In 2012/13, funding was provided by NAEDI for the e-RAT and QCancer to be put together as electronic Clinical Decision Support (e-CDS) tools and to be made available as widely as possible to GPs (Green et al., 2015). The tools each consist of three components namely: (i) on-screen prompts that display calculated cancer risk in percentage format and flash up on the computer screen during consultation; (ii) an interactive risk calculator, which is accessed from a drop-down menu at the top of the prompts box. GPs can then enter new symptoms and re-calculate cancer risk during consultation; and (iii) tables of patients with calculated Positive Predictive Values (PPV), which enables GPs to review the cancer risk of their practice population. The project was managed by Macmillan Cancer Support, while Cancer Research UK (CRUK) funded the evaluation of the project (Green et al., 2015; Usher-Smith et al., 2015).

In terms of how the tools can be used, it has been suggested that, the relevant cancer risk assessment tools (e.g. RAT and QCancer) can be either integrated into clinical computer systems or used as standalone/web-based electronic tools such as the Disease Risk Index developed by the Harvard School of Public Health (Usher-Smith et al., 2015, Macmillan Cancer Support, 2015). The output can be presented either as absolute or relative risk, rank or peer comparison, with more sophisticated tools presenting risk in a variety of formats along with the potential impact of risk-reducing interventions.

For patients with symptoms, these tools can then be used to guide investigation and referral. Consequently, working in collaboration with Macmillan Cancer Support, BMJ Informatica developed the e-CDS tools within general practice computer systems to provide three functions for GPs (Usher-Smith et al., 2015, Macmillan Cancer Support, 2015): (a) Prompts during consultations if patients have a risk of 2% (adjustable) for the different cancers e.g. lung, colorectal, pancreatic, ovarian or oesophago-gastric cancer; (b) A series of ‘symptom checkers’ for patients in whom GPs have identified symptoms suggestive of cancer, which enable them to enter additional symptomatic information and update the cancer risk estimates; and (c) A risk stratification tool intended for use separately from consultations. Working as an audit tool, it allows practices to generate lists of all registered patients in whom a risk score can be calculated and sorts them by cancer type and risk category. To provide more understanding relating to these cancer risk assessment tools, several relevant questions are discussed below.

How do these cancer risk assessment tools differ from other types of risk prediction tools, and how do they fit into the framework of predictive/prognostic tools?

I have mentioned (see page 45 above) other types of risk prediction tools such as the QRisk (a cardiovascular risk prediction tool), QDiabetes (a diabetes risk prediction tool), QFracture (a fracture risk prediction tool) etc., that operate on a similar principle as risk prediction tools designed for use in primary care. That is, these other risk tools are like the cancer risk assessment tools of interest to my research, because they may all be used to predict risk in primary care.

However, some of these tools like the QRisk are usually used for asymptomatic individuals who may be administered preventive interventions (or treatment) when a risk of disease is detected. In contrast, the cancer risk assessment tools of interest to this research are designed for symptomatic individuals who should be referred for investigation and diagnosis of cancer before appropriate treatment may be prescribed. In addition, tools like QRisk are already integrated into the general practice IT systems, while cancer risk assessment tools which are relatively newer are not yet widely integrated and used in general practice systems and consultations.

With reference to the Prognosis Research Strategy (PROGRESS) framework the cancer risk assessment tools in this study fit into the prognostic model (or predictive model) which is a combination of multiple predictors from which risks of a specific endpoint can be calculated for individual patients (Steyerberg et al., 2013). They also fit into one of the four themes of the Prognosis Research Strategy (PROGRESS) framework (Hemingway et al., 2013): the development, validation, and impact of statistical models that predict individual risk of a future outcome [prognostic model research] (Steyerberg et al., 2013), which includes cancer risk assessment tools like QCancer and RATs that predict individuals' risk of a current or future cancer.

What is the evidence that these cancer risk assessment tools will be used or are used and why they are not used?

I have discussed and referred to evidence from previous studies (Hamilton et al., 2013; Green et al., 2015; Dikomitis et al., 2015; Chiang et al., 2015) in the scoping review and discussion chapters. For example, the evidence suggests that using the tools in primary care consultations could be beneficial, although the tools are currently not widely used.

It is worth adding that the evidence from the previous feasibility studies on cancer risk assessment tools such as the eCancer Decision Support Tools (eCDS) points to potential benefits associated with the use of the tools in primary care. These potential benefits may encourage a wider implementation of the tools across general practices in the UK.

One question that arises given the evidence about potential benefits, is why the cancer risk assessment tools are not currently widely used. As found in the scoping review for this research, possible reasons may include barriers to use such as lack of integration of the tools into the general practice IT system, difficulties in terms of practitioners understanding how to access and use these tools in consultations and how best to communicate the risk information to patients once a risk is generated through using the tools.

These barriers to implementation of the tools are outlined in my scoping review as reported in previous literature (e.g. Green et al., 2015; Chiang et al., 2015; Usher-Smith et al., 2015), and were also found in the current study based on the views of service users and practitioners.

What is the precedent, or lack of it, for practitioners using these types of risk tools?

It is worth considering the precedent for practitioners using cancer risk assessment tools in primary care consultations. Similar risk tools like the

QRisk, QDiabetes, QFracture etc. are already integrated in general practice computer systems and being used in patient consultations. These serve as examples or precedent for practitioners to use cancer risk assessment tools in primary care consultations.

It is recognised here that tools like QRisk are used to identify risk in asymptomatic individuals leading to preventive interventions, while cancer risk assessment tools predict risk in symptomatic patients leading to investigations and referral for diagnosis and treatment. Despite this difference, all the tools predict a risk of an individual's disease or health problem and the risk information is then communicated to the individual. Hence, the current use of QRisk in UK primary care serves as a precedent that cancer risk assessment tools can be successfully implemented, if due processes are followed.

What is the actual place these cancer risk assessment tools could have in practice?

For the actual place of these cancer risk assessment tools in practice, using the Macmillan electronic cancer decision support tools (eCDS) tools, Usher-Smith et al. (2015) outlined potential ways by which the tools could be used by practitioners in clinical practice.

One way is that, the tools could be used as prompts during consultations if patients have a risk of ≥2% (or whatever risk is chosen as the threshold) for lung, colorectal, pancreatic, ovarian or oesophago-gastric cancers, using information added as read-codes in the past. That is, when the tools are integrated in the general practice system and activated during a consultation, practitioners could be alerted of a potential cancer. Practitioners may then apply the NICE guidelines to activate an urgent referral or, if appropriate, make a normal referral. Practitioners could use these tools when they are in doubt, when the presenting symptoms are not clear, or when they are considering cancer as a differential diagnosis. Using these tools practitioners could then be alerted to investigate a patient's symptoms based on their quantified risk information even if the patient does not qualify for urgent referral.

Another way of using the tools is through a series of ‘symptom checkers’ for patients in whom GPs have identified symptoms suggestive of cancer, which enable them to enter additional symptomatic information and update the cancer risk estimates.

The tools could also be used to stratify the risk of patients outside a consultation. That is, for auditing, the tools could be used by practices to generate lists of all registered patients in whom a risk score can be calculated and sorted by the likely cancer type and risk category.

It is also possible for the tools to be used to help monitor the risk level in patients who have been referred but turned out (initially) to be false positives (i.e. no immediate cancer diagnosis). Such patients can be advised on life style and other health risk modifications with the hope of reducing the initial risk to a lower (less harmful) level.

What is the difficulty in how patients and practitioners perceive different levels of risk presented by the tools and the consequence of this?

One difficulty in perception of the different levels of risk is that patients could be concerned about or even frightened when a low risk of cancer is generated using the tools, which practitioners may consider too small to act. This can happen if a risk level is not framed well by a practitioner during communication with patients who may perceive a relatively low level of risk as high. Therefore, the use of the tools can be difficult for both patients and practitioners, especially around understanding and communicating a risk generated.

Another difficulty is the possibility of false positives and negatives which can lead to over-referral and under-referral respectively for investigations and diagnosis. This can result in unnecessary worry or anxiety on the part of patients, and practitioners may also be concerned about the consequences of these false positives and negatives and the resulting pressure on limited human and material resources.

How do other types of risk prediction tools actually work?

Other risk prediction tools like QRisk, a cardiovascular disease (CVD) risk prediction tool, estimate a patient's 10-year risk of developing cardiovascular disease [CVD] (Hippisley-Cox et al., 2008). This tool is used in the United Kingdom to identify high-risk people aged 30-84 years for primary prevention, calculating risk compared with the contemporary UK population, adjusted for variables such as obesity, social deprivation, ethnicity, rheumatoid arthritis and current treatment with anti-hypertensive drugs. It has been validated in the UK and is being updated every year to ensure that it takes account of changes in the population, improvements in data quality and changes in national guidelines and requirements (Tidy, 2016).

Other CVD risk calculators are based on the Framingham risk equation, but it is thought that such tools have a limitation in terms of overestimating risk by about 5% for UK populations of men (Collins & Altman, 2012). Although the QRisk score is relatively less well established than the Framingham score, the wide range of advantages of QRisk (stated above) may explain why it is more widely integrated into all major GP computer systems and included in national guidelines (Tidy, 2016). This may also explain why it is preferred in the UK over the other CVD risk tools such as ETHRISK and other coronary risk prediction tools (e.g. ASSIGN, Reynolds risk score and INDANA etc). Other risk prediction tools, such as those for frailty; falls; dementia and admission, work slightly differently. These are discussed further.

Frailty risk tools include the QFrailty categories (Hippisley-Cox & Coupland, 2017), Electronic Frailty Index [eFI] (Clegg et al., 2016) and the LASA-Frailty Index [LASA-FI] (Hoogendijk et al., 2016). These tools work by grouping individuals into four categories: fit, mild, moderate and severe frailty, for example, in the QFrailty score based on an individual’s absolute risks of an unplanned hospital admission or death within a year (Hippisley-Cox & Coupland, 2017).

Similar to the QFrailty score, the eFI score is calculated by the presence or absence of individual deficits as a proportion of the total possible (Clegg et al., 2016). This frailty risk tool aids identification of older people who are fit, and those who have mild, moderate and severe frailty. Hence, using the eFI tool, increasing severity of frailty suggests an older person is at increased risk of future nursing home admission, hospitalisation, longer length of hospital stay, and mortality (Clegg et al., 2016).

The falls risk assessment score is considered better than other falls risk tools in primary care because it is able to discriminate between multiple and non-multiple fallers; it identifies people at increased risk of multiple falls based on multiple performance items or risk factors including: low contrast visual acuity, tactile sensitivity, sit to stand, alternate step, and near tandem stand ability; and measures of previous falls and medications (Tiedemann et al., 2010). The ability of this tool to identify multiple falls is important since multiple falls within a 1-year period are more predictable and are likely to indicate underlying physiological impairments and chronic conditions (Newitt et al., 1989; Lord et al., 1994).

Like the frailty risk tools mentioned above, admission risk tools such as the QAdmission tool can be used to assess individuals' risk for hospital admission. However, unlike the frailty risk tools, the QAdmission tool predicts an individual's risk of emergency admission to hospital over the next one or two years based on a patient's variables record including age, sex, ethnicity, and clinically relevant variables such as diagnoses, medication, prior admissions and laboratory measurements (Hippisley-Cox & Coupland, 2013). Hence, the QAdmission tool operates by identifying patients at high risk of an emergency admission for further assessment and management to reduce their risk of hospital admission.

As for the cancer risk assessment tools, dementia risk scores work by predicting an individual's risk of developing dementia. For example, the 5-year dementia risk score derived from primary healthcare data, can be used to predict a risk of dementia based on several risk factors: age, sex, social deprivation, smoking, BMI, heavy alcohol use, anti-hypertensive drugs, diabetes, stroke/TIA, atrial fibrillation, aspirin, depression (Walters et al., 2016).

How are these cancer risk assessment tools based on 'partial knowledge'?

In the development of the QCancer algorithms there is a possibility of missing data, since not all patients with symptoms will attend their GP, and in those who do, not all symptoms will be reported or recorded by practitioners (Hippisley-Cox & Coupland, 2012). This could have resulted in an overestimate of the hazard ratios if they were derived from more severe symptoms, or an underestimate, if symptoms were not recorded (Hippisley-Cox & Coupland, 2012).

The cancer risk assessment tools of interest to this research are based on specific knowledge of risk factors. There are other risk factors which may not be recorded or added to the calculation of a patient's cancer risk during consultation. One factor is genetic, for example the Breast Cancer (BRCA) genes. Recent estimates indicate that 55 to 65 percent of women who inherit a harmful *BRCA1* mutation and around 45 percent of women who inherit a harmful *BRCA2* mutation will develop breast cancer by the age of 70 years (Antoniou et al., 2003; Chen & Parmigiani, 2007). Environmental factors such as exposure to carcinogens like asbestos and soot are also important cancer risk factors. In fact, individuals who experienced consistent exposure to asbestos were found to have increased risk of mesothelioma. Yet, these environmental factors have been excluded in the cancer risk prediction algorithms, which may therefore underestimate risk of cancer in some individuals with histories of asbestos exposure. Another example relates to behavioural factors, e.g. exercise and diet, which are known to increase a person's cancer risk (America Cancer Society, 2017).

The use of these risk assessment tools may have psychological impacts for individual service users, patients and their carers or families. Such psychological issues related to risk assessment are discussed below.

3.6 Effects of cancer risk assessment

Many individuals may express distress in the form of anxiety or depression when told about being at risk of developing a disease. Some level of distress may be useful in terms of promoting participation in risk assessments and adherence to risk related advice (Shaw et al., 1999). However, excessive distress can be harmful in many ways including: reducing individuals' quality of life; reducing understanding of information leading to poor informed decision-making about treatment options (Lerman & Croyle, 1995); and reducing participation in future risk assessment programmes (Kash et al., 1992; Lerman et al., 1993). Evidence from a systematic review of the psychological impact of predicting individuals' risks of illness found several effects of positive test results including: increased anxiety; depression; psychological distress; intrusive thoughts; poor perception of health and absenteeism (Shaw et al., 1999).

In this systematic review, the receipt of positive test results relates to a short-term increase in anxiety (Bennett et al., 1990; Ironson et al., 1990; Huggins et al., 1991; Wardle et al., 1995; Bennett et al., 1995; LaPerriere et al., 1990; Croyle et al., 1997). However, the anxiety disappeared or decreased in the long-term (Ambrosio et al., 1984; Rudd et al., 1986; Perry et al., 1993; Jadresic et al., 1994; Pugh et al., 1994). This suggests that risk assessment related anxiety could be more of a problem in the short-term than in the long-term.

Similarly, depression can be a problem in the short-term (Wiggins et al., 1992; Bloom & Monterossa, 1981; Antoni et al., 1991; Huggins et al., 1991; LaPerriere et al., 1990; Lerman et al., 1996; Croyle et al., 1997) following the receipt of a positive result for a risk assessment. Psychological distress also increased shortly after test results were given (Wiggins et al., 1992; Soghikian et al., 1981; Monk, 1981; Kash et al., 1992; Wardle et al., 1995; Reelick et al., 1984). However, there was mixed evidence of the long-term effect of depression with some studies reporting an increase (Brandt et al., 1989; Sands et al., 1981; Fischer et al., 1990; Lerman et al., 1991; Codori et al., 1997; Quaid & Wesson, 1995;) while others reported a decrease in psychological distress (Wiggins et al., 1992; Mann, 1977).

Another psychological effect of positive test results is intrusive thoughts, which evidence suggests can increase in the short term (Ironson et al., 1990) or decrease in the longer term (Hornsby et al., 1985). Perception of poor health is also a psychological effect which is more likely to occur among recipients of positive results (Bloom & Monterossa, 1981; Houts & McDougall, 1988).

Overall, the evidence suggests that adverse psychological effects are a common immediate outcome of positive test results from risk assessment, but these disappear after about a month after receipt of test results (Shaw et al., 1999). Also, explaining the test results to the understanding of patients and providing relevant support can be useful for reducing psychological distress generated by risk assessments, particularly for positive test results (Shaw et al., 1999).

The above psychological effects of positive test results may also relate to how the risk or a test result is communicated to individuals, which is discussed in the next section.

3.7 Communicating cancer risk

Risk communication has been described as an open two-way exchange of information and opinion about risk, leading to better understanding and decisions about clinical management (Edwards et al., 2000; Edwards et al., 2001., Schwart, 1999; Mazur, 2001; Elwyn et al., 2001; O'Connor et al., 2001; Wilson et al., 1988). This definition distances itself from the views that information is communicated only from clinician to patient and acknowledges that acceptability (or not) of the risk is communicated back (Edwards et al., 2002).

Similarly, risk communication has been defined as the "process of exchanging information among interested parties about the nature, magnitude, significance, or control of a risk" (Covello, 1992:359). Other definitions of risk communication emphasise the need for dialogue between communicators and stakeholders (Palenchar, 2005), and the need for ongoing risk monitoring (Coombs, 2012).

This dialogue refers, for example, to the discussion between a primary care practitioner and a patient about a result indicating a high risk of cancer. This may lead to the practitioner having to share some relatively unexpected or unpleasant information with a patient, which may be described as ‘breaking bad news’.

Bad news has been described as information that affect an individual’s view of his or her future in an adverse way (Buckman, 1992). Breaking bad news to cancer patients has been described as “hitting the patient over the head” or “dropping a bomb” (Miyaji, 1993). Breaking bad news can be more stressful with a less experienced practitioner, when the patient is young, or if the treatment options are limited in their prospect of success (Ptacek & Eberhardt, 1996).

Despite the unpleasant nature of bad news, patients may still want to hear the truth. Since the late 1970s many practitioners have approached cancer patients with openness when telling them about their diagnosis (Novack et al., 1979). However, evidence suggests that patients often desire additional information (Edwards et al., 2002). A study involving 1,251 Americans found 96% desired to know if they had a diagnosis of cancer, while 85% wished to be told realistically how long they had to live (Morris & Abram, 1982), and these findings are supported by several other studies from the United States (Ley,1982; Cassileth et al., 1980; Blanchard et al., 1988; Davison et al., 1995; Sutherland et al., 1989; Dunsmore & Quine, 1995; Benbassat et al., 1998). Patient expectations for additional information have not always been met (Degner et al., 1997; Davidson et al., 1999; Hoffman et al., 1997; Lobb et al., 1999). The wishes of European patients for further information in addition to the diagnosis are like those expressed by American patients: for example, a study involving 250 patients recruited from an oncology centre in Scotland revealed 91% and 94% of patients, respectively, desired to know the chances of cure for their cancer and the side effects of treatment (Meredith et al., 1996).

There are also ethical and legal imperatives driving patient – practitioner communication which relate directly to the problem of risk communication. The principles of informed consent and patient autonomy oblige doctors to provide patients with as much information as they desire about their illness and related treatment (Goldberg, 1984; Annas, 1994). In other words, GPs are expected to share medical information with the patient who requests it even if negative effects on the patient are anticipated. However, disclosing the truth needs to be done with concern for the sensitivity and the obligation to support the patients in their decision-making process; otherwise, the patient can be as upset as not being told the truth (Lind et al., 1989).

Other barriers to communicating risk to patients are due to difficulties of breaking bad news on the part of the bearer of bad news. In the view of Tesser et al. (1971), the bearer of bad news may experience stress in the form of strong anxiety and a burden of responsibility for the news. This can lead to a reluctance to deliver bad news - the so-called “MUM” effect (Tesser et al., 1971), particularly when the recipient of the bad news is already distressed (Tesser & Comlee, 1973). These risk communication problems may be more apparent when it comes to delivering bad news of possible cancer to patients (DelVecchio-Good et al., 1990; Buckman, 1984).

The format for presenting risk information is crucial, as it affects both clinicians’ use of the tool and patients’ perception of risk (Usher-Smith et al., 2015). As mentioned earlier, a study with GPs and simulated consultations using the QCancer tool found that GPs preferred traffic-light colour coding of risks (red, amber and green) with secondary access to numeric risks, rather than initially being presented with absolute numeric risks or diagnostic guidance (Chiang et al., 2015). Despite this finding, it is possible that GPs may differ in their preferences and such preferences may change over time with different patients, so it is not entirely clear how best to present risk information to patients (Usher-Smith et al., 2015). From the field of cardiovascular disease, it is known that numerical presentation of risk rather than simple risk categories together with time-frames of 10 years lead to more accurate risk perceptions (Usher-Smith et al., 2015). On the other hand, presenting relative risk reductions maximises acceptance of treatment and ‘heart age’ appears to increase intention to change behaviour (Waldron et al., 2011).

Further problems of risk communication relate to the risk language, as terms like probably, unlikely and rarely may convey “elastic” concepts (Schydlower et al., 1995). That is, one person may interpret “likely” as a chance of 1 in 10, while another may understand it as a chance of 1 in 2 (Edwards et al., 2002). Also, there could be problems with the interpretation of numerical information. For example, Yamagishi found that death rates of 1286 out of 10 000 were rated as riskier than rates of 24.14 out of 100 (Yamagishi, 1997).

In addition, the interpretation of the probabilistic elements of risk cannot be divorced from the importance of the harm, which includes the meaning of the harm and its implications for lifestyle and health (such as the threat of cancer). To standardise the language of risk, a scale with standardised terms for specified frequencies (for example, “high” for risks of 1 in 100 or greater and “moderate” for between 1 in 100 and 1 in 1000) has been proposed (Calman & Royston, 1997; Paling, 1997) to familiarise the public and professionals with different risks. This could have many advantages, although language evolves and patients may not interpret such standardised terms consistently over time (Edwards et al., 2002).

Another risk communication problem arises from framing effects, due to different patient perceptions of prognosis depending on whether survival or mortality data are used (Wilson et al., 1988). Framing effects are also used to encourage individuals to adopt a course of action, such as pharmaceutical companies using persuasive techniques to present effects of their drugs to professionals. Similarly, a study on mammography revealed that using only information on relative risk was more “effective” in encouraging uptake (Slater, 1998). While this may seem appropriate in some situations, such as maximising public health gain, using framing effects or persuasive approaches may conceal the whole truth, which is inconsistent with genuine informed decision making (Elwyn & Edwards, 2001). Although these problems can affect the effectiveness of risk communication, adhering to recommended principles (outlined below in Box 4 below) can eliminate or minimise the impact of risk communication problems.

Box 4 Principles for effective communication of risk information

- Relative risk should not be presented in isolation. May use both absolute and relative risk formats, and information should be presented clearly.
- It is advisable to present information as absolute risk such as percentages or integers (Skolbekken, 1998).
- Present as ‘number needed to’, for example: Number needed to treat (NNT) and Number Needed to Harm (NNH). Number Needed to Screen, Number Needed to Test, and Number (of tablets) Needed to Take (NTNT) to Prevent an adverse outcome (Skolbekken, 1998).
- Visual presentation of risk information. Many patients might prefer simple bar charts to other formats such as thermo-meter scales, crowd figures (e.g showing how many of 100 people are affected), survival curves, or pie charts (Lipkus & Hollands, 1999; Fortin et al., 2001).
- Avoid overload of information. Many patients express a strong desire for information (Ende et al., 1989), but people's ability to assimilate information varies. Hence, it is useful to consider providing and discussing information over several consultations.
- Risk information relevant to individuals is more valuable than average population data (Edwards et al., 2000).
- Decision aids e.g booklets, tapes, videodiscs, interactive computer programs, or paper-based charts, may help to present and discuss risk information with patients (O'Conner et al., 2001).
- Paper based graphs can be used to support discussions with patients (Edwards et al., 2002).
- Patients could be referred to sources like the Database of Individual Patient Experiences, the UK National Electronic Library for Health, and Health Crossroads (Edwards et al., 2002).
- Time is a problem in the short term. External sources may enable much of information gathering from outside consultations. Discussions will still be required, but an investment of time at the decision-making stage may result in more succinct discussions in the future - and then save time.

In addition to the above principles, the application of relevant risk communication theories might contribute to effective risk communication. Relevant risk communication theories for this study are presented below.

3.8 Theoretical models that support effective risk communication

From the perspective of this research, two theoretical models of risk communication are considered: the heuristic-systematic model (Griffin et al., 2002) and the risk analysis [risk perceptions and communication unplugged: 20 years of process] framework (Fischhoff, 1995). Although these theoretical models are both relevant to the research, more attention will be paid to the risk analysis framework (Fischhoff, 1995), because, despite its inherent irony, it provides helpful strategies to support how cancer risk information may be best communicated to patients in primary care consultations.

3.8.1 The heuristic-systematic model

The heuristic-systematic model helps communicators like primary care practitioners to understand the connections between a person’s desire for accurate and sufficient information and their drive or ability to process that information (Griffin et al., 2002).

While the heuristic part of the model looks at how individuals use superficial cues such as colour, visual information, or identity of the source to process information, the systematic part of the model looks at how individuals comprehensively analyse information to understand it (Sheppard et al., 2012). Hence, the overall model states that individuals will use superficial cues and/or comprehensive strategies in accordance with the risk situation. A review of three case studies investigating suspected cancer clusters in individuals found that superficial cues were associated with a lower evaluation of risk, and that individuals who focussed on message credibility instead of message content may have perceived the risk presented as being less important (Trumbo, 2002). Additionally, being confident in one’s intellectual abilities was a good predictor of using shortcuts to make risk-based decisions (Trumbo, 2002).

Similarly, a study involving over 1,000 telephone interviews of adults living in the Midwestern United States found that individuals with previous knowledge (or hold strong beliefs) about the information presented were more likely to use systematic processing (Griffin et al., 2002). This suggests that, primary care practitioners with knowledge of processing abilities and interest in cancer risk may be able to adapt messages and determine how to best present complicated cancer risk information to patients.

The heuristic model concentrates on how people use cues to make sense of information. This could be useful for patients understanding of risk information, but it does not help to understand how practitioners can best communicate risk information to patients. The risk analysis framework discussed below clearly outlines potential risk communication strategies as stages of risk communication, helping to explain how cancer risk information might be communicated to patients.

3.8.2 The risk analysis framework

The risk analysis framework consists of 8 developmental stages derived from a review of the history of risk communication research and practice over 20 years (Fischhoff, 1995). The 8 stages or strategies are stated, partly ironically, with each stage being built on the previous stage as discussed in detail below.

1. Get the numbers right

This communication strategy places emphasis on accuracy of the risk, with no intention to mention the risk involved in a situation. Primary care practitioners may sometimes perceive they are experts who understand risk and may not see the need to tell a patient about their specific risk, or may feel that the risk is too small to tell a patient (Fischhoff, 1995). However, this approach can be problematic if the risk results in a complication and the patient questions why the risk was not mentioned in the first place. This ethical principle of autonomy advocates that it is important to covey to patients the right and accurate information.

2. Tell them the numbers

This stage is about telling patients what the risk is, especially if this is demanded by the patient, but suggests this is done without offering any explanation. How well practitioners tell patients about the numerical risk numbers will depend on the accuracy of the numbers.

There can be problems here depending on how the risk number is framed and presented, as there can be uncertainty and misinterpretation by patients. The uncertainty and misinterpretation can lead to mistrust, worry, anger and refusal to cooperate with investigations (Fischhoff, 1995). It is also possible that the patient will just follow instructions from the practitioner without questioning, which could mean a decision-making process which does not involve the patient. Hence, any unwanted consequences (e.g. anxiety or depression) experienced by patients following a misinterpretation of the results, in the case of a cancer risk assessment in general practice, can be blamed on the lack of explanation by practitioners. The next communication strategy that follows telling the numbers is about explaining what the numbers mean as discussed below.

3. Explain what we mean by the numbers

Relating this stage to the previous (second stage above), when the numbers told patients are not self-explanatory or understandable to patients, practitioners should explain them. Depending on the approach used, the explanation could end up confusing patients if technical or professional jargons are used, or expressions of uncertainty (Funtowicz & Ravetz, 1990) show up in the process of explaining what the risk numbers mean.

While it is important for practitioners not to hide any information from patients, it is possible for patients to remain uncertain and even begin to question the risk information presented to them (Fischhoff, 1995). Hence, telling more than necessary information to the patient may not be helpful. Practitioners need to tell patients only about the risk information they need to know, although that will require thinking and knowing more about individual patient circumstances

(Fischhoff, 1995). It can be difficult to select the information patients need to know. However, practitioners may refer to evidence from researchers (Merz, 1991; Merz et al., 1993) who selected a decision-relevant information by creating explicit models of peoples' decisions. By applying the models to a medical procedure, Merz found that only a few of many side effects made practical sense. Hence, while practitioners should not hide any information from patients, their main concern should be to ensure the few important facts are understood by patients about their risk of a disease condition (Fischhoff, 1995).

4. Show them that they've accepted similar risks in the past

This stage relates to comparing an existing risk with a new and different risk. For example, practitioners may ask patients to accept a risk of cancer because the patient might have previously accepted a risk for cardiovascular disease. However, even when they are created with a good intention, risk comparisons can backfire, since the two risk situations may not be the same.

An example of comparison of risk is when practitioners try to impress upon a patient that there is a risk in everything (Freudenberg & Pastor, 1992), but there is limited evidence to support this claim (Zentner, 1979). Hence, comparison of risk may not be helpful for communicating risk information to individuals with different risk situations.

5. Show them that it's a good deal for them

This stage is like telling patients about the benefits of using cancer risk assessment tools and engaging in a discussion with the practitioner about possible referral for investigations. This may involve telling patients that the benefits outweigh the risk. However, there may be problems like 'framing effect' with presenting benefits versus risk. In 'framing effects' inconsistent evaluations may result from formally equivalent representations of the same trade-offs (Fischhoff, 1991; Fischhoff, et al., 1980; Hogarth, 1982; Kahneman & Tversky, 1984). For example, a health programme may appear more attractive if described with respect to the lives to be saved as opposed to lives that will be lost (Fischhoff, 1995).

Another example of framing effects is, explicitly showing the cumulative benefits of a protective measure, which may increase its attractiveness, although that can be inferred directly from its short-term benefits (Fischhoff, 1995).

Framing effects can also lead to suspicions of manipulations in the choice of frames. However, as with risk comparison in stage 4 above, the choice of frames does not necessarily indicate a bad or harmful intention, as practitioners may usually just choose to present a risk in the way that makes sense to them.

6. Treat them nicely

Individual people usually want to be treated with respect as people see disrespect as disenfranchising or disempowering. Hence, to communicate cancer risk effectively to patients, practitioners need to have a suitable demeanour, which is being recognised as a practical necessity (Fischhoff, 1995). However, treating people with respect may be a challenge in terms of knowing the best way to communicate with them, but this challenge can be addressed with training in communication skills (Fischhoff, 1995).

To effectively communicate cancer risk information to patients, in-person communication may be helpful, but this presents both pitfalls and opportunities. For example, blank looks and hostile expressions can quickly expose messages that need refinement, while adlib responses may make matters better or worse (Fischhoff, 1995). Also, nonverbal cues can support or undermine an open message. For example, nervousness over speaking can be misinterpreted as discomfort over what is being said. To help reduce or keep nervousness under control, practitioners involved in risk communication may benefit from training in presentation skills, and this can help to eliminate unnecessary suspicions (Fischhoff, 1995).

Another approach to communicating nicely and respectively with individuals like primary care patients is the act of a smooth delivery of the risk message. However, this approach may bring problems if the content of the message is inadequate, resulting in smoothness being misinterpreted as a substitute for substance (Fischhoff, 1995).

7. Make them partners

Being nice or respectful when communicating risk information is important but it is also important to make patients partners. Some people may have information to discuss or they may just want a seat at the table, and these are elements of partnership in risk communication (Hallman & Wandersman, 1992).

To encourage patient involvement when communicating risk information, practitioners should do well to ask patients for their views, and indeed, it will help to encourage patients to ask about any concerns they may wish to consider. Asking helps to redefine a relationship, in ways that recognise the public’s reality and competence (Fischhoff, 1995).

Risk information about cancer, for example, should be presented in ways that suit patients’ understanding, and if practitioners perceive things differently, then a mutually respectful relationship will provide a forum for making their case clear to patients. Additionally, regarding cancer risk information, the more people know about a technology like a cancer risk assessment tool, the more they will like or dislike it-as its true colours emerge (Maharik & Fischhoff, 1993).

Overall, it will be helpful for effective risk communication if practitioners recognise that patients are humans with emotions, and that a mutual partnership with patients is important for creating the human relations needed to avoid the social amplification of minor risks-as well as to generate concern where it is necessary (Bums & Clemen,1993; Kasperson et al., 1988).

8: All the above

Fischhoff concludes that for effective risk communication all the seven stages or strategies should be combined, while ensuring that each strategy is used as it applies to a risk situation and communication.

As mentioned above, this risk analysis model is chosen to inform this research because it more clearly informs the research question about risk communication. While the risk analysis framework presented here is meant to inform the question of how best to communicate cancer risk information, it will be useful to discuss a relevant implementation theoretical framework for informing the secondary research question about barriers and enablers to the implementation of cancer risk assessment tools. A relevant implementation theoretical framework is discussed below.

3.9 Implementation theories

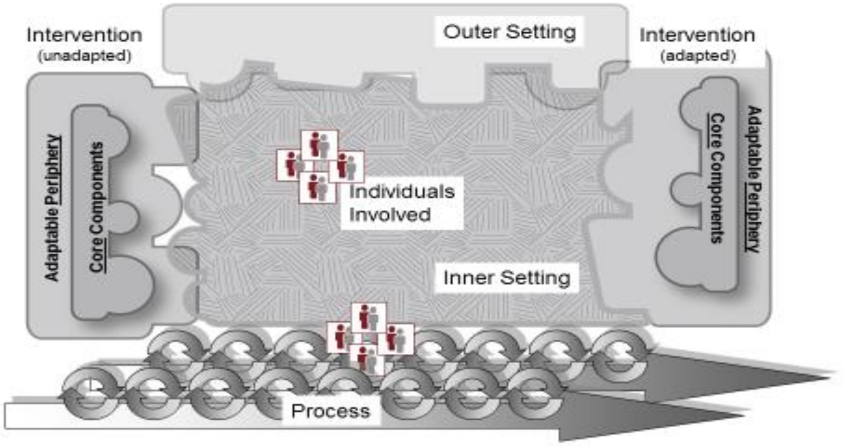
To help inform the secondary research question about barriers and enablers to the implementation of cancer risk assessment tools, some relevant implementation theories were considered. These included: Normalization Process Theory [NPT] (May, 2006), Diffusion of Innovations [DOI] (Roger, 1995) and the Consolidated Framework for Implementation Research [CFIR] (Damschroder et al., 2009). Although these three theories appeared relevant and are referenced in the discussion of the results where relevant, more details of the CFIR are presented here. This CFIR serves as the main theoretical framework for informing the barriers and enablers as reflect in the interview guide, the analysis, presentation and discussion of the results. This is because the CFIR provides a pragmatic structure which unifies and consolidates the overlapping key constructs from other relevant implementation theories through its five domains.

3.9.1 Consolidated Framework for Implementation Research (CFIR)

The CFIR is derived from 19 theories about dissemination, innovation, organisational change, implementation, knowledge translation, and research uptake (Damschroder et al., 2009). Well-suited for implementation research on health service delivery, CFIR addresses the need to assess and maximise the effectiveness of implementation within a specific context and to promote dissemination to other contexts (Damschroder et al., 2009; Kalkan et al., 2014).

CFIR can inform the implementation of innovations like cancer risk assessment tools through its five domains (Damschroder et al., 2009): intervention characteristics, outer setting, inner setting, characteristics of individuals, and process of implementation. These five domains are all important, but as recommended (Damschroder et al., 2009), the first domain of the CFIR (the intervention characteristics), and specific constructs within the remaining four domains (the outer setting, inner setting, characteristics of individuals involved and the process of implementation) which are more applicable to this study were used. The fifth concept (the process of implementation) will be more applicable to future research relating to the piloting of QCancer in primary care settings. The five domains of CFIR and the constructs within them as shown in Figure 3 are described further.

Figure 3 Main domains of the Consolidated Framework for Implementation Research



Adopted from: The Consolidated Framework for Implementation Research (Damschroder et al., 2009).

3.9.1.1 Intervention characteristics

Within the intervention characteristics, there are eight constructs that can influence the implementation of cancer risk assessment tools: intervention source, evidence strength and quality, relative advantage, adaptability, trialability, complexity, design quality and packaging and cost (Damschroder et al., 2009).

The intervention source relates to the perception of key stakeholders as to whether an innovation was developed externally (outside their own setting) or internally [within their own setting] (Damschroder et al., 2009). Potential users of cancer risk assessment tools may be more willing to implement them in primary care consultations if they believe the tools were developed within primary care, rather than outside it.

The strength and quality of evidence refers to the notion that stakeholders such as service users and practitioners may be more likely to adopt a new technology relating to cancer risk assessment tools, if they believe there is valid and accurate evidence in support of the effectiveness of the tools compared with current practice (Damschroder et al., 2009). That is, if there is evidence to suggest that using cancer risk assessment tools is linked with improvement in early diagnosis of cancer.

From the perspective of CFIR, relative advantage relates to the notion that, people may be more willing to implement cancer risk assessment tools if they perceive them to be more effective than alternatives such as existing guidelines (Damschroder et al., 2009).

In terms of adaptability, practitioners may be more likely to use the new tools if they thought that it was possible to tailor, refine or modify them to meet local needs (Damschroder et al., 2009).

Trialability relates to the possibility of testing cancer risk assessment tools even on a small scale in primary care (Greenhalgh et al., 2004), and to be able to reverse its implementation if necessary (Damschroder et al., 2009).

The complexity of an intervention might discourage people who feel it will be difficult to use (Damschroder et al., 2009). This may be due to the duration and disruptiveness during patient consultations, and the number of steps required to implement the intervention. Integrating cancer risk assessment tools in general practice computer systems to facilitate use, and how best to communicate cancer risk information to patients, without causing undue anxiety, also relate to complexity.

Design, quality and packaging might also contribute to the uptake of cancer risk assessment tools if the way the tools are presented is perceived as excellent (Damschroder et al., 2009). The final construct of the intervention characteristic is cost (Damschroder et al., 2009). This refers to costs of the intervention, implementation and opportunity costs. For example, extra consultation time and workload could represent additional costs to users of cancer risk assessment tools.

3.9.1.2 Outer setting

Outer setting is about the economic, political, and social context of an organisation (Pettigrew, 2001). Outer setting relates to the implementation of cancer risk assessment tools in terms of four constructs: patient needs and resources, cosmopolitanism, peer pressure and external policy and incentives (Damschroder et al., 2009).

Patient needs and resources relate to knowing for example, how patients want to be communicated to (Damschroder et al., 2009). This could facilitate the use of cancer risk assessment tools, as communicating risk to patients currently appears to be problematic.

Cosmopolitanism refers to the degree to which an organisation is networked with other external organisations (Damschroder et al., 2009). In this case, general practices within one network (or close networks) may influence each other to implement cancer risk assessment tools when they share their success stories about the impact or effectiveness of the tools.

Peer pressure may also play a vital role in the adoption of the new tools (Damschroder et al., 2009). This could relate to competitive pressure to use the tools because peer (e.g federated) general practices might have already implemented them or about to do so. In order, not to be left behind users may be influenced to implement cancer risk assessment tools as others have done.

Similarly, the presence of external policy and incentives can encourage the implementation of cancer risk assessment tools in the primary care setting (Damschroder et al., 2009). For example, a government policy relating to pay-for-performance or some other funding in support of implementation of the tools may encourage or promote their use among practitioners.

3.9.1.3 Inner setting

The inner setting is described as the features of structural, political, and cultural contexts through which the implementation process will proceed (Pettigrew, 2001). There are five constructs in the inner setting domain that may influence the implementation of cancer risk assessment tools: structural characteristics; networks and communications; culture, implementation climate and readiness for implementation (Damschroder et al., 2009).

Structural characteristics can influence the use of the tools through the demographic characteristics of general practices such as a practice size or number of patients relative to the number of practitioners (Damschroder et al., 2009). Practitioners may be reluctant to implement the tools if they feel that using them for their patients may give extra workload. This may particularly apply if they choose to use the tools for assessing all patients rather than just those suspected of cancer symptoms.

Networks and communications refers to the nature and quality of relationships and formal and informal communications within an organisation (Damschroder et al., 2009). General practice staff who meet regularly to discuss improvement in practice including research findings and new ideas may be more likely to be interested in implementing cancer risk assessment tools. This is also linked to culture, in terms of norms and values of general practices and their practitioners (Damschroder et al., 2009), which can influence them to value improvement in quality of care using innovations like cancer risk assessment tools.

Implementation climate relates to the willingness of individual practitioners within an organisation to accept and implement innovations (Damschroder et al., 2009). The level of reception by practitioners will depend on the expectation or perception of the usefulness of cancer risk assessment tools. Implementation climate can influence the uptake of these tools in terms of: tension for change or practitioners perceiving the need for change relative to cancer risk detection; compatibility, that is, if use of the cancer risk assessment tools fits in with current practice and relative priority, or if use of the tools is considered most important relative to other innovations (Damschroder et al., 2009). The presence of organisational incentives and rewards, goals and feedback and a learning climate are also implementation climate factors that can encourage the uptake of cancer risk assessment tools (Damschroder et al., 2009).

In addition to the other constructs of inner setting, readiness for implementation can contribute to the implementation of cancer risk assessment tools if there are: favourable leadership engagements such as practice managers and leading partners committing to using the tools; and available resources such as extended consultation time and sufficient number of practitioners to support the use of the tools (Damschroder et al., 2009).

3.9.1.4 Characteristics of individuals involved

Potential individual users of cancer risk assessment tools may contribute to the implementation of the tools in a range of ways that are largely influenced by the individual characteristics (Damschroder et al., 2009).

The knowledge and beliefs of individuals about the tools is relevant for their effective implementation, as individuals who value the tools as useful may be interested in using the tools in their practice. Self-efficacy is another characteristic of individuals that can contribute to the success of cancer risk assessment tools implementation, in terms of self-efficient people utilising their capabilities to achieve the goals of planning and implementing the tools (Bandura, 1982; Damschroder et al., 2009). An individual practitioner's stage of change (Damschroder et al., 2009), may also contribute to the implementation of the tools in consultation as they progress from the initial trialling to become more experienced and interested in sustaining the use of the tools in consultation.

Another attribute relates to a practitioner's identification with their general practice organisation (Damschroder et al., 2009). This could mean that practitioners who are committed to their general practices may be ready to use the tools if they perceive it as useful for improving consultation or practice. Other characteristics of individuals relate to personal traits. For example, potential users may support the implementation of the tools to succeed, if they are tolerant to ambiguity or uncertainty, less sceptical; or if they are innovators or early adopters (Roger, 1995).

3.9.1.5 Process of implementation

From the perspective of CFIR, the process of implementing cancer risk assessment tools may relate to four constructs: planning, engaging, implementation process and reflecting and monitoring (Damschroder et al., 2009).

Planning for implementation of the tools relates to a process of identifying relevant resources by users. It will also involve identifying how best the tools may be rolled out across practices.

Engaging users of the tools may be achieved by developing a protocol and involving or training key practitioners [who may be innovators and early adopters (Roger, 1995)] at primary care general practices. Within the construct of engaging, the following influencing groups may support an effective implementation process: opinion leaders; formally appointed internal implementation leaders; champions and external change agents.

Executing, which is about carrying out or accomplishing the implementation plan relates to implementation of cancer risk assessment tools in terms of the rolling out process of the tools across general practices in primary care.

The process of reflecting and monitoring relates to evaluative and feedback processes about the impact on quality of care following the use of the tools in patient consultations. In relation to this research, a formal evaluation of the impact of implementing cancer risk assessment tools may be one way of reflecting and monitoring the process of implementation. Another example relates to informal evaluations such as individual or group of practitioners discussing and self-questioning about the effectiveness of the tools on patient consultations and detection of cancer risk and diagnosis.

Like other theoretical frameworks, CFIR has weaknesses but it also has strengths. One weakness is that the long list of constructs can be a source of confusion when all the domains and constructs are used in one study (Damschroder et al., 2009). Secondly, the broad and comprehensive nature of CFIR (which is also its strength) does not discriminate between the relative importance of its many constructs (Varsi et al., 2015). In this study, the weakness of CFIR were managed by being selective and giving more weight to some domains and the constructs within them than others.

The CFIR is a useful implementation framework because of its strength of providing a broad and comprehensive list of clearly defined constructs for which data can be collected, and the possibility that CFIR can be used for outcome and impact evaluations. This is not only relevant for this study but will be relevant for the future research plans arising from the findings of this study.

Several implementation studies have used CFIR. Some studies have used it as an evaluation framework (Alexander & Hearld, 2011; Kalkan et al., 2014; Williams et al., 2011), while others have used it for detecting factors influencing implementation (Kalkan et al., 2014; Sanchez et al., 2014; Ramsey et al., 2014). Other studies have also used it for classifying influencing factors as facilitators or barriers (Lash et al., 2011; Robins et al., 2013; Balas et al., 2013).

More recently, CFIR has been used to inform a qualitative study to identify barriers and facilitators for the implementation of an internet-based patient-provider communication service in five settings (Varsi et al., 2015).

For this study, CFIR was used to inform the qualitative research design (including the methods [for example the interview guide] for data collection, the approach to the data analysis as well as the presentation and discussion of the results) to explore perceptions of service users and practitioners about the barriers and enablers to the implementation of cancer risk assessment tools use in primary care consultations.

3.10 Conclusion of the chapter

This conceptual background chapter has covered the key ideas underpinning the research. The policy structure and functions of primary care in the UK are discussed, and the referral or gatekeeping function of primary care is related to risk assessment for early detection using risk assessment tools.

Issues relating to the effects of risk assessment and the communication of risk information are also discussed. Finally, theoretical frameworks that inform the research are discussed. These include a risk communication framework to inform how risk information may be best communicated to patients, and an implementation theoretical framework informing the implementation of cancer risk assessment tools in primary care consultations. Chapter Four follows this conceptual background chapter with the methodology for the research.

CHAPTER 4 METHODOLOGY

4.1 Summary of the chapter

The scoping literature review in Chapter Two identified two research questions: (i) What are the perceptions of service users and practitioners about how best cancer risk information can be communicated to patients during general practice consultations? (ii) What do service users and practitioners perceive as barriers and enablers (facilitators) to the implementation of cancer risk assessment tools?

This chapter discusses the methodology in the context of these research questions aligned to the aims and objectives, the philosophical stance that informs the research design and methods. The chapter is therefore organised into the following four main sections: the aim and objectives, philosophical stance, qualitative research design and methods. The key points from these main parts of the chapter are stated in Section 4.2 below

4.2 Key points

The key points in this chapter include a discussion of:

- The aim and objectives which restated are to explore (i) the views of participants about how best to communicate cancer risk to patients, and (ii) the enablers and barriers to implementation of cancer risk assessment tools in primary care consultations
- The philosophical stance, which highlights pragmatism as the position adopted for this research to enable the use of the methods which best address the research question, for example, the use of individual and focus group interviews and framework analysis to this study
- The qualitative research design which led to an in-depth exploration of views of participants using individual and focus group interviews
- Ethics and governance approval from the relevant bodies obtained before the commencement of the research.

4.3. Aim and objectives of this study

The aim of this study was to explore the perceptions of service users and practitioners about the use (implementation) of cancer risk assessment tools in primary care consultations. The specific objectives were set:

- To explore the perceptions of service users on how best cancer risk information can be communicated to patients during a consultation
- To explore what service users and practitioners perceive as barriers and enablers to the implementation of cancer risk assessment tools in primary care
- To compare the service user and practitioner perceptions
- To make recommendations for practice and further research.

The next section discusses the philosophical stance for this research.

4.4 Philosophical stance

This research was grounded in a philosophical position for the following reasons. Firstly, it enabled understanding of the different methods which might be employed. Next, it helped refine and clarify the research methods used to gather the relevant evidence to appropriately address the research questions and aim of this thesis. The relevant philosophical lens that informs the research is discussed below.

4.4.1 Relevant philosophical lenses considered

Research philosophy includes ontology, axiology and epistemology, each of which influence consideration of the research process. Ontology refers to the nature of reality and assumptions about the way the world operates, whereas axiology concerns judgments about value, and epistemology the theory of knowledge in a field of study (Blaikie, 2009).

Ontology is often considered in two polar forms: objectivism and subjectivism. Objectivism relates to the position that social entities exist externally to social actors concerned with their existence (Saunders et al., 2012; Bryman, 2012). Subjectivism (sometimes called constructionism or interpretivism) relates to the position that social phenomena are created from the perceptions and consequent actions of those social actors concerned with their existence (Bryman, 2012).

Epistemology is sometimes considered in terms of a continuum between positivism and interpretivism: both are considered in relation to the current study. Positivism usually relates very specifically to a set of beliefs about objective reality which can be verified scientifically (Saunders et al., 2009) whereas interpretivism is about understanding social phenomena in the social contexts in which they are constructed and reproduced through their activities (Ormston et al., 2013 in Ritchie et al., 2013:19).

There are several interpretivist approaches in research that were considered for this study: symbolic interactionism, phenomenology, realism, hermeneutics and naturalistic inquiry (Gray, 2004). Symbolic interactionism relates to the symbolic meaning people develop and use in social interactions (Blumer, 1969). Phenomenology relates to the experiences of people about an event and how those experiences are interpreted (Willis, 2007). Realism relates to the idea of independence of the reality from the human mind, and this is classified into two types: direct and critical realism (Saunders et al., 2012; Novikov & Novikov, 2013). Hermeneutics places emphasis on subjective interpretations in the research of meanings of texts, art, culture, social phenomena and thinking, while naturalistic enquiry relates to how people behave when they are in genuine natural settings (Frey et al., 1999).

Research approaches are usually seen somewhere on a positivist or interpretivist scale, with a deductive reasoning often used by positivist researchers while an inductive reasoning is usually used by interpretivist researchers. While a deductive approach to research relates to the development and testing of a conceptual or theoretical framework using empirical observations, an inductive research relates to the development of theory from observing a phenomenon (Hussey & Hussey, 1997; Goddard & Melville, 2004; Bradford, 2015).

While inductive approaches are usually associated with qualitative research, deductive approaches usually relate to quantitative research (Gabriel, 2013). This gives the impression that the deductive and inductive approaches are opposites. However, there are no fixed rules as some qualitative studies may have deductive elements (Gabriel, 2013). In fact, individual researchers usually fall somewhere along the continuum between the inductive and deductive approaches (Deshpande, 1983; Bryman, 1988). This might relate to the view that the research question should determine the approach to be used (Mays & Pope, 1995; Silverman, 2005; Creswell, 2007).

This study has both deductive and inductive elements because it involved using data to explore existing theory as well as generating new theory from the research question, so a pragmatic position was adopted which enabled a framework approach to be used (Richie & Spencer, 1994). Framework is a type of thematic data analysis (Boyatzis, 1998; Braun & Clarke, 2006) which is appropriate for analysing both deductive (‘a priori’) and inductive (‘de novo’) themes. A pure interpretivist inductive approach such as grounded theory (Glaser & Straus, 1967) would have only addressed the inductive element while the framework approach was useful in supporting a mixed inductive and deductive approach to coding and analysing the qualitative data (Boyatzis, 1998; Fereday & Muir-Cochrane, 2006; McQueen et al., 2009). Pragmatism as adopted for this study is discussed in Section 4.4.2 below.

4.4.2 Pragmatism

The philosophical assumptions underlying this research are based on a pragmatic stance, which it is argued, is appropriate for answering the research question. Pragmatism is a philosophical view that the research question should determine the methods used (Saunders et al., 2009). Thus, a pragmatic researcher may adopt a middle or dual position between positivist and interpretivist positions to appropriately address a particular research question (Goles & Hirschheim, 2000). The pragmatic position is often adopted in mixed method research which uses multiple methodological approaches, such as combining the quantitative and qualitative research designs to address a research question.

However, since pragmatism supports the research approach that best addresses the research question, it can also inform the use of qualitative designs, particularly where these employ a dual interpretivist-positivist (inductive-deductive) approach to the collection and analysis of qualitative data to appropriately address a specific research question. This pragmatist position guided the selection of the qualitative research approach (Section 4.5 below) and the specific methods used for the data collection and analysis, which are presented in Section 4.6 below. To inform and provide a background understanding to the specific methods selected for this study, the qualitative research approach is discussed in Section 4.5 below.

4.5 Qualitative research design

This study aimed to explore the perspectives of service users and practitioners on how cancer risk information could be communicated to patients. The study also aimed to explore what participants perceived as barriers and enablers to implementation of cancer risk assessment tools. Hence, a qualitative research design was considered most appropriate. The qualitative research design as the approach of choice for this study is discussed here in comparison with the quantitative research design which is one of the main research designs commonly used by researchers in the study area. In doing so, I provided reasons in support of the choice of the qualitative research approach for this study.

Both the qualitative and quantitative research methodologies have been referred to as processes used to collect data for any research (Clark, 1999; Lincoln & Guba, 2000), but there have also been arguments for and against qualitative and quantitative research methodologies (Clark, 1999; Lincoln & Guba, 2000).

Qualitative research methodology implies a process where researchers realise that all knowledge-production is related to the perceptions that researchers take with them to their study (Clark, 1999). Here, reality is argued to be 'knowable' except that it may be imperfect. Hence, qualitative researchers seek to get as close as possible to the meanings attributed to different words and actions by the research participants they want to study. Mostly, using the constructivist paradigm, researchers in the qualitative divide have much interest in the co-construction of knowledge between the researcher and the research participants. Through this, any bias with the situation is discussed between the researcher and the participant (Clark, 1999).

Qualitative research has also been described as a universal term of interpretive techniques that can be used to describe, decode, translate and understand the meaning of some naturally occurring phenomena in the social world (Van Manen, 1990; Al-Busaidi, 2008). Hence, researchers regard qualitative research as the approach of choice when the main goal is a search for meaning, understanding and to generate ideas (Rotchford et al., 2002). To generate ideas qualitative studies usually address clearly defined questions that begin with words like: ‘how’, ‘why or ‘what’ (Greenhalgh, 2007).

Qualitative research designs are useful for a range of reasons (Snape & Spencer, 2003). Firstly, qualitative research allows research participants to express their views about a phenomenon or subject of study. Secondly, qualitative research is open ended, in the sense that respondents’ own priorities can lead the data collection. In addition, small samples which are common in qualitative studies allow rich or detailed data to be collected and such data may also be context-rich.

However, qualitative interpretive approaches have been criticised in several ways. These include criticisms relating to the issues of bias, issues in replicating a study, lack of precision, and issues relating to trustworthiness and validity. From the view of some critics, qualitative approaches may not be independent of the unmethodical observations of the researcher, in addition to establishing close ties with the individuals studied (Bryman, 1994; Bryman, 2001). Qualitative strategies may be difficult to reproduce, in the view of its critics. This may be so because of the individuality of the study participants, the fact that the interview questions during interviews may be unstructured, and the direct involvement of the researcher in data collection process. I have reflected on some of these issues in this study, and I have highlighted the relevant limitations in the discussion of the results in Chapter Six.

In contrast to qualitative research, quantitative research often places emphasis on generalisability, which ensures that, the knowledge arising from the research is representative of the population a study sample represents (Palinkas et al., 2015). The empirical data is then regarded as a reflection of the real world, thereby constituting what is considered as adequate knowledge (Bryman, 2001). This position suggests that research is devoid of personal values, meanings, and moral judgments. Hence, quantitative approaches which are usually based on methods such as surveys could be used to generate quantitative data to measure the outcomes of implementing cancer risk assessment tools such as rates of investigations, referrals and diagnoses. However, this approach cannot adequately explore in-depth views or perspectives of service users and practitioners as this study seeks to achieve. Consequently, the qualitative research approach and related methods are considered most suitable for exploring the research questions in this study.

Depending on the subject of investigation, qualitative researchers usually employ a wide range of data collection methods which include individual interviews, focus groups, participant and non-participant observations and documentary analysis (Denzin & Lincoln, 2005; Greenhalgh, 2007). When qualitative research designs involve the use of interviews, these could be unstructured or semi-structured and may include a list of open-ended questions that allow for the participant to respond and express what is important to them.

The decision to use the qualitative research design for this study was guided by a pragmatist position, using both deductive and inductive approaches as highlighted in Sections 4.4.1 and 4.4.2 above. In line with this position, individual and focus group interviews based on semi-structured questions were used to collect data, and framework method was used for analysis. These are discussed further within the methods used for this study in Section 4.6 below.

4.6 The methods used for this study

The previous sections in this chapter have explained the philosophical lens (pragmatism) and methodological (qualitative) approach taken by the researcher in the conduct of this study. These positions informed the selection of the methods for the data collection and analysis for this research. This section now describes recruitment of participants, collection and analysis of data.

The qualitative study took place in three phases to address the research questions stated in Section 4.1 above. Before describing these phases, the study setting is described.

4.6.1 Setting

The study was set in Lincolnshire, a large rural county in England. Cancer statistics from Lincolnshire show that more than 4,500 people are diagnosed with cancer each year and over 2,100 ultimately die of the disease, accounting for 29% of all deaths in the area annually (Lincolnshire Public Health Observatory, 2012).

Cancer prevalence rates within Lincolnshire are significantly higher than the national average. Someone is diagnosed with cancer every two minutes in the UK (Cancer Research UK). Cancer in England is on the rise, with the number of cancer diagnoses expected to reach over 300,000 a year by 2020 (Cancer Research UK). This increase is reflected in Lincolnshire with a rising diagnosis of all cancers.

The most common cancers in the UK are breast, lung, colorectal and prostate cancers (ONS, 2017; Lincolnshire Research Observatory, 2017). Of these, colorectal cancer is the most common in Lincolnshire (Lincolnshire Research Observatory, 2017).

Early diagnosis of cancer across Lincolnshire is poor in comparison to national averages (Lincolnshire Research Observatory, 2017). This may be due to patients in Lincolnshire presenting their symptoms at a late stage in primary care (Lincolnshire Research Observatory, 2017), or it may be due to late detection by practitioners.

4.6.1.1 Cancer survival in Lincolnshire

Reports from the Lincolnshire Research Observatory show the picture of cancer survival in Lincolnshire (The Lincolnshire Research Observatory, 2017), as follows. One-year survival rates for all cancers across Lincolnshire are comparable to the national average (70.2%), South Lincolnshire (72.3%) is the only Clinical Commissioning Group (CCG) area where survival rates exceed the national equivalent. Of the defined types of cancer, survival rates are highest for breast cancer (all Lincolnshire CCGs have over 95.8% survival rate), with rates comparable to England (96.7%). Around three quarters of adults across Lincolnshire initially diagnosed with colorectal cancer survive at one year (all Lincolnshire CCGs have over 73.9% survival rate) compared to the national average of 77.7%. One-year survival rates for lung cancer at between 30.5% and 39.4% are much lower across Lincolnshire but are like the national average of 35.4%. Any measures to improve early diagnosis in Lincolnshire could potentially improve the cancer survival further.

4.6.1.2 Cancer mortality in Lincolnshire

Mortality information from the Lincolnshire Research Observatory shows the picture of cancer mortality in Lincolnshire (The Lincolnshire Research Observatory, 2017), as follows below.

Premature cancer mortality rates in Lincolnshire are lower than the national equivalent for all persons (both male and female). Deaths from all cancers were lowest across South and South West Lincolnshire and highest in

Lincolnshire East. Between 2012 and 2014, there were 2,896 cancer deaths of people aged under-75 in Lincolnshire. Lung cancer deaths made up the largest proportion of cancer deaths. In the same period, Lincolnshire West had 672.8 Potential Years of Life Lost (PYLL) per 10,000 due to cancers, while South West Lincolnshire had 627.8 PYLL per 10,000. In comparison, the national equivalent rate was 620.5 PYLL per 10,000. Hence, all areas of Lincolnshire present higher rates of PYLL.

The overall cancer mortality rate in Lincolnshire was 274.3 per 100,000 population in 2012-14, closed to the national rate of 276.8 per 100,000. Lincolnshire East had the highest mortality rate of 283.6 per 100,000, and South Lincolnshire had the lowest mortality rate of 258.4 per 100,000 (Lincolnshire Research Observatory, 2017).

The three phases of the study, the perspectives of service users (Phase 1), the perspectives of practitioners prior to using the tools in general practice consultations (Phase 2) and the perspectives of practitioners after they have used the tools in general practice consultations (Phase 3), are presented in the following sections.

4.6.2 Phase 1: Service user perspectives

Phase 1 was aimed at exploring views of service users on using cancer risk assessment tools in primary care consultations. Service users were recruited from public places which included the: The University of Lincoln; the central library located in Lincoln city centre; community centres; and voluntary groups.

4.6.2.1 Sampling

A purposive sample of service users (aged 18 years and above) was recruited from the public. In deciding on the sample size of participants for this qualitative study, the aim of the research, the resources available including funding and time for the research were taken into consideration (Baker & Edwards, 2012).

While there may be other factors that affect sample size in qualitative studies, researchers generally use saturation as a guiding principle during their data collection and analysis (Mason, 2010). Glaser & Strauss (1967) argue that, if the principles of qualitative research are complied with, sample size in most qualitative studies should generally follow the concept of data saturation. In fact, in a recent study, the concept of data saturation has been described as important in guiding sample sizes in qualitative studies (Hennink et al., 2016). Hennink and colleagues believe that, data saturation relates to code saturation (researchers have heard it all) with about 9 interviews and meaning saturation (researchers have understood it all) with 16 to 24 interviews (Hennink et al., 2016). This phase of the study clearly achieved both code and meaning data saturation with the 19 service users. Thus, the achievement of both code and meaning data saturation were the main reasons why it was decided not to recruit more service users.

4.6.2.2 Recruitment of service users for individual interviews

As mentioned above a purposive sample of individual service users (n=19), with an interest in the delivery of cancer services who might have survived cancer or had a relative or friend who might have survived cancer, or who might have an interest in cancer for other reasons and who were 18 years or older) was recruited from the public through three different approaches.

Service users who might have survived cancer or had a relative or friend who has survived cancer were recruited instead of people with cancer, mainly because cancer risk assessment tools are used in people who are yet to be diagnosed with cancer and are less relevant to people already diagnosed with the condition. Moreover, cancer risk assessment tools are meant for use with people presenting with initial symptoms (which may be those of cancer to aid earlier diagnosis), rather than those already diagnosed with cancer. Service users who had survived a previous cancer, were included in the study because in was considered that they would also be interested in early diagnosis of a (subsequent) cancer. In addition, although some cancer patients might have important views to contribute, it was important to balance this with the need to avoid causing potential distress to patients with active or recent cancer during the interviews. The three approaches are described below.

Recruitment plan 1 (through voluntary groups)

A consultation about the research was carried out with the Healthier Ageing Patient and Public Involvement (HaPPI) group. This consultation included the development of the participant information sheet containing information about the study, informed consent and topic guide materials.

The HaPPI group, which was established by the Community and Health Research Unit (CaHRU) at the University of Lincoln in 2014, works with CaHRU researchers to: inform bids for funding, give a patient and public perspective on current research projects, review documents to help make them more accessible to the public and actively help with the recruitment of participants for studies. For this study, the HaPPI group members assisted with the identification of individuals from voluntary groups that were willing to participate in the research, as HaPPI group were also involved in several other voluntary groups. These voluntary groups are concerned with supporting those individuals with cancer or their relatives, or those who might have survived cancer or having a relative or friend who has survived cancer.

A flyer (see Appendix 2.4) was provided to these representatives, who raised this information with their group members. For groups that agreed, the flyer about the research was placed on their notice boards or websites with details to contact the researcher. Interested individuals then contacted the researcher and they were given information about the research by post or by email as preferred by participants (see Appendices 2.1 and 2.2 for copies of participant invitation letters and participant information sheets respectively). Participants then confirmed their willingness to participate in the research after reading the information about the research. This recruitment plan helped to recruit a total of 8 participants, which was considered successful relative to the total number of 19 service user participants.

The only challenge of this plan was that some participants preferred to be interviewed at their own homes, and there was a potential risk of external noise and interruptions when the interviews were conducted at participants' homes. However, this was managed with the help of participants, by having the interviews in a quiet location in a participant's home, and participants advised their family members not to interrupt once the interviews were in progress.

Recruitment plan 2 (through the University of Lincoln community)

The second approach was to recruit participants from the University of Lincoln community. Information about the research was sent out using a flyer (see Appendix 2.4 for copy of flyer) to students and staff through the University Daily Alerts System. As in Plan 1 above, a flyer was sent out to potential participants aged 18 years and above (who might have survived cancer or having a relative or friend who has survived cancer or having an interest in cancer for another reason) inviting them to participate in face-to-face individual interviews. The information on the flyer indicated clearly that, individuals interested in participating in the research should contact the researcher for further details about the research. The contact details for the researcher (email address and telephone number) were stated on the flyer, which was sent out to students and staff through the University Daily Alerts System. Participants who expressed interest through email or telephone to the researcher, were contacted by the researcher with information (see Appendices 2.1 and 2.2 for copies of service user invitation letters and participant information sheets respectively) about the research. Participants then contacted the researcher again to confirm their willingness to participate after reading the information sent to them by email as preferred. Following this, an appointment for a face-to-face individual interview was arranged with participants.

This recruitment plan yielded 9 participants (consisting of students and University staff). This plan appeared to be the most successful, relative to the total number of 19 participants, in terms of the promptness in contacting the researcher after hearing about the research through the University Daily Alert System, and in terms of the number of participants that responded and agreed to participate. It is possible that the willingness of students and staff to participate in the research was influenced by their membership of the University community, which is a research or academic setting. However, my perception after interviewing and interacting with participants was that, the University students and staff were willing to participate in the study because of their interest in cancer services. There were no real challenges as all interviews were conducted in University interview rooms, which were pre-booked for the interviews.

Recruitment plan 3 (through the central library and community halls in Lincoln)

Flyers (see copy in Appendix 2.4) were put up at the central library and community halls in Lincoln with permission from the respective authorities. The information on the flyer was clear that, individuals interested in participating in the research should contact the researcher for further details about the research. The contact details for the researcher (email address and telephone number) were stated on the flyer. Participants who expressed interest by emailing or telephoning the researcher, were contacted by the researcher with information about the research (see Appendices 2.1 and 2.2 for copies of service user invitation letters and participant information sheets respectively). After reading the information sent to them, participants then contacted the researcher again to confirm their willingness to participate, and an appointment for a face-to-face individual interview was arranged. This plan yielded only two participants and may be considered the least successful relative to the total number of 19 service user participants. It could be that people saw the flyers at the central library and community halls, but they were either not interested in cancer research or they could not find time to participate in the research.

Summary of the recruitment procedure for service users

Once interested participants were identified the researcher contacted them with a research pack consisting of invitation letters and participant information sheets with the contact details of the researcher using their preferred method of contact. Participants were asked to contact the researcher to confirm their willingness to participate and to arrange a date for a face-to-face individual interview or for more information if they wished to know more about the research. The information sheet was clear that participation was entirely voluntary, and participants were free to withdraw from the study at any stage without giving reasons for their withdrawal. Any information already collected was not used if participants so wished. It was made clear to participants that all the data collected would be treated as confidential and only key members of the research team would have access to the data. Twenty-four hours prior to the interview, the participant was contacted again, to discuss any concerns and to reiterate that they were free to withdraw at any time or stage of the research.

4.6.2.3 Data collection using individual face-to-face interviews with service users

To capture relevant and detailed views of service users about the use of cancer risk assessment tools, semi-structured questions were used to conduct face-to-face interviews with individual service users. The interview guide for the individual interviews was piloted with two members of the HaPPI group who participated as service users. The semi-structured questions were then refined following comments from the pilot interviews.

Face-to-face individual interviews based on semi-structured questions were preferred for the data collection because these techniques offered several advantages (Gubrium & Holstein, 2002). One advantage was that, these techniques offered the researcher the opportunity to obtain detailed and varied information from participants. Secondly, these allowed the researcher who conducted the interviews to utilise social cues such as voice, intonation and body language (Opdenakker, 2006). These social cues gave the interviewer a lot of extra information relative to the topic of interest or what the interviewer was interested in knowing from the service users (Gubrium & Holstein, 2002).

However, face-to-face interviews can lead to interviewer effects, for example when the interviewer guides the interviewee in a special direction (Gubrium & Holstein, 2002). In study, this disadvantage was minimised by using an interview guide (Patton, 2015), and by the awareness of the interviewer of this effect. For this purpose, the interview guide (see Appendix 2.5) was designed, pilot tested with members of HaPPI group, and then revised for the data collection. Furthermore, in conducting the interviews care was taken not to misguide the service users towards the researchers own perceptions about the topic being discussed.

A further advantage is that face-to-face interviews can be recorded with the permission of the interviewee. Using a recorder can be useful in enhancing the accuracy of the interview report than writing out notes. However, recording also brings with it the danger of not taking any notes during the interview. Taking notes during the interview is important for the interviewer, even if the interview is audio recorded for the following reasons: to check if all the questions have been answered and in case the recorder fails to function. In addition, transcribing recorded interviews can be time consuming. In the view of Bryman (2001), one hour of a recorded interview can take up to six hours to transcribe. In this research, the data were recorded using a digital voice recorder, and some notes were taken which proved useful when part of the recording for one service user was not clear and the service user was not available to be interviewed the second time. Thus, my analysis for approximately 10 minutes of a 50-minute interview with one service user was based on partial written notes, rather than a verbatim transcript.

Another advantage of the face-to-face interview method is that it is apparent when the interview is finished as compared to other methods (Wengraf, 2001). At the end of the interviews service users were thanked for their cooperation and asked if they had further remarks. This sometimes led to emergence of new information from some participants (Wengraf, 2001).

It is worth noting that some individuals preferred to be interviewed at their own homes where they felt comfortable, while others preferred to be interviewed at an interview room in the University. The choices of participants were respected. For those who preferred to be interviewed at the University, a quiet and comfortable interview room was booked, and participants were given directions to the room. Participants who were interviewed at their own homes ensured there was a quiet and comfortable home environment conducive for a face-to-face individual interview.

During the individual face-to-face interviews with service users

At the interviews, I introduced myself as the researcher. I then explained and clarified concerns about the research and the consent forms (see Appendix 2.3 for copy of service user consent form) were signed by the participant before the commencement of the interview. Introductory questions were asked, and then three vignettes of how cancer risk assessment tools (using the QCancer tool as an example) work were shown to service users. Each vignette showed how some risk factors and symptoms presented by a person could be entered in the QCancer tool to calculate a cancer risk represented by blue sad faces (those at risk of having cancer within two years) and yellow smiley faces (those not at risk of cancer).

After showing the vignettes to interviewees and using the interview guide (which was informed by the theoretical frameworks discussed in Chapter 3, Sections 3.8 and 3.9), questions were asked to explore the views of participants about cancer risk assessment tools relative to the research questions in mentioned earlier. During the interview, care was taken to support the individual being interviewed. For example, it was planned that if an individual became distressed, the interview was to be stopped, the recorder to be switched off and support to be provided. The interview was only to be continued if the individual felt ready and happy to continue. If the individual wished to continue but preferred to do so on another day, this was to be respected and a further interview was to be arranged. Where individuals became distressed in the interview and wished to withdraw this was to be respected and their data was to be destroyed.

Prior to leaving, I asked the individual interviewee if they wished for me to contact their GP, their friends or family. Interviewees were encouraged to contact their GP if they became distressed later after the interviews. In addition, it was planned that additional support such as counselling was to be arranged in consultation with the individual's GP, if they required it. However, throughout the interviews no participant experienced distress and no one required referral to their GP or a counselling service. When all the semi-structured questions were asked, each interview was terminated by thanking participants, reassuring them of maintaining confidentiality of the data, and then asking them if they had any more information to add.

Period of data collection from service users

Overall, the process of recruitment and interviewing the 19 service users lasted a total of 12 months (from March 2014 to February 2015). About half of this period was used for the interviewing of service users (from September 2014 to February 2015).

4.6.3 Phase 2: Practitioner perspectives before using the tools

The aim of this phase of the study was to explore the views of primary care practitioners about using cancer risk assessment tools in patient consultations. The setting for this phase of the study was primary care general practices in Lincolnshire. General practice settings were selected because these were considered the first point of access for service users with health problems or concerns. Hence, general practice settings are likely places where a person's risk of developing cancer based on their presenting symptoms can first be detected. Additionally, practitioners whose views are required before the cancer risk assessment tools may be implemented are usually located in general practice settings.

The sampling and sample size of practitioners, recruitment of practitioners and data collection using individual and focus group interviews with practitioners are discussed below.

4.6.3.1 Sampling and sample size of practitioners

The target population was all practitioners in general practice settings in Lincolnshire, but a purposive sample of 17 practitioners (Practice Nurses and GPs who were interested and willing to participate in the research) were interviewed. Although the resources available were considered important in determining the sample size for the research, the researcher was prepared to interview more participants. However, only the 17 practitioners responded to the invitation and expressed interest to participate in the research. The researcher could have sent more invitation letters and reminders to practitioners who had not responded. However, after analysing the data collected from 17 practitioners, no new themes or ideas were generated, and so this was considered a data saturation point. Therefore, the 17 practitioners were recruited based on the principle of data saturation as discussed above under sample size for service users (see Section 4.6.2.1 above).

4.6.3.2 Recruitment of practitioners for individual and focus group interviews

There were two approaches to the recruitment of practitioners. Practitioners with an interest in the delivery of cancer services were identified through the Lincolnshire Community Health Service (LCHS) NHS Trust.

The research pack consisting of invitation letters and participant information sheets with the contact details of the researcher (see Appendices 2.1 and 2.2 for copies of practitioner invitation letters and participant information sheets) was given to interested practitioners by the LCHS. After reading the research pack, practitioners then contacted the researcher to confirm their willingness to participate and to arrange a date for either individual interviews or focus groups and/or more information about the research.

The information sheet was clear that participation was entirely voluntary and that participants were free to withdraw from the study at any stage of the research without having to explain their reasons for withdrawal. Any information already collected was not used if participants so wished. It was also made clear to participants that all the data collected would be treated as confidential and only key members of the research team would have access to the data. Twenty-four hours prior to the interview, the individual practitioner was contacted again to discuss any concerns and to reiterate that they were free to withdraw at any time.

The practitioners who participated in focus groups made it easy for me to meet them by inviting me to one of their monthly meetings. Interested practitioners then stayed after their meeting to attend a focus group discussion with me. In total, there were 17 practitioners, 12 of whom participated in focus groups, and 5 in individual face-to-face interviews, as described below in the data collection with practitioners using individual and focus group interviews.

4.6.3.3 Data collection with practitioners using individual interviews and focus groups

To capture relevant and detailed views of practitioners to address the research questions, individual interviews and focus groups were used as preferred by practitioners. This approach has been used in previous studies for exploring research questions around improving the quality of clinical care (Lambert & Loiselle, 2008; Togher et al., 2013; Davy et al., 2015).

As for the service users in Phase 1, the practitioner interview guides 1 and 2 (see Appendix 2.5) for the individual interviews and focus groups with practitioners were piloted. My supervisor who is a practising General Practitioner also reviewed the interview guide and offered useful suggestions. The semi-structured questions were then refined making use of the comments and suggestions offered.

The individual interviews with practitioners

In order, not to miss the valuable contributions of practitioners who were unable to join focus groups, they were interviewed as individuals. A total of five practitioners from five different practices were recruited for individual interviews. The advantages of using individual interviews with service users noted above (see Section 4.6.2.3) also apply to the use of individual interviews with practitioners. For example, the face-to-face individual interviews with practitioners were useful in terms of making it easier to explore issues in depth. Other practitioners were willing to be interviewed in focus groups as discussed below.

Focus groups interviews with practitioners

As mentioned above, practitioners from 2 general practices were willing to meet up for group discussions. Hence, two focus groups (1 in each of the two practices) were conducted. There were 6 participants (2 practice nurses and 4 GPs) in each focus group making a total of 12 participants for the focus groups.

One important feature of the focus groups in this study was the opportunity for the research participants (practitioners in general practice) to be involved in discussing the possibility of using cancer risk assessment tools in primary care consultation, which can potentially inform a policy decision (Race et al., 1994), about the implementation of the tools. Rather than relying on the views of individual practitioners, it was useful to have practitioners who usually work as a team, to meet up in a group to discuss and share their views about using the tools.

The focus group discussions also had the advantage of empowering the participants as this was an opportunity for practitioners to be valued as experts, with the opportunity to express their views through working with researchers (Goss & Leinbach, 1996), and contributing to the validation of cancer risk assessment tools that could be useful in primary care consultations. Although, focus groups can be intimidating especially for inarticulate or shy participants (Gibbs, 1997), this was not the case in this study as all the practitioners in the focus groups actively participated in the discussion. Also, primary care practitioners have very busy schedules and it is usually difficult to get them to meet in groups for research data collection. Fortunately, for this research, more practitioners were willing to meet up for focus group interviews or discussions. The details of what happened during the individual and focus group interviews are described below.

During the individual and focus group interviews with practitioners

During the individual interviews and focus groups, practitioners were asked introductory questions and then shown an actual working cancer risk assessment tool (using the QCancer tool as an example) whenever it was possible to do so. Whenever it was not possible due to lack of internet connection, the three vignettes of the QCancer tool were shown to them. Questions were then asked to explore the views of practitioners in respect of the research questions. With permission from participants, the interviews were recorded and later transcribed verbatim for analysis.

At the individual interviews and focus groups, I explained or clarified any concerns about the research and the consent forms (see Appendix 2.3 for copy of practitioner consent form) were signed by the participant before the commencement of the interviews. During the interviews, care was taken to accommodate the practitioner's work schedules. For example, it was planned that if the practitioner was unable to continue with the interview for some reason such as work pressure, the interview would be stopped, and another appointment arranged to complete the interview.

However, there were no problems during the interviews. The individual interviews and focus groups commenced and finished as scheduled with no interruptions. As in the individual service user interviews described above, the individual interviews and focus groups with practitioners were terminated by thanking participants, reassuring them of maintaining confidentiality of the data, and then asking them if they had any more information to add.

Period of data collection from practitioners

I anticipated challenges such as practitioners being too busy and not having enough time to participate in the interviews. However, this was not the case, as interested practitioners arranged to meet and be interviewed within reasonable time of receiving the invitation to participate in the study. Overall, the process of recruitment and interviewing of the 17 practitioners lasted a total of 6 months (from April 2015 to September 2015).

4.6.4 Phase 3: Practitioner perspectives after using the tools

The aim of this phase of the research was to explore the perspectives of practitioners after they had used the cancer risk assessment tools, and to compare these perspectives with those expressed before the use of the tools. Any other perceptions expressed by practitioners after using the tools were also considered.

The practitioners that had already participated in the earlier individual interviews and focus groups were contacted, and practitioners from only one general practice agreed to meet up to discuss their perceptions after using the cancer risk assessment tools. An initial meeting with practitioners in this practice revealed that they had not used the tools in patient consultations since hearing about the tools during the initial data collection for this research. The practitioners however, agreed to use the tools with patients for a minimum of one month before sharing their views and experiences. A focus group discussion which consisted of 4 practitioners (all GPs) was subsequently arranged and conducted as agreed.

These 4 practitioners also participated in one of the earlier focus groups. As these practitioners were already part of the study, the sample size of 17 practitioners remained the same. Also, the conduct of this third focus group with practitioners was as discussed for the first and second focus groups with practitioners in Section 4.6.3.3 above.

4.6.5 Data analysis

I considered several qualitative data analysis methods including grounded theory and interpretive phenomenological analysis (IPA) approaches before choosing the framework approach (Richie & Spencer, 1994) for this study.

Grounded theory is an approach for developing theory that is grounded in data systematically gathered and analysed (Glaser & Strauss, 1967; Strauss & Corbin, 1994). In grounded theory, the data analysis is mainly inductive and arising from the data collected, which usually leads to the development of a theory.

However, this study has some elements of both inductive (arising from the data collected) and deductive (a priori) themes. The deductive themes were derived from the interview guide which related to the cancer risk assessment tools and the relevant constructs within the risk communication framework (Fischhoff, 1995) and implementation theoretical framework (Damschroder et al., 2009) chosen for this research. Hence, while grounded theory was a possible approach, it was considered less suitable for this study. Similarly, IPA was considered unsuitable at this stage of the research because, the phenomena (cancer risk assessment tools) had not yet been experienced by majority of the participants so their experiences could not be analysed. Indeed, all the service user participants and most of the practitioners expressed their views and beliefs before the tools were used in patient consultations.

The framework approach was developed by social policy researchers in the UK (Ritchie & Spencer, 1994), as a pragmatic approach to different types of research, and is increasingly used in healthcare studies (Furber, 2010; Swallow et al., 2011; Tierney et al., 2011). Framework approach was developed for addressing specific questions. In that sense, it is an applied research approach that is useful for informing both policy and practice (Ward et al., 2013). The framework approach (Ritchie & Spencer, 1994), was used for the data analysis in this study, because this approach is appropriate for analysing both inductive and deductive data. It was useful for analysing the data in this study as it allowed for different aspects of the phenomenon under investigation to be covered (Ritchie & Lewis, 2003). The process of data analysis in this study based on the framework method is described in the next section.

4.6.5.1 The process of framework analysis in this study

The analysis of the data in this study was conducted using the five stages of the Framework approach: familiarization; identifying recurrent and important themes; indexing and charting; summarising the data and mapping and interpreting.

Stage 1: Familiarisation – through immersion in the data

This stage usually involves immersing in the details of each transcript, to gain a sense of the whole interviews prior to dividing them into sections and identifying recurring themes (Rabiee, 2004).

In this study, I familiarised myself with all the transcripts. I undertook all the interviews and transcription which enhanced my effort to fully familiarise myself with the data (Ritchie & Lewis, 2003). In addition, I read the field notes (that I made immediately following each interview) alongside the transcripts to ensure that the context was taken into consideration. I also found the field notes useful when it came to the development of the codes or themes and indexing later in the analysis process (in stages 2 and 3 below). It is known that field notes enable the researcher to record what is seen and heard during interviews, what thoughts and feelings occur and issues that may be relevant during analysis (Arthur & Nazroo, 2003).

Due to a large volume of data in some qualitative studies, not every piece of material may be reviewed at this stage (Srivastava & Thomson, 2009). However, in this study, I felt that the sample size was small enough for all transcripts to be studied. This ensured that all data from all participants were considered and that no data were overlooked. Although a considerable amount of time was spent reviewing all the transcripts, it was worth the time commitment for a full inclusion and understanding of data.

Stage 2: Identifying recurrent and important themes

At this stage, the recurring codes identified in stage 1 above can be added to a chart either on paper or using a computer software such as NVIVO, Microsoft excel (Swallow et al., 2003) and Microsoft Word (Furber, 2010). In this study, the recurrent codes were added to an NVIVO version 10 software to facilitate the analysis process. Referring and comparing with the framework of deductive themes (see Tables 11-13 and Tables 14-16 in Chapter Five) which was derived from the interview guide which related to the relevant constructs within the theoretical frameworks for this research), a framework of inductive themes (see Tables 11-13 and Tables 14-16) were derived from immersing in the data and in consultation with my supervisory team. This stage took several weeks to complete because it was as time consuming as the first stage above.

Stage 3: Indexing and charting

At this stage I applied the framework of themes developed in stage 2 above back to the transcripts. This allowed me to become further immersed in the data, and the themes were refined (Ritchie & Lewis, 2003). The decisions I took at this stage were based on similarities and differences between initial themes and themes becoming clearer through further data immersion. It was identified that some themes in the initial framework could belong in either of the initial themes. This formed the basis for the adjustment of themes to more accurately reflect the data. At this point a refined framework resulted to ensure that the themes were grouped into key themes.

Stage 4 Summarising data

This stage allowed me to reduce the material into understandable but brief summaries of what was said by participants (Ritchie & Lewis, 2003), to support the themes identified. Again, I used a computer package (NVIVO) to manage the data, making it easy for me to link summaries back to full text in the transcripts (Swallow et al., 2003).

Stage 5 Mapping and interpreting

This stage demonstrates the transparency of framework analysis, because at each stage, the analysis process can be compared back to the original data, which enhances rigour as well as facilitating the inductive and iterative approach in qualitative research (Ezzy, 2002). At this stage of the data analysis, I reviewed the charts to see the whole data set. This included checking the summaries on the charts against the original data and comparing the themes with each other to see if any further merging of themes was required. However, no changes were required to be made to the themes, and the final framework of themes was agreed. These final themes were then described, interpreted and presented as the results.

4.7 Ethics and governance

In the UK, all research on National Health Service (NHS) patients must be approved by a Local or Multicentre Research Ethics Committee (LREC or MREC) (Central Office for Research Ethics Committee, 2006), and non-NHS research may require approval from one or more other bodies such as a university ethics committee or a school governing body. Ethical approval from a formal body does not necessarily make a research study ethical, nor does the refusal of an ethics committee to grant approval necessarily make it unethical, though it may make it illegal to continue with the project (Rotchford et al., 2002; Rocha, 2004; Central Office for Research Ethics Committee, 2006). However, active involvement of participants such as service users and practitioners in the management and governance of the research projects may reduce the chance of unethical practices (Central Office for Research Ethics Committee, 2006).

The data collection for this study did not involve NHS patients. Therefore, an NHS Ethics approval was not required. The protocol for the research was reviewed and approved by the College of Social Science Ethics Committee of the University of Lincoln (see Appendix 3.1). The issues that were potentially of ethical concerns in relation to the recruitment and data collection procedures with service users and practitioners included: informed consent, anonymity, confidentiality and data storage.

4.7.1 Informed consent

Informed consent, usually in the form of a document signed by the research participant, relays all relevant research information, such as risks and benefits, to the potential participants (Rotchford et al., 2002; Rocha, 2004; Central Office for Research Ethics Committee, 2006). This allows the participants to make an informed decision about participating in the research, and it also allows for the confirmation of anonymity among all research participants. However, informed consent is not merely a legal requirement or a document to be signed; it is a communication process between the researcher and the participant that starts before the research is initiated and continues throughout the study (Rotchford et al., 2002; Rocha, 2004; Central Office for Research Ethics Committee, 2006). Therefore, it is important that the information provided is understood by the potential participant and empowers that person to make a voluntary decision about whether to participate in the study. Subsequently, the participant is given the opportunity to withdraw from the research at any time before the end of the study without giving any reasons.

To ensure informed consent for the recruitment and collection of data from service users and practitioners in this research, in accordance with the National Patient Safety Agency (NPSA) and National Research Ethics Service (NRES) guidance, the research procedures described below for recruitment of participants, collection and analysis were followed in relation to the anonymity and confidentiality of the data (NPSA & NRES, 2010).

4.7.2 Anonymity of the data

Safeguarding the research data especially personal identifying information is a key part of the relationship of trust and respect that exists between the researcher and the participant. Depending on the type of study, researchers are expected to take steps to ensure privacy and confidentiality by anonymising personal identifiable information such as names, birthdates and places of residence (Department of Health, 2005; Department of Health, 2008). This may be done by:

- Using participant codes to label data instead of using names, and keeping a separate list of code-to-name match-ups
- In interview studies, using the participant's first name only (or even using an alias) when recording or publishing data to help protect the participant
- Being careful not to publish enough information that the participant can be identified.

To ensure anonymity of the data collected from service users and practitioners, several measures were observed. Firstly, all interviews were transcribed anonymously, removing names and identifiable locations of all participants. The data were transcribed by the researcher who holds a current Disclosure and Barring Service (DBS) document as an NHS employee. Secondly, once the interviews were transcribed, the software version of the anonymous transcriptions were stored in a University of Lincoln password protected computer and hard copies of data were stored in a locked file cabinet stored in a locked office at the Community and Health Research Unit (CaHRU), University of Lincoln. Only the researcher and his supervisor had direct access to the soft and hard copies of the data.

4.7.3 Data confidentiality

One of the conditions on which informed consent depends is respect for the privacy of participants. Hence, a participant should not be forced to reveal information to the researcher that the participant does not wish to reveal. Confidentiality of the information is important (Rotchford et al., 2002; Rocha, 2004; Central Office for Research Ethics Committee, 2006), and researchers, particularly those involved in medical research, are responsible for safeguarding personal information that participants have agreed to disclose.

To ensure confidentiality of the data collected from participants in this research, the data were stored in a confidential manner per the requirements of the research governance framework for health and social care (Department of Health, 2008). In line with this, it was planned that all relevant data would be archived confidentially for seven years after the study. It was made clear to participants that all the data collected would be treated as highly confidential.

4.7.4 Governance and access

Research governance is the system of administration and supervision through which research is managed, participants are protected, and accountability is assured. In the UK, the main reference point is the Research Governance Framework for Health and Social Care (Department of Health, 2002) whose stated purpose is to enhance ethical and scientific quality, promote good practice, reduce adverse incidents and ensure lessons are learned.

The protocol for the study was reviewed and the governance and access to NHS premises and staff were granted by the Lincolnshire Community Health Services (LCHS) NHS Trust (see Appendix 3.2). The University ethics and NHS governance approvals were received before the commencement of data collection. As an NHS employee, the researcher did not require a research passport. Instead, the researcher was granted access to NHS premises and staff (Practitioners).

4.8 Insurance and indemnity for the research

Insurance and indemnity for the participants (practitioners) was covered within the NHS Indemnity Arrangements for clinical negligence claims in the NHS, issued under cover of Health and Safety Guidance (HSG) (96) 48. There were no special compensation arrangements, but study participants had recourse through the NHS complaints procedures. Service user participants recruited from the public (Non-NHS participants) were covered by the University of Lincoln Insurance and Indemnity Arrangement for researchers and research participants.

4.9 Trustworthiness

Various approaches have been published for assessing trustworthiness or quality of qualitative studies (Mays & Pope, 1995; Mays & Pope, 2000;

Barbour, 2007). For this study, several measures were carried out, contributing to the trustworthiness of the results from this research.

Firstly, the interview guide was piloted with two volunteers who were members of the HaPPI group and acted as service users. The project supervisor who is a GP, also reviewed the semi-structured questions within the interview guide. This helped to refine the interview guide.

The audio recorded interviews and transcripts were shared with my supervisor who confirmed the quality of the recorded data and the detailed transcripts. The analysis process base on the Framework technique, was overseen by my supervisor. The codes or themes and subthemes generated from the analysis were shared with all members of my supervisory team who then met with me and discussed, and we agreed on the final themes and subthemes.

Applying the Framework technique to the data gathered

In Section 4.6.5.1 above, I have described the process of data analysis in line with the five key stages of the framework data analysis. The Framework approach to qualitative data analysis is suitable for analysing data with both deductive (a priori) and inductive themes (Richie & Spencer, 1993). Using the framework approach in my analysis meant a framework of several deductive or a priori themes were predetermined based on key concepts or themes from the theoretical frameworks selected for the study. In fact, these theoretical concepts formed the basis for the interview questions stated in the interview guides. Using each of these deductive themes, data or statements from each interviewee that matched or fitted the deductive themes were noted down as codes.

The codes were then examined, and similar codes were grouped into one overarching theme. This was repeated for all the transcripts of individual interviews and focus groups. While looking out for codes that agreed with the deductive themes, some unexpected but relevant codes emerged from the data and these were also noted down as inductive themes until a point of data saturation was reached - no new codes emerging from additional transcripts of data.

The relationship of the use of Framework analysis to the theoretical frameworks

The relationship of this framework analysis to the theoretical frameworks, lies in the fact that, the framework of deductive themes used to guide the search for appropriate codes from the data, were derived from the relevant key concepts or themes of the theoretical frameworks that informed the study. These concepts also helped in the design or formulation of the interview guide and questions for the data collections.

Presentation of the results at a GP Educator

In addition to the above measures of trustworthiness for this study, the results were presented in the form of a workshop which was attended by 15 GP Educators at a conference organised by the GP Educators in Lincolnshire. The GP educators were also practitioners in their respective general practices and some of them had already participated in the individual and focus group interviews conducted for this study. I was invited by the organisers of the GP Educators conference to coordinate the workshop relating to the research findings from this study. To begin the workshop, I asked the GPs to discuss in groups the following questions which related to the findings from the research:

- **Group 1:** What are the implications for you as a GP using cancer risk assessment tools to quantify cancer risk?
- **Group 2:** What are the potential benefits of cancer risk prediction tools in general practice consultations?
- **Group 3:** In what ways, can cancer risk information be discussed with patients?
- **Group 4:** What do you perceive as barriers to the use of cancer risk assessment tools in general practice consultations?

Each group then shared their reflections on the above questions to the rest of the groups. After the discussions, I presented the actual results from the study to the workshop participants. It was clear that the results were in line with the reflections of the workshop participants in relation to the questions they had discussed. This was confirmed by participants when they were asked for their reflections at the end of the presentation of the results. The workshop was an opportunity for me to listen to the views of GP Educators. It was also an opportunity for me to share the findings from my study with them, a group who were likely to use cancer risk assessment tools in patient consultations as well as share the information about the tools with other practitioners under their mentorship.

4.10 Conclusion of the chapter

The aim of the study was to explore the perspectives of service users and primary care practitioners about how best cancer risk information can be communicated to patients; and the enablers and barriers to the implementation of cancer risk prediction tools. This Methodology chapter has presented the pragmatic philosophical stance which informed the use of individual interviews and focus group techniques, and the analysis of the data using the framework analysis method. The pragmatic stance of this study was to allow for a combination of the inductive and deductive (that is to combine the interpretivist and positivist) elements in this research with respect to the data analysis.

The ethics approval for the study was granted by the College of Social Science Ethics Committee, University of Lincoln. The research governance and access to primary care practitioners were granted by the Lincolnshire Community Health Services NHS Trust. These ethics and governance documents were received before the commencement of recruitment of participants, data collection and analysis of the data.

There was a purposive sample of 19 service users recruited from the public and 17 primary care practitioners recruited from general practices in Lincolnshire. This resulted in a total sample of 36 participants from whom data were collected and analysed.

The data collection was done using face-to-face individual interviews with service users. Face-to-face individual interviews and focus groups were also used to collect data from primary care practitioners. The interview guide was developed in line with the relevant constructs within two theoretical frameworks [a risk communication framework (Fischhoff, 1995) and Consolidated Framework for Implementation Research (Damschroder et al., 2009)] which were chosen for this research. The interview guide was piloted with two members of the Healthier Ageing Patient and Public Involvement group (HaPPI). Comments from the pilot interviews and the project supervisors were used to refine the semi-structured questions within the interview guide.

In addition to piloting the interview guide, the trustworthiness of the results of the study was established through several measures in the research process. These measures included presentation of the results at a GP Educators conference in Lincoln. The workshop was attended by several practitioners some of whom had participated in the interviews. The process of data collection, transcription and analysis was shared, discussed and agreed with the project supervisory team, adding to the trustworthiness of the results. The results of the qualitative data analysis are presented in Chapter Five, which follows in the next pages.

CHAPTER 5 RESULTS

5.1 Summary of the chapter

The aim of this chapter is to present the results of the qualitative study addressing the two research questions:

i. What are the perceptions of service users and practitioners about how best cancer risk information can be communicated to patients during general practice consultation?
ii. What do service users and practitioners perceive as enablers and barriers to the implementation of cancer risk assessment tools?

The results are organised into: the characteristics of the participants (Table 10); summary of the codes and themes from the analysis of the qualitative data (Tables 11-13 and Tables 14-16 below); perceptions about how best to communicate cancer risk; and perceptions about the enablers and barriers to implementation of cancer risk assessment tools**.** These are presented in terms of the perceptions of participants before and after using cancer risk assessment tools. Participants (service users and practitioners) were interviewed before and only practitioners were interviewed after they had used cancer risk assessment tools in patient consultations.

For Phase 3, the interview guide was redesigned to accommodate practitioners who had used any of the cancer risk assessment tools of interest (either RAT or QCancer). During the data collection, practitioners discussed their perceptions after using the tools but indicated that they preferred QCancer to the RAT because QCancer was easier to understand and use, and that they needed training to inform the use of the tools

5.2 Key points

The findings presented in this chapter include:

- Suggested ways to best communicate cancer risk information to patients during a general practice consultation. These include tailoring a visual representation of risk; being open and honest; involving patients in the use of cancer risk assessment tools and providing time for listening
- Perceived enablers to the implementation of cancer risk assessment tools including supporting clinical decision-making; identifying and modifying health risk behaviours; improving process and speed of assessment and treatment; personalising care and ease of use
- Perceived barriers to implementation of cancer risk assessment tools including: additional time requirement; worry or anxiety related to referral for investigations; potential over-referral; conflict with existing guidelines; symptoms suggestive of cancer will need referral whatever the quantified risk; need for integration of the tools into all general practice IT systems; need to involve secondary care or hospital consultants and other specialists in the use of the tools; and the need to pilot and evaluate the effectiveness of the tools against current practice.

5.3 Characteristics of participants

The characteristics of participants are presented in Table 10 and described further below.

Table 10 Participant characteristics

		Service users	*Practitioners*
Gender			
	Male	7	13
	Female	12	4
Age group			
	20-29	3	-
	30-39	4	3
	40-49	1	10
	50-59	3	4
	60-69	5	-
	70-79	3	-
Ethnicity			
	White British	19	6
	Indian	-	6
	Pakistani	-	3
	Asian British	-	1
	Bangladeshi	-	1
Practice patient list size			
	200-2900	-	1
	3000-3900	-	-
	4000-4900	-	-
	5000-5900	-	-
	6000-6900	-	8
	7000-7900	-	-
	8000-8900	-	-
	9000-9900	-	8

Thirty-six participants, 19 service users (aged between 21 and 71 years) and 17 practitioners (aged between 33 and 55 years) were interviewed. Out of the 19 service users, there were two who had survived cancer, and the rest either had relatives or family members and friends who had survived cancer, which motivated them to participate in the study. The summary of codes and themes following the data analysis are presented in the next section.

5.4 Summary of the codes, themes and quotes

The themes and quotes following a framework analysis informed by the relevant theoretical frameworks are presented in Tables 11-13**.**

Table 11 How best to communicate cancer risk information – themes, codes and quotes

Stages of risk communication framework	**Key words/phrases/codes**		**Key themes**	**Meaning of themes**	**Quotes**	
	Services users	Practitioners			Service users (SU)	Practitioners (P)
-Tell them the numbers **-Explain what the numbers mean**	-Provide a simplified visual representation of risk e.g. smiley and sad faces	-Simplify presentation of risk -Should be user friendly -Providing a simplified visual representation of risk e.g. smiley and sad faces	Tailoring a visual representation of risk	Seeing the risk presented in a visual way will enhance understanding	"I really like this. I like the pictorial representation; I like the fact that it is simple but it's effective because it draws you really right to the point. You know the happy faces and a mixed of smiley and sad faces can get you an idea. I think it is simple and clear so most people will be able to understand this and take that information on board as opposed to if the doctor just mentions cancer risk it will put you off. But if you look at this and they talk you through this I think that will be really useful" (SU12: individual interview)	"I like the smiley faces as well, it's a good way of showing things. But I think it should be lined not random. I will like the blue sad faces to be in line, in a row, otherwise if they are scattered it gives the impression that they are many when they are not. And it's easier to read when they are lined in rows" (P 6 [GP]: Focus Group1)
-Tell them the numbers **-Explain what the numbers mean**	-Listen to patients during consultation -Explain to patient's understanding -Both oral and written information (to take away) -General information patients need about risk of cancer - Provide reassurance for both low and high cancer risk	-Give sufficient time -Provide clear plan -Listen to patients during consultation -Convey information based on patient's understanding -Provide information on how to explain a person's risk (to both patient and practitioners) -Give both oral and written information about cancer risk to patients	Providing time for informing, listening, explaining and reassuring in a professional away	Enough time for informing and explaining will help patients to listen, understand and be reassured.	- "You wouldn't want to feel that you've been rushed, you would want them to take time to talk with you, and if they try to cut this conversation short you would think that they didn't care, and again that could reduce your confidence" (SU12: individual interview). - "I think with that, if you're looking more likely that you're going to have something then I suppose you would probably want some reassurance, more also about treatment. But whereas before it's coming up which you were worried, I think it's probably now that you need reassurance that is finding it early and treatment, if it can be treated and if they know the risk of having it there's also the possibility of surviving it" (SU5: individual interview).	- "What I feel is, I would try and give as much time as possible and be as accurate as possible" (P1 [GP]: individual interview). - "I normally give them a chance to ask questions, what they think, what they know about cancer and the kind of support they will need" (P3 [GP]: individual interview). -In contrast: "It's more a question of more time really, because at the moment we're in crisis, GPs are in crisis, and the future is very bleak for GPs. Because you come in at 5 in the morning and you get back home in the night and it's a nightmare really. So, we don't want more work" (P6 [GP]: Focus Group1) - "talking about risk is quite difficult" (P3 [GP]: Focus Group1).

					- “In my opinion clinicians should discuss the patients' risks with them, but they should take time to do so in a professional and responsible manner in order to help the patient understand and feel less worried about their situation” (SU15: individual interview). - “Yes, you wouldn't want them to speak in difficult medical terms; you would want them to bring it down to the level of the person you're speaking to” (SU14: individual interview)	- “do the patients actually understand me, what I am trying to tell them?” (P3 [GP]: Focus Group1).
-Treat them nicely/with respect	-Being open -Being honest -Manners and attitude of clinicians	-Be open and honest with patients -Give patients the right information for an informed decision	Being open and honest with patients	Telling patients, the truth about their risk of cancer will make them feel respected and able to make informed decisions	- “I would like to be told the truth about what this 10% means and whether I've got a chance” (SU3: individual interview). - “When I go to the doctor I expect to be honest with him and be clear as best as I can and you would expect the same from the practitioner, open conversation, open details from both sides to avoid misunderstanding” (SU19: individual interview)	- “I will be quite open and honest with them that, you've come with these symptoms, some of them are already in, and we can use the tool to work out what it is. If you bear with me, I will check your risk and I could put those figures and what is coming out is your risk, and we can try that” (P6 [GP]: Focus Group1). -“I think the only time you might do it without informing the patient is when you are uncertain, you might go back and use it and then call the patient and inform them when you are sure of the risk” (P1 [GP]: Focus Group2)
-Make them partners **-All of the above**	-Prompting people to communicate their concerns -Seeking informed consent -Involve patients -patients seeing the results on computer screen -Someone to attend consultation with patient when discussing cancer diagnosis	-Involve patients (patients to see results on computer screen) -Engage with patients to calm anxiety -Gain informed consent with patient	Involving patients when using cancer risk assessment tools	Involving patients when using the tools will mean recognising them as partners in their care and will promote autonomy	- “Again, I will like to be involved and I will like to see them using the tool and I like to see the smiley faces on the screen, and I will expect them to then explain to me what the results mean in terms of my risk” (SU15: individual interview) - “I think the word prompt is important because a lot of patients might be embarrassed to tell you something but if they are prompted, they can then tell you” (SU4: individual interview).	- “If you don't tell them before using the tool it means you are not being honest. I mean you can't do anything without telling the patient, you need their consent” (P4 [GP]: individual interview). -“I think the only time you might do it without informing the patient is when you are uncertain, you might go back and use it and then call the patient and inform them when you are sure of the risk” (P1 [GP]: Focus Group2).

Table 12 Facilitators/enablers to implementation of cancer risk assessment tools – themes, codes and quotes

CFIR construct	**Key words/phrases/codes**		**Key themes**	**Meaning of theme**	**Quotes**	
	Service users	Practitioners			Service users	Practitioners
Relative advantage	-Promotes consistent decision making - Will promote awareness of cancer symptoms -Adds to clinician's knowledge and skills -Useful if combined with clinical knowledge and skills	-Cancer risk assessment tools could aid decision making -Aid at initial consultation -For a differential decision or diagnosis -For cancer screening programmes in general practice -Those with suspicion of cancer -For patients with vague or doubtful or borderline symptoms -Empowering patients in decision making -Breaking bad news to patients - Will generate data e.g. for research	Supporting decision making	Participants perceive the benefit of supporting decision making as a facilitator to the implementation of CRATs	- “a structured way of going through risk” (SU7: individual interview) - “It will help to make decisions appropriately” (SU1: individual interview). - “Yes, it is useful because the tool will help the practitioners to ask the right questions, and I know you have just 5 or 10 minutes with the doctor, and if the use of the risk assessment tools helps with the process then I think they should be used” (SU18: individual interview)	- “I think somebody where you thought they have a cancer, probably you wouldn't go on a QCancer, and you would do what you do now. I think with people who are at the borderline, I think for these people you might want to use it” (P4 [GP]: Focus Group2) - “I think one of the ways I can use this tool is when you have got a differential in your mind, how can you put the cancer which may be at the lower end of the spectrum to come on top?” (P5 [GP]: Focus Group1). In contrast: “GP experience is more important than tools and guidelines” (P5 [GP]: individual interview), - “I will recommend that CRATs like QCancer be available to patients to use before coming to their GP.” (P5 [GP]: individual interview)
	-Earlier detection of cancer symptoms -Provides structured risk assessment	-Will help to improved speed of assessment -Earlier detection and treatment -More rapid investigation and referral -Improved outcomes -Capture of cases missed by two-week wait	Improving process and speed of assessment and treatment	The benefit of helping to improving process of and speed of assessments and treatment is perceived a facilitator to implementing CRATs	- “it will help with early diagnosis through early detection of cancer risks” (SU10: individual interview) - “I think my first worry is that I may have cancer and most of us would like to know early so they can get it sorted. But a lot of things can be picked up, can't they, if they spot check risk if you like” (SU4: individual interview)	- “Well as a tool, it's useful, for helping practitioners' ability to spot cancer or the possibility of cancer at an earlier stage than we could do. You know all emphasis is on cancer care, and GPs are sometimes a bit, a bit stuck to know what to pick as symptoms of cancer” (P3 [GP]: Focus Group1) - “With everyone on board because we need more investigations, we

		-Will generate data e.g. for research				need more tests quickly” (P6 [GP]: Focus Group1)
	-Will promote education and awareness of cancer symptoms -Information about modifying health behaviours -Identification and modification of cancer risk factors	-Promoting understanding and behaviour -Patient education about cancer risk -Support lifestyle advice and patient motivation to reduce cancer risk -Encourage patients to check risk and seek advice from GP	Identifying and modifying health risk behaviours	The potential benefit of helping to identify and advise people to modify their health risk behaviours is perceived as a facilitator for the implementing CRATs	“I think it might be just raising awareness, so people realise what's happening, and what can go wrong with them and where the risks are and may be, they can reinforce them where someone else like the young person who has given up smoking it might be used to reinforce by saying well you've got a very low risk so if you've given up smoking carry on with that. Rather than saying you've got a very high risk later” (SU5: individual interview) - “to be forewarned is to be forearmed, so they change their lifestyles such as stopping smoking or drinking alcohol” (SU10: individual interview) - “It can help to identify the individual's risk, isn't it? Because the input you've given is about your own risk rather than the general population, and if it's done over some years and your risk is increasing they could turn around and say well we need to increase or make more changes in your life style. So, if they were to do it every 5 years and if they see that the risk is increasing then maybe they could start giving me some lifestyle advice” (SU18: individual interview)	“They don't understand the risks, you know what I mean? I mean like someone who is a smoker, he is smoking, smoking. You can use this tool to help them modify their lifestyle. People who are refusing referral, you can use the tool to estimate their risk to show and explain to them” (P2 [GP]: individual interview - “I am saying they could also check and then come to us, and they could be helping us as well. If what they regard as risk, you know almost the fact that they've come that might suggest they regard whatever number they've got as something we will be able to discuss with them. We go over it and you could recheck. You could recheck the cancer risk with the patient to see whether you have the same result” (P3 [GP]: Focus Group1)
	-Will help clinicians to know the patient -Promote individualised patient centred care	-More accurate and specific information for individual patients -Individualised assessment and care -Reassurance for both low and high cancer risk -Reduced complaints from different patients	Personalising patient care	The benefit of helping personalise patient care is perceived a facilitator to CRATs implementation	- “I think it will make the care more patient-centred because you're presenting them with their own risk not a general risk, it's personal to them and it will just make the consultation more patient focused, and I think it will make patients feel more involved in the consultation and just feel more cared for I think” (SU12: individual interview) - “So, it needs to be about me. I think it’s an excellent idea, the tool. I mean it's dealing with the individual very specifically and there's an opportunity to explain things in more details and delay the inevitable anxiety” (SU19: individual interview)	“Patients will go away with a lot more targeted information about their personalised risk of cancer rather than a vague statement” (P1: individual interview).

Table 13 Barriers to implementation of cancer risk assessment tools – themes, codes, and quotes –before use of the tools

CFIR constructs	**Key words/phrases/codes**		**Key themes**	**Meaning of theme**	**Quotes**	
	Service users	Practitioners			Service users	Practitioners
Patient needs & resources	-More time to discuss risk of cancer) -There may be cost e.g. time initially with implementation	-Time and workload pressure -That will give us a little bit extra time, which is assuming the patient has only one problem -All that information in, it will be difficult	Additional consultation time required	Perceived additional time required for the extra task of using CRATs could challenge the implementation of CRATs	- “more time to use the tool in consultations” (SU7: individual interview)	- “the uncertainty and putting all the data manually” (P1 (GP): Focus Group2) - “It should be integrated in our system SystmOne, rather than every time we have to go on Google to get it. Like you put all that information in, it will be difficult, it should be completely automatic, and think of the investigations, people are more likely to use it” (P1 [GP]: Focus Group2) - “It’s more a question of more time really, because at the moment we're in crisis, GPs are in crisis, and the future is very bleak for GPs. Because you come in at 5 in the morning and you get back home in the night and it’s a nightmare really. So, we don't want more work. But we can target and do what we need, so unless we really suspect cancer” (P6 [GP]: Focus Group1) - “Well I believe if, in the ideal world, you may be aware of that, if there is a push to implement that; I think we should have 15 minutes’ appointments. That will give us a little bit extra time, which is assuming the patient has only one problem, but they have multiple problems in one appointment, I think it will be done well if something like cancer risk assessment, communication, organising of the test that follow, 15 minutes will be ideal” (P1 [GP]: individual interview)
Patient needs & resources	-Worry due to investigations –Anxiety due to referral	-Generating unnecessary patient anxiety	Worry/anxiety relating to cancer referral & investigations	Perceived unnecessary worry/anxiety related to using CRATs could challenge the	- “Some people may not understand and they can be too worried especially if they don't explain that it is just a risk but it is not guaranteed that they will get	- “You can probably make them more worried” (P5 [Practice Nurse]: Focus Group2).

	-Misinformation of a person's risk			implementation of the tools	cancer, then it is not good enough ethically" (SU11: individual interview). - "I think they may be, have to assess their patients first to see if they were going to promote great anxiety on the patients by using some of these tools. I think emotionally I would be quite distraught and worried, and this is where having another person in there is important, I think. But I think until you've got some sort of appointment and then further tests and so forth, you will be in a state of limbo, I think, you know, not being able to concentrate properly" (SU6: individual interview)	- "The thing is if you tell the patient they've got 1% cancer, which is creating unnecessary anxiety" (P2 [GP]: individual interview)
Patient needs & resources	-Potential for over referral -Potential burdening of resources	-Potential for over referral and burden or strain on NHS resources -Need for sufficient secondary care capacity for rapid assessment	Over-referral & over burdening of services	The perceived additional referrals could over-burden services	- "It could be useful if the right patients are referred but it could also lead to over referral as some people may have a certain risk but will not have cancer after they have been referred and tested" (SU17: individual interview)	- "But on the other side it will put a strain on the NHS; you know what I mean, on the services there. You know, you don't want to over burden the services as well" (P4 [GP]: individual interview) - "I think we should not be worried about resources. Now many more people are dying from cancer, so they want more referral and diagnosis earlier. I am not sure using the tool is cheaper but I will say it is good for patient safety because people will be diagnosed earlier if referred earlier and they will be helped earlier" (P3 [GP]: individual interview)

Table 13 Barriers to implementation of cancer risk assessment tools – themes, codes, and quotes –before use of the tools

CFIR constructs	**Key words/phrases/codes**		**Key themes**	**Meaning of theme**	**Quotes**	
	Service users	Practitioners			Service users	Practitioners
Compatibility / Complexity	-Everybody should use the same sort of guidelines	-Current risk assessment is based on practitioners' knowledge of patients' symptoms, cancer risk factors and NICE guideline -Referral also depends on important single risk factors e.g. age	Conflict with existing guidelines	Potential confusion in use with existing tools could challenge the use of CRATs	- "I think it is good for everybody to have the same sort of guidelines, so to use risk assessment tools everybody should use the same sort of guidelines" (SU1: individual Interview).	- "I will be quite confused about using the tool. I mean you know with the NICE guidelines; you couldn't focus on another criterion for any other risk here" (P6 [GP]: Focus Group1).
Complexity	-It doesn't really matter about percentages - the fact is the symptom is there which is quite worrying	-Some symptoms need referral whatever the risk percentage -High risk prompts further investigation -Some patients may wish to be investigated at a low 1% risk -Varying perception of risk from 1-10%, e.g. 4%-10% risk of cancer is high and needs referral with investigations for low risk e.g 1%	Symptoms suggestive of cancer need referral whatever the quantified risk	The tools may not need to be used where symptoms are suggestive of cancer	- "It doesn't really matter about percentages; I know 1% is less risk. But the fact is the symptom is there, the coughing out of blood, which is quite worrying" (SU13: individual interview) - "to see whether it is cancer or something else" (SU9: individual interview)	- "as I said, if I suspect cancer and I put in the tool 1%, 2% doesn't matter to me" (P5 [GP]: individual interview) - "Since they've got symptoms, it is urgent x-ray straight away. I always send my patients for x-ray and say not to worry about the symptom, because I am going to investigate. Because even if he came with 1%, that's the thing. Regardless of what QCancer said I will refer them for investigation with the symptoms. So, it doesn't matter 1% or 0%, I will always do one thing, investigation if the symptoms are suggestive of cancer" (P6 [GP]: Focus Group1)
Knowledge & beliefs of individuals involved	N/A	-Some practitioners may be sceptical	Practitioner scepticism about using CRATs	Those sceptical about the new tools may be unwilling to use them	N/A	- "GP experience is more important than tools and guidelines" (P5 [GP]: Focus Group1) - "Until you said this thing, you know initially I was very sceptical about this tool" (P3 [GP]: individual interview) - "I think for it to be useful there needs to be some benchmarks for us to really relate with. If you say 7% or 6%, should I worry?

						I think they need to tell us. So, for cancers, unless we have those things it will probably be difficult to use the tool" (P1 [GP]: Focus Group2)
Reflecting & monitoring	-Need for further investigation of symptoms and risk of cancer	-Need to compare with current practice before and after implementing CRATs	Need to establish effective of CRATs	Waiting to pilot and evaluate the tools before rolling them out could delay or challenge full implementation	- "But I think if you are going to roll something out rather than going to everybody I would start with the doctors, see how the doctors do with it after evaluation and then move on to the practice nurses" (SU12: individual interview).	- "review, we have to make sure that it is better than what we are already doing" (P2 [GP]: Focus Group2) - "One of the things I think will be really useful is, it's been devised but getting it in real life and then reporting back on that, it will be really useful to know how good a tool it is (P1 [GP]: individual interview)

The codes (see Tables 11 – 13 above) generated using Framework analysis, were examined and similar codes merged. After merging the similar codes, several themes from both service users and practitioners emerged in respect of the two research questions. These themes included: perceived ways about how best to communicate cancer risk information to patients; and the perceived enablers and barriers to the implementation of cancer risk assessment tools in primary care consultations. These perceptions were gathered from service users and practitioners before practitioners used the tools with patients.

5.5 Perceived ways about how best to communicate cancer risk information to patients

To address the research question about how best cancer risk information can be communicated during general practice consultation, the analysis of data and presentation of the results were informed by the 8-staged risk communication framework described in detail above (see 3.8.2 Fischhoff, 1995):

1. Get the numbers right
2. Tell them the numbers
3. Explain what the numbers mean
4. Show them they have accepted similar risks in the past
5. Show them it is a good deal for them
6. Treat them nicely/with respect
7. Make them partners
8. All the above

The views expressed by service users and practitioners about how best to communicate cancer risk to patients included:

- Tailoring visual representation of risk
- Providing time for informing, listening, explaining and reassuring in a professional manner
- Being open and honest
- Involving patients when using cancer risk assessment tools.

5.5.1 Tailoring visual representation of risk

Tailoring a visual representation of risk relates to the risk communication framework stage of telling patients and explaining to their level of understanding what the cancer risk information means (Fischhoff, 1995). Visual representation suggests the use of visual aids such as pictures, symbols etc. to enhance understanding of the risk being explained to the patient. It relates to the notion that seeing a pictorial illustration of a phenomenon like risk, makes the explanation less abstract and enhances understanding of the information being presented.

Referring to the QCancer tool as an example, both service users and practitioners discussed the idea of tailoring a visual representation of risk reflected in the QCancer risk chart. The QCancer risk chart consists of an icon array or Cates plot with a 10 by 10 arrangement of blue sad (each expressing 1% 2-year cancer risk) and yellow smiling (no risk) faces. Service users believed that, using the QCancer graphics would ensure a visual representation which is clear and easy to understand by patients. For example, one service user said:

"I really like this. I like the pictorial representation; I like the fact that it is simple but it's effective because it draws you right to the point. You know the happy faces and a mixed of smiley and sad faces can get you an idea. I think it is simple and clear, so most people will be able to understand this and take that information on board as opposed to if the doctor just mentions cancer risk it will put you off. But if you look at this and they talk you through this I think that will be really useful" (Service User 12: individual interview).

Practitioners liked the idea of pictorial representation expressed by service users. In contrast, some practitioners felt that the QCancer icon arrays should be presented differently, for example, the icons representing risk could be arranged together in rows or lines rather than placed at random. Arranging the risk icons together would make them easier to read, count and understand, whereas this was more difficult when they were scattered, which sometimes made them appear more numerous. For example, a practitioner explained:

“I like the smiley faces as well, it's a good way of showing things. But I think it should be lined not random. I will like the blue sad faces to be in line, in a row, otherwise if they are scattered it gives the impression that they are many when they are not. And it's easier to read when they are lined in rows” (Practitioner 6 [GP]: Focus Group1).

The next point discussed by participants was about providing time.

5.5.2 Providing time for listening, explaining and reassuring in the context of a professional approach

The provision of time for listening, explaining and reassuring patients in a professional manner was expressed by participants as an important communication strategy that needed to be considered when planning for implementing cancer risk assessment tools in the primary care consultation. This relates to the risk communication framework stage of explaining to patients what the cancer risk information means (Fischhoff, 1995). This means that if enough time is not provided for explaining risk information and the related plan of care to patients, they may feel rushed and may not understand important information communicated to them. This could make patients feel anxious and less reassured by practitioners, and they may even feel disrespected and lose trust or faith in the healthcare delivery system. This was reflected in the views expressed by participants in this study.

Service users preferred a longer consultation time to discuss cancer related risks, stating that they would otherwise feel not cared for, which could result in loss of their confidence. For example, one service user said the following:

“You wouldn't want to feel that you've been rushed, you would want them to take time to talk with you, and if they try to cut this conversation short you would think that they didn't care, and again that could reduce your confidence” (Service User 12: individual interview).

Many of the practitioners interviewed agreed with the views of service users, that more time should be provided in the form of a longer consultation, to have clearer communication and an opportunity for service users to ask questions or discuss what was being conveyed. Such a discussion would also enable service users to express their views about cancer and the support they would require. One practitioner said: *“What I feel is, I would try and give as much time as possible and be as accurate as possible”* (Practitioner 1 [GP]: individual interview). Another practitioner stated: *“I normally give them a chance to ask questions, what they think, what they know about cancer and the kind of support they will need”* (Practitioner 3 [GP]: individual interview).

Although many practitioners saw the importance of allowing more time for the patient to listen and understand what they had been informed about, some practitioners expressed concerns about the limited patient consultation time currently available. For example, a practitioner said:

“It’s more a question of more time really, because now we're in crisis, GPs are in crisis, and the future is very bleak for GPs. Because you come in at 5 in the morning and you get back home in the night and it’s a nightmare really. So, we don't want more work” (Practitioner 6 [GP]: Focus Group 1).

Service users also wanted practitioners to demonstrate professional manners and a reassuring attitude towards them especially when it came to using cancer risk assessment tools and discussing the risk with patients. Such a professional approach would help service users to understand what was being communicated but would also help them feel reassured and less worried about the situation. Below are examples of these views:

“I think with that, if you're looking more likely that you're going to have something then I suppose you would probably want some reassurance, more also about treatment. But whereas before it's coming up which you were worried, I think it's probably now that you need reassurance that is finding it early and treatment, if it can be treated and if they know the risk of having it there's also the possibility of surviving it” (Service User 5: individual interview).

“In my opinion clinicians should discuss the patients' risks with them, but they should take time to do so in a professional and responsible manner to help the patient understand and feel less worried about their situation” (Service User 15: individual interview).

In addition to good manners and a reassuring attitude, service users felt that practitioners should avoid difficult medical terms and convey information at a level appropriate to the service user. For example, a service user stated that:

“Yes, you wouldn't want them to speak in difficult medical terms; you would want them to bring it down to the level of the person you're speaking to” (Service User 14: individual interview).

Practitioners admitted that, *“talking about risk is quite difficult”* (Practitioner 3 (GP): Focus Group 1), but it would be important to check, “*do the patients actually understand me, what I am trying to tell them?”* (Practitioner 3 [GP]: Focus Group1).

Participants also discussed openness and honesty when communicating cancer risk information.

5.5.3 Being open and honest

Being open and honest relates to the risk communication framework stage of treating patients nicely or with respect (Fischhoff, 1995). This relates to the importance of recognising the right of individuals to know the truth about their health information as far as possible and in the interests of the individual. Patients can feel disrespected, worried or even lose trust in health practitioners if they perceive that practitioners are being dishonest or hiding something from them.

Service users and practitioners in this study expressed the view that being open and honest would enhance cancer risk communication during the patient consultation. From the perspectives of service users, it was important to know the implications of a quantified cancer risk including whether they had a chance of not getting cancer or surviving cancer if they were diagnosed with the condition. A service user said, *"I will like to be told the truth about what this 10% means and whether I've got a chance"* (Service User 3: individual interview). Service users expected to be told the truth about their health when they consulted a practitioner. In the same vein, service users believed that practitioners should be ready to tell them everything about their health. Failure to tell the patient the truth or missing key information could mean the practitioner was hiding something which could bring about misunderstanding or even loss of confidence or trust between the practitioner and the patient when the truth was eventually known. Below is an example of what another service user said:

"When I go to the doctor I expect to be honest with him and be clear as best as I can, and you would expect the same from the practitioner, open conversation, open details from both sides to avoid misunderstanding" (Service User 19: individual interview).

Practitioners supported the views of service users about the importance of honesty. They confirmed that being open and honest with patients and about the nature of their symptoms, explaining and planning their care with them was more helpful. In other words, as perceived by service users, openness and honesty cultivated confidence and trust in the patient-practitioner relationship and the health care delivery system. Below is an example of views expressed by practitioners:

"I will be quite open and honest with them that, you've come with these symptoms, some of them are already in, and we can use the tool to work out what it is. If you bear with me I will check your risk and I could put those figures and what is coming out is your risk, and we can try that" (Practitioner 6 [GP]: Focus Group1).

Although many practitioners supported the idea of being open and honest with patients, one practitioner did state that they may not be open with a patient if they were uncertain of the patient's risk information. The practitioner said:

“I think the only time you might do it without informing the patient is when you are uncertain, you might go back and use it and then call the patient and inform them when you are sure of the risk” (Practitioner 1 [GP]: Focus Group2).

Participants also expressed views about informing and involving patient when using cancer risk assessment tools as detailed below.

5.5.4 Informing and involving patients when using cancer risk assessment tools

Informing or involving patients in their risk assessment during a consultation is in line with the risk communication framework stage of making patients partners in the use of cancer risk assessment tools (Fischhoff, 1995). This means that patients could be given the opportunity to see the visual representation of their risk on the computer screen which could enhance understanding when the practitioner then conveys the risk information to the patient. Also, without involving patients before using the tools to assess them could mean their ethical right of giving consent to their care is ignored. If patients feel ignored, this could negatively impact on healthcare policies relating to patient-centred care and making patients partners in their care. This reflects in the views of participants in this study.

Service users and practitioners expressed the need to inform and involve patients in the use of cancer risk assessment tools during the consultation. In addition to informing them before using the tools, service users felt that it would be good practice for practitioners to involve them in the consultation process such that they could see and view the risk assessment results on the practitioner’s computer. One service user said:

“Again, I will like to be involved and I will like to see them using the tool and I like to see the smiley faces on the screen, and I will expect them to then explain to me what the results mean in terms of my risk” (Service User 15: individual interview).

Service users also felt that, to encourage patient involvement in a cancer risk communication process, there was a need to prompt discussion about relevant health issues during the consultation process especially for those who might be too embarrassed or unable to talk for one reason or another. For example, a service user stated:

"I think the word 'prompt' is important because a lot of patients might be embarrassed to tell you something but if they are prompted, they can then tell you" (Service User 4: individual interview).

Supporting the views of service users, a practitioner suggested that, it would be an act of dishonesty to perform a risk assessment on a patient without first seeking their consent. Although some patients may not know that a practitioner is using a tool to assess their risk of cancer, not informing patients would be unethical and could result in loss of trust and confidence if the patients eventually get to know later. A practitioner said:

"If you don't tell them before using the tool it means you are not being honest. I mean you can't do anything without telling the patient, you need their consent" (Practitioner 4 [GP]: individual interview).

In contrast, another practitioner thought that there may be times when they were uncertain or unsure about risk, and therefore reluctant to inform the patient when using the tool:

"I think the only time you might do it without informing the patient is when you are uncertain, you might go back and use it and then call the patient and inform them when you are sure of the risk" (Practitioner 1 [GP]: Focus Group2).

Other practitioners agreed that it can be difficult to inform the patient when they were uncertain about the risk information but noted that patients would need to be informed once some certainty about use of the tool has been established. This is because failure to inform could amount to not involving patients in the consultation process. The next section deals with what service users and practitioners perceived as enablers and barriers to implementation.

5.6 Perceived enablers and barriers to implementation of cancer risk assessment tools in primary care

To address the perceptions of service users and practitioners about enablers and barriers to the implementation of cancer risk assessment tools, data analysis was informed by relevant constructs within the Consolidated Framework for Implementation Research [CFIR] (Damschroder et al., 2009): relative advantage (for enablers); patient needs and resources, compatibility, knowledge and beliefs of individuals involved, and reflecting and monitoring the implementation process (for the barriers to implementation).

5.6.1 Perceived enablers to implementation of cancer risk assessment tools

In relation to the CFIR construct of relative advantage (Damschroder et al., 2009), participants expressed four potential benefits of cancer risk assessment tools, which they perceived as enablers to the implementation of cancer risk assessment tools in primary care: supporting decision making, improving processes and speed of assessment and treatment, identifying and raising awareness for modifying health risk behaviours, and personalising care. That is, practitioners perceived these as enabling their use of the tools if they thought the tools were useful or had relative advantage.

5.6.1.1 Supporting decision-making

The perception of cancer risk assessment tools as having the potential to support decision-making means that practitioners could use the tools to detect cancer risk sooner than later. This could also lead to earlier investigations, diagnosis, treatment and improvement in the rates of survival of people diagnosed with cancer. In line with this, service users and practitioners in this study expressed views suggesting that cancer risk assessment tools had the potential to support decision-making in primary care consultations. Service users believed that, using a cancer risk assessment tool like QCancer would be *“a structured way of going through risk”* (Service User 7: individual interview), which could help practitioners *“to make decisions appropriately”* (Service User 1: individual interview). In other words, the tool could enable practitioners to ask the right questions within the limited time available for the consultation.

“Yes, it is useful because the tool will help the practitioners to ask the right questions, and I know you have just 5 or 10 minutes with the doctor, and if the use of the risk assessment tools helps with the process then I think they should be used” (Service User 18: individual interview).

While supporting the views of service users that the tools enabled appropriate decision-making, practitioners insisted that they would be more likely to use a cancer risk assessment tool for patients with vague, doubtful or borderline symptoms than for patients with symptoms suggestive of cancer. A practitioner said:

“I think somebody where you thought they have a cancer, probably you wouldn't go on a QCancer, and you would do what you do now. I think with people who are at the borderline, I think for these people you might want to use it” (Practitioner 4 [GP]: Focus Group2).

Furthermore, practitioners believed cancer risk assessment tools could help with differential diagnosis. In other words, if a patient presented with symptoms suggestive of conditions other than cancer, practitioners could rule out or rule in cancer by using a cancer risk assessment tool before referring for further cancer investigations. According to one practitioner:

“I think one of the ways I can use this tool is when you have got a differential in your mind, how can you put the cancer which may be at the lower end of the spectrum to come on top? I think that's something which I find useful” (Practitioner 5 [GP]: Focus Group1).

Although practitioners generally perceived the potential benefit of supporting clinical decision-making as an enabler to the implementation of cancer risk assessment tools, one practitioner did state that: *“GP experience is more* *important than tools and guidelines”* (Practitioner 5 [GP]: individual interview), and others felt that cancer risk assessment tools should be made available to patients to use at home before consulting their practitioners for further advice. A practitioner stated further: *“I will recommend that QCancer be available to patients to use before coming to their GP”* (Practitioner 5 [GP]: individual interview).

The next enabler is about the benefit of improving processes and speed of assessment and treatment.

5.6.1.2 Improving process and speed of assessments and treatment

Improving the process and speed of cancer risk assessments and treatment through early detection was also mentioned by participants as a potential benefit which could serve as an enabler to the implementation of cancer risk assessment tools. They implied that using the tools could streamline and speed up necessary clinical processes such as investigations and referral to specialists at secondary care settings. In other words, the use of the tools could avoid or reduce the usual delay in the processes of assessment and referral, which usually results in late diagnosis and treatment.

Service users in this study believed that, the tools “*will help with early diagnosis through early detection of cancer risks”* (Service User 10: individual interview). In the view of service users, the use of cancer risk assessment tools to improve processes and speed of cancer assessments and treatment was important because many people worry about cancer; hence, checking and detecting cancer risk early and managing cancer risk in time would be helpful to them. One service user stated:

“I think my first worry is that I may have cancer and most of us will like to know early so they can get it sorted. But a lot of things can be picked up, can't they, if they spot check risk if you like” (Service User 4: individual interview).

Practitioners expressed similar views. According to practitioners, although emphasis is currently on early detection of cancer, practitioners are sometimes unable to detect cancer at an early stage of symptoms. Cancer risk assessment tools could bridge that gap by enhancing the ability of a practitioner to spot cancer risk earlier. One practitioner stated:

“Well as a tool, it's useful, for helping practitioners' ability to spot cancer or the possibility of cancer at an earlier stage than we could do. You know all emphasis is on cancer care, and GPs are sometimes a bit, a bit stuck to know what to pick as symptoms of cancer” (Practitioner 3 [GP]: Focus Group1).

Practitioners also believed that to achieve early detection of cancer there is often a need for cancer investigations to be done prior to patients seeing a consultant in secondary care. Hence, the use of cancer risk assessment tools could prompt earlier investigations and referral. One practitioner stated:

“With everyone on board because we need more investigations, we need more tests quickly” (Practitioner 6 [GP]: Focus Group1).

Another perceived enabler to the use of cancer risk assessment tools was in helping to identify health risk behaviours and raise awareness for modifying these.

5.6.1.3 Identifying and raising awareness for modifying health risk behaviours

One potential benefit (perceived as an enabler to use) of cancer risk assessment tools is that, the tools could be used by practitioners to generate a patient’s risk of having or developing cancer. They could then use the information to advise the patient on ways to eliminate or reduce their health risk behaviours such as smoking and excessive alcohol intake. They may also be advised on having regular suitable exercises. Indeed, participants expressed the view that the use of cancer risk assessment tools could help to identify and raise awareness of cancer risk behaviours, and that this could facilitate implementation of the tools.

From the perspective of service users, this could also help people to modify their risk behaviours, reducing risk and promoting health and wellbeing. One service user said:

“I think it might be just raising awareness, so people realise what's happening, and what can go wrong with them and where the risks are and may be, they can reinforce them where someone else like the young person who has given up smoking, it might be used to reinforce by saying well, you've got a very low risk, so if you've given up smoking carry on with that. Rather than saying you've got a very high risk later” (Service User 5: individual interview).

In terms of identifying and modifying cancer risk factors, service users felt that, *“to be forewarned is to be forearmed, so they change their lifestyles such as stopping smoking or drinking alcohol”* (Service User 10: individual interview). Service users also believed that if an individual’s risk of cancer was identified and monitored over a period, the individual might benefit from lifestyle modification and risk reduction advice. One service user said:

“It can help to identify the individual's risk, isn't it? Because the input you've given is about your own risk rather than the general population, and if it's done over some years and your risk is increasing they could turn around and say well we need to increase or make more changes in your life style. So, if they were to do it every 5 years and if they see that the risk is increasing then maybe they could start giving me some lifestyle advice” (Service User 18: individual interview).

Similarly, practitioners believed that the use of cancer risk assessment tools might help people to modify risk factors such as smoking, as well as using the estimated risk to encourage people to accept a referral for further investigations or to adopt lifestyle changes. This would be important for people refusing lifestyle changes or those not willing to be referred for further investigations.

“They don't understand the risks, you know what I mean? I mean like someone who is a smoker, he is smoking, smoking. You can use this tool to help them

modify their lifestyle. People who are refusing referral, you can use the tool to estimate their risk to show and explain to them" (Practitioner 2 [GP]: individual interview).

In addition, practitioners suggested that it would be useful to encourage patients to use cancer risk assessment tools to check their risk and then seek advice from practitioners if they were concerned about their risk of cancer. In the view of practitioners, the fact that a patient had checked their own risk and decided to consult a practitioner suggested their level of concern and willingness to engage in discussion and possibly referral for further investigations. This could be helpful to the practitioner in terms of making a patient-informed decision.

"I am saying they could also check and then come to us, and they could be helping us as well. If what they regard as risk, you know almost the fact that they've come that might suggest they regard whatever number they've got as something we will be able to discuss with them. We go over it and you could recheck. You could recheck the cancer risk with the patient to see whether you have the same result" (Practitioner 3 [GP]: Focus Group1).

The next perceived enabler relates to the potential benefit of helping to personalise patient care.

5.6.1.4 Personalising care

Personalising care was mentioned by service users and practitioners as another way that cancer risk assessment tools could be useful, hence an enabler to the use of the tools. This means, a cancer risk assessment tool like QCancer could help to personalise care and encourage patient-centred care by highlighting the patient's own specific cancer risk and a plan of care rather than a more generalised plan of care. Because the risk that would be presented to patients would be specific and personal to them, patients would feel more involved and reassured of being well cared for in the consultation process. This could in turn allay any worries or anxiety relating to being informed about a cancer risk and subsequent referral for further investigations. Below are examples of the views expressed by service users:

“I think it will make the care more patient-centred because you're presenting them with their own risk not a general risk, it's personal to them and it will just make the consultation more patient focused, and I think it will make patients feel more involved in the consultation and just feel more cared for I think” (Service User 12: individual interview).

“So, it needs to be about me. I think it’s an excellent idea, the tool. I mean it's dealing with the individual very specifically and there's an opportunity to explain things in more details and delay the inevitable anxiety” (Service User 19: individual interview).

The views of practitioners supported those of services users. For example, a practitioner said, *“patients will go away with a lot more targeted information about their personalised risk of cancer rather than a vague statement”* (Practitioner 1 [GP]: individual interview), which they felt would be helpful in conveying understanding to the patient and allaying anxiety associated with cancer risk assessments and related processes.

Service users and practitioners also perceived barriers to the use0 of cancer risk assessment tools which are discussed below.

5.6.2 Perceived barriers to the implementation of cancer risk assessment tools

Practitioners perceived issues related to CFIR constructs of: readiness for implementation; patient needs and resources; compatibility; knowledge and beliefs of individuals involved; and monitoring the implementation process (Damschroder et al., 2009), as potential barriers to the implementation of cancer risk assessment tools in primary care. The barriers identified were:

- Additional consultation time required (related to CFIR constructs of readiness for implementation and patient needs and resources)

- Worry/anxiety related to investigations (relates to CFIR construct of patient needs and resources)
- Over referral and burdening of services (patient needs and resources)
- Practitioner scepticism (relates to CFIR construct of knowledge and beliefs of individuals involved)
- Conflict with existing guidelines (relates to CFIR construct of compatibility)
- High risk symptoms need referral (i.e. compatibility)
- Need for piloting and monitoring of CRATs implementation (relates to CFIR construct of reflecting and monitoring the implementation process).

5.6.2.1 Additional consultation time required

In line with the CFIR constructs of readiness for implementation and patient needs and resources, service users were concerned that general practices were already busy, and that introduction of a new risk assessment tool would mean additional work for general practitioners. Hence, practitioners in general practice would need *"more time to use the tool in consultations"* (Service User 7: individual interview).

Practitioners also agreed with these views stating that more time would be needed for using a cancer risk assessment tool like QCancer during the consultation. That is, incorporating additional tasks of using a cancer risk assessment tool and spending time to discuss the options with the patient (which may include immediate action) will suggest more time should be added to current consultation time.

Indeed, practitioners felt the use of the tools could be time-consuming because of, *"the uncertainty and putting in all the data manually"* (Practitioner 1 [GP]: Focus Group2); unless the tool was automated and integrated in the general practice information system (for example, SystmOne or EMIS) making it easier to use the tool during consultations.

"It should be integrated in our system, SystmOne, rather than every time we have to go on Google to get it. Like you put all that information in, it will be difficult, it should be completely automatic, and think of the investigations, people are more likely to use it" (Practitioner 1 [GP]: Focus Group2).

Furthermore, practitioners were concerned that general practices had become very busy making it difficult to introduce cancer risk assessment tools, because practitioners would not want more work, unless they targeted patients who were likely to benefit from the use of the tool. A practitioner said:

"It's more a question of more time really, because now, we're in crisis, GPs are in crisis, and the future is very bleak for GPs. Because you come in at 5 in the morning and you get back home in the night and it's a nightmare really. So, we don't want more work. But we can target and do what we need, so unless we really suspect cancer" (Practitioner 6 [GP]: Focus Group1).

Practitioners also felt that one way to address the issue of time was to increase the time available, from a standard consultation length of 10 minutes to at least 15 minutes. A longer consultation would make room for the processes of a cancer consultation including risk assessment, communicating the risk to the patient and referral for further investigations if needed.

"Well I believe if, in the ideal world, you may be aware of that, if there is a push to implement that; I think we should have 15 minutes' appointments. That will give us a little bit extra time, which is assuming the patient has only one problem, but they have multiple problems in one appointment, I think it will be done well if something like cancer risk assessment, communication, organising of the test that follow, 15 minutes will be ideal" (Practitioner 1 [GP]: individual interview).

The next barrier identified by participants was worry or anxiety related to cancer investigations.

5.6.2.2 Worry or anxiety generated by referral for cancer investigation

Participants identified unnecessary worry generated for patients as a potential barrier to the use of cancer risk assessment tools during consultations. This related to the concept of ‘patient needs, and resources’ as expressed within the CFIR (Damschroder et al., 2009). For example, patients may worry if their need for involvement and understanding of the risk information presented to them, is not met.

Indeed, participants felt that people might worry if it was not explained to them that the tool provided a risk assessment rather than a cancer diagnosis. In the absence of adequate explanation, it was felt that some people might assume that a referral for cancer investigations meant a cancer diagnosis, which may not have been the case. This indicates the importance of involving patients when assessing their risk of cancer while ensuring adequate explanation is done to their understanding. Many people consider cancer as bad news and they can be frightened and become worried or anxious when they are told that they have cancer.

In view of potential worry or anxiety that could make some patients miss or misunderstand important information when being informed about their risk of cancer with the practitioner, it was felt that some patients might like someone (e.g a family member or friend) to be with them at an appointment to discuss their cancer risk. Some of these views expressed by service users are stated below:

“Some people may not understand, and they can be too worried especially if they don't explain that it is just a risk, but it is not guaranteed that they will get cancer, then it is not good enough ethically” (Service User 11: individual interview).

“I think they may be, have to assess their patients first to see if they were going to promote great anxiety on the patients by using some of these tools. I think emotionally I would be quite distraught and worried, and this is where having another person in there is important, I think. But I think until you've got some

sort of appointment and then further tests and so forth, you will be in a state of limbo, I think, you know, not being able to concentrate properly" (Service User 6: individual interview).

Practitioners were also concerned that, *"you can probably make them more worried"* (Practitioner 5 [Practice Nurse]: Focus Group2), especially if the explanation was not tailored properly to the understanding of patients. One practitioner observed that care must be taken not to start a patient worrying about an apparently low risk of cancer such as 1%:

"The thing is if you tell the patient they've got 1% cancer, which is creating unnecessary anxiety" (Practitioner 2 [GP]: individual interview).

Participants were also concerned about the potential for over-referral and over-burdening of services.

5.6.2.3 Over-referral and over-burdening of services

The issue of over-referral was mentioned by several participants as a potential challenge to the implementation of cancer risk assessment tools. This was linked to the CFIR construct of patient needs and resources. In other words, there is a potential for too many patients to be referred for investigations or specialist attention and they may not have cancer at the end of the day and did not need to be referred in the first place. These unnecessary referrals and investigations could cause worry and anxiety to patients and could also overburden the limited healthcare resources.

Indeed, expressing their views, some service users suggested that the use of a cancer risk assessment tool like QCancer could result in too many people being referred for cancer investigations, and some of those referred may end up not having cancer, and this may give the impression that they were referred unnecessarily. A service user said:

"It could be useful if the right patients are referred but it could also lead to over referral as some people may have a certain risk but will not have cancer after they have been referred and tested" (Service User 17: individual interview).

Some practitioners supported the views of service users about over-referral but suggested further that over-referral could put a strain on the NHS resources which could have been reserved for patients who genuinely needed them. A practitioner said:

"But on the other side it will put a strain on the NHS; you know what I mean, on the services there. You know, you don't want to over burden the services as well" (Practitioner 4 [GP]: individual interview).

In contrast, another practitioner noted that despite the potential strain on resources due to over referral, it was important to continue to refer patients for further investigations if they met referral criteria because the advantages of referral outweighed the disadvantages. In other words, the number of people dying from cancer was increasing, and more referrals could lead to earlier diagnosis and treatment which could help to save lives.

"I think we should not be worried about resources. Now many more people are dying from cancer, so they want more referral and diagnosis earlier. I am not sure using the tool is cheaper, but I will say it is good for patient safety because people will be diagnosed earlier if referred earlier and they will be helped earlier" (Practitioner 3 [GP]: individual interview).

The next barrier identified by participants was the potential conflict with existing guidelines.

5.6.2.4 Conflict with existing guidelines (relates to CFIR construct of compatibility)

In line with the CFIR constructs of compatibility and complexity, participants identified conflict with existing guidelines as a potential barrier to the implementation of cancer risk assessment tools. This implies a potential confusion between the use of cancer risk assessment tools and guidelines like the NICE guidelines, which are currently used to support cancer risk assessments in primary care.

Indeed, service users were of the view that, to avoid confusion, it would be a good idea for all practitioners to use the same guidelines or tools in assessing patients' risk of developing cancer, rather than different tools or guidelines. There were concerns that a cancer risk assessment tool like QCancer could conflict with existing guidelines such as the NICE guidelines for cancer referral. For example, a service user stated:

"*I think it is good for everybody to have the same sort of guidelines, so to use risk assessment tools everybody should use the same sort of guidelines"* (Service User 1: individual Interview).

Similar to the views of service users, practitioners felt that there may be some confusion in using the new cancer risk assessment tools alongside existing clinical decision tools such as the NICE guidelines, which could confuse practitioners about when to refer to secondary care. Practitioners felt that using both could result in a repeated cancer assessments and referrals to secondary care, unless existing NICE guidelines were modified in such a way as to incorporate the cancer risk assessment tools. Below is an example of the views expressed by practitioners.

"I will be quite confused about using the tool. I mean you know with the NICE guidelines; you couldn't focus on another criterion for any other risk here" (Practitioner 6 [GP]: FGD1).

Another barrier identified was high risk symptoms needing referral.

5.6.2.5 Symptoms suggestive of cancer will need referral whatever the quantified risk- compatibility

In line with the CFIR construct of compatibility and complexity, service users and practitioners expressed the view that referral for further investigations might be warranted whatever the quantified risk when using a cancer risk assessment tool. Service users spoke about their preference for a referral for further investigation of possible cancer symptoms irrespective of the calculated risk. This suggests that, what mattered to service users was the presence of the symptom which would worry them more than a percentage risk. Therefore, if they had high risk symptoms, service users expressed that they would prefer to be referred for further investigations, even if the percentage risk, for example a 1% risk, was considered low. One service user said:

“It doesn't really matter about percentages; I know 1% is less risk. But the fact is the symptom is there, the coughing out of blood, which is quite worrying” (Service User 13: individual interview).

Service users explained that when a symptom such as coughing up blood was worrying for them, they would want to be referred for further investigation, *“to see whether it is cancer or something else”* (Service User 9: individual interview).

Similarly, practitioners stressed that if a patient presented with symptoms suspicious of cancer, they would refer them for investigation. As one practitioner put it*, “as I said, if I suspect cancer and I put in the tool 1%, 2% doesn't matter to me”* (Practitioner 5 [GP]: individual interview). Indeed, practitioners made their views clear that it was more important to look at the symptoms and refer especially if the symptoms were suggestive of cancer. This implied that, for practitioners, symptoms suggestive of cancer could mean the presence of cancer irrespective of the risk calculated. Therefore, practitioners could tell patients with high risk symptoms that their symptoms would be investigated immediately to rule out cancer. Below is an example of the views expressed by practitioners.

“Since they've got symptoms, it is urgent x-ray straight away. I always send my patients for x-ray and say not to worry about the symptom, because I am going to investigate. Because even if he came with 1%, that's the thing. Regardless of what QCancer said I will refer them for investigation with the symptoms. So, it doesn't matter 1% or 0%, I will always do one thing, investigation if the symptoms are suggestive of cancer” (Practitioner 6 [GP]: Focus Group1).

The next barrier identified by participants is practitioner scepticism.

5.6.2.6 Practitioner scepticism

In line with the CFIR construct of knowledge and beliefs of individuals involved in the implementation process, practitioner scepticism was perceived as a potential barrier to implementing cancer risk assessment tools in primary care. In other words, some practitioners may not like the new tools especially if they are not innovators, and they may trust their clinical experience more than guidelines or risk assessment tools.

Indeed, a practitioner remarked that, *"GP experience is more important than tools and guidelines"* (Practitioner 5 [GP]: Focus Group1). This perception which was shared by other practitioners could be due to the fact that cancer risk assessment tools are currently not widely known or used by practitioners. Hence, many practitioners could be uncertain about how the tools work. Being uncertain of how the tools work could discourage some practitioners from using them, especially at the initial stages when practitioners have not yet fully become familiar with the tools. A practitioner said: *"Until you said this thing, you know initially I was very sceptical about this tool"* (Practitioner 3 [GP]: individual interview).

Similarly, participants felt some practitioners might be reluctant to use the tools until a recommended risk threshold to prompt investigations or referral was established. In other words, it would be difficult to use the tools without knowing at what percentage risk a practitioner should investigate or refer:

"I think for it to be useful there needs to be some benchmarks for us to really relate with. If you say 7% or 6%, should I worry? I think they need to tell us. So, for cancers, unless we have those things it will probably be difficult to use the tool" (Practitioner 1 [GP]: Focus Group2).

The next barrier identified was about need for piloting and monitoring before rolling out cancer risk assessment tools.

5.6.2.7 Need for piloting before rolling out cancer risk assessment tools

In line with the CFIR construct of reflecting and monitoring, participants identified the need to establish evidence of effectiveness of the tools by piloting and monitoring before rolling out. Service users suggested that it would be useful to trial the tools with doctors and evaluate the outcomes of using the tools before expanding the use of the tools to all primary care practitioners including nurses.

Due to the busy nature of the general practice system, one service user felt that there may be times when experienced practice nurses do the initial assessments before referring patients to doctors for key or major decisions especially with serious conditions like cancer. Since doctors make the key and final decisions in terms of referral for cancer investigations and diagnosis by the specialists at secondary care, it makes sense to trial the tool with doctors before rolling out to all practitioners at general practice. A service user said:

“But I think if you are going to roll something out rather than going to everybody I would start with the doctors, see how the doctors do with it after evaluation and then move on to the practice nurses” (Service User 12: individual interview).

Similarly, practitioners pointed out that, it would be useful to test the impact of the tools through trials in a real-life situation, measure the outcomes and then review. Indeed, a practitioner noted, *“we have to make sure that it is better than what we are already doing”* (Practitioner 2 [GP]: FGD2). Trialling the tool would not only test its effectiveness but could also highlight any challenges associated with using the tool. One practitioner said:

“One of the things I think will be really useful is, it's been devised but getting it in real life and then reporting back on that, it will be really useful to know how good a tool it is. I don't know whether that makes sense, what I am saying? It's almost like an ongoing research where people use the tool and then say well actually the 4% risk that we calculated when we are using in finding who is at risks, we are sending 500 people and 1% is getting diagnosed. Or it’s an

underestimate. So, to get it to start it will be really useful" (Practitioner 1 [GP]: individual interview).

The next section deals with perceptions and experiences of practitioners after they had had an opportunity to actively use cancer risk assessment tools during patient consultations. These perceptions included ways to best communicate cancer risk information to patients and the perceived enablers and barriers to the use of cancer risk assessment tools.

5.7 Perceptions of practitioners after using cancer risk assessment tools in patient consultations

In Section 5.6 above, the views expressed by practitioners before using cancer risk assessment tools related to: perceived ways to best communicate cancer risk information to patients; perceived enablers and perceived barriers to the use (implementation) of the tools.

The purpose of exploring the views of practitioners after they used the tools was to know whether they experienced the earlier perceptions before using the tools. Any other perceptions expressed by practitioners after using the tools were also considered.

As mentioned earlier, the general practices that had already participated in the earlier individual and focus group interviews were contacted, and one general practice agreed to meet to discuss their perceptions after using the tools. A meeting with practitioners was held in the practice, and practitioners agreed to use the tools for a minimum of one month before meeting for a second focus group interview. A focus group with 4 practitioners was subsequently conducted. Using the themes from the interviews conducted before the use of the tools as a guide, the perceptions gathered from the focus group with practitioners after they had used the cancer risk assessment tools with patients were analysed using the Framework approach. The resulting codes were examined, and similar codes were merged. The emerging codes and themes are presented in Tables 14 – 16 below.

Table 14 Perceptions of how best to communicate cancer risk information – themes, codes and quotes –after practitioners used the tools

Risk communication framework (Fischhoff, 1995)	**Key words/phrases/codes**	**Key themes**	**Meaning of themes**	**Quotes**
	Practitioners			Practitioners
-Tell them the numbers **-Explain what the numbers mean**	-Pictorial representation convinced patients - The yellow smiley faces and blue sad faces were easy to understand - The presentation and icon arrays were very user friendly -Showed them the QCancer chart, the yellow smiley and blue sad faces	Tailoring a visual representation of risk	Before using the cancer risk prediction tools, practitioners had perceived that tailoring a visual representation of risk was one way to best communicate cancer risk information to patients. That is, seeing the risk presented in a visual way will enhance understanding. After using the tools in patient consultations, the practitioners interviewed expressed similar views about tailoring a visual representation of risk as stated below.	“The pictorial representation and multi cancer symptom approach is useful with QCancer” P1 [GP]: Focus Group 3). “I showed them the QCancer chart, the yellow smiley and blue sad faces, and it was easy for them to understand” P1 [GP]: Focus Group3) “The Pictorial presentation will convince the patient about their risk as it is yellow smiley faces and blue sad faces are easy to understand. The presentation and icon arrays are also very user friendly” (P2 [GP]: Focus Group 3).
-Tell them the numbers **-Explain what the numbers mean**	-took time in explaining -reassured by explaining - it’s only a risk and not a cancer diagnosis - They understood and were alright with that	Providing time for informing, listening, explaining and reassuring in a professional away	After using the cancer risk assessment tools, practitioners expressed similar views as before using the tools in patient consultation. In using the tools with patients, practitioners took time to explain what the risk meant and indicated any plans e.g. for investigations and referral to a specialist.	“I reassured the patient by explaining that the risk is only a risk and not a cancer diagnosis. I explained what a 2% risk, meant, which is not a diagnosis of cancer, but a risk. I also explained that, early detection of risk will help with early investigations, diagnosis and early treatment” (P3 [GP]: Focus Group 3).

				I explained that I needed to do some investigations and possibly to refer them. They understood and were alright with that (P1[GP]: Focus Group3).
-Treat them nicely/with respect	-Didn't hide anything from patient -Was honest throughout consultation	Being open and honest with patients	Like the views expressed by practitioners before using the tools, practitioners who used the tools believe telling the truth will make people feel respected and able to make informed decisions. Hence, practitioners believed patients were less worried or anxious because they were honest with them as they did not hide anything from them when they used the tools during consultation.	"I didn't hide anything from the patient, I was honest with them throughout. I think that help to ease their worry" (P1 [GP]: Focus Group3).
-Make them partners **-All the above**	-I informed them -Asked for their consent to use the tool. -They agreed -I involved them from the beginning	Involving patients when using cancer risk assessment tools	Like the views expressed before practitioners used the CRATs with patients, practitioners who used the tools believe that, involving patients when using the tools will mean recognising them as partners in their care and will promote autonomy. Consequently, practitioners involved patients in the use of the tools by informing, explaining and seeking the consent of patients, which patients were happy with.	"As I said, I informed them and asked for their consent to use the tool. They agreed and I involved them in the use of the tool from the beginning, when I was about to use the tool" (P1 [GP]: Focus Group3) "Yes, I also involved them from the beginning by taking time in explaining what I wanted to do to assess their risk of cancer and the patient I was dealing with was happy for me to carry on" (P2 [GP]: Focus Group3).

Table 15 Perceived facilitators to implementation of cancer risk assessment tools – themes, codes and quotes – after practitioners used the tools

CFIR construct (Damschroder et al., 2009)	**Key words/phrases**	**Key themes**	**Meaning of theme**	**Quotes**
	Practitioners			Practitioners
Relative advantage	-The tools will help to guide the clinician to see the broad level of differential diagnosis. - It also facilitates referral of patients -Quantitative risk value to help make decision	Supporting decision making	As perceived before using the tools, the practitioners who later used the tools confirmed that the tools helped them to enabled them to make a clinician decision like referral of the patient	"I think the tools will help to guide the clinician to see the broad level of differential diagnosis. It also facilitates referral of patients by presenting quantitative risk value to help explain risk and make a decision" (P2 [GP]: Focus Group3).
	-Time saving -Faster consultation, the assessments, investigations, and referral processes	Improving process and speed of assessment and treatment	Before using the tools with patients, the benefit of helping to improving process of and speed of assessments and treatment was perceived an enabler to the implementing CRATs. After using the tools in patient consultation, practitioners confirmed that the tools helped with quicker processes of assessment and referrals.	"I think when the tools are fully integrated in our IT systems and every practitioner get familiar with using them, it will be time saving in the long term, as the consultation, the assessments, investigations and referral processes will be faster" (P1 [GP]: Focus Group3). "It was easy to assess a patient's risk of cancer by entering their symptoms and risk factors into the QCancer calculator. It was also easy to use the risk generated to explain why they I needed to refer them for investigations and for a more specialised attention in the hospital, where early diagnosis and treatment could be done sooner than later" (P1 [GP]: Focus Group3).
	-Potential for using the tools for screening in other health categories e.g asymptomatic individuals	Identifying and modifying health risk behaviours	Another perception before using tools was a potential benefit of helping to identify and advise people to modify their health risk behaviours is perceived as a	"I think there is a potential for using the tools for screening in other health categories. The tools could be modified or redesigned to suit other conditions in primary care. They could also be modified for asymptomatic patients,

	-Modify or redesigned the tools to suit other conditions in primary care -They could also be modified for asymptomatic patients -The tool helped in using the risks generated to advise patients who need behavioural changes. -Told them to maintain healthier lifestyles by exercising, eating a healthy diet, less alcohol and to stop smoking if they were smoking. -The tools can help to empower patient to take control of their risk factors and live healthier lifestyles		facilitator for the implementing CRATs. This reflected in the views of practitioners who used a cancer risk prediction tool in patient consultation. The views of practitioners included a suggestion to modify or redesign the cancer risk prediction tools for other conditions or asymptomatic individuals as the statements below reflect	for example the QCancer 10 years' risk tool, I understand can be used to predict of cancer in asymptomatic individuals" (P3 [GP]: Focus Group3). "I also found that using the tool helped in using the risks generated to advise patients who need behavioural changes. Their risk was small, and I told them to maintain healthier lifestyles by exercising, eating a healthy diet, less alcohol and to stop smoking if they were smoking. Yes, as I said, these tools can help to empower patient to take control of their risk factors and live healthier lifestyles" (P2 [GP]: Focus Group3).
Relative advantage	-QCancer is based on current presentation (Q cancer) and easier to understand -We don't quite understand the RAT yet -The pictorial representation and multi cancer symptom approach is useful with QCancer	Ease of use	Practitioners thought ease of user was an enabler to the use of the tools. Those interviewed used the use QCancer tool because they found it easier to use than the RAT which they don't seem to understand	"QCancer is based on current presentation (Q cancer). But I think, we don't quite understand the RAT yet. The pictorial representation and multi cancer symptom approach is useful with QCancer" (P1 [GP]: Focus Group3).

Table 16 Perceived barriers to implementation of cancer risk assessment tools – themes, codes, and quotes – after practitioners used the tools

CFIR constructs (Damschroder et al., 2009)	**Key words/phrases/codes**	**Key themes**	**Meaning of theme**	**Quotes**
	Practitioners			Practitioners
Patient needs & resources	-Thought it was going to be time consuming using the tool. -But time is only a short-term issue -Only when you must google the tools -Time saving when fully integrated in IT systems -Time saving when practitioners are familiar with using the tools -Time saving in the long-term -The processes will be faster later	Additional consultation time in the short-term	Before using the tools, there was perceived additional time required for the extra task of using CRATs the implementation of CRATs. After using the tools with patient, practitioners perceived that additional consultation time will only be need initially, and that the using the tool can save time in the long term.	"I thought it was going to be time consuming using the tool. But I realised that will only be the case in the short term when you must google the tools before using for every patient. I think when the tools are fully integrated in our IT systems and every practitioner get familiar with using them, it will be time saving in the long term, as the consultation, the assessments, investigations and referral processes will be faster" (P1 [GP]: Focus Group3).
Patient needs & resources	-helped to reassure patients - Knowing that their symptoms were not cancer related -Knowing their symptoms would be investigated and cancer ruled out	Worry/anxiety relating to cancer referral & investigations	Before using the tools, practitioners thought there would be anxiety, but no patients were anxious when practitioners used the tool. It may be too early to conclude with a few patients in a short time of use. But practitioners explained that using the tools rather helped to reassure and calm patients once they got to	"There was no problem. You are probably expecting them to be worried, but they were not. The patients I dealt with using the tool didn't appear worried at all. I think that was partially because they understood that it was a small risk and it was not that they had cancer but just a risk" (P2 [GP]: Focus Group3). "…and using the tools, I think helped to reassure patients who probably were anxious about their symptoms before coming to see the GP. Knowing that their symptoms were not cancer related and

			know something is being done. Also, the neutral colour of the QCancer icon arrays help to prevent anxiety or worry upon when you show it to the patients.	that their symptoms would be investigated, and cancer ruled out, could have helped with to reduce anxiety” (P2 [GP]: Focus Group3). “Background colours of icons in QCancer for the risk levels could have been red rather than the blue sad faces which are more neutral. But then, I think we may have to leave them that way, because the neutral colour probably helped patients not to be anxious - red could have scared them” (P3 [GP]: Focus Group3).
Patient needs & resources	-Clinical judgements is used as well -Referred only those that needed referral -There will be over referral, -Haven’t referred many in a month -Referred a few for investigations & diagnosis	Over-referral & over burdening of services	Before using the tools, it was perceived that using the tool could cause over-referrals. But after using the tools practitioners felt this may not happen as they use their judgement alongside the tools to refer. So far just a few patients qualified for referral in a month	“Yes, we were thinking that using the tools in consultation could result in unnecessary …. over referrals. But as we have said before, we are not just referring but we are using our clinical judgements as well, so we only referred those patients that needed to be referred and we haven’t seen many in a month – I don’t think there will be over-referrals” (P1 [GP]: Focus Group3)
Compatibility / complexity	-The tools are not known to the secondary or hospital setup. -They may not recognise QCancer referrals -They are only used to NICE referral guidelines	Conflict with existing guidelines	Before using the tools, it was perceived that there will be conflict with existing guidelines. After using the tools, Practitioners maintained that using CRATs could conflict with NICE referral guidelines as the specialists in hospitals expect only referrals relating to NICE 2-week or urgent referral guidelines	“My concern is that the tools are not known to the secondary or hospital setup. So, I referred some patients, and I am concerned they may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals. So, when I am thinking, if they see the patients, I referred using QCancer, they will ask - who is this? Is this a new doctor, a new GP?” (P1 [GP]: Focus Group3)

Complexity	-Symptoms suggestive of cancer	Symptoms suggestive of cancer need referral whatever the quantified risk	Before using the tools, it was perceived that patients with symptoms suggestive of cancer would need whatever the quantified risk. After using the tools, practitioners suggested that they only used the tools when they were not clear or wanted to differentiate cancer symptoms for other conditions.	"You know, I won't use these tools if the symptoms are clear to me that there is a cancer." (P3 [GP]: Focus Group3).

Table 16 Perceived barriers to implementation of cancer risk assessment tools – themes, codes, and quotes – after practitioners used the tools

CFIR constructs (Damschroder et al., 2009)	Key words/phrases/codes	Key themes	Meaning of theme	Quotes
	Practitioners			Practitioners
Knowledge & beliefs of individuals involved	-The tools are useful -For clinical decision making -Happy to use the tools -Will use the QCancer which is easier to use. -Have no problem using the tools -believed it will be good to use the tools	Willingness to use the tools	Practitioner before using the tools had expressed scepticism on using the tools. Although only a few practitioners have used the tools, they have expressed a willingness to roll a cancer risk assessment tools out with no scepticism.	"Yes, I will use the tools. I think the tools are useful in helping with clinical decision making as we already discussed" (P1 [GP]: Focus Group3). "Me too, I am happy to use the tools especially the QCancer, which is easier to use" (P3 [GP]: Focus Group3). "I have no problem using the tools, and I believe it will be good to use cancer risk assessment tools to facilitate early diagnosis of cancer, and as you know, early diagnosis will help with early treatment" (P2 [GP]: Focus Group3).
Patient/practitioner needs & resources	-Problem of accessing the tools as they are not integrated in our IT system. - It was not easy downloading or googling the tools during patient consultation. -The tools are not linked with the current NHS system	Need to integrate the tools into general practice system	Practitioners who used the tools in patient consultation found it difficult because the tools are currently not integrated into their general practice IT system. To use the tool, practitioners had to search for the QCancer tool from the internet for each patient they needed to assess for cancer risk. Practitioners expressed the following views.	"There was a problem of accessing the tools as they are not integrated in our IT system. It was not easy downloading or googling the tools during patient consultation, but that was the only option as I wanted to use the QCancer tool to check whether the patient was at risk of cancer, as the symptoms were a bit unclear" (P2 [GP]: Focus Group3). "The tools are not linked with the current NHS system, so you can't really use them in patient consultation, unless you google and then use, all that, while the patient is waiting" (P3 [GP]: Focus Group3).

Patient/practitioner needs & resources	-Problem is the RAT is not clear. -The RAT is more complicated to use than the QCancer. -We don't quite understand how to use that tool. We need to have proper education or training on using these tools.	Need for training on using the tool in consultation	Another barrier identified by practitioners who used the tool was that practitioners don't understand clearly how to use the tools, and that practitioners need to know how to use the tools, especially the RAT. Training on how to use the tools in consultation is needed.	"One problem is that the RAT is not very clear. The RAT is looking more complicated to use than the QCancer. We don't quite understand how to use that tool. I think we need to have proper education or training on using these tools. The other day I met a lady from the Macmillan Cancer I support, and I asked them to see if they could come and give us a training session or talk on how to use the cancer risk assessment tools in patient consultations. I think we need to follow that up because the tools look good to use" (P2 [GP]: Focus Group3).
Patient/practitioner needs & resources	-The tools are not known to the secondary or hospital setup. - They may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals.	Need to involve in-hospital specialists in use of the tools	After using the tools practitioners also identified that Specialist in hospital need to be aware and expect referrals relating to the tools, otherwise the staff at hospitals will not recognised cancer risk referrals based on the use of cancer risk prediction tools.	"My concern is that the tools are not known to the secondary or hospital setup. So, I referred some patients, and I am concerned they may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals. So, when I am thinking, if they see the patients, I referred using QCancer, they will ask - who is this? Is this a new doctor, a new GP?" (P1 [GP]: Focus Group3).
Reflecting & monitoring	-We will use these tools for a while and then evaluate. -Need to see effectiveness of the tools they are against existing practice. -Need to assess the impact of using these tools on investigations, referral, diagnosis etc	Need to establish effectiveness of CRATs	As identified before using the tools in patient consultation, practitioners who used a cancer risk assessment tool confirmed the need for further evaluation of the impact of using the tools on outcomes such as investigations, referral, diagnosis and patient and practitioner satisfaction	"The only thing is, as I have said before, we will need to use these tools for a while and then evaluate to see how effective they are against existing practice. I mean we have to assess the impact of using these tools on investigations, referral, diagnosis etc" (P1 [GP]: Focus Group3)

5.7.1 Perceptions of practitioners after using the tools, about how best to communicate cancer risk information to patients

When practitioners were interviewed before they used cancer risk assessment tools in patient consultations, they suggested several strategies that could help to best communicate cancer risk information to patients. After using the tools, practitioners maintained these suggestions as presented below. As in Section 5.6 above, these perceptions are informed by Fischhoff's risk communication framework (Fischhoff, 1995).

5.7.1.1 Tailoring a visual representation of risk

Before using the cancer risk assessment tools, practitioners perceived that tailoring a visual representation of risk was one way to best communicate cancer risk information to patients. That is, seeing the risk presented in a visual way, such as through pictures or symbols, could enhance understanding of a patient's risk information. After using the tools in patient consultations, practitioners maintained these views about tailoring a visual representation of risk as the following statements indicate:

"The pictorial representation and multi cancer symptom approach is useful with QCancer" P1 [GP]: Focus Group 3).

"I showed them the QCancer chart, the yellow smiley and blue sad faces, and it was easy for them to understand" P1 [GP]: Focus Group3).

"The Pictorial presentation will convince the patient about their risk as it is yellow smiley faces and blue sad faces are easy to understand. The presentation and icon arrays are also very user friendly" (P2 [GP]: Focus Group 3).

5.7.1.2 Providing time for informing, listening, explaining and reassuring in a professional away

After using the cancer risk assessment tools, practitioners expressed similar views as they did before they used the tools in patient consultation. That is, in using the tools with patients, practitioners took time to explain what the risk meant and indicated to patients that there was a plan to investigate and refer for a specialist's attention in hospital. Explaining and reassuring patients can help them to understand the risk information presented to them. Understanding of the risk information can also help to reduce unnecessary worry or anxiety that may be experienced by patients during a consultation with a practitioner. In line with this, some practitioners said:

"I reassured the patient by explaining that the risk is only a risk and not a cancer diagnosis. I explained what a 2% risk, meant, which is not a diagnosis of cancer, but a risk. I also explained that, early detection of risk will help with early investigations, diagnosis and early treatment" (P3 [GP]: Focus Group 3).

"I explained that I needed to do some investigations and possibly to refer them. They understood and were alright with that" (P1[GP]: Focus Group3).

5.7.1.3 Being open and honest with patients

Like the views expressed by practitioners before using the tools, practitioners who used the tools with patients believed not telling patients the right information about their health could mean practitioners may be 'hiding something' from the patient. On the other hand, telling patients the truth about their risk of cancer could make them feel respected, less worried and able to make informed decisions. Hence, practitioners believed patients were less worried because they were honest with them as they did not hide anything from them when they used the tools during consultation. A practitioner said:

"I didn't hide anything from the patient, I was honest with them throughout. I think that help to ease their worry" (P1 [GP]: Focus Group3).

5.7.1.4 Involving patients when using cancer risk assessment tools

Similar to the views expressed before practitioners used the cancer risk assessment tools with patients, practitioners who used the tools believed that, involving patients when using the tools would mean recognising them as partners in their care and will promote autonomy or empowerment. Consequently, practitioners involved patients in the use of the tools by informing, explaining and seeking the consent of patients, which patients were happy with. Practitioners expressed the following views:

"As I said, I informed them and asked for their consent to use the tool. They agreed and I involved them in the use of the tool from the beginning, when I was about to use the tool" (P1 [GP]: Focus Group3).

"Yes, I also involved them from the beginning by taking time in explaining what I wanted to do to assess their risk of cancer and the patient I was dealing with was happy for me to carry on" (P2 [GP]: Focus Group3).

The next section deals with the enablers to the implementation of cancer risk assessment tools as perceived by practitioners after using the tools.

5.7.2 Perceived enablers to implementation after practitioners used the tools

After using cancer risk assessment tools in patient consultations, practitioners perceived several enablers to the use of the tools which are similar to those expressed before the use of the tools in patient consultations: supporting decision-making; improving process and speed of assessment and treatment; identifying and modifying health risk behaviours; and ease of use. These are explained further below and informed by the CFIR construct of relative advantage (Damschroder et al., 2009) as stated in Section 5.6 above. That is, practitioners perceived these as enabling their use of the tools if they thought the tools were useful or had relative advantage.

5.7.2.1 Supporting decision making

As perceived before using the tools, the practitioners who later used the tools confirmed that the tools enabled them to make clinical decisions like referral of the patients. This was more likely to be the case when practitioners were not sure if a patient's symptoms related to cancer or another condition. In line with this, a practitioner said:

"I think the tools will help to guide the clinician to see the broad level of differential diagnosis. It also facilitates referral of patients by presenting quantitative risk value to help explain risk and make a decision" (P2 [GP]: Focus Group3).

5.7.2.2 Improving process and speed of assessments and treatment

Before using the tools with patients, the benefit of helping to improve process and speed of assessments and treatment was perceived as an enabler to the implementation of cancer risk assessment tools in primary care. After using the tools in patient consultation, practitioners maintained that the tools helped with quicker processes of assessment and referrals of patients. This was because a risk of cancer was likely to be detected on a single consultation with the practitioner and investigations and referrals were done sooner than later. Also, assessing a patient's risk using their risk factors and symptoms was probably easier and quicker for some practitioners. A quicker than usual assessment also meant that practitioners could to decide with the patient on investigations and referral options without wasting time. In this direction, some practitioners said:

"It was easy to assess a patient's risk of cancer by entering their symptoms and risk factors into the QCancer calculator. It was also easy to use the risk generated to explain why they I needed to refer them for investigations and for a more specialised attention in the hospital, where early diagnosis and treatment could be done sooner than later" (P1 [GP]: Focus Group3).

“I think when the tools are fully integrated in our IT systems and every practitioner get familiar with using them, it will be time saving in the long term, as the consultation, the assessments, investigations and referral processes will be faster” (P1 [GP]: Focus Group3).

5.7.2.3 Identifying and modifying health risk behaviours

Another perception before practitioners used the tools was about the potential benefit of the tools helping to identify and advise people to modify their health risk behaviours. In other words, using a patient’s risk information, they could be encouraged to modify health risk behaviours like smoking, excessive alcohol consumption and lack of regular exercises, which could lead to a reduction in the patient’s cancer risk level. This idea of identifying and encouraging patients to modify their health risk behaviours reflected in the views of practitioners who used the tools in patient consultations. Apart from maintaining that the tools helped to identify and advise individual patients about modifying their health risk behaviours, practitioners also suggested that the tools could be modified or redesigned for other conditions or asymptomatic individuals. Practitioners said:

“I think there is a potential for using the tools for screening in other health categories. The tools could be modified or redesigned to suit other conditions in primary care. They could also be modified for asymptomatic patients, for example the QCancer 10 years’ risk tool, I understand can be used to predict of cancer in asymptomatic individuals” (P3 [GP]: Focus Group3).

“I also found that using the tool helped in using the risks generated to advise patients who need behavioural changes. Their risk was small, and I told them to maintain healthier lifestyles by exercising, eating a healthy diet, less alcohol and to stop smoking if they were smoking. Yes, as I said, these tools can help to empower patient to take control of their risk factors and live healthier lifestyles” (P2 [GP]: Focus Group3).

5.7.2.4 Ease of use

Ease of use of the tools was not mentioned by practitioners who had not used the tools in patient consultation, but this was identified as an enabler to the use of the cancer risk assessment tools by practitioners who used the tools. Ease of use here describes how easy or difficult it was for practitioners to use any of the tools (e.g QCancer or RAT). Indeed, practitioners felt that the QCancer tool was easier to use than the RAT which seemed difficult to understand and use in patient consultations. A practitioner said:

“QCancer is based on current presentation (QCancer). But I think, we don’t quite understand the RAT yet. The pictorial representation and multi cancer symptom approach is useful with QCancer” (P1 [GP]: Focus Group3).

As perceived by practitioners after using a cancer risk assessment tool, the barriers to the use of the tools are presented in the next section.

5.7.3 Perceived barriers to implementation after practitioners used the tools

Following the use of cancer risk assessment tools in patient consultations, practitioners perceived several barriers to the use of the tools which are like those expressed before practitioners used the tools in patient consultations: additional consultation time in the short term; worry or anxiety relating to cancer referral & investigations; over-referral of patients; conflict with existing guidelines; symptoms suggestive of cancer need referral whatever the quantified risk; practitioner scepticism; need to integrate the tools into general practice system; need for training on use of the tools in patient consultations; need to involve in-hospital specialists in the use of the tools; and need to establish effectiveness of the tools. These are explained further below and informed by the relevant constructs from the CFIR (Damschroder et al., 2009) as stated in Section 5.6 above.

5.7.3.1 Additional consultation time in the short-term

Before using the tools, there was perceived additional time required for the extra task of using cancer risk assessment tools in patient consultations. After using the tools with patients, practitioners perceived that additional consultation time will only be needed in the short-term, and that using the tools can save time in the long-term. From this point of view, it seems that time could be saved when the tools are integrated in the general practice IT system making it easier for practitioners to use the tools without having to switch between the patient's records and the internet. When the tools are not integrated in the general practice system, switching from the patient's records to the internet to access and use the tools, could be very time consuming. In line with this, a practitioner said:

"I thought it was going to be time consuming using the tool. But I realised that will only be the case in the short term when you must google the tools before using for every patient. I think when the tools are fully integrated in our IT systems and every practitioner get familiar with using them, it will be time saving in the long term, as the consultation, the assessments, investigations and referral processes will be faster" (P1 [GP]: Focus Group3).

5.7.3.2 Worry or anxiety relating to cancer referral & investigations

Before using the tools, practitioners thought there would be anxiety or worry relating to cancer referrals and investigations. In contrast, the practitioners who used the tools said they did not observe any worries or anxiety in patients. Given the short time available for practitioners to use the tools before meeting with the researcher to express their views, it may be too early to conclude or rule out any future episodes of worries associated with the use of the tools. It is also possible that, even with the limited time that the tools were used, patients did not worry because practitioners took time to explain the use of the tools to patients, which might have helped to reassure and calm the nerves of patients. Also, as perceived by some practitioners, the neutral colour of the QCancer icon arrays might have helped to prevent anxiety or worry when they were shown and explained to patients. In line with this, some practitioners expressed the following statements:

"There was no problem. You are probably expecting them to be worried, but they were not. The patients I dealt with using the tool didn't appear worried at all. I think that was partially because they understood that it was a small risk and it was not that they had cancer but just a risk" (P2 [GP]: Focus Group3).

"…and using the tools, I think helped to reassure patients who probably were anxious about their symptoms before coming to see the GP. Knowing that their symptoms were not cancer related and that their symptoms would be investigated, and cancer ruled out, could have helped with to reduce anxiety" (P2 [GP]: Focus Group3).

"Background colours of icons in QCancer for the risk levels could have been red rather than the blue sad faces which are more neutral. But then, I think we may have to leave them that way, because the neutral colour probably helped patients not to be anxious - red could have scared them" (P3 [GP]: Focus Group3).

5.7.3.3 Over-referral of patients

Before using the tools, it was perceived that using the tools could lead to over-referrals of patients. In contrast, after using the tools practitioners felt this might not happen as they used their judgement alongside the tools to refer patients for investigations and specialists' attention. This suggests that practitioners are not likely to depend entirely on the tools which could lead to over-referral. Applying their professional judgement when using the tools implies that only patients who are likely to have cancer will be referred for investigations or the attention of a specialist. Indeed, practitioners who used the tools felt that, so far just a few patients qualified for referral in a month of using the tools. A practitioner said:

"Yes, we were thinking that using the tools in consultation could result in unnecessary …. over referrals. But as we have said before, we are not just

referring but we are using our clinical judgements as well, so we only referred those patients that needed to be referred and we haven't seen many in a month – I don't think there will be over-referrals" (P1 [GP]: Focus Group3).

5.7.3.4 Conflict with existing guidelines

Before using the tools, it was perceived that there could be conflict with existing guidelines like the NICE referral guidelines. After using the tools, practitioners maintained using the tools could conflict with NICE referral guidelines especially as the specialists in the hospitals only know and expect only referrals relating to NICE two-week or urgent referral guidelines. Like many practitioners in primary care, cancer specialists in secondary care may be more familiar with NICE guidelines associated with cancer referrals. In this respect, a practitioner said:

"My concern is that the tools are not known to the secondary or hospital setup. So, I referred some patients, and I am concerned they may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals. So, when I am thinking, if they see the patients, I referred using QCancer, they will ask - who is this? Is this a new doctor, a new GP?" (P1 [GP]: Focus Group3).

5.7.3.5 Symptoms suggestive of cancer need referral whatever the quantified risk

Before using the tools, it was perceived that patients with symptoms suggestive of cancer would need to be referred for cancer investigations and diagnosis even if the quantified risk was low. After using the tools, practitioners maintained this position, but they made clear that they only used the tools when they were not clear or wanted to differentiate cancer symptoms for other conditions. This implies that practitioners may not need to use a cancer risk assessment tool if a patient is already presenting with recognisable symptoms of cancer. In line with this, a practitioner said, *"you know, I won't use these tools if the symptoms are clear to me that there is a cancer."* (P3 [GP]: Focus Group3).

5.7.3.5 Willingness to use the tools

Practitioners, before using the tools had expressed that scepticism was a potential barrier to the implementation of cancer risk assessment tools. This could relate to the knowledge and beliefs of practitioners some of whom may not be innovators and may not like new tools. It may also be that they are being cautious about the new tools because of lack of evidence of their effectiveness.

In contrast to the views held by those who used did not actively use the tools in patient consultations, those who used the tools were not sceptical about the tools. Indeed, practitioners said they were willing to roll out the tools after the necessary preparation or groundwork was completed. Practitioners said:

"Yes, I will use the tools. I think the tools are useful in helping with clinical decision making as we already discussed" (P1 [GP]: Focus Group3).

"Me too, I am happy to use the tools especially the QCancer, which is easier to use" (P3 [GP]: Focus Group3).

"I have no problem using the tools, and I believe it will be good to use cancer risk assessment tools to facilitate early diagnosis of cancer, and as you know, early diagnosis will help with early treatment" (P2 [GP]: Focus Group3).

5.7.3.6 Need to integrate the tools into general practice system

Practitioners who used the tools in patient consultation experienced difficulties accessing the tools because the tools are currently not integrated into their general practice IT system. In fact, practitioners had to search for the QCancer tool from the internet for each patient they assessed for cancer risk. This was difficult and time consuming. This suggests the need to integrate the tools in the general practice IT system which will address the issues associated with too much time being spent on accessing and using the tools. In this connection, practitioners expressed the following views.

"There was a problem of accessing the tools as they are not integrated in our IT system. It was not easy downloading or googling the tools during patient consultation, but that was the only option as I wanted to use the QCancer tool to check whether the patient was at risk of cancer, as the symptoms were a bit unclear" (P2 [GP]: Focus Group3).

"The tools are not linked with the current NHS system, so you can't really use them in patient consultation, unless you google and then use, all that, while the patient is waiting" (P3 [GP]: Focus Group3).

5.7.3.7 Need for training on how to use the tools in primary care consultations

Another barrier identified by practitioners who used the tools was lack of understanding on the part of practitioners on how to use the tools. Practitioners said they had problems understanding and using the RAT. Hence, training on how to use the tools in patient consultations (including training needs like how the tools are integrate into the general practice IT systems and how to access them), is needed. In line with this, a practitioner said:

"One problem is that the RAT is not very clear. The RAT is looking more complicated to use than the QCancer. We don't quite understand how to use that tool. I think we need to have proper education or training on using these tools. The other day I met a lady from the Macmillan Cancer I support, and I asked them to see if they could come and give us a training session or talk on how to use the cancer risk assessment tools in patient consultations. I think we need to follow that up because the tools look good to use" (P2 [GP]: Focus Group3).

5.7.3.8 Need to involve cancer specialists at secondary care settings

Practitioners who used the tools also identified that Specialists in hospital settings need to be involved in the implementation of the cancer risk assessment tools, so they can expect referrals relating to the tools. Otherwise, any referrals to hospitals settings will not be recognised by consultants since they are likely to be more familiar with cancer referrals based on NICE guidelines than any other tools like the cancer risk assessment tools. In relation to this, one practitioner said:

"My concern is that the tools are not known to the secondary or hospital setup. So, I referred some patients, and I am concerned they may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals. So, when I am thinking, if they see the patients, I referred using QCancer, they will ask - who is this? Is this a new doctor, a new GP?" (P1 [GP]: Focus Group3).

5.7.3.9 Need to establish effectiveness of the tools

As identified before using the tools in patient consultation, practitioners who used the tools maintained that, an evaluation of the impact of using the tools on outcomes such as investigations, referral, diagnosis and patient and practitioner satisfaction would be helpful. That any evidence of effectiveness associated with the use of the tools could encourage practitioners to implement the tools widely across general practices. The evidence could also inform policy issues relating to the recognition and appropriate integration of the tools into the general practice IT systems and alongside existing NICE guidelines. In this direction, a practitioner said:

"The only thing is, as I have said before, we will need to use these tools for a while and then evaluate to see how effective they are against existing practice. I mean we have to assess the impact of using these tools on investigations, referral, diagnosis etc" (P1 [GP]: Focus Group3).

The conclusion of this chapter is presented in Section 5.8 below.

5.8 Conclusion of the chapter

The results are presented in this chapter in respect of the research questions about how best to communicate cancer risk information to patients; and the enablers and barriers to implementation of cancer risk assessment tools from the perspectives of service users and primary care practitioners.

The analysis of the qualitative data was informed by two theoretical frameworks: the risk analysis framework (Fischhoff, 1995) for the question about how best to communicate cancer risk information; and the consolidated framework for implementation research (Damschroder et al., 2009) for the question about enablers and barriers to implementation.

Service users and practitioners suggested several ways for effectively communicating cancer risk information to patients during a general practice consultation. These include tailoring a visual representation of risk; being open and honest; involving patients in the use of cancer risk assessment tools and providing time for listening and explaining to patient's understanding. These perceptions were gathered when practitioners had not used the tools with patients in consultations. However, practitioners maintained these suggestions when they were interviewed after using the tools in general practice patient consultations.

Before the use of cancer risk assessment tools, service users and practitioners perceived several enablers to the implementation of cancer risk assessment tools. These included: supporting clinical decision-making; identifying and modifying health risk behaviours; improving process and speed of assessment and treatment; and personalising care. After using the tools in general practice consultations, practitioners maintained these enablers, and stated an additional enabler - ease of use.

Similarly, before the tools were used, participants perceived several barriers to implementation of cancer risk assessment tools including: additional time requirement; worry or anxiety related to referral for investigations; potential over-referral; conflict with existing guidelines; symptoms suggestive of cancer will need referral whatever the quantified risk; and need to pilot and evaluate for the effectiveness of the tools against current practice.

After using the tools in patient consultation, practitioners maintained these barriers perceived earlier, and then added the following barriers to implementation of the tools: need for integration of the tools into all general practice IT systems; need to involve secondary care or hospitals consultants and other relevant specialist in the use of the tools. These results are discussed in Chapter 6 which follows next.

CHAPTER 6 DISCUSSION

6.1 Summary of the chapter

In this chapter, the results are discussed in relation to the research questions which were to explore the perspectives of service users and practitioners about: (a) how best cancer risk information can be communicated to patients during consultations, and (b) the enablers and barriers to the implementation of cancer risk assessment tools in primary care. A summary of the main findings; statement of original findings; limitations and strengths of the study are stated. The findings are discussed in the context of the existing literature and the implications for practice and research.

6.2 Summary of key findings

Before using the cancer risk assessment tools in patient consultations, both service users and practitioners suggested several ways of effectively communicating cancer risk information to patients: tailoring visual representation of risk; being open and honest; informing and involving patients in the use of the tools; and providing time for listening, informing, explaining and reassuring in a professional way. After using the tools in patient consultations, practitioners maintained that these strategies helped communicate cancer risk with patients.

Also, before using the tools, both service users and practitioners perceived the benefits of using cancer risk assessment tools as the enablers to the implementation of tools. These included: supporting decision-making; raising awareness for modifying health behaviours; improving process and speed of assessments and treatment; and personalising patient care. After using the tools, practitioners perceived ‘ease of use’ as an additional enabler to their use of the tools.

In addition, perceived barriers to implementation identified before the tools were used included: additional time requirement; unnecessary worry related to referral for cancer investigations; over-referral; practitioner scepticism;

conflict with existing guidelines; need to refer patients with symptoms suggestive of cancer whatever the quantified risk; and the need for evidence of effectiveness before introducing the tools widely in primary care patient consultations. After using the tools, practitioners mentioned the following as additional barriers observed during the use of the tools: need to integrate the tools into IT systems of all general practices; need to involve secondary care consultants and need for training of practitioners about how to use the tools in patient consultations.

6.3 Statement of original findings

One important aspect of the originality of this study relates to the gathering of the views of service users in addition to those of practitioners, as most previous studies are based on the perspectives of practitioners on the barriers and facilitators to the use of cancer risk assessment tools in primary care.

The findings also add to existing knowledge in terms of the strategies or ways suggested for enhancing communication of cancer risk information to patients. These include the importance of tailoring a visual representation to enhance patients’ understanding of the risk being communicated to them. Another way to effectively communicate cancer risk is by being open and honest on the part of both patients and practitioners. Others include involving patients in the use of the tools and providing time for listening while using a professional approach to explain, inform and reassure patients. This study sought to explore how cancer risk information may be best communicated to patients when using cancer risk assessment tools in primary care consultations. These findings are new and will bridge that gap about how best cancer risk information can be communicated to patients during consultations.

6.4 Limitations and strengths

The findings from this study were limited in various ways. One recurrent question I encountered during my PhD was, why the philosophical position of pragmatism and the use of Framework analysis were adopted instead of a pure interpretive position, for example, using grounded theory for data analysis. I acknowledge there may have been limitations to not using an interpretive approach when collecting and analysing the data, but this was balanced by the specific aims of the study and the need to compare patient and practitioner views. While a pure interpretive or inductive approach may be common with most qualitative research, the nature of my research required me to adopt the pragmatic philosophical position, which allowed me to use methods that best addressed the research questions.

It was also necessary to ground the research in relevant theoretical frameworks, which were useful in informing the interview guides and subsequent analysis of the data. The framework approach allowed both deductive as well as relevant inductive themes. A limitation arising from this approach was the potential for the researcher to consciously or unconsciously influence the way the questions were asked, and the type of data collected. However, I was careful enough to minimise this by piloting and revising the data collection tools with potential participants and my supervisors. Additionally, the interviews, data collection and analysis were carefully discussed with my supervisors to ensure objectivity, authenticity and accuracy.

The initial data collection involved participants (service users and practitioners) who had not yet used the tools in clinical practice. It was thought important to collect additional data from practitioners who had used the tools with patients, to assess whether their views about the use of tools would differ from those who did not actively use the tools. Hence, an additional focus group was conducted with practitioners who had actively used the tools.

While the additional focus provided additional useful information from practitioners after using the tools, there were limitations worth acknowledging. The additional focus group was conducted in one of the general practices that had participated in the earlier data collection. Hence, one limitation was the potential for some practitioners to be influenced by the perceptions they expressed before actively using the tools in consultations. It would have been ideal to gather the views of practitioners who had not participated in the earlier focus groups. It would have also been good to have more than one focus group, but this was the only practice willing to use the tools and then find time to meet for a focus group, within the time frame available for the completion of the project and submission of the thesis. The honesty and professionality of practitioners in not allowing their pre-use perceptions to influence their post-use perceptions of the tools was trusted.

A further limitation is that many service users and practitioners might have received or seen the information inviting them to participate in this study but could not participate. It is possible that those who were unable to participate might have expressed different views from those who took part in the study. For example, practitioners who did not participate may have been less positive about them and less likely to take them up, the so-called late majority or laggards in taking up innovation (Rogers,1995). Their knowledge and beliefs about the new tools (Damschroder et al., 2009) might have differed from those who participated. This is because participants generally felt that cancer risk assessment tools would be beneficial, and the benefits would serve as enablers to the implementation of the tools. This raises a question of selection bias, a common problem with the selection of volunteers to qualitative interviews (Collier & Mahoney,1996).

The finding of code (‘I have heard it all’) and meaning (‘I have understood it all’) data saturation (Hennink et al., 2016) in the data analysis process, an important guide for sample size selection in qualitative research, suggested that no new ideas would have been found if more participants were interviewed.

Another limitation is in generalising the findings from this study to other populations because the sample size may be considered small. However, the primary aim of qualitative studies is usually not to generalise but to explore or generate ideas, which this study has effectively achieved.

Although there are an increasing number of people from minority ethnic groups in the study area and in the UK, no service users from these groups responded to the invitation to participate in the study. Hence, all nineteen service users who participated in the study were White British. It is not clear why service users from ethnic minorities did not respond. However, the study advertised for participants who had interest in the delivery of cancer services, for reasons such as having recovered from cancer or having a relative or a friend who had recovered from cancer or for some other reason. The advertisement for participants was spread widely, but it is possible that members of ethnic minority groups did not see the advertisement, were unable to understand it due to language difficulties, or had no interest in participating in the study.

Previous research findings suggest that members of minority ethnic groups are less likely to participate in research if they lack confidence in knowing what to say, or if there was fear or worry of the unknown, or if there was a language barrier resulting in lack of understanding about the research (Lo & Garan, 2008; Gill et al., 2013). It has also been suggested that people from minority ethnic groups are more likely to participate in research if they are approached with sensitivity and they understand or perceive the study to be beneficial to them (Ejiogu et al., 2011; Gill et al., 2013).

As explained previously in the methods section and bearing in mind the importance of approaching potential participants with sensitivity, potential participants were provided with clear information about the research using a flyer, and they had enough time to decide on whether to participate in the study, before approaching the researcher.

Among service user participants, there were fewer men than women. This may have been because women were more willing to participate in the study than men, although previous research has found that men and women, if they were eligible, were equally willing to participate in cancer research (Huang et al., 2013). Among practitioners, there were more participants from ethnic minority groups than White British, but this may be due to the demography of general practitioners in the study.

A key strength of the study was the comparison of service user and practitioner perspectives, and the use of both individual and focus groups interviews. The use of individual interviews helped to gather detailed or in-depth information from individual participants, while the use of focus groups for some practitioners enabled the possibility for discussion with colleagues who were likely to work as a practice team when it came to the implementation of the cancer risk assessment tools in primary care consultations. Service users and practitioners were candid in expressing their views which helped to gather tangible findings to address the research question.

The data collection, analysis and interpretation followed recognised processes to ensure the findings were valid. The rigour in data processes included the following. Recorded interviews were transcribed verbatim. The five stages of the framework approach (Ritchie & Spencer, 1994) were followed for data analysis. The data analysis was monitored and guided by the primary supervisor, with all three members of the supervisory team providing feedback during the process.

In the conduct of the study, particularly in the analysis and interpretation of the data, the researcher applied his background knowledge and experience in nursing and psychology coupled with the expertise of his supervisory team, which included an experienced general practitioner (GP) and supervisors with a nursing background. The presence of a GP in the supervisory team helped to clarify and interpret certain terms and expressions used by participants, particularly those who were GPs. Additionally, the different backgrounds of the research team added diverse perspectives to the analysis and interpretation of the results.

Reflection on the use of QCancer with service users (at Phase 1) and practitioners at Phase 2, and non-specific (any) risk assessment tools

Although the thesis was initially structured around QCancer, the initial interview guide and questions for Phases 2 and 3 were directed more broadly across cancer risk assessment tools including QCancer and used to collect data from both service users and practitioners. Only data related to QCancer were presented in the initial thesis submitted. Subsequently data were reanalysed to derive themes more broadly relating to cancer risk assessment tools since data had already been collected around cancer risk assessment tools.

Reflection on any relative difference between the data gathered by the different means

There were no major differences since both individual interviews and focus groups are usually used to generate ideas through the collection of in-depth qualitative data. The two methods can complement each other depending on what is suitable for participants. In this research, individual interviews were used for service users because it was suitable for them to attend, while both individual interviews and focus groups were used for practitioners depending on their availability to attend. Since they are different approaches or methods, there may be minor differences (as discussed below). It would have been ideal to use either only individual interviews or only focus groups for easy comparison of the data. Using the both individual interviews and focus groups according to the preference or suitability for practitioners' schedule for example, may pose questions relating to selection bias. However, it was not within the control of the researcher as some practitioners could meet for focus groups while others could not but were willing to do individual interviews. In order not to miss potentially valuable information, these individual interviews were conducted with practitioners.

The minor differences between individual interviews and focus groups lie in the process of collecting the in-depth data rather. In the individual interviews with service users and some practitioners, individuals had the freedom and privacy to express themselves with prompts from the research, thereby generating a wealth of in-depth data. For the focus groups, there was a possibility of group members interrupting each other or some out-speaking others. But there was also that advantage of group discussion whereby participants were prompted or encouraged to express their views after issues were raised by other participants. This resulted in the generation of in-depth data as the use of individual interviews did. Since the data collected through both individual interviews and focus groups were generally in-depth qualitative ideas, it was possible to compare the ideas raised by service users with those of practitioners using the codes or themes and quotations from each group.

6.5 Context of existing literature

To the best of my knowledge this study is the first to investigate the perspectives of both service users and practitioners to help inform the implementation of cancer risk assessment tools in primary care consultations. The findings about communicating cancer risk information to patients, the enablers and barriers to implementation of the tools are discussed in the context of existing literature.

6.5.1 Communicating cancer risk information to patients

The scoping review in Chapter Two of this thesis found limited evidence on communicating cancer risk information when using cancer risk assessment tools with patients in primary care consultations. In fact, evidence suggests that discussion of risk information was less likely to occur if patients did not prompt practitioners (Guerra et al., 2009).

In this study, both service users and practitioners, before the tools were used, suggested several ways to effectively communicate cancer risk information to patients. After using the tools in patient consultations, practitioners maintained these suggested ways of communicating risk. Firstly, tailoring a visual representation of the risk generated by a cancer risk assessment tool, is in line with the assertion that the use of simple visual aids can improve doctor-patient communication (Paling, 2003). It also relates to the risk communication framework stage of telling patients and explaining to their understanding what the cancer risk information means (Fischhoff, 1995). This strategy of tailoring risk information is also in line with the CFIR construct of adaptability which refers to the degree to which interventions like cancer risk assessment tools can be adapted, tailored, refined, or reinvented to meet local needs (Damschroder et al., 2009). In a related example, Dikomitis et al. (2015) found problems in the design of electronic decision support (eCDS) tools, resulting in a recommendation for further development of these tools to make them more user friendly.

With reference to the need to tailor and present cancer risk information visually, evidence from a systematic review also suggested that communication tools were more likely to increase patients' understanding if they were tailored, structured and made interactive; and that illustrations such as vertical bar charts, might help to convey more understanding (Trevana, 2006).

In another systematic review investigating design features of graphs in health risk communication (Ancker et al., 2006), there was evidence of patients being more able to recognise proportions with part-to-whole sequential icon arrays [that is, icons arranged in an ordered pattern] (Fuller et al., 2001) than in randomly arranged icon arrays (Feldman-Stewart et al., 2000), and jittered icons [that is small unsteady or difficult to visualise icons] (Royak-Schaler et al., 2004). This may explain the dislike of random-arrangement arrays reported in a previous qualitative study (Schapira et al., 2001) and found in the current study. Both service users and practitioners in the current study agreed that, to improve patients' understanding, the QCancer risk chart (for example), consisting of an icon array or Cates plot with a 10 by 10 arrangement of blue sad (each expressing 1% 2-year cancer risk) and yellow smiling (no risk) faces, should appear in rows or columns according to the colour of icons rather than being scattered about the graph. Participants thought that scattering blue sad faces gave the impression that they were more numerous, that the risk was higher, and that better structured graphics would ensure a visual representation which was clearer and easier for patients to understand.

The importance of such design and other features also fit with the notion expressed in the CFIR that the design, quality and packaging characteristics of an intervention can contribute to the implementation of cancer risk assessment tools (Damschroder et al., 2009).

Being open and honest when communicating cancer risk with patients was another communication strategy mentioned by service users and practitioners. Being truthful with patients relates to the risk communication framework stage of treating patients nicely or with respect (Fischhoff, 1995). This is ethically important and contributes to building trust and credibility between patients and practitioners, as well as promoting autonomy and empowerment for patients. To demonstrate sincerity, practitioners need to communicate early and often with patients, and they must be willing to admit mistakes, deliver bad news and share required information in a professional and responsible manner (GMC, 2013).

Although a few service users did not mind if they were not informed, and a few practitioners felt they might not inform patients, before using cancer risk assessment tools, most participants agreed that to effectively communicate cancer risk, patients should be informed and involved in the use of cancer risk assessment tools in the consultation. Informing and involving patients in the use of cancer risk assessment tools relates to the risk communication framework stage of making patients partners in the use of cancer risk assessment tools (Fischhoff, 1995).

In relation to patient involvement, it is important to understand that practitioners can underestimate the degree to which patients wish to be informed about or involved in a decision-making process about their health (Elwyn et al., 1999). That is, decisions are sometimes made by assuming what patients prefer (Little et al., 2004), rather than involving them in that decision-making process. If patients were not informed when a cancer risk assessment tool was being used this could detract from the importance of gathering their views or preferences in the decision-making process.

Providing time for listening, informing, explaining and reassuring patients in the context of a professional approach was also cited by participants as important for improving effective communication. This relates to the risk communication framework stage of explaining to patients what the cancer risk information means (Fischhoff, 1995) - making clear that a risk of cancer is not the same as a diagnosis of cancer. From the perspective of service users and practitioners in this study, not listening or not making efforts to explain issues to patients could destroy an otherwise trusted patient-practitioner relationship.

Practitioners should explain using lay terms rather than technical medical expressions or jargon which could leave patients feeling worried and anxious, not understanding the options available, or with erroneous expectations of possible benefits and harms. As mentioned earlier, a previous systematic review showed that when patients use decision aids, they: improve their knowledge of the options; are helped to have more accurate expectations of possible benefits and harms or barriers, such as a positive effect on communication with their health practitioner in a consultation and some effect on the time required for this consultation (Stacey et al., 2011).

The overall findings presented here about the communication needs of those aiming to use cancer risk assessment tools can be explained further by the CFIR, in terms of the networks and communication construct, which describes how the nature and quality of communications is important for the implementation process (Damschroder et al., 2009).

6.5.2 Perceived enablers to implementation of cancer risk assessment tools

Participants in this study perceived the benefits of cancer risk assessment tools as the enablers to the implementation of the tools. These perceptions were expressed before practitioners used the tools in patient consultations. After using the tools, practitioners added ease of use to the enablers to implementation of the tools.

Participants felt that one enabler to the use of the tools was that cancer risk assessment tools could support decision-making especially with patients whose cancer symptoms were unclear, or when cancer was a differential diagnosis. In addition, the tools could help to speed up the assessment, diagnosis and treatment of cancer. These findings support findings from a previous study of GPs' experiences of using diagnostic tools, which found that the Risk Assessment Tool (RAT) helped GPs with lung and colorectal cancer symptom recognition and confirmed their decision about whether to refer (Green et al., 2015). In another study, embedding electronic decision-support tools was found to have educational benefits, with GPs reportedly learning about cancer symptoms using cancer risk assessment tools (Dikomitis et al., 2015). Green et al. (2015) also found that embedding clinical decision support tools in clinical practice was more likely to be achieved when they were used to support, rather than supersede the clinical judgement of practitioners. This corresponds with the views expressed by practitioners in the current study that whatever the quantified cancer risk, they would refer patients with symptoms suggestive of cancer based on their clinical judgement.

Another enabler to the use of the tools perceived by participants in the current study was that cancer risk assessment tools could have the benefit of helping to identify and raise awareness for promoting positive health behaviours in patients. This adds to findings from a recent systematic review of randomised controlled trials of cancer risk assessment tools in primary care, which suggests that health promotion messages within tools may have positive effects on behaviour change (Walker et al., 2015).

Indeed, tools that have the potential to help with early detection of cancer risk as well as helping to raise awareness for people to modify their health behaviours, could be used both for purposes of early diagnosis and treatment and as a public health preventive measure for cancer and similar health conditions. This may be part of the reasoning behind suggestions by some participants that the QCancer risk predicting period should be more than the current period of two years, to allow for a longer period of monitoring and modifying health risk behaviours. Indeed, it appears that this view is shared by many people including the developers of the QCancer algorithm. There is now a QCancer algorithm designed to predict the risk of common cancers in men and women over a 10-year period (Hippisley-Cox & Coupland, 2015). However, the 10-year QCancer algorithm may worsen potential issues of false positives, false negatives, over-investigation, over-referral and patient anxiety that may relate to use of cancer risk assessment tools.

Another enabler was that cancer risk assessment tools could help to personalise patient care. One possible explanation for this relates to the fact that the QCancer quantified risk, for example, is based on an individual patients' risk factors and symptoms rather than a risk calculated for a population or group of patients. Since the risk generated is for an individual patient, the referral and further investigations as well as the subsequent diagnosis and treatment or cancer care will be specific to that individual patient considering their individual demographic and psychosocial characteristics. Personalised or person-centred care is about taking into consideration the desires or values, social circumstances and lifestyles of people, while working with people as individuals to develop appropriate solutions (Sepucha et al., 2008; Gill, 2013).

The overall findings on the benefits of cancer risk assessment tools (perceived enablers to implementation) can be explained further by the CFIR (Damschroder et al., 2009). That is, participants who regarded positively the characteristics of a cancer risk assessment tool, such as its relative advantage and adaptability, were more likely to perceive it as beneficial for their practice (Damschroder et al., 2009). Similarly, in line with the construct of knowledge and beliefs described within the individual characteristics domain of the CFIR (Damschroder et al., 2009), individual participants, particularly practitioners, might have perceived the tools as beneficial because they had knowledge (understanding), positive beliefs and attitudes concerning cancer risk assessment tools. Barriers to the implementation of cancer risk prediction tools were also identified by participants in this study as discussed below.

6.5.3 Perceived barriers to the implementation of cancer risk assessment tools

Despite the perceived benefits of electronic decision-support tools, Dikomitis et al. (2015) found challenges to the implementation of these tools into routine practice, resulting in a need for training and guidance around their use. Similarly, the current study found barriers such as practitioners having trouble in understanding and accessing or using cancer risk assessment tools. Hence, primary care practitioners needed training on accessing the tools when they are integrated in the general practice IT system and using them for patient consultations.

Also, a previous study involving the use of a cancer risk assessment tool (QCancer) found several barriers that needed to be considered for the implementation of cancer risk assessment tools in primary care. These included: lack of trust on the part of some GPs in the risk calculation, especially when it conflicted with clinical judgement; variable interpretation of symptoms by participants leading to wide variations in risk assessment when the risk output was high, and the difficulties experienced by some GPs in communicating numerical risk outputs to patients (Chiang et al., 2015). Participants in the current study also expressed several other barriers to the implementation of cancer risk assessment tools.

Firstly, it was felt that more time would be needed for consultations when using the tools to enable practitioners to inform, explain and listen to the patient, and then discuss further investigations with the patient if required. The average primary care consultation time of about ten minutes was not felt to be sufficient for a practitioner to effectively communicate cancer risk to a patient without patients feeling that they were being rushed or ignored.

The need for extra time is an example of the construct of cost, an intervention characteristic expressed within the CFIR (Damschroder et al., 2009). Additional time, which is not always available in the face of increasing practitioner workload, could affect the implementation of cancer risk assessment tools. The requirement for extra time also relates to the construct of intervention complexity (Damschroder et al., 2009). Going online and manually entering the data needed for the risk calculation during the consultation (unless it is integrated into practice computer systems and linked with patient data), together with the need for explanation adds complexity. Indeed, practitioners who used the tools in patient consultations maintained that the current limited consultation time was a barrier to the implementation of the tools. However, this would only be a short-term barrier, because when the tools are integrated into the general practice IT system and linked to patient data, and practitioners trained on how to use the tools, it will be less time consuming in the long-term.

From the perspectives of service users and practitioners who were interviewed before the tools were used, the use of cancer risk assessment tools could potentially create unnecessary worry or anxiety for patients during the consultation or referral for further investigation. For some patients, the possibility of prompt investigation and early appropriate treatment of cancer may be helpful. For others, being told that they are at risk of cancer, being referred for cancer investigations, and waiting for the results could trigger worry and anxiety. This may be the case, whether the investigations prove positive or negative.

However, practitioners who used the tools in patient consultations said they did not come across patients who were worried or anxious about being referred for cancer investigations. Instead, patients felt relieved that something was being done in the form of investigations, with a potential for early diagnosis and treatment, rather than leaving it too late. This supports a recent systematic review of randomised controlled trials of cancer risk assessment tools in primary care which found no increase in cancer worry (Walker et al., 2015). Despite this, the point of worry and anxiety remains important.

The QCancer (as an example of cancer risk assessment tools) predicts either a cancer which is present but not yet diagnosed, or a cancer that might develop within two years. This means that a patient can still develop cancer even if the initial investigations do not reveal cancer. The uncertainty of not knowing whether or when a cancer might develop could be the source of further distress to patients. Even if patients are cleared of cancer after being monitored for the two years, cancer may still develop in subsequent years not covered within the predicting period, even if the initial cancer risk factors that triggered the risk were modified. This perceived worry or anxiety adds to the construct of intervention complexity (Damschroder et al., 2009), as it poses the problem of how best to communicate a patient's cancer risk to them without causing undue anxiety or worry.

Another barrier identified by participants before the use of the tools was over-referral that could result from too many people being unnecessarily referred when cancer risk assessment tools were used in primary care consultations. However, after using the tools in patient consultations, primary care practitioners thought over-referral was not likely to be a problem because they used the tools alongside their professional judgement and only referred patients who they felt needed to be referred based on their symptoms and quantified cancer risk. This is in line with the notion that, Cancer Decision Support tools should prompt primary care practitioners to think about the possibility of cancer, and then decide on referral based on their clinical judgment (Macmillan Cancer Support, 2015).

Although practitioners who used the tools in this study did not see over-referral as a problem, it may be too early to dismiss it. Over-referral may be observed later when the tools are more widely rolled out in primary care consultations, and in instances of workload or other quality opposing factors, there may be a temptation to rely on guidelines which can then lead to over-referral. This could put pressure on limited human and material resources in both primary and secondary care settings. Hence, the potential costs of over-referral will need to be weighed against not referring early enough. This is another example of the construct of cost within the domain of intervention characteristics (Damschroder et al., 2009), as a potential barrier to implementation of cancer risk assessment tools.

This study also found practitioner scepticism as a barrier to implementation, which was expressed before practitioners used the tools in patient consultations. Practitioners in a stimulation study conducted in Australia appeared not to trust some risk outputs of the QCancer tool (Chiang et al., 2015), which relates to practitioner scepticism expressed by some participants in this study.

Although practitioners who used the tools expressed in focus groups that scepticism was not a problem, and that they were willing to continue to use the tools in patient consultations, this perceived barrier remains important especially when the tools are more widely rolled out.

Practitioners might be sceptical because they may perceive cancer risk assessment tools as new with limited evidence available on their impact on quality of practice and patient health outcomes. This is in line with the CFIR construct of evidence strength and quality described within the domain of intervention characteristics (Damschroder et al., 2009).

Similarly, practitioners who are sceptical of the new tools may be the late majority or laggards who are usually the last to adopt an innovation as explained within the theory of Diffusion of Innovations (Rogers, 1995). Similar to the views of Rogers (1995), the CFIR explains that characteristics of an intervention (intervention source; evidence Strength & Quality; relative advantage; compatibility; adaptability; trialability; complexity; design quality and packaging and cost) may influence the rate of adoption of an innovation (Damschroder et al., 2009).

The knowledge and beliefs as explained within the CFIR (Damschroder et al., 2009) could also explain why some practitioners may be sceptical to adopt or use the cancer risk assessment tools. As the tools are new in the system, primary care clinicians may have limited knowledge and beliefs about their effectiveness, and how to access the tools during patient consultations.

Indeed, practitioners who used the tools felt that they needed to be integrated into their general practice IT system, otherwise it would-be time-consuming switching from the practice IT system to download the tools from the internet. Some practitioners also appeared not to understand how to use the tools especially the RAT. Consequently, practitioners who used the tools identified lack of integration of the tools into the practice IT system and lack of training on how to use the tools as barriers to implementation of the tools. For a successful implementation of cancer risk assessment tools in primary care consultations, training on how to use the tools after they have been integrated into the practice IT system, should be provided for all general practice clinicians.

It may also be that many practitioners or clinicians are sceptical of using cancer risk assessment tools because they tend to trust the accuracy of their own clinical judgement over statistical predictions or algorithms (Kahneman, 2011). It is important to remember that clinical judgement of clinicians is important and should be used as expected of them as trained professionals. Yet, it is equally important to remember that algorithms have been proven to be more accurate and reliable for predicting risk than the clinical judgement of clinicians (Kahneman, 2011). A meta-analysis of 136 studies that compared the efficacy of clinical judgement versus statistical prediction revealed that statistical predictions were equal or superior to clinical prediction methods for a wide range of circumstances (Grove et al., 2000).

Furthermore, statistical tools or algorithms may have advantages over clinical judgement in different ways. Firstly, the volume of information such as the risk factors and symptoms required (in the case of QCancer) to predict a person’s risk of developing cancer within two years may be too much for the human brain to effectively hold and process. Clinicians may be able to process such information for a short-term prediction, but this could be more difficult for a prediction over a long-term period such as two or more years.

Cancer risk assessment tools are also more reliable and therefore more objective than the human brain, by providing a repeatable and consistent risk prediction, given the same data inputs. Secondly, since the statistical calculation is faster it will save the clinician time, freeing up time for other things. It not surprising that practitioners who used the tools suggested that additional time requirement is only a barrier to implementation in the short-term.

Another barrier perceived by participants was that the tools might conflict with existing guidelines. This is in line with the construct of compatibility (Damschroder et al., 2009), i.e. whether interventions like cancer risk assessment tools fit with existing workflows as expressed within the inner setting domain of the consolidated framework for implementation research (CFIR) (Damschroder et al., 2009). This conflict with existing guidelines issue will show itself when it comes to referral of a patient to secondary care specialists who may be familiar with NICE two-week or urgent referral guidelines, but not cancer risk assessment tools. It is not surprising that practitioners who used the tools in patient consultations also identified the need to involve cancer specialists in the referral pathway as their non-involvement or lack of awareness of the implementation of the tools could constitute another barrier to implementation.

Another barrier identified was the perception that patients with symptoms suggestive of cancer would need to be referred for further investigations irrespective of their quantified risk. It was understandable that practitioners with their medical knowledge and experience cannot fail to refer patients with high risk symptoms even if such patients have a low quantified risk; but with high risk symptoms suggestive of cancer, practitioners may find it easier to refer a patient for cancer investigations even without using a risk assessment tool. Indeed, it has been suggested that when using Cancer Decision Support tools, primary care practitioners who suspect a possible cancer diagnosis can refer a patient even if their quantified risk is low or does not meet the referral NICE guidelines (Macmillan Cancer Support, 2015).

Furthermore, the Macmillan Cancer Support team who have integrated the QCancer and RAT and have called them the electronic Cancer Decision Support (eCDS) tools, have suggested that, these tools can complement existing NICE guidelines by flagging an alert on the computer screen about the possibility of cancer. Following this flagging on the computer, the clinician can then decide whether to refer a patient, based on NICE guidelines (Macmillan Cancer Support, 2015).

Participants in this study felt strongly about the need for further research to establish the evidence of effectiveness of cancer risk assessment tools compared with current practice before rolling the tools out in primary care. The domain of reflecting and monitoring (formal or informal evaluations of interventions) in the CFIR (Damschroder et al., 2009) supports this finding of the need to establish the effectiveness of the tools against current practice.

With reference to the enablers and barriers to implementation of cancer risk assessment tools discussed above, the similarities and differences in the findings between the current study and the previous studies, particularly those relating to the cancer risk assessment tools such as the RAT and QCancer (Green et al., 2015; Dikomitis et al., 2015; Chiang et al., 2015), are reflected in the similarities and differences in their methods of enquiry. Like Green et al. (2015) and Dikomitis et al. (2015), this study used semi-structured interviews to collect data, which were analysed using framework analysis to explore the perceptions of primary care practitioners. However, Green et al. (2015) and Dikomitis et al. (2015) conducted their semi-structured interviews by telephone while the current study used face-to-face individual semi-structured interviews and focus groups to explore the perspectives of both service users and primary care practitioners. This study also enabled comparison of service user and practitioner perspectives to inform the use of the tools in primary care consultations.

Chiang et al. (2015) also used face-to-face semi-structured individual interviews with general practitioners, but unlike the current study which was conducted in a UK primary care context, Chiang et al. (2015) conducted a study of simulated consultations with practitioners in a primary care setting in Australia.

Despite different methodological approaches, and while findings from these previous studies remain relevant, the findings from this study are important in bridging the research gap not covered by these previous studies. For example, the gap identified through the scoping review in Chapter Two of this thesis relating to how best cancer risk can be communicated to patients when using cancer risk assessment tools in primary care consultations. This also corresponds with the research gap identified in a previous systematic review of 86 studies of the need to understand how to enhance patient and practitioner communication when using a decision aid (Stacey et al., 2011). Overall, the findings from this study point to some important implications for practice and further research as discussed in Section 6.6 below.

6.6 Implications for practice and further research

The communication strategies suggested by participants should be used to enhance communication between patients and practitioners when using cancer risk assessment tools during primary care consultations.

Several barriers to the implementation of cancer risk assessment tools were expressed by participants including: lack of integration of the tools into the general practice IT system; lack of involvement of cancer specialists at secondary care settings and poor knowledge and understanding of how to access or use the tools in patient consultations on the part of primary care practitioners. Therefore, it is recommended that tools should be properly integrated into the general practice IT systems, and practitioners should be trained on how to access and use the tools in patient consultations. Fortunately, the Macmillan Cancer Support and Cancer Research UK, are working with the major primary care IT providers (EMIS, SystmOne and Vision+) to integrate the eCDS tools into the general practice systems. Such an effort should be encouraged and supported to ensure all general practices in the UK have access to the tools in their IT systems.

To avoid conflict with existing guidelines especially with referrals for investigations and diagnosis, cancer specialists should be involved in the implementation of the tools so, they are open to primary care referral for cancer investigations using cancer risk assessment tools. The implementation of the tools should also be flexible, so practitioners can refer patients with symptoms suggestive of cancer whatever their quantified risk if these fall within NICE cancer referral guidelines.

In relation to the need for more evidence before rolling out the tools, further research on the impact of cancer risk assessment tools on patient outcomes such as rates of referral, investigation and diagnosis compared with current primary care practice needs to be conducted. The experiences or perceptions of patients and practitioners following the implementation of the tools should also be explored alongside the measurement of quantitative outcomes. The concluding points for this chapter are outlined in Section 6.7 below.

6.7 Conclusion of the chapter

This chapter has highlighted the key findings that add to existing knowledge, and these findings have been discussed in relation to the existing literature and the relevant theoretical frameworks. The ways to best communicate cancer risk information to bridge the research gap in this area, and the enablers and barriers to implementation of cancer risk assessment tools add to the existing evidence from the few relevant studies already conducted in this area. A more detailed overall conclusion is presented in Chapter 7 that follows next.

CHAPTER 7 CONCLUSION

7.1 Summary of the chapter

This conclusion chapter summarises the thesis, covering the previous chapters: the background to the study; scoping literature review; conceptual background literature, methodology, results and discussion. The current developments relating to cancer risk assessment tools since this study, my personal reflection and a statement of next steps are also outlined in this chapter.

7.2 Summary of the thesis

To conclude the work, key points from the chapters of the thesis are highlighted here.

The background to the study

The background to the research highlighted the problem of cancer globally and in the context of UK. Also, discussed were the efforts to improve early diagnosis of cancer in the UK such as the NAEDI policy and the increased interest in the development of cancer risk assessment tools for detection of cancer risk in symptomatic individuals. It also highlighted that, evidence about the use of cancer risk assessment tools in primary care was lacking, hence the need to explore the existing evidence using a scoping literature review.

The scoping literature review

Using a widely used framework (Arksey & O'Malley, 2005), the scoping literature review explored the evidence around use of cancer risk assessment tools available for symptomatic individuals in primary care. The results arising from the analysis of the evidence extracted from included studies were stated and discussed in relation to the existing literature. Research questions for further qualitative exploration were identified from the scoping literature review.

Overall, the evidence from the scoping review suggested that there could be benefits if cancer risk assessment tools were used in patient consultations, but there are also barriers to implementation of the tools. A research gap relating to communication of cancer risk information was identified and the following research questions were stated for further exploration: (a) what are the perceptions of service users and practitioners about how best cancer risk information can be communicated to patients during consultations, (b) what do service users and practitioners perceive as enablers and barriers to the implementation of cancer risk assessment tools in primary care? Before moving on to address these research questions, a conceptual background literature was reviewed.

The conceptual background literature review

An understanding to the relevant concepts relating to the research were discussed within the conceptual background literature. For example, the policy, structure and functions of UK primary care in relation to cancer and cancer diagnosis. The 'gatekeeping' functions of primary care general practices which includes specialist referral of patients are outlined. Additionally, the cancer risk assessment tools for symptomatic individuals in primary care, the effects of risk assessment on individuals, communicating cancer risk and the relevant communication and implementation theoretical frameworks, are discussed within the conceptual background literature. To appropriately address the research questions identified, the methodology for the study is discussed.

The methodology

The methodology is discussed, highlighting pragmatism as the philosophical stance for this research. The qualitative research approach that informed the use of the relevant qualitative research methods is also discussed. Specifically, the methods included the use of individual and focus group interviews to collect qualitative data from service users and primary care practitioners, and the use of the framework approach for the data analysis.

The choice of a pragmatic philosophical stance was useful in terms of allowing for the use of framework analysis (Ritchie & Spencer, 1994) to appropriately address the research question, which presented with both deductive and inductive elements. Hence, the framework analysis approach facilitated the analysis of both the deductive and inductive themes.

The results and discussion of the qualitative study

The results from individual interviews with service users, and individual interviews and focus groups with practitioners are reported in a way that sought to address the research questions. Participants suggested ways to best communicate cancer risk information to patients. These include tailoring a visual representation of risk; being open and honest; involving patients in the use of cancer risk assessment tools and allowing enough time for informing, listening and explaining to patients in a professional manner. These add to our knowledge and bridges the research gap in this area.

In addition, participants perceived several enablers (for example, supporting decision-making; improving speed of processes and ease of use) and barriers (for example, additional time requirement, worry or anxiety related to referral for investigations and need for integration of the tools into the GP IT system) to the implementation of cancer risk assessment tools. The findings about enablers and barriers support the existing evidence from the few recent published studies.

To appropriately address the research questions, the perspectives of participants were presented in three parts. The first and second parts presented the collective perspectives of service users and primary care practitioners respectively, expressed before the use of the tools. The third part of the results described the perspectives of primary care practitioners after using the tools in patient consultations.

The results are discussed in the discussion chapter, relative to the existing literature and the relevant theoretical frameworks, and key and original findings are highlighted.

Although the results are discussed in the discussion chapter relative to the existing literature and the relevant theoretical frameworks, it is important to discuss further in this concluding chapter, the original contribution of this study to knowledge and the implications of the other key findings.

Original contribution to knowledge

An important original contribution to knowledge that needs highlighting is the collection of data from service users to explore ways to best communicate cancer risk information, as well as to explore the barriers and enablers to the implementation of cancer risk assessment tools in the primary care consultation.

The views of service users were compared with those of practitioners and there was general agreement among participants with most aspects. Most previous research (e.g. Hamilton et al., 2013; Green et al., 2015; Dikomitis et al., 2015; Chiang et al., 2015) in the subject area has been based on the views of practitioners, which although useful need to be complemented by the views of patients or service users.

The implication of needing more consultation time to use the tool

The need for extra time could imply the need for a policy decision on increasing the current consultation of time of 10 -12 minutes per patient.

On a positive side, additional consultation time could mean practitioners will take time to involve patients by explaining, listening and reassuring them without appearing to be rushing through things. This could contribute to the promotion of patient centred care, which patients value and enhance experience with the care provided.

However, with the increasing numbers of patients seeking primary care and a limited number of practitioners, more consultation time could mean more pressure on practitioners who could be spending longer hours to see all patients per day.

How the tools should be integrated within clinical systems

The cancer risk assessment tools can be integrated within primary care clinical systems through the major primary care IT systems such as EMIS, SystmOne and Vision+. At the national level, the integration of the tools in primary care clinical systems can inform national policy pathways in the form of NICE guidelines. That is, the tools may be integrated into the NICE guidelines like other existing risk tools in primary care (e.g. QRisk).

At the local level, the integration of the tools within clinical systems can inform local policy pathways agreed through Clinical Commissioning Groups (CCGs). Locally agreed pathways could include how and what to use the tools for. For example, there could be a local decision to use the tools for only assessment of risk, investigations and referral during patient consultations. There could also be local agreement through CCGs to use the tools outside consultations such as auditing or batch processing and then calling patients at risk to discuss investigations and referral for diagnosis.

Possible training needs and how they should be undertaken

The need for training as suggested by participants could cover several areas. One area of training would relate to helping practitioners to understand how the tools are integrated into the general practice IT system and how to access and use them appropriately during consultation.

Practitioners could also benefit from training on what action to take after using the tools to generate certain risk levels. This relates to possible options such as triggering a referral to NICE guidelines, request investigations, or a decision to monitor the patient for change in the symptoms or risk level.

A training programme that involves helping practitioners on how best to communicate a risk information to patients could also be undertaken as recommended by some participants. Helping practitioners to know what and how to communicate with patients will help patients to understand and receive information about their cancer risk or referral for investigation, with less worry or anxiety.

How the risk scores can interface with, and influence NICE guidelines

Risk scores can interface and influence NICE guidelines in several ways. A generated risk score could trigger referral of a patient for investigation and diagnosis, if the risk score was high and the practitioner suspected cancer from the presenting symptoms. When the tools are integrated in the general practice IT system, during a consultation, a practitioner could be alerted about the possibility of cancer risk in a patient.

The practitioner may then refer to NICE guidelines before deciding to refer the patient for cancer investigations and diagnosis. Conversely, where a practitioner is in doubt about a patient's risk status after first using NICE guidelines, they can use the tools to generate a cancer risk level. This could then inform a decision for appropriate action.

Since this study, there have been some developments relating to the research area. These are outlined below.

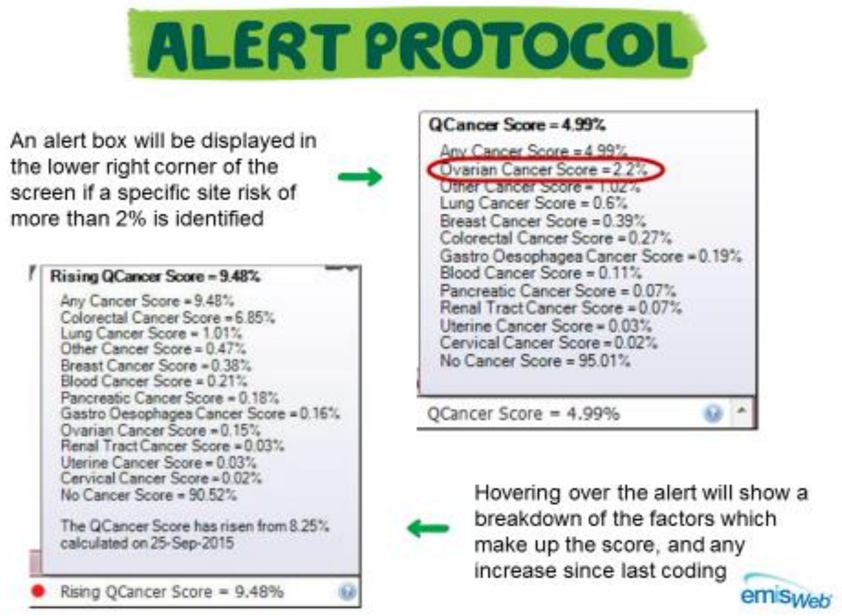
7.3 Developments relating to cancer risk assessment tools since my study

Current development since my research include plans to establish an early diagnosis school and plans for extensive research on the use of cancer diagnostics tools (including cancer risk assessment tools). Connected to this is the 'CanTest' Collaborative led by a team of experienced cancer diagnosis research experts including Professor Richard Neal (University of Leeds), Professor Willie Hamilton (University of Exeter), Professor Fiona Walter from University of Cambridge and other colleagues. The collaborative which involves four UK institutions, and four international partners, has been funded by CRUK for clinical cancer detection research in the UK and internationally (www.cantest.org). The overall research task is to examine which tests for cancer or risk of future cancer (such as blood tests, imaging tests, decision support tools etc.) can be performed in primary care (www.cantest.org).

Currently there are two common types of symptom-based cancer risk assessment tools for use in primary care settings in the UK: the QCancer and RAT. The updates for QCancer and RAT for the current year (2016) relate to a collaboration between the developers of QCancer (Hippisley-Cox & Coupland, 2011; Hippisley-Cox & Coupland, 2012; Hippisley-Cox & Coupland, 2013) and RAT (Hamilton, 2009), Macmillan Cancer Support and three major IT providers to integrate the tools into the primary care (general practice) IT system. These IT systems are the EMIS Web, Vision+ and SystmOne (Macmillan Cancer Support, 2016), and the integrated tools are collectively known as the Macmillan electronic Cancer Decision Support (eCDS) tools. This CDS tool which alerts GPs of patients with a risk score of 2% or more is available to all Vision users in Scotland (Macmillan Cancer Support, 2016). The tool has three functions in patient consultations: providing risk indicator pop up alerts, data entry templates and practice reports.

Macmillan Cancer Support (2015) updates indicate that, EMIS Web users in England and Wales are now able to access an updated version of the QCancer tool in EMIS Web 5.9. The update includes risk score prompts, a symptom checker template, an additional template to record QCancer outcomes and follow up, and new Safety Netting searches. The alert triggering threshold has changed from a 5% composite risk score, to a site-specific score of 2% or above. Further information on how primary care practitioners may activate the prompt function or access the active symptom checker and follow up templates is provided in the EMIS Health support centre. Figures 4 is an example of an EMIS Web QCancer alert as will appear on a user’s computer screen, while Figure 4 illustrates an EMIS Web QCancer symptom checklist template.

Figure 4 Example of an EMIS Web QCancer alert protocol



An alert box will be displayed in the lower right corner of the screen if a specific site risk of more than 2% is identified

QCancer Score = 4.99%
Any Cancer Score = 4.99%
Ovarian Cancer Score = 2.2%
Other Cancer Score = 1.02%
Lung Cancer Score = 0.6%
Breast Cancer Score = 0.39%
Colorectal Cancer Score = 0.27%
Gastro Oesophagea Cancer Score = 0.19%
Blood Cancer Score = 0.11%
Pancreatic Cancer Score = 0.07%
Renal Tract Cancer Score = 0.07%
Uterine Cancer Score = 0.03%
Cervical Cancer Score = 0.02%
No Cancer Score = 95.01%

QCancer Score = 4.99%

Rising QCancer Score = 9.48%
Any Cancer Score = 9.48%
Colorectal Cancer Score = 6.85%
Lung Cancer Score = 1.01%
Other Cancer Score = 0.47%
Breast Cancer Score = 0.38%
Blood Cancer Score = 0.21%
Pancreatic Cancer Score = 0.18%
Gastro Oesophagea Cancer Score = 0.16%
Ovarian Cancer Score = 0.15%
Renal Tract Cancer Score = 0.03%
Uterine Cancer Score = 0.03%
Cervical Cancer Score = 0.02%
No Cancer Score = 90.52%

The QCancer Score has risen from 8.25% calculated on 25-Sep-2015

● Rising QCancer Score = 9.48%

Hovering over the alert will show a breakdown of the factors which make up the score, and any increase since last coding

Adopted from Macmillan Cancer Support (2016)

Figure 5 Example of an EMIS Web QCancer symptom checklist template

QCancer Symptom Checklist

Review the symptoms and then calculate the QCancer Score

QCancer Cancer Risk %

To view site specific QCancer risk scores before reviewing symptoms, click Calculate then View. Then re-calculate a

Symptom Check List

The following check list is not exhaustive but allows the clinician to ensure that symptoms the patient is experiencing

QCancer uses a current symptoms algorithm therefore all symptoms should be reviewed and re-recorded if present.

Pre-existing information from the medical record will also be evaluated if within the indicated time frames.

Does the patient currently have.... (brackets denote how long symptoms are considered by QCancer e.g. 1m for 1 montl

☐ - Appetite loss (1m)
☐ - Abnormal or Unexplained weight loss (1m)
☐ - Abdominal pain (1m)
☐ - Abdominal swelling (1m)
☐ - Difficulty swallowing liquids (1m)
☐ - Difficulty in swallowing solids (1m)
☐ - Indigestion (1m)
☐ - Heartburn (1m)
☐ - Cough (12m)
☐ - Change in bowel habit (12m)

Adopted from Macmillan Cancer Support (2016)

7.4 Personal reflection on completing this study

This personal reflection takes into consideration six key stages of my experience in conducting this research project. These include: the preliminary stage of the research; going into the field to speak with research participants; the writing task; the final journey; the learning experience (knowledge gained) and personal development.

7.4.1 The preliminary stage of the research

At the beginning, I was very excited to start my PhD studies. But the excitement soon gave way to my first challenge of identifying the research question or questions by conducting a scoping literature review, developing an appropriate research methodology, and then submitting a protocol.

With little chance of financial support, I decided to embark on the difficult option of self-funding my studies. Over the years this lack of funding has been for me the most depressing challenge. This financial challenge, and my commitment to complete the project within schedule as a full-time student compelled me to rethink the size of the project. These considerations brought about major changes in the plan of the study.

7.4.2 Going into the field to speak with research participants

The fieldwork involved travelling several miles a day to meet the research participants. It was very difficult to get practitioners who were willing to use the cancer risk assessment tools with patients and then meet with me to discuss their perceptions.

Though the travelling and interactions with the research participants were very tiring, I found the field work to be an interesting part of the research process. It was interesting in terms of getting to know different parts of the study area and meeting new people, and I was excited to start collecting data from participants as a major step forward.

On reflection, I found that it was helpful that I already had a good understanding of the research area and the research question I was trying to address. It was also helpful that I did not know any of the participants at a personal level, so I interacted with them as a neutral person. Knowing that I was a researcher with an independent mind, the service users and practitioners also felt free to express their views about the questions asked during the interviews. As a qualified nurse, I have previous experience of nursing and interacting with many cancer patients and their families, and I felt within me that the use of cancer risk assessment tools to aid early detection of cancer risk leading to early diagnosis would be good. However, I was careful not to allow my personal views as a health professional to interfere with my role as a researcher, particularly in conducting the interviews with participants and the data analysis and interpretation.

7.4.3 The writing task

I feel good that the thesis has now taken shape. However, the shaping of my thesis was a slow and sometimes frustrating process. Fortunately, I was always encouraged by the people around me, particularly fellow research students and my PhD project supervisors. My family has also encouraged me a lot while waiting patiently for life to return to normal, as my moments of tension have sometimes spilled over to them.

Indeed, I found it helpful to spend some quiet time alone to think deeply and work on my thesis, but I also found it helpful sharing my thoughts and ideas, and taking comments made by supervisors and other people through conference and seminar presentations.

There were times I felt that the PhD thesis was a task that would never end. But from my experience, I can confidently say the key to completing such a project is perseverance, hard work, good time management and praying to the All Mighty God. In addition, I realised the importance of keeping the thesis and research question in focus when writing the different chapters. This has helped me to avoid getting side-tracked.

During the writing process, I often encountered the difficulty of depending too much on other authorities rather than my own primary ideas. My supervisors advised that, I should be careful to organise my materials in a way that will allow much of my original data to stand relatively free, while I use the existing evidence to support my arguments. Although putting this to practice was initially difficult, I persevered because I knew this approach was necessary for the originality of my work. Reflecting on my initial proposal, I am aware that my academic reasoning and writing with respect to the research process has improved. During the process of writing, I have had to revise my thesis outline, and on occasions adjusted my research question. This, no doubt came because of interaction with my supervisors and other researchers, and through the learning experience of preparing several drafts of my thesis chapters.

7.4.4 The final journey

Once I finished writing the thesis, I found it necessary to consider the final shape for submission. The University has policy and procedures on thesis presentation, which I considered carefully and applied to the presentation of my thesis. Many practical decisions such as the standard of word processing expected, the preferred font size, margins, and the binding specifications needed to be considered as soon as the thesis was completed. I was conscious of all these practical issues, to make it possible for the work to be done in the way required by the University.

7.4.5 Learning experience (knowledge gain) and personal development

My learning experience and personal development relating to this project include development in primary research skills, improvement in project and time management skills and improvement in my self-confidence.

Development of primary research skills

Upon reflection, I realised that I have acquired a lot of research skills while conducting this study. It was a great experience for me to have engaged in a research that involved primary data collection and analysis in a relatively independent manner. The research methods relevant to my research and related areas informed by the appropriate philosophical stance and the relevant theoretical frameworks have been learned during the study. I have also gained practical experience of developing an interview guide and conducting individual and group interviews with service users and primary care practitioners. The importance of sampling and the choice of the most suitable sampling method have also been learnt. In addition, I have learnt about the importance of applying for ethics, governance and access approvals before commencing the research activities of recruitment of participants and data collection.

I have gained substantial presentation skills through the practice of presenting my research findings at conferences, workshops and seminars within and outside the University of Lincoln. I have also gained some experience in writing for publication and I have learnt to take peer review comments as part of the research practice rather than taking them personally. The project supervisors were supportive in my development along these lines.

Improved project and time-management skills

On personal and professional levels, I have greatly benefited from the research experience through improving my project and time management skills. Specifically, the research process required extensive preparation and planning for each stage of the study, which had to be conducted in an organised manner with time schedules.

However, I initially faced challenges in terms of ensuring the progress of the study per the timetable and in meeting deadlines and attending meetings on time. These challenges mainly started from the scoping literature review stage of the research, as I initially underestimated the duration of time required for literature review and I was constantly behind the schedule. This issue was addressed through adjusting the time-plan for the study and increasing my personal discipline and commitment to the time-plan. I avoided all unnecessary activities during the research process, and I set daily plans to do a specific portion of the project every day, while making provisions for occasional days off within the plan. This was to help me avoid being over-pressurised and over-stretched which could have impacted negatively on the project.

In general, this research experience has contributed to the improvement of my time and project management skills, which is useful for my professional development. As I worked as a nurse on part-time basis to fund my studies, a positive approach to planning and self-discipline enhanced my ability to balance the demands of working as a nurse and my full-time studies.

Improved self-confidence

Looking back to the time I started my studies, my self-confidence has improved significantly because of the conduct of this research and benefitting from a good supervisory team. This was achieved through overcoming my fears and insecurity, communicating with my research participants and presentation of the findings and interaction with the research audience in a confident manner. The effort I put in, which included spending many hours to prepare for the data collection, and the encouragement from my supervisors, friends and family helped me to overcome the sense of insecurity and to conduct the data collection process in a confident manner.

In fact, I believe my communication skills have also been enhanced after conducting this research. I have no doubt that I will benefit a lot from my improved self-confidence in the future as an individual and as an independent researcher with interest in primary care research, particularly in early detection of cancer risk and the use of cancer risk assessment tools.

7.4.6 How will I do this research differently?

If I were to do this research again, I will first ensure that there was adequate funding to cover the project over three years, given the financial difficulties I faced as a self-funding student.

I will also ensure that realistic objectives that are achievable within the time frame available for the research are set. I will try not to be distracted or misled and I will take control of the key stages of the research while consulting with more experience researchers. The next steps after this study are stated below.

7.5 Statement of next steps

The next steps will aim to address the research gap identified from this qualitative work. These steps will include:

i. To conduct a trial of cancer risk assessment tools and compare with current practice using quantitative methods to measure outcomes of implementation including rates of referral, diagnosis and survival. This will also allow for the use of qualitative methods to explore the experiences of patients and practitioners involved in the trial implementation of the tools in primary care consultations.

ii. To be able to conduct the trial, I intend to develop a research protocol, which I will use to apply for NHS ethics and governance approvals as well as funding to support the future research plans.

REFERENCES

Abel, G.A., Mendonca, S.C., McPhail, S., Zhou, Y., Elliss-Brookes, L., Lyratzopoulos, G. (2017) *Emergency diagnosis of cancer and previous general practice consultations: Insights from linked patient survey data*. Br J Gen Pract., 67(659) 377-387.

Adelstein, B.A., Macaskill, P., Chan, S.F., Katelaris, P.H., Irwig, L. (2011) *"Most bowel cancer symptoms do not indicate colorectal cancer and polyps: A systematic review*." BMC Gastroenterology, 11(65).

Adler, P.S., Kwon, S.W., Singer, J.M.K. (2003) The "Six-West" Problem: Professionals and the Intraorganizational Diffusion of Innovations, with Particular Reference to the Case of Hospitals. Working paper 3-15. Los Angeles. Marshall School of Business, University of Southern California, 3-15.

Ahearn, A. & Kerr, S. (203) *General practitioners' perceptions of the pharmaceutical decision-support tools in their prescribing software*. Medical Journal of Australia, 179:34-37.

Ahmad, A.S., Ormiston-Smith, N., Sasieni, P.D. (2015) *Trends in the lifetime risk of developing cancer in Great Britain: Comparison of risk for those born from 1930 to 1960*. British Journal of Cancer, 112: 943-947.

Al-Azri, M.H. (2016) *Delay in cancer diagnosis: Causes and possible solutions*. Oman Medical Journal, 31(5) 325.

Alborg, A.J. & Same, J.M. (2010) *Murray & Navel's Textbook of Respiratory Medicine*, 5th edition: Saunders Elsevier.

Al-Busaidi, Z. (2008) *Qualitative research and its uses in health care*. Sultan Qaboos Univ Med J., 8(1) 11-19.

Alexander, J.A & Hearld, L.R. (2011) *The science of quality improvement implementation: Developing capacity to make a difference*. Med Care, 49: 6-20.

Allen, D. (2017) *From polyformacy to formacology.* BMJ Qual Saf., 26(9) 695-697.

Allgar, V.L. & Neal, R.D. (2005) *Delays in the diagnosis of six cancers: Analysis of data from the national survey of NHS patients*. Br J Cancer., 92(11) 1959-70.

America Cancer Society (2017) Diet and Physical Activity: What's the Cancer Connection? Available online at: https://www.cancer.org/cancer/cancer-causes/diet-physical-activity/diet-and-physical-activity.html. Last accessed:20/01/18.

American Cancer Society (2011) Colorectal Cancer Facts & Figures.

Ancker, J.S., Senathirajah, Y. and Kukafka, R. & Starren, J.B. (2006) *Design features of graphs in health risk communication: A systematic review.* Journal of the American Medical Informatics Association, 13(6) 608-618.

Annas, G. (1994) *Informed consent, cancer, and truth in prognosis*. N Engl J Med, 330:223-225.

Antoniou, A., Pharoah, P.D., Narod, S., et al. (2003) *Average risks of breast and ovarian cancer associated with BRCA1 or BRCA2 mutations detected in case series unselected for family history: A combined analysis of 22 studies.* American Journal of Human Genetics; 72(5):1117–1130.

Antman, E., Lau, J., Kupeinick, B., Mosteller, F., Chalmers, T. (1992) *A comparison of results of meta-analysis of RCTs and recommendations of clinical experts*. Journal of American Medical Association, 268(2) 240-248.

Ambrosio, G.B., Dissegna, L., Zamboni, S., Santonastaso, P., Canton, G., Dal, Palu C. (1984) *Psychological effects of hypertension labeling during a community survey. A two-year follow-up*. Journal of Hypertension 2, 171-173.

Antoni, M.H., Baggett, L., Ironson, G., LaPerriere, A., August, S., Klimas, N., Schneiderman, N., Fletcher, M.A. (1991) *Cognitive-behavioral stress management intervention buffers distress responses and immunologic changes following notification of HIV-1 Seropositivity*. Journal of Consulting and Clinical Psychology 59, 906-915.

Arksey, H. & O’Malley, L. (2005) *Scoping studies: Towards a methodological framework. International Journal of Social Research Methodology: Theory & Practice*, 8:19-32.

Armitage, C.J. & Conner, M. (2001) *Efficacy of the theory of planned behaviour: A meta-analytic review*. British Journal of Social Psychology, 40:471-499.

Armstrong, R., Hall, B.J., Doyle, J., Waters, E. (2011) *Scoping the scope’ of a cochrane review.* Journal of Public Health, 33(1) 147-150.

Aronson, J. (1994) A pragmatic view of thematic analysis. the qualitative report, 2.

Arthur, S. & Nazroo, J. (2003) *Designing field work strategies and materials. In Qualitative Research Practice: A Guide for Social Science Students and Researchers* (Ritchie J., Lewis J., eds), London: Sage Publications.

Astin, M., Griffin, T., Neal, R.D., Rose, P., Hamilton, W. (2011) "*The diagnostic value of symptoms for colorectal cancer in primary care: A systematic review".* The British Journal of General Practice: The Journal of the Royal College of General Practitioners, 61(586) 231-243.

Attride-Stirling, J. (2001) *Thematic networks: An analytic tool for qualitative research.* Qualitative Research, 1(3) 385-405.

Aubert, B.A. & Hamel, G. (2001) *Adoption of smart cards in the medical sector: The Canadian experience.* Social Science & Medicine, 53(7) 879-94.

Ayatollahi, H., Bath, P.A., Goodacre, S. (2010) *Factors influencing the use of IT in the emergency department: A qualitative study*. Health Inform J, 16(3) 189-200.

Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A., Kudelka, A.P. (2000) *SPIKES-A six-step protocol for delivering bad news: Application to the patient with cancer.* Oncologist, 5:302-311.

Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A., Kundelka, A.P. (2000) *SPIKES-a six-step protocol for delivering bad news: Application to the patient with cancer*. Oncologist, 5: 302-311.

Baker, S.E. & Edwards, R. (2012) How many qualitative interviews is enough? expert voices and early career reflections on sampling and cases in qualitative research. National centre for research methods review paper. Southampton, GB, National Centre for Research Methods, 43.

Balas, M.C., Burke, W.J., Gannon, D., Cohen, M.Z., Colburn, L., Bevil, C., Franz, D., Olsen, K.M., Ely, E.W., Vasillevskis, E.E. (2013) *Implementing the awakening and breathing coordination, delirium monitoring/management, and early exercise/mobility bundle into everyday care: Opportunities, challenges, and lessons learned for implementing the ICU pain, agitation, and delirium guidelines.* Crit Care Med, 41(9) 116-27.

Bandura, A. (1982) *Self-efficacy mechanism in human agency.* American Psychologist, 37(2) 122-147.

Banks, J., Hollinghurst, S., Bigwood, L., Peters, T., Walter, F.M., Hamilton, W. (2014) *Preferences for cancer investigation: A vignette-based study of primary-care attendees*. The Lancet Oncology, 15(2) 232-240.

Banks, J., Walter, F.M., Hall, N., Mills, K., Hamilton, W., Turner, K.M. (2014) *Decision making and referral from primary care for possible lung and colorectal cancer: A qualitative study of patients' experiences*. Br J Gen Pract, 64:775-782.

Barbour, R. (2007) *Doing focus groups*. Canadian Journal of Action Research Volume 15, Issue 3, 2014, Pages 65-66, 15(3) 65-66.

Barnard, M., Webster, S., O’Connor, W., Jones, A., Donmall, M. (2009) The drug treatment outcomes research study (DTORS): qualitative study. London: Home Office.

Behera, D. & Balamugesh, T. (2004) *"Lung cancer in india*". Indian Journal of Chest Diseases and Allied Sciences, 46(4) 269-281.

Benbassat, J., Pilpel, D., Tidhar, M. (1998) *Patients' preferences for participation in clinical decision-making: A review of published surveys*. Behav Med, 24:81-88.

Bernard, H.R. (2000) *Social research methods*. CA: Thousand Oaks: Sage.

Bennett, Johnson S., Riley, W., Hansen, C.A., Nurick, M.A., (1990) *Psychological impact of islet cell-antibody screening*. Diabetes Care 13, 93-97.

Bennett, Johnson S., Tercyak, K.P. (1995) *Psychological impact of islet cell antibody screening for IDDM on children, adults, and their family members*. Diabetes Care 18, 1370-1372.

Blaikie, N. (2009) *Designing Social Research*. Second edition. Cambridge: Polity Press.

Blanchard, C.G., Labrecque, M.S., Ruckdeschel, J.C., Blanchard, E.B. (1988) *Information and decision-making preferences of hospitalized adult cancer patients*. Soc Sci Med, 27:1139-1145.

Bloom, J.R. & Monterossa, S. (1981) *Hypertension labeling and sense of well-being*. American Journal of Public Health 71, 1228-1232.

Blumer, H. (1969) *Symbolic interactionism: perspective and method*. Berkeley: University of California Press.

Bowen, E.F. & Rayner, C.F. (2002) *Patient and GP led delays in the recognition of symptoms suggestive of lung cancer.* Lung Cancer, 37:227-8.

Boyatzis, R. (1998) *Transforming qualitative information: thematic analysis and code development.* London: Sage.

Bradford, A. (2015) *Deductive VRS inductive reasoning*. Live Science.

Brandt, J., Quaid, K., Folstein, S.E., Garber, P., Maestri, N.E., Abbott, M.H., Slavney, P.R., Franz, M.L., Kasch, L., Kazazian, H.H. (1989) *Presymptomatic diagnosis of delayed-onset disease with linked DNA markers*. Journal of the American Medical Association 261, 3108-3114.

Braun, V. & Clarke, V. (2006) "*Using thematic analysis in psychology".* Qualitative Research in Psychology, 3(2) 77-101.

Breakwell, G.M. & Rowett, C. (1982) *Social Work: The Social Psychological Approach*. Wokingham: Van Nostrand Reinhold.

Brien, S.E., Lorenzetti, D.L., Lewis, S. (2010) *Overview of a formal scoping review on health system report cards.* Implement Sci, 5:2-10.

Brown, S.M., Culver, J.O., Osann, K.E., MacDonald, D.J., Sand, S., Thornton, A.A., Grant, M., Bowen, D.J., Metcalfe, K.A., Burke, H.B., Robson, M.K., Friedman, S., Weitzelb, J.N. (2011) *Health literacy, numeracy, and interpretation of graphical breast cancer risk estimates*. Patient Educ Couns, 83:92-98.

Bryman, A. (1988) *“Quantity and quality in social research”.* London: Unwin Hyman.

Bryman, A. (ed.) (1994*) Analysing qualitative data*: Routledge.

Bryman, A. (2001) *Social research methods*. 0xford: Oxford University Press.

Bryman, A. (2012) *Social Research Methods*. 4th edition. Oxford: Oxford University Press.

Buckman, R. (1984) *Breaking bad news: Why is it still so difficult?* BMJ, 288: 1597-15.

Buckman, R. (1992) *Breaking Bad News: A Guide for Health Care Professionals.* Baltimore: Johns Hopkins University Press.

Budescu, D.V., Weinberg, S., Wallsten, T.S. (1995) *Decisions based on numerically and verbally expressed uncertainties.* J Exp Psychol Gen, 14: 281-94.

Bums, W. & Clemen, R. (1993) *Covariance structure models and influence diagrams*. Management Science, 39, 8 16-834.

Calman, K. & Royston, G. (1997) *Risk language and dialects.* BMJ, 315: 939-42.

Cancer Genome Atlas Network (2012) *Comprehensive molecular characterization of human colon and rectal cance*r, Nature, 487: 330-337.

Cancer Research UK (2013) Bowel cancer incidence statistics http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/incidence/. Accessed:19/05/2013.

Cancer Research UK, (2013) Cancer statistics: lung cancer key facts.

Cancer Research UK. (2014) England and Wales Survival (2010-2011).

Carmona, R.H. (2006) "The Health Consequences of Involuntary Exposure to Tobacco Smoke: A Report of the Surgeon General". U.S. Department of Health and Human Services. "Second-hand smoke exposure causes disease and premature death in children and adults who do not smoke.

Cassileth, B.R., Zupkis, R.V., Sutton-Smith, K., March, V. (1980) *Information and participation preferences among cancer patients*. Ann Intern Med, 92:832-836.

Central Office for Research Ethics Committee (2006) Information sheets & consent forms. guidance for researchers & reviewers. Central Office for Research Ethics Committee (2006) Information Sheets & Consent Forms. Guidance for Researchers & Reviewers, Version 3., version 3.

Centre for Reviews and Dissemination. (2008) Centre for Reviews and Dissemination (2008) Systematic Reviews: CRD's Advice for Undertaking

Reviews in Health Care. York: Centre for Reviews and Dissemination, University of York.

Centre for Reviews and Dissemination, University of York (2001) Undertaking Systematic Reviews of Research on Effectiveness: CRD’s Guidance for those Carrying Out or Commissioning Reviews, CRD Report. 2nd edition. NHS Centre for Reviews and Dissemination, University of York.

Chapman, S., Robinson, G., Sradling, J., West, S. (2009) *Oxford Handbook of Respiratory Medicine.* 2nd Ed edition. Oxford University: Oxford University Press.

Charloux, A., Quoix, E., Wolkove, N. (1997) *The increasing incidence of lung adenocarcinoma: Reality or artefact? A review of the epidemiology of lung adenocarcinoma*. International Journal of Epidemiology, 26(1) 14-23.

Chen, S. & Parmigiani, G. (2007) *Meta-analysis of BRCA1 and BRCA2 penetrance*. Journal of Clinical Oncology 2007; 25(11):1329 -1333.

Chiang, P.P.C., Glance, D., Walker, J., Walter, F.M., Emery, J.D. (2015) *Implementing a QCancer risk tool into general practice consultations: An exploratory study using simulated consultations with Australian general practitioners*. Br J Cancer, 112:77-83.

Chowdhury, S., Dent, T., Pashayan, N., Hall, A., Lyratzopoulos, G., Hallowell, N., Hall, P., Pharoah, P., Burton, H. (2013) *Incorporating genomics into breast and prostate cancer screening: Assessing the implications*. Genet Med, 15:423-432.

Clegg, A., Bates, C., Young, J. et al (2016) *Development and validation of an electronic frailty index using routine primary care electronic health record data.* Ageing 45:353–360.

Clarke, A. (1999) *Evaluation Research: An Introduction to Principles, Methods and Practice.* London: Sage.

Cline, P.B. (2005) "*The merging of risk analysis and adventure education*". Wilderness Risk Management, 5(1) 43-45.

Codori, A., Slavney, P.R., Young, C., Miglioretti, D.L., Brandt, J. (1997) *Predictors of psychological adjustment to genetic testing for Huntington's disease*. Health Psychology 16 (1), 36-50.

Cohen, L. and Manion, L., Morrison, K. (2000) *Research Methods in Education*, 5th edition. London: Routledge Falmer.

Coleman, M.P., Forman, D., Bryant, H., Butler, J., Rachet, B., Maringe, C., Nur, U., Tracey, E., Coory, M., Hatcher, J., McGahan, C.E., Turner, D., Marrett, L., Gjerstorff, M.L., Johannesen, T.B., Adolfsson, Lambe, M., Lawrence, G., Meechan, D., Morris, E.J., Middleton, R., Steward, J., Richards, M.A., the ICBP Module 1 Working Group (2011) *Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995–2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data.* The Lancet, 377 (9760), 127- 138.

Collier, D. & Mahoney, J. (1996) *“Insights and Pitfalls: Selection Bias in Qualitative Research.” World Politics* 49:56-91.

Collins, G. & Altman, D. (2012) *Predicting the risk of chronic kidney disease in the UK: An evaluation of QKidney scores using a primary care database.* Br J Gen Pract, 62(597) 243-250.

Collins, G.S. & Altman, D.G. (2009) *"An independent external validation and evaluation of QRISK cardiovascular risk prediction: A prospective open cohort study".* BMJ, 339:2584.

Collins, G.S., Altman, D.G. (2012) *Predicting the 10-year risk of cardiovascular disease in the United Kingdom: independent and external validation of an updated version of QRISK2*. BMJ. 21344: e4181.

Collins, G.S. & Altman, D.G. (2010) *An independent and external validation of QRISK2 cardiovascular disease risk score: A prospective open cohort study*. BMJ, 340:2442.

Collins, G.S. & Altman, D.G. (2011) *External validation of QDSCORE® for predicting the 10-year risk of developing type 2 diabetes*. Diabetic Medicine, 28:599-607.

Collins, G.S. & Altman, D.G. (2012) *Identifying patients with undetected colorectal cancer: An independent validation of QCancer (colorectal).* British Journal of Cancer, 107(2) 260-265.

Collins, G.S. & Altman, D.G. (2012) *Predicting the 10-year risk of cardiovascular disease in the United Kingdom: Independent and external validation of an updated version of QRISK2.* BMJ, 344:4181.

Collins, G.S. & Altman, D.G. (2013) *Identifying patients with undetected gastro-oesophageal cancer in primary care: External validation of QCancer (gastro-oesophageal).* Eur J Cancer, 49(5) 1040-8.

Collins, G.S. & Altman, D.G. (2013) *Identifying patients with undetected pancreatic cancer in primary care: An independent and external validation of QCancer (pancreas).* The British Journal of General Practice., 63(614) 636-642.

Collins, G.S. & Altman, D.G. (2013) *Identifying patients with undetected renal tract cancer in primary care: An independent and external validation of QCancer (renal) prediction model.* Cancer Epidemiol., 37(2) 115-20.

Collins, G.S. & Altman, D.G. (2013) *Identifying women with undetected ovarian cancer: Independent and external validation of QCancer(®) (ovarian) prediction model.* Eur J Cancer Care (Engl)., 22(4) 423-9.

Collins, G.S., Mallett, S. and Altman, D.G. (2011) *Predicting risk of osteoporotic and hip fracture in the United Kingdom: Prospective independent and external validation of QFracture Scores*. BMJ, 342:3651.

Collins, L., Haines, C., Perkel, R., Enck, R.E. (2007) *Lung cancer: Diagnosis and management.* American Family Physician (American Academy of Family Physicians), 75(1) 56-63.

Cook, N., Thomson, G., Dey, P. (2014) *Managing risk in cancer presentation, detection and referral: A qualitative study of primary care staff views.* BMJ Open, 4(6) 4820.

Corbett, K.S. (1999) *Infant feeding styles of West Indian women*. Journal of Transcultural Nursing, 10:22-30.

Courtney, R.J., Paul, C.L., Sanson-Fisher, R.W., Macrae, F.A., Carey, M.L., and Attia, J., McEvoy, M. (2012) *Colorectal cancer risk assessment and screening recommendation: A community survey of healthcare providers' practice from a patient perspective.* BMC Family Practice, 13(1) 1.

Creswell, J.W. (2007) *Qualitative Inquiry and Research Design: Choosing Among Five Traditions.* London: Sage Publications.

Creswell, J.W. (2011) *Controversies in mixed method research.* In: Denzin, N.K & Lincoln, Y.S (ed.) *The sage handbook of qualitative research*. 4th edition edition. CA: Sage: Thousand Oaks, 269-284.

Croyle, R.T., Smith, K.R., Botkin, J.R., Baty, B., Nash, J. (1997) *Psychological responses to BRCA1 mutation testing: preliminary endings*. Health Psychology 16 (1), 63-72.

Cunningham, D., Atkin, W., Lenz, H.J., Lynch, H.T., Minsky, B., Nordlinger, B., Starling, N. (2010) "*Colorectal cancer*". Lancet, 375(9719) 1030-47.

D'Ardenne, P. & Mahtani, A. (1989) *Transcultural Counselling in Action.* London: Sage.

D'Agostino, R.B., Grundy, S., Sullivan, L.M., Wilson, P. (2001) *Validation of the Framingham coronary heart disease prediction scores: Results of a multiple ethnic groups investigation.* Jama, 286(2) 180-7.

D'Agostino, R.B., Vasan, R.S., Pencina, M.J., Wolf, P.A., Cobain, M., Massaro, J.M., Kannel, W.B. (2008) *General cardiovascular risk profile for use in primary care: The Framingham heart study*. Circulation, 117(6) 743-753.

Damschroder, L.J., Aron, D.C., Keith, R.E., Kirsh, S.R., Alexander, J.A., Lowery, J.C. (2009) *Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science.* Implement Sci, 4(50).

Daudt, H.M., van Mossel, C., Scott, S.J. (2013) *Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework.* BMC Medical Research Methodology, 13: 48.

Davidson, J.R., Brundage, M.D., Feldman-Stewart, D. (1999) *Lung cancer treatment decisions: Patient's desires for participation and information*. Psychooncology, 8: 11-20.

Davis, K., Drey, N., Gould, D. (2009) *What are scoping studies? A review of the nursing literature*. International Journal of Nursing Studies, 46(10) 1386-1400.

Davison, B.J., Degner, L.F., Morgan, T.R. (1995) *Information and decision-making preferences of men with prostate cancer*. Oncol Nurs Forum, 22:1401-1408.

Davy, Z., Middlemass, J., Siriwardena, A.N. (2015) *Patients' and clinicians' experiences and perceptions of the primary care management of insomnia: Qualitative study.* Health Expectations, 18(5) 1371-1383.

De Angelis, R., Sant, M., Coleman, M.P., Francisci, S., Baili, P., Pierannunzio, D., Trama, A., Visser, O., Brenner, H., Ardanaz, E., Bielska-Lasota, M., Engholm, G., Nennecke, A., Siesling, S., Berrino, F., Capocaccia, R. (2014) *Cancer survival in europe 1999–2007 by country and age: Results of EUROCARE-5-a population-based study*. Lancet Oncology, 15: 23-34.

Degner, L.F., Kristjanson, L.J., Bowman, D., Sloan, J.A., Carriere, K.C., O'Neil, J., Bilodeau, B., Watson, P., Mueller, B. (1997) *Information needs and decisional preferences in women with breast cancer.* Jama, 18: 1485-1492.

Deledda, G., Moretti, F., Rimondini, M., Zimmermann, C. (2013) *How patients want their doctor to communicate. A literature review on primary care patients' perspective.* Patient Education and Counselling, 90(3) 297-306.

Delvecchio-Good, M.J., Good, B.J., Schaffer, C., Lind, S.E. (1990) *American oncology and the discourse on hope.* Cult Med Psychiatry, 59-79.

Denis, J.L., Hebert, Y., Langley, A. and Lozeau, D., Trottier, L.H. (2002) *Explaining diffusion patterns for complex health care innovations*. Health Care Management Review, 27(3) 60-73.

Denscombe, M. (2003) *The Good Research Guide: For Small-Scale Social Research Projects.* 2nd edition. Buckingham: Open University Press.

Denzin, N.K. & Lincoln, Y.S. (2005) *Introduction: The discipline and practice of qualitative research.* In N.K. Denzin & Y.S. Lincoln (Eds.), *The sage handbook of qualitative research*. 2nd edition. CA: Sage: Thousand Oaks, CA: Sage.

Department of Health (2000) *Referral guidelines for suspected cancers*. London: Department of Health.

Department of Health (2002) *Research Governance Framework for Health and Social Care*. London: Her Majesty's Stationary Office.

Department of Health (2005) *Research Governance Framework for Health and Social Care*. 2nd edition. London: Department of Health.

Department of Health (2007) *Cancer reform strategy*. London: Department of Health.

Department of Health (2008) *Research Governance Framework for Health and Social Care*. 2nd edition. London: Department of Health.

Department of Health (2011) Improving outcomes: a strategy for cancer.

Deshpande, R. (1983) “*Paradigms lost: On theory and method in research in marketing”*. Journal of Marketing, 47 101-110.

Dewey, J. (1931) *The development of American pragmatism.* In: J. Dewey (ed.) Philosophy and civilization. New York: Minton, Balch & Co.

Dikomitis, L., Green, T., Macleod, U. (2012) Macmillan Electronic Risk Assessment Tool Summary. Dealing with Uncertainty: A Qualitative Evaluation of the Usability and Acceptability of an Electronic Risk Assessment Tool to Aid Cancer Diagnosis in General Practice. London, UK: Macmillan Cancer Support.

Dikomitis, L., Green, T., Macleod, U. (2014) Electronic Cancer Decision Support Tools (eCDS). Project Summary and Update. London, UK: Macmillan Cancer Support.

Dikomitis, L., Green, T., Macleod, U. (2015) *Embedding electronic decision-support tools for suspected cancer in primary care: A qualitative study of GPs' experiences*. Primary Health Care Research & Development, 16:548-555.

Dirksen, C.D., Ament, A.J., Go, P.M (1996) *Diffusion of six surgical endoscopic procedures in the Netherlands. Stimulating and restraining factors*. Health Policy, 37(2) 91-104.

Dommett, R.M., Redaniel, T., Stevens, M.C., Martin, R.M., Hamilton, W. (2013) *Risk of childhood cancer with symptoms in primary care: a population-based case-control study*. Br J Gen Pract; 63: e22–29.

Donald, K.M., Matesic, B., Contopoulos-Ioannidis, D.G., Lonhart, J., Schmidt, E., Pineda, N., Ioannidis, J.P. (2013) *Patient safety strategies targeted at diagnostic errors: A systematic review.* Ann Intern Med., 158: 381-389.

Dunsmore, J. & Quine, S. (1995) *Information, support and decision-making needs and preferences of adolescents with cancer: Implications for health professionals*. J Phychosoc Oncol, 13: 39-56.

Ende, J., Kazis, L.E., Ash, A., Moskowitz, M. (1989) *Measuring patients' desire for autonomy.* J Gen Intern Med; 4:23-30.

Edwards, A., Elwyn, G., Mulley, A. (2002) *Explaining risks: Turning numerical data into meaningful pictures*. BMJ, 324: 827-830.

Edwards, A., Hood, K., Matthews, E., Russell, D., Russell, I., Barker, J., Bloor, M., Burnard, P., Covey, J., Pill, R., Wilkinson, C., Stott, N. (2000) *The effectiveness of one-to-one risk communication interventions in health care: A systematic review.* Med Decis Making, 20: 290-7.

Edwards, A.G.K., Elwyn, G., Mathews, E., Pill, R. (2001) *Presenting risk information - a review of the effects of "framing" and other manipulations on patient outcomes.* J Health Commun, 6: 61-82.

Ejiogu, N., Norbeck, J.H., Mason, M.A., Cromwell, B.C., Zonderman, A.B., Evans, M.K. (2011) *Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighbourhoods of diversity across the life span study.* Gerontologist, 51(1) 33-45.

Elkington, H., White, P., Addington-Hall, J., Higgs, R., Petternari, C., Elkington, H., White, P., Addington-Hall, J., Higgs, R., Petternari, C. (2004) *The last year of life of COPD: a qualitative study of symptoms and services*. Respir Med, 98(5):439-445.

Ellis, J., Wagland, R., Tishelman, C., Williams, M.L., Bailey, C.D. (2012) *Considerations in developing and delivering a nonpharmacological intervention for symptom management in lung cancer: The views of patients and informal caregivers.* J Pain Symptom Manag., 44(6) 831-842.

Elwyn, G. & Edwards, A.G.K. (2001) *Evidence-based patient choice*. In: Edwards, A.G.K. & Elwyn, G. (ed.) *Evidence-based patient choice—inevitable or impossible?* Oxford: Oxford: Oxford University Press, 3-18.

Elwyn, G., Edwards, A., Kinnersley, P. (1999) *Shared decision-making in primary care: The neglected second half of the consultation*. Br J Gen Pract, 49: 477-82.

Emery, J., Morris, H., Goodchild, R., Fanshawe, T., Prevost, A.T., Bobrow, M., Kinmonth, A. L. (2007) *The GRAIDS trial: A cluster randomised controlled trial of computer decision support for the management of familial cancer risk in primary care.* British Journal of Cancer, 97(4) 486-493.

Ezzy, D. (2002) *Qualitative Analysis Practice and Innovation*. Routledge, London. London: Routledge.

Fischer, P.M., Guinan, K.H., Burke, J.J., Karp, W.B., Richards, J.W. (1990) *Impact of a public cholesterol screening program*. Archives of Internal Medicine 150, 2567-2572.

Feldman-Stewart, D., Kocovsky, N., McConnell, B.A., Brundage, M.D., Mackillop, W.J. (2000) *Perception of quantitative information for treatment decisions*. Med Decis Making., 20:228-38.

Fereday, J. & Muir-Cochrane, E. (2006) *Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development*. International Journal of Qualitative Methods, 5(1) 80-92.

Ferlay, J., Shin, H.R., Bray, F.E.A. (2010) *Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008.* International Journal of Cancer, 127(12) 2893-2917.

Ferlay, J., Shin, H.R., Bray, F., Forman, D., Mathers, C., Parkin, D.M. (2010) GLOBOCAN 2008 v2.0, Cancer Incidence and Mortality Worldwide: IARC Cancer Base No. 10. Lyon, France: International Agency for Research on Cancer.

Ferlay, J., Soerjomataram, I., Ervik, M., Dikshit, R., Eser, S., Mathers, C.E.A. (2013) GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: Lyon, France: International Agency for Research on Cancer.

Ferlie, E., Gabbay, J., Fitzgerald, L., Locock, L., Dopson, S. (eds.) (2001) *Evidence-Based Medicine and Organisational Change: An Overview of Some Recent Qualitative Research*. In: Ashburner, L. editor. *Organisational Behaviour and Organisational Studies in Health Care*: Reflections on the Future. Basingstoke: Palgrave.

Fijten, G., Muris, J., Starmans, R., Knottnerus, J.A., Blijham, G., Krebber, T. (1993) *The incidence and outcome of rectal bleeding in general practice*. Fam Pract., 10:283-287.

Fischhoff, B. (1991) *Value elicitation: Is there anything in there?* American Psychologist, 46:835-847.

Fischhoff, B. (1995) *Risk perception and communication unplugged: Twenty years of process.* Risk Anal, 15:137-145.

Fischhoff, B., Slovic, P., Lichtenstein, S. (1980) *Knowing what you want: Measuring labile values*. In: T. Wallsten (ed.) Cognitive processes in choice and decision behaviour. Hillsdale: NJ: Erlbaum., 117-141.

Fixsen, D.L., Naoom, S.F., Blase, K.A., Friedman, R.M., Wallace, F. (2005) Implementation Research: A Synthesis of the Literature. Book Implementation Research: A Synthesis of the Literature. Louis de la Parte Florida Mental Health Institute. University of South Florida.

Flemming, A. (2011) Cancer: *Hope for smoking-associated lung cancer*. Nat Rev Drug Discov., 10(2) 98-9.

Fortin, J., Hirota, L., Bond, B., O'Connor, A., Col, N. (2001) *Identifying patient preferences for communicating risk estimates: a descriptive pilot study*. BMC Med Inform Decis Mak;1.

Foy, R., MacLennan, G., Grimshaw, J., Penney, G., Campbell, M., Grol, R. (2002) *Attributes of clinical recommendations that influence change in practice following audit and feedback*. Journal of Clinical Epidemiology, 55(7) 717-22.

Francis, J., Eccles, M.P., Johnston, M., Walker, A.E., Grimshaw, J.M., Foy, R., Kaner, E.F.S., Smith, L., Bonetti, D. (2004) Constructing questionnaires based on the theory of planned behaviour. A manual for health services researchers. Centre of Health Services Research, Newcastle upon Tyne: University of Newcastle upon Tyne.

Freudenberg, W.R. & Pastor, S.K. (1992) *NIMBYs and LULUs: Stalking the syndromes.* Journal of Social Issues, 48(4) 39-62.

Frey, L., Botan, C., Kreps, G. (1999*) Investigating communication: An introduction to research methods*. 2nd edition. Boston: Allyn & Bacon.

Fuller, R., Dudley, N., Blacktop, J. (2001) *Risk communication and older people - understanding of probability and risk information by medical inpatients aged 75 years and older.* Age Ageing, 30(473) 6.

Funtowicz, S.O. & Ravetz, J.R. (1990) *Uncertainty and quality in science for policy*. Boston: Kluwer.

Furber, C. (2010) Framework analysis: *A method for analysing qualitative data*. African Journal of Midwifery & Women’s Health, 4(2) 97-100.

Gabriel, D. (2013) Inductive and deductive approaches to research; http://deborahgabriel.com/2013/03/17/inductive-and-deductive-approaches-to-research/ Accessed 20/11/2016.

Gale, N. & Sultan, H. (2013) *Telehealth as ‘peace of mind’: Embodiment, emotions and the home as the primary health space for people with chronic obstructive pulmonary disorder.* Health Place, 21:140-147.

Gale, N.K., Heath, G., Cameron, E., Rashid, S., Redwood, S. (2013) *Using the framework method for the analysis of qualitative data in multi-disciplinary health research.* BMC Medical Research Methodology, 13: 117.

Gandhi, T.K., Kachalia, A., Thomas, E.J., Puopolo, A.L., Yoon, C., Brennan, T.A., Studdert, D.M. (2006) *Missed and delayed diagnoses in the ambulatory setting: A study of closed malpractice claims*. Ann Intern Med., 145:488-496.

Global Burden of Disease 2015 Risk Factors Collaborators (2016) *Global, regional, and national comparative risk assessment of 79 behavioural, environmental and occupational, and metabolic risks or clusters of risks, 1990-2015: A systematic analysis for the global burden of disease study 2015*. Lancet, 388(10053) 1659-1724.

General Medical Council [GMC] (2013) Good Medical Practice: Working with Doctors Working with Patients. www.gmc-uk.org/guidance. General Medical Council.

Gibbs, A. (1997) Focus Groups. Social research update. University of Surrey: Winter.

Gibson K. (2016) Software glitch puts thousands of heart patients on statin alert; The Times; 12-05-2016.

Gilbert, N. (2008) *Researching social life.* 3rd edition. London: Sage Publications Ltd.

Gill, P.S. (2013) *Patient engagement: An investigation at a primary care clinic.* Int J Gen Med, 6: 85-98.

Gill, P.S., Plumridge, G., Khunti, K., Greenfield, S. (2013) *Under-representation of minority ethnic groups in cardiovascular research: A semi-structured interview study.* Fam Pract, 30(2) 233-241.

Gillam, S. & Siriwardena, A.N. (2011) *The Quality and Outcomes Framework: QOF - transforming general practice*. Oxford: Radcliffe Publishing Ltd.

Glaser, B. & Strauss, A. (1967) *The discovery of grounded theory: Strategies for qualitative research*. New York: Aldine Publishing Company.

Goddard, W. & Melville, S. (2004) *Research Methodology: An introduction.* 2nd edition: Blackwell Publishing.

Goldberg, R.J. (1984) *Disclosure of information to adult cancer patients: Issues and update*. J Clin Oncol, 2:948-955.

Goldkuhl, G. (2012) *Pragmatism vs interpretivism in qualitative information systems research.* European Journal of Information Systems, 21(2) 135-146.

Goles, T. & Hirschheim, R. (2000) *The paradigm is dead, the paradigm is dead … long live the paradigm: The legacy of Burrell and Morgan*. Omega, 28:249-268.

Goss, J.D. & Leinbach, T.R. (1996) *Focus groups as alternative research practice.* Area, 28(2) 115-23.

Gray, D.E. (2004) *Doing research in the real world.* 3rd edition. London: Sage.

Green, T. & Macleod, U. (2014) Risk Assessment Tools (RATs) for cancer: a qualitative investigation. SEDA Research Summaries No. 3, Hull York Medical School: University of Hull.

Green, T., Atkin, K., Macleod, U. (2015) *Cancer detection in primary care: Insights from general practitioners.* British Journal of Cancer, 112(1) S41-S49.

Green, T., Dikomitis, L., Macleod, U. (2014) Electronic Risk Assessment Tools: qualitative evaluation. SEDA Research Summaries No. 4. Hull York Medical School: University of Hull.

Green, T., Walabyeki, J., Macleod, U. (2016) Clinical decision support for cancer diagnosis: qualitative evaluation, SEDA Research Summaries No. 5. Hull York Medical School: University of Hull.

Green, T., Atkin, K., Macleod, U. (2015) *GPs' perceptions and experiences of public awareness campaigns for cancer: A qualitative enquiry*. Health Expectations, 19(2) 377-387.

Green, T., Martins, T., Hamilton, W., Rubin, G., Elliott, K., Macleod, U. (2015) *Exploring GPs' experiences of using diagnostic tools for cancer: A qualitative study in primary care*. Family Practice, 32(1) 101-105.

Greenfield, G., Foley, K., Majeed, A. (2016) *Rethinking primary care's gatekeeper role.* BMJ, 4803.

Greenhalgh, T. (2007) *Primary Health Care: Theory and Practice*. Oxford: Blackwell publishing.

Greenhalgh, T., Robert, G., Bate, P., Kyriakidou, O., Macfarlane, F., Peacock, R. (2005) *Diffusion of Innovations in Health Service Organisations: A Systematic Literature Review*. Oxford: Blackwell.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., Kyriakidou, O. (2004) *Diffusion of innovations in service organizations: Systematic review and recommendations*. Milbank Q., 82:581-629.

Grewal, K., Hamilton, W., Sharp, D. (2013) *Ovarian cancer prediction: Development of a scoring system for primary care.* An International Journal of Obstetrics & Gynaecology, 120(8) 1016-1019.

Griffin, R. J., Neuwirth, K., Giese, J., Dunwoody, S. (2002) *Linking the heuristic-systematic model and depth of processing.* Communication Research, 29(6), 705-732.

Grilli, R. & Lomas, J. (1994) *Evaluating the message: The relationship between compliance rate and the subject of a practice guideline*. Medical Care, 32(3) 202-13.

Grove, W.M., Zald, D.H., Lebow, B.S., Snitz, B.E., Nelson, C. (2000) *Clinical vs. mechanical prediction: A meta-analysis*. Psychological Assessment, 12:12-30.

Gubrium, J. F. & Holstein, J. A. (2002) *From the individual interview to the interview society.* In: Gubrium, J. F. & Holstein, J. A. (ed.) *Handbook of interview research.* Thousand Oaks, CA: Sage Publications.

Guerra, C.E., Sherman, M., Armstrong, K. (2009) *Diffusion of breast cancer risk assessment in primary care*. Journal of the American Board of Family Medicine, 22(3) 272-279.

Habermas, J. (1984) *Theory of Communicative Action,* translated by Thomas McCarthy, Boston: Beacon Press.

Hamilton, W. (2009) *The CAPER studies: Five case-control studies aimed at identifying and quantifying the risk of cancer in symptomatic primary care patients*. Br J Cancer, 101(2) 80-86.

Hamilton, W. (2015) *Diagnosing symptomatic cancer in primary care – fast tract referral is one part of an improving picture*. BMJ, 351: 5311.

Hamilton, W. & Sharp, D. (2004) *Diagnosis of colorectal cancer in primary care: The evidence base for guidelines*. Family Practice, 21: 99-106.

Hamilton, W., Green, T., Martins, T., Elliott, K., Rubin, G., Macleod, U. (2013) *Evaluation of risk assessment tools for suspected cancer in general practice: A cohort study.* The British Journal of General Practice, 63(606) 30-36.

Hansson, S.O. & Zalta, E.N. (2014) "*Risk*". The Stanford Encyclopedia of Philosophy. Retrieved 29/04/2017.

Heath, G., Cameron, E., Cummins, C., Greenfield, S., Pattison, H., Kelly, D., Redwood, S. (2012) *Paediatric 'care closer to home': Stake-holder views and barriers to implementation.* Health Place, 18(5) 1068-1073.

Hennenfert, B. (2005) *Surviving prostate cancer without surgery.* 1st edition: Roseville Books.

Hennink, M.M., Kaiser, B.N., Marconi, V.C. (2016) *Code saturation versus meaning saturation: how many interviews are enough?* Qual Heath Res; 27: 591-608.

Hippisley-Cox, J., Coupland, C., Vinogradova, Y., Robson, J., Brindle, P. (2008) *Performance of the QRISK cardiovascular risk prediction algorithm in an independent UK sample of patients from general practice: a validation study*. Heart; 94:34-9.

Hippisley-Cox, J. & Coupland, C. (2017) *Development and validation of QMortality risk prediction algorithm to estimate short term risk of death and assess frailty: cohort study*. BMJ;358: j4208

Hippisley-Cox, J. & Coupland, C. (2013) *Predicting risk of emergency admission to hospital using primary care data: derivation and validation of QAdmissions score*. BMJ: e003482.

Hippisley-Cox, J. & Coupland, C. (2009) *Predicting risk of osteoporotic fracture in men and women in England and wales: Prospective derivation and validation of QFracture Scores.* BMJ, 339: 229.

Hippisley-Cox, J. & Coupland, C. (2009) *Predicting risk of type 2 diabetes in England and wales: Prospective derivation and validation of QDScore*. BMJ, 338: 880.

Hippisley-Cox, J. & Coupland, C. (2010) *Predicting the risk of chronic kidney disease in men and women in England and wales: Prospective derivation and external validation of the QKidney scores.* BMC Fam Pract, 11(1) 49.

Hippisley-Cox, J. & Coupland, C. (2011) *Development and validation of risk prediction algorithm (QThrombosis) to estimate future risk of venous thromboembolism: Prospective cohort study*. BMJ, 343:4656.

Hippisley-Cox, J. & Coupland, C. (2011) *Identifying patients with suspected gastro-oesophageal cancer in primary care: Derivation and validation of an algorithm.* The British Journal of General Practice, 61(592) 707-714.

Hippisley-Cox, J. & Coupland, C. (2011) *Identifying patients with suspected lung cancer in primary care: Derivation and validation of an algorithm*. British Journal of General Practice, 61(592) 715-723.

Hippisley-Cox, J. & Coupland, C. (2012) *Identifying patients with suspected colorectal cancer in primary care: Derivation and validation of an algorithm*. Br J Gen Pract., 62(594) 29-37.

Hippisley-Cox, J. & Coupland, C. (2012) *Identifying patients with suspected pancreatic cancer in primary care: Derivation and validation of an algorithm*. Br J Gen Pract., 62(594) 38-45.

Hippisley-Cox, J. & Coupland, C. (2012) *Identifying patients with suspected renal tract cancer in primary care: Derivation and validation of an algorithm*. Br J Gen Pract., 62(597) 251-60.

Hippisley-Cox, J. & Coupland, C. (2013) *Symptoms and risk factors to identify men with suspected cancer in primary care: Derivation and validation of an algorithm.* The British Journal of General Practice, 63(606) 1-10.

Hippisley-Cox, J. & Coupland, C. (2013) *Symptoms and risk factors to identify women with suspected cancer in primary care: Derivation and validation of an algorithm.* The British Journal of General Practice, 63(606) 11-21.

Hippisley-Cox, J. & Coupland, C. (2015) *Development and validation of risk prediction algorithms to estimate future risk of common cancers in men and women: Prospective cohort study.* BMJ, 5(3) 7825.

Hippisley-Cox, J. and Coupland, C. (2012) *Identifying women with suspected ovarian cancer in primary care: Derivation and validation of algorithm*. BMJ, 344: 8009.

Hippisley-Cox, J., Coupland, C., Vinogradova, Y., Robson, J., Brindle, P. (2008) *"Performance of the QRISK cardiovascular risk prediction algorithm in an independent UK sample of patients from general practice: A validation study".* Heart, 94:3439.

Hippisley-Cox, J., Coupland, C., Robson, J., Brindle, P. (2010) *Derivation, validation, and evaluation of a new QRISK model to estimate lifetime risk of cardiovascular disease: Cohort study using QResearch database.* BMJ, 341:6624.

Hingorani, A.D., van der Windt, D.A., Riely, R.D., Abrams, K., Moons, K.G.M., Steyerberg, E.W., Schroter, S., Sauerbrei, W., Altman, D.G., Hemingway, H*. (2013) Prognosis research strategy (PROGRESS) 4: stratified medicine research.* BMJ; 346: e5793.

Hoogendijk, E.O., Theou, O., Rockwood, K., Onwuteaka-Philipsen, B.D, Deeg, D.J.H., Huisman, M. (2016) *Development and validation of a frailty index in the Longitudinal Aging Study Amsterdam*. Aging Clin Exp Res. 2016.

Hofmann, J.C., Wenger, N.S., Davis, R.B., Teno, J., Connors, A.F., Desbiens, N., Lynn, J., Phillips, R.S. (1997) *Patient preferences for communication with physicians about end-of-life decisions. SUPPORT investigators. study to understand prognoses and preferences for outcomes and risks of treatment.* Ann Int Med, 127:1-12.

Hogarth, R. (1982) *New directions for methodology of social and behavioural science: Question framing and response consistency*. San Francisco: Jossey-Bass.

Horn, L., Pao, W., Johnson, D.H. (2012) *Harrison's Principles of Internal Medicine. 1*8th edition: McGraw-Hill.

Hornsby, J.L., Sappington, J.T., Mongan, P., Gullen, W.H., Bono, S.F., Altekruse, E. (1985) *Risk for bladder cancer: psychological impact of notification.* Journal of the American Medical Association 253, 1899-1902.

Houts, P.S. & McDougall, V. (1988) *Effects of informing workers of their health risks from exposure to toxic materials.* American Journal of Industrial Medicine 13, 271-279.

Huggins, J., Elman, N., Baker, C., Forrester, R.G., Lyter, D., (1991) *Affective and behavioural responses of gay and bisexual men to HIV antibody testing*. Social Work 36, 61-66.

Huang, H., Ezenwa, M.O., Wilkie, D.J., Judge, M.K. (2013) *Monitoring gender and ethnic minority recruitment and retention in cancer symptom studies.* Cancer Nursing, 36(3).

Hussey, J. & Hussey, R. (1997) *Business Research: A practical guide for undergraduate and post-graduate students*. London: MacMillan Press Ltd.

International Agency for Research on Cancer (2017) Global Initiative for Cancer Registry Development. Lyon, France: International Agency for Research on Cancer.

Ives, J., Damery, S., Redwod, S. (2013) *PPI, paradoxes and plato: Who's sailing the ship?* J Med Ethics, 39(3) 181-185.

Ironson, G., LaPerriere, A., Antoni, M., O'Hearn, P., Schneiderman, N., Klimas, N., Fletcher, M.A., (1990) *Changes in immune and psychological measures as a function of anticipation and reaction to news of HIV-1 anti-body status.* Psychosomatic Medicine 52, 247-270.

Jadresic, D., Riccio, M., Hawkins, D.A., Wilson, B., Shanson, D.C., Thompson, C. (1994) *Long-term impact of HIV diagnosis on mood and substance use - St Stephen's cohort study*. International Journal of STD and AIDS 5, 248-252.

Janssen-Heijnen, M.L., Gatta, G., Forman, D., Capocaccia, R., Coebefgh, J.W. (1998) *Variation in survival of patients with lung cancer in europe, 1985–1989.* Eur J Cancer, 34: 219-6.

Janzen, I. (1991) *The theory of planned behaviour: Organizational behaviour and human decision processes*. 50(2) 179-211.

Jemal, A., Bray, F., Center, M.M., Ferlay, J., Ward, E., Forman, D. (2011) *Global cancer statistics*. CA: A Cancer Journal for Clinicians, 61(2) 69-90.

Jensen, T. & Aanestad, M. (2007) *Hospitality and hostility in hospitals: A case study of an EPR adoption among surgeons*. European Journal of Information Systems, 16:672-680.

Jiwa, M. (2010) *Referral from primary to secondary care*. BMJ, 341(6175).

Jones, R.K. (2000) *The unsolicited diary as a qualitative research tool for advanced research capacity in the field of health and illness*. Qualitative Health Res, 10(4) 555-567.

Kadara, H., Kabbout, M., Wistuba, I.I. (2012) *Pulmonary adenocarcinoma: A renewed entity in 2011*. Respirology (Carlton, Vic), 17(1) 50-65.

Kahneman, D. (2011) *Thinking fast and slow*. 1st edition. London, England.: Penguin books Ltd.

Kahneman, D. & Tversky, A. (1984) *Choices, values, and frames*. American Psychologist, 39:341-350.

Kalkan, A., Roback, K., Hallert, E., Carlsson, P. (2014) *Factors influencing rheumatologists' prescription of biological treatment in rheumatoid arthritis: An interview study*. Implement Sci, 9:153.

Kanis, J.A. [on behalf of the WHO Scientific Group] (2008) Assessment of osteoporosis at the primary health-care level. Technical Report. WHO Collaborating Centre, University of Sheffield, UK.

Kanis, J.A., Burlet, N., Cooper, C., Delmas, P.D., Reginster, J.Y., Borgstrom, F., Rizzoli, R. (2008) *European guidance for the diagnosis and management of osteoporosis in postmenopausal women*. Osteoporos Int 19:399-428.

Kash, K.M., Holland, J.C., Halper, M.S., Miller, D.G., (1992) *Psychological distress and surveillance behaviours of women with a family history of breast cancer.* Journal of the National Cancer Institute 84, 24-30.

Kasperson, R.E., Renn, O., Slovic, P., Brown, H.S., Emel, J., Goble, R., Kasperson, J.S., Ratick, S. (1988) *Social amplification of risk: A conceptual framework.* Risk Analysis, 8, 177- 187.

Katz, J. (2001) *Analytic Induction*. In: Smelser and Baltes (ed.) *International Encyclopaedia of the Social and Behavioural Sciences*.

Kawamoto, K., Houlihan, C.A., Balas, E.A., Lobach, D.F. (2005) *Improving clinical practice using clinical decision support systems: A systematic review of trials to identify features critical to success*. BMJ, 330(7494) 765.

Kemp, F.B. (2009) *Smoke free policies in Europe. An overview*. Pneumologia, 58(3) 155-158.

Khan, N. (2009) *Colorectal clinical studies group implementation of a diagnostic tool for symptomatic colorectal cancer in primary care: A feasibility study*. Prim Health Care Res Dev., 10:54-64.

Kirsh, S.R., Lawrence, R.H., Aron, D.C. (2008) *Tailoring an intervention to the context and system redesign related to the intervention: A case study of implementing shared medical appointments for diabetes.* Implement Sci, 3:34-10.

Koyi, H., Hillerdal, G., Branden, E. (2002) *Patients' and doctors' delays in the diagnosis of chest tumours.* Lung Cancer, 35:53-7.

Kungwani, P. (2014) *Risk management - an analytical study*. Journal of Business and Management, 83-89.

Kurz-Milcke, E., Gigerenzer, G., Martignon, L. (2008) *Transparency in risk communication: Graphical and analog tools.* Ann N Y Acad Sci, 1128:18-28.

LaPerriere, A.R., Antoni, M., Schneiderman, N., Ironson, G., Klimas, N., Caralis, P., Fletcher, M.A. (1990) *Exercise intervention attenuates emotional distress and natural killer cell decrements following notification of positive serologic status for HIV-1.* Biofeedback and Self-Regulation 15, 229-242.

Lambert, S.D & Loiselle, C.G. (2008) *Combining individual interviews and focus groups to enhance data richness.* J Adv Nurs, 62(2) 228-37.

Lash, S.J., Timko, C., Curran, G.M., McKay, J.R., Burden, J.L. (2011) *Implementation of evidence-based substance use disorder continuing care interventions. Implementation of Evidence-Based Substance Use Disorder Continuing Care Interventions*. Psychol Addict Behav; 25(2):238-51.

Leung, G., Yu, P., Wong, I., Johnston, J., Tin, K. (2003) *Incentives and barriers that influence clinical computerisation in Hong Kong: A population-based* *physician survey.* Journal of the American Medical Informatics Association, 10(2) 201-212.

Lerman, C., Daly, M., Sands, C., Balshem, A., Lustbader, E., Heggan, T., Goldstein, L., James, J., Engstrom, P. (1993) *Mammography adherence and psychological distress among women at risk for breast cancer*. Journal of the National Cancer Institute 85, 1074-1080.

Lerman, C., Croyle, R.T., (1995) *Genetic testing for cancer predisposition: Behavioural science issues.* Journal of the National Cancer Institute Monographs 17, 63-66.

Levac, D., Colquhoun, H., O'Brien, K.K. (2010) *Scoping studies: Advancing the methodology*. Implement Sci, 5(69).

Ley, P. (1982) *Giving information to patients*. In: J. R. Eiser (ed.) *Social Psychology and Behavioural Science.* New York: John Wiley, 353.

Lincoln, Y. S., & Guba, E. G. (2000) *Paradigmatic controversies, contradictions, and emerging confluences.* In: Denzin, N.K. & Lincoln, Y.S. (ed.) *The handbook of qualitative research*. 2nd edition. Beverly Hills: Sage, 163-188.

Lincolnshire County Council (2005) Thebythams.org.uk. Lincolnshire County Council.

Lincolnshire Public Health Observatory (2012) Health profile Lincolnshire.

Lincolnshire Research Observatory (2017) Lincolnshire Strategic Needs Assessment (JSNA) Topic: Cancer. http://www.research-lincs.org.uk/JSNA-Cancer.aspx. Accessed: 10/10/2017.

Lind, S.E., DelVecchio, M.J., Seidel, S., Csordas, T., Good, B.J. (1989) *Telling the diagnosis of cancer*. J Clin Oncol, 7: 583-589.

Lipkus, I.M. & Hollands, J.G. (1999) *The visual communication of risk*. J Natl Cancer Inst Monogr; 25:149-62.

Little, P., Dorward, M., Warner, G., Stephens, K., Senior, K. and Moore, M. (2004) *Importance of patient pressure and perceived pressure and perceived medical need for investigations, referral, and prescribing in primary care: Nested observational study*. BMJ, 328(7437) 444.

Lo, B. & Garan, N. (2008) *Research with ethnic and minority populations*. In: E. J. Emanuel, C. Grady and R. A. Crouch (eds.) *The Oxford textbook of clinical research ethics.* New York: Oxford University Press.

Lobb, E.A., Butow, P.N., Kenny, D.T., Tattersall, M.H. (1999) *Communicating prognosis in early breast cancer: Do women understand the language used?* Med J Aust, 171: 290-294.

Lord, S.R., Ward, J.A., Williams, P., Anstey, K. (1994) *Physiological factors associated with falls in older community-dwelling women.* J Am Geriatr Soc, vol. 42 (pg. 1110-1117).

Lu, C., Onn, A., Vaporciyan, A.A. (2010) *Cancer of the Lung". Holland-Frei Cancer Medicine*. 8th edition. People's Medical Publishing House.

Iyen-Omofoman, B., Tata, L., Baldwin, D., Smith, C., Hubbard, R. (2013) *Using socio-demographic and early clinical features in general practice to identify people with lung cancer earlier.* Thorax; 68:451–59.

Macmillan Cancer Support (2015) Macmillan Cancer Decision Support (CDS) tool. Macmillan Cancer Support.

Maharik, M. & Fischhoff, B. (1993) *Contrasting perceptions of risks of using nuclear energy sources in space*. Journal of Environmental Psychology, 13**,** 243-250.

Maitra, A. & Kumar, V. (2007) *Robbins Basic Pathology*. 8th edition. Saunders, Elsevie.

Mann, A.H. (1977) *The psychological effect of a screening programme and clinical trial for hypertension upon the participants*. Psychological Medicine 7, 431-438.

Marshall, J.G. (1990) *Diffusion of innovation theory and end-user searching*. Library & Information Science Research, 6(1) 55-69.

Marshall, T., Lancashire, R., Sharp, D., Peters, T.J., Cheng, K.K.., Hamilton, W. (2011) *The diagnostic performance of scoring systems to identify symptomatic colorectal cancer compared to current referral guidance.* Gut 60(9):1242–1248.

Mason, M. (2010) Sample size and saturation in PhD studies using qualitative interviews. Forum: Qualitative Social Research, 11(3). Available from http://www.qualitative-research.net/index.php/fqs/article/view/1428/3027.

May, C. (2006) *Rational model for assessing and evaluating complex interventions in health care*. BMC Health Serv Res, 6:86.

May, C. & Finch, T. (2009) *Implementation, embedding, and integration: an outline of Normalization Process Theory*. Sociology in Press.

May, C., Murray, E., Finch, T., Mair, F., Treweek, S., Ballini, L., Macfarlane, A. and Rapley, T. (2010) Normalization Process Theory On-line Users' Manual and Toolkit.

Mays, N. & Pope, C. (1995) *Reaching parts other methods cannot reach: An introduction to qualitative methods in health and health services research*. British Medical Journal, 311:42-45.

Mays, N., Roberts, E., Popay, J. (2001) *Synthesising research evidence*. In: N. Fulop, P. Allen, A. Clarke and N. Black (eds.) *Studying the Organisation and Delivery of Health Services: Research Methods*. London: Routledge, 188-220.

Mazur, D.J. (2001) Shared decision making in the patient-physician relationship. Tampa, FL: American College of Physician Executives.

McCowan, C., Donnan, P.T., Dewar, J., Thompson, A., Fahey, T. (2011) *Identifying suspected breast cancer: Development and validation of a clinical prediction rule*. British Journal of General Practice, 10.

McDonald, K.M., Matesic, B., Contopoulos-Ioannidis, D.G., Lonhart, J., Schmidt, E., Pineda, N., Loannidis, J.P. (2013) *Patient safety strategies* *targeted at diagnostic errors: A systematic review.* Ann Intern Med., 158:381-389.

McQueen, A., Bartholomew, L.K., Greisinger, A.J., Medina, G.G., Hawley, S.T., Haidet, P., Betttencourt, J.L., Shokar, N.K., Ling, B.S., Vernon, S.W. (2009) *Behind closed doors: Physician-patient discussions about colorectal cancer screening*. Journal of General Internal Medicine, 24:12228.

Mead, G.H. (1998) *Philosophy of the act*: University of Chicago Press.

Meehl, P. (1996) *Clinical versus Statistical Prediction: A Theoretical Analysis and a Review of the Evidence*. 1st edition: Jason Aronson Inc.

Meredith, C., Symonds, P., Webster, L., Lamont, D., Pyper, E., Gillis, C.R., Fallowfield, L. (1996) *Information needs of cancer patients in west Scotland: Cross sectional survey of patients' views*. BMJ, 313:724-726.

Merika, E., Saif, M.W., Katz, A., Syrigos, K., Morse, M. (2010) *Review. colon cancer vaccines: An update*. In Vivo (Athens, Greece), 24(5) 607-28.

Merriel, S.W.D., Carroll, R., Hamilton, F., Hamilton, W. (2016) *Association between unexplained hypoalbuminaemia and new cancer diagnoses in UK primary care patients.* Family Practice, 33(5) 449-452.

Merz, J.F. (1991) Toward a standard of disclosure, for medical informed consent: Development and demonstration of a decision-analytic methodology. Ph.D. dissertation. Camegie Mellon University.

Merz, J.F., Fischhoff, B., Mazur, D.J., Fischbeck, P.S. (1993) *A decision-analytic approach to developing standards of disclosure for medical informed consent*. Journal of Products and Toxics Liabilities, 15:191-215.

Meyer, A.D. & Goes, J.B. (1988) *Organisational assimilation of innovations: A multi-level contextual analysis*. Academy of Management Review, 31:897-923.

Meyer, M. and Johnson, D. & Ethington, C. (1997) *Contrasting attributes of preventive health innovations.* Journal of Communication, 47:112-31.

Michael, Q. & Patton, M.Q. (2002) *Qualitative Research & Evaluation Methods*; SAGE.

Miyaji, N. (1993) *The power of compassion: Truth-telling among American doctors in the care of dying patients*. Soc Sci Med, 36:249-264.

Monk, M. (1981) *Blood pressure awareness and psychological well-being in the health and nutrition examination survey*. Clinical and Investigative Medicine 4, 183-189.

Morgan, I. & Wilkes, S. (2017) *Improving early diagnosis of cancer in UK general practice.* Br J Gen Pract., 67 (659) 276-277.

Morris, B. & Abram, C. (1982) Making Healthcare Decisions. The Ethical and Legal Implications of Informed Consent in the Practitioner-Patient Relationship. Washington: United States Superintendent of Documents.

Moynihan, R. (2013) Moynihan R (2013) *Science of over diagnosis to be served up with a good dose of humility*. BMJ, 347:5157.

Müller-Riemenschneider, F., Holmberg, C., Rieckmann, N., Kliems, H., Rufer, V., Müller-Nordhorn, J. and Willich, S.N. (2010) *Barriers to routine risk-score use for healthy primary care patients: Survey and qualitative study*. Arch Intern Med, 170:719-724.

Murtagh, J., Dixey, R. and Rudolf, M. (2006) *A qualitative investigation into the levers and barriers to weight loss in children: Opinions of obese children*. Archives Dis Child, 91(11) 920-923.

Nabi, R.L. & Oliver, M. B. (2009) *The SAGE Handbook of Media Processes and Effects. "Ecological fallacy (or fallacy of division) is the inverse of the fallacy of composition*": SAGE.

National Cancer Institute (2010) SEER stat fact sheets: Lung and Bronchus. Surveillance Epidemiology and End Results.

National Institute for Health and Care Excellence [NICE] (2014) National Institute for Health and Care Excellence (2014) "Lipid modification (CG181): cardiovascular risk assessment and the modification of blood lipids for the primary and secondary prevention of cardiovascular disease". Retrieved 16/04/2017.

National Institute for Health and Care Excellence [NICE] (2015) Suspected cancer: recognition and referral (NG12). www.nice.org.uk/guidance.

National Institute for Health and Care Excellence [NICE] (2015) Tackling the causes of premature mortality (early death), https://www.nice.org.uk/advice/lgb26/chapter/introduction. Accessed 15/09/17.

Neal, R.D. (2009) *Do diagnostic delays in cancer matter?* Br J Cancer., 101(2) S9-S12.

Neal, R.D. (2015) *Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? systematic review*. BJC, 112: 92-107.

NEDST (2002) Report to Health Ministers: Electronic Decision Support in Australia. Canberra, Australia: National Health Information Management Advisory Council.

Nevitt, M., Cummings, S., Kidd, S., et al. (1989) *Risk factors for recurrent non-syncopal falls.*, JAMA, 1989, vol. 261 (pg. 2663-2668).

Novack, D.H., Plumer, R., Smith, R.L., Ochitill, H., Morrow, G.R., Bennett, J.M. (1979) *Changes in physicians' attitudes toward telling the cancer patient.* Jama, 241:897-900.

Novikov, A.M. & Novikov, D.A. (2013) "*Research Methodology: From Philosophy of Science to Research Design*". CRS Press.

NPSAs & NRES (2010) Time to consent.

Nursten, J., Williams, P., Woodward, M. (2000) *Should all literature reviews be systematic?'* Evaluation and Research in Education, 14(3 & 4) 220-230.

O'Connor, A., Stacey, D., Bennett, C., Barry, M., Col, N., Eden, K., Entvistle, V., Holmes-Rovner, M., Khangura, S., Llewellyn-Thomas, H., Rovner, D. (2009) *Decision aids for people facing health treatment or screening decisions.* Cochrane Database of Sys, (3).

O'Connor, A.M., Stacey, D., Rovner, D., Holmes-Rovner, M., Tetroe, J., Llewellyn-Thomas, H., Entwistle, V., Rostom, A., Fiset, V., Barry, M., Jones, J. (2001) *Decision aids for people facing health treatment or screening decisions.* Cochrane Database Syst Rev, 3 (CD001431.).

Office for National Statistics (2012) Cancer Incidence and Mortality in the United Kingdom, 2008-10. United Kingdom: Office for National Statistics.

Office National Statistics (2012) Cancer registration statistics from the office for national statistics.

Office of National Statistic (2017) Cancer Registration Statistics, England: 2015 -Cancer diagnoses and age-standardised incidence rates for all cancer sites by age, sex and region. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/cancerregistrationstatisticsengland/2015. Accessed: 10/10/2017.

O'Neill, H.M., Pouder, P.W., Buchholtz, A.K. (2002) *Patterns in the diffusion of strategies across organisations: Insights from the innovation diffusion literature.* Academy of Management Review, 23(1) 98-114.

Opdenakker, R. (2006) *Advantages and disadvantages of four Interview Techniques in qualitative research*. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 7(4).

O'Reilly, K.M., Mclaughlin, A.M., Beckett, W.S., Sime, P.J. (2007) *Asbestos-related lung disease*. American Family Physician, 75(5) 683-688.

Ormston, R., Spencer, L., Barnard, M., Snape, D. (2013) *The foundations of qualitative research*. In: Ritchie et al. (ed.) *Qualitative research practice. A guide for social science students and researchers*. 2nd edition.: Sage, 19.

Øvretveit, J., Bate, P., Cleary, P., Cretin, S., Gustafson, D., McInnes, K., McLeod, H., Molfenter, T., Plsek, P., Robert, G., Shortell, S., Wilson, T. (2002) *Quality collaboratives: Lessons from research*. Quality and Safety in Health Care, 11:345-51.

Paling, J. (1997) Up to your armpits in alligators: how to sort out what risks are worth worrying about. Gainesville, FL: Risk Communication and Environmental Institute.

Paling, J. (2003) *Strategies to help patients understand risks.* BMJ, 327: 745-74.

Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N., Hoagwood, K. (2015) *Purposeful sampling for qualitative data collection and analysis in mixed method implementation research.* Administration and Policy in Mental Health, 42(5) 533-544.

Palmer, S.J. (2013) *The impact of national policy on the early diagnosis of cancer.* Br J Nurs, 22:16-23.

Papadopoulos, I. (2000) *An exploration of health beliefs, lifestyle behaviours, and health needs of the London-based Greek Cypriot community*. Journal of Transcultural Nursing, 11:182-190.

Pare, G., Sicotte, C., Jacques, H. (2006) *The effects of creating psychological ownership on physicians' acceptance of clinical information systems.* Journal of the American Medical Informatics Association, 13(2) 197-205.

Paton, M.Q. (2015) *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*. 4th edition. USA: Sage Publications Inc.

Patton, M.Q. (2002) *Qualitative Research & Evaluation Methods*. 3rd edition. Thousand Oaks, CA: SAGE Publications Inc.

Pearce, N. (2000) *The ecological fallacy strikes back*. J Epidemiol Community Health, 54(5) 326-327.

Peiris, D.P., Joshi, R., Webster, R.J., Groenestein, P., Usherwood, T.P., Heeley, E., Patel, A.A. (2009) *An electronic clinical decision support tool to assist primary care providers in cardiovascular disease risk management: Development and mixed methods evaluation*. Journal of Medical Internet Research., 11(4).

Pennington, R., Kelton, S., DeVries, D. (2006) *The effects of qualitative overload on technology acceptance.* Journal of Information Systems, 20(2) 25-36.

Persson, M., Mjörndal, T., Carlberg, B., Bohlin, J., Lindholm, L. (2000) Evaluation of a computer-based decision support system for treatment of hypertension with drugs: Retrospective, non-intervention testing of cost and guideline adherence. Journal of Internal Medici, 247(1) 87-93.

Perry, S., Jacobsberg, L., Card, C.A.L., Ashman, T., Frances, A., Fishman, B. (1993) *Severity of psychiatric symptoms after HIV testing*. American Journal of Psychiatry 150, 775-779.

Pettigrew, A.M., Woodman, R.W., Cameron, K.S. (2001) *Studying organizational change and development: Challenges for future research.* Acad Manage J, 44:697-713.

Pham, M.T., Rajic, A., Greig, J.D., Sargeant, J.M., Papadopoulos, A., McEwen, S.A. (2014) *A scoping review of scoping reviews: Advancing the approach and enhancing the consistency*. Res Synth Methods, 5:371-85.

Plsek, P.E. & Greenhalgh, T. (2011) *Complexity science: The challenge of complexity in health care.* British Medical Journal, 323:625-628.

Plummer, M., de Martel, C., Vignat, J., Ferlay, J., Bray, F., Franceschi, S. (2016) *Global, regional, and national comparative risk assessment of 79 behavioural, environmental and occupational, and metabolic risks or clusters* *of risks, 1990-2015: A systematic analysis for the global burden of disease study 2015.* Lancet Glob Health, 4(9) 609-16.

Pope, C., Ziebland, S., Mays, N. (2000) *Analysing qualitative data*. British Med J, 320 114-116.

Price, S.J., Shephard, E.A., Stapley, S.A., Barraclough, K., Hamilton, W.T. (2014) *Non-visible versus visible haematuria and bladder cancer risk: A study of electronic records in primary care.* The British Journal of General Practice, 64(626) 584-589.

Ptacek, J.T. & Eberhardt, T.L. (1996) *Breaking bad news. A review of the literature*. Jama, 276:496-502.

Pugh, K., Riccio, M., Jadresic, D., Burgess, A.P., Baldeweg, T., Catalan, J., Lovett, E., Hawkins, D.A., Gruzelier, J., Thompson, C. (1994) *A longitudinal study of the neuropsychiatric consequences of HIV-1 infection in gay men. Psychological and health status at baseline and at 12-month follow-up.* Psychological Medicine 24, 897-904.

Quaid, K.A. & Wesson, M. (1995) *Exploration of the effects of predictive testing for Huntington disease on intimate relationships*. American Journal of Medical Genetics 57, 46-51.

Quillin, J.M., Fries, E., McClish, D., Shaw de Paredes, E., Bodurtha, J. (2004) *Gail model risk assessment and risk perceptions*. J Behav Med., 27(2) 205-14.

Rabiee, F. (2004) *Focus-group interview and data analysis*. Proceedings of the Nutrition Society, 63(4) 655-660.

Race, K.E., Hotch, D.F., Parker, T. (1994) *Rehabilitation program evaluation: Use of focus groups to empower clients*. Evaluation Review, 18(6) 730-40.

Ramsey, K., Moyo, W., Mbuyita, S., Kujawski, S., Mbaruku, G., Freedman, L.P. (2014) *Studying moderators of implementation: Analysis from an* *intervention to reduce disrespect and abuse in facility-based childbirth*. BMC Health Serv Res, 14(2).

Rashidian, A., Eccles, M.P., Russell, I. (2008) *Falling on stony ground? A qualitative study of implementation of clinical guidelines' prescribing recommendations in primary care.* Health Policy, 85(2) 148-161.

Reelick, N.F., De Haes, W.F.M., Schuurman, J.H. (1984) *Psychological side-effects of the mass screening on cervical cancer.* Social Science and Medicine 18, 1089-1093.

Richardson, J.T.E. (1996) *Handbook of qualitative research for psychology and social sciences*: BPS, Blackwell.

Ritchie, J. & Lewis, J. (2003) *Qualitative research practice: a guide for social science students and researchers*. London: Sage.

Ritchie, J. & Spencer, E. (1994) *Qualitative data analysis for applied policy research.* In: Bryman, A. and Burgess, R.G. (ed.) *Analyzing Qualitative Data*. London: Routledge.

Robins, L.S., Jackson, J.E., Green, B.B., Korngiebel, D., Force, R.W., Baldwin, L. (2013) *Barriers and facilitators to evidence-based blood pressure control in community practice*. J Am Board Fam Med, 26(5) 539-57.

Robinson, L. (2009) Understanding Diffusion of Innovations: A summary of Diffusion of Innovations.

Rocha, S. (2004) Has anyone said "ethics"? "Safety" of beneficiaries? Some considerations about info gathering in the field. Analysis and Advocacy Unit, MSF B.

Rocque, R. & Leanza, Y. (2015) *A systematic review of patients' experiences in communicating with primary care physicians: Intercultural encounters and a balance between vulnerability and integrity*. Plos One, 10(10) e0139577.

Rogers, E.M. (1995) *Diffusion of Innovations*. New York: Free Press.

Roland, G. (2012) *Primary medical care in the United Kingdom*. J Am Board Fam Med, 25:6-11.

Rotchford, A.P., Rotchford, K.M., Mthethwa, L.P., Johnson, G.J. (2002) *Reasons for poor cataract surgery uptake - a qualitative study in rural South Africa*. Tropical Medicine and International Health, 7(3) 288-292.

Royak-Schaler, R., Blocker, D., Yali, A., Bynoe, M., Briant, K. & Smith, S. (2004*) Breast and colorectal cancer risk communication approaches with low-income African American and Hispanic women: Implications for healthcare providers.* J Nat Med Assoc., 96(5) 598-608.

Royal Commission on the NHS Chapter 7 (1979) Royal Commission on the NHS Chapter 7. Retrieved 19/08/17.

Rudd, P., Price, M.G., Graham, L.E., Beilstein, B.A., Tarbell, S.J.H., Bacchetti, P., Fortmann, S.P. (1986) *Consequences of worksite hypertension screening: differential changes in C. Shaw et al. Social Science & Medicine 49 (1999) 1571-1598 1597 psychosocial function.* The American Journal of Medicine 80, 853-860.

Ryan, G. W. & Bernard, H.R. (2000) *Data management and analysis methods.* In: Denzin, N. & Lincoln, Y. (ed.) *Handbook of qualitative research*. California: Sage, 769-802.

Sands, R.G., Newby, L.G., Greenberg, R.A. (1981) *Labeling of health risk in industrial settings.* The Journal of Applied Behavioural Science 17, 359-374.

Sanchez, S.H., Sethi, S.S., Santos, S.L., Boockvar, K. (2014) *Implementing medication reconciliation from the planner's perspective: A qualitative study*. BMC Health Serv Res, 14 290.

Saunders, M. and Lewis, P., Thornhill, A. (2009) *Research Methods for Business Students.* Fifth edition. Prentice Hall: Financial Times Ldt.

Saunders, M., Lewis, P., Thornhill, A. (2012) *Research Methods for Business Students*. 6th edition: Pearson Education Limited.

Scambler, G. & Britten, N. (2001) *System, lifeworld, and doctor–patient interaction.* In: G. &. H. Scambler (ed.) Critical Theory and Health. London: Routledge.

Schapira, M.M. and Nattinger, A.B., McHorney, C.A. (2001) *Frequency or probability? A qualitative study of risk communication formats used in health care.* Med Decis Making., 21:459-67.

Schmidt-Hansen, M., Berendse, S., Hamilton, W., Baldwin, D.R. (2017) *Lung cancer in symptomatic patients presenting in primary care: A systematic review of risk prediction tools*. Br J Gen Pract, 67(659) 396-404.

Schwartz, L., Woloshin, S., Welch, G. (1999) *Risk communication in clinical practice: Putting cancer in context.* J Natl Cancer Inst Monogr, 25:124-33.

Schydlower, M., Foley, J., Copeland, R.L. (1995) *Adolescents' misinterpretation of health risk probability expressions.* Pediatrics, 95:713-6.

Seale, C., Gobo, G., Gubrium, J.F., Silverman, D. (2007) *Qualitative Research Practice.* London: Sage.

Selvachandran, S.N., Hodder, R.J., Ballal, M.S., Jones, P., Cade, D. (2002) *Prediction of colorectal cancer by a patient consultation questionnaire and scoring system: A prospective study*. Lancet, 360:278-83.

Sepucha, K., Uzogarra, B., O'Connor, M. (2008) *Developing instruments to measure the quality of decisions: Early results for a set of symptom-driven decisions.* Patient Educ Counsel, 73(3) 504-510.

Shaw, C., Abrams, K., Marteau, T.M. (1999) *Psychological impact of predicting individuals' risk of illness: A systematic review*. Soc Sci Med, 49:1571-1598.

Sheard, L., Prout, H., Dowding, D., Noble, S., Watt, I., Maraveyas, A., Johnson, M. (2012) *Barriers to the diagnosis and treatment of venous thromboembolism in advanced cancer patients: A qualitative study*. Palliative Med, 27(2) 339-348.

Sheppard, B., Janoske, M., Brooke, L.B. (2012) Understanding Risk Communication Theory: A Guide for Emergency Managers and Communicators," Report to Human Factors/Behavioural Sciences Division, Science and Technology Directorate. U.S: Department of Homeland Security.

Sheppard, B., Melissa, J., Brooke, L. (2012) Sheppard, B.; Melissa, J.; Brooke, L. (2012) "Understanding Risk Communication Theory: A Guide for Emergency Managers and Communicators," Report to Human Factors/Behavioural Sciences Division, Science and Technology Directorate, Department of Homeland, US.

Shephard, E., Neal, R., Rose, P. et al. (2013) *Clinical features of kidney cancer in primary care: a case-control study using primary care records*. Br J Gen Pract;63: e250–5.

Shephard, E.A., Stapley, S., Neal, R.D. et al. (2012) *Clinical features of bladder cancer in primary care*. Br J Gen Pract; 62: e598–604.

Shephard, E. *et al*. (2014) *Quantifying the risk of myeloma from symptoms reported in primary care patients: a large case–control study using electronic records. Br. J. Gen. Pract.* 65, 631 (2014).

Shephard, E. A. et al. (2015) *Quantifying the risk of multiple myeloma from symptoms reported in primary care patients: a large case–control study using electronic records. Br. J. Gen. Pract.* 65, e106–e113.

Shephard, E.A., Neal, R.D., Rose, P.W et al. (2015) *Quantifying the risk of Hodgkin's lymphoma in symptomatic primary care patients aged ≥40 years: a case-control study using electronic records*. Br J Gen Pract; 65: e289–94.

Shephard, E.A., Neal, R.D., Rose, P.W et al. (2015) *Quantifying the risk of non-Hodgkin's lymphoma in symptomatic primary care patients aged ≥40 years: a large case-control study using electronic records*. Br J Gen Pract; 65: e281–8.

Shephard, E. A., Neal, R. D., Rose, P. W., Walter, F. M., Hamilton, W. (2016) *Symptoms of adult chronic and acute leukaemia before diagnosis: large* *primary care case–control studies using electronic records*. *Br. J. Gen. Pract.* 66, e182–e188.

Shibl, R., Lawley, M., Debuse, J. (2012) Factors influencing decision support system acceptance.

Shu, K., Boyle, D., Spurr, C., Horsky, J., Heiman, H., O'Connor, P., Bates, D. (2001) *Comparison of time spent writing orders on paper with computerized physician order entry. Medinfo 2001 Proceedings:* Studies in Health Technology and Informatics, 1207-1211.

Silverman, D. (2005) *Doing Qualitative Research: A Practical Handbook*. Sage edition: London.

Silverman, D. (2006) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*. 3rd edition. London: Sage.

Silverman, D. (2011*) Interpreting qualitative data*. London: Sage.

Sinchenko, V., Westbrook, J., Tipper, S.M., Mathie, M., Coiera, E. (2002) Electronic Decision Support Activities in Different Healthcare Settings in Australia, Commissioned Study.

Singh, H., Kadiyala, H., Bhagwath, G., Shethia, A., El-Serag, H., Walder, A., Velez, M.E., Petersen, L.A. (2009) *Using a multifaceted approach to improve the follow-up of positive faecal occult blood test results*. Am J Gastroenterol., 104:942-952.

Singh, H., Thomas, E.J., Khan, M.M., Petersen, L.A. (2007) *Identifying diagnostic errors in primary care using an electronic screening algorithm*. Arch Intern Med., 167: 302-308.

Skolbekken, J.A. (1998) *Communicating the risk reduction achieved by cholesterol reducing drugs*. BMJ; 316:1956-8.

Slater, E. (1998) *How risks of breast cancer and benefits of screening are communicated to women: Analysis of 58 pamphlets*. BMJ, 317: 263-4.

Schmidt-Hansen, M., Berendse, S., Hamilton, W. (2015) *Symptoms of pancreatic cancer in primary care: a systematic review. Pancreas 2015*, Epub ahead of print.

Soghikian, K., Fallick-Hunkeler, E.M., Ury, H.K., Fisher, A.A. (1981) *The effect of high blood pressure awareness and treatment on emotional well-being*. Clinical and Investigative Medicine 4, 191-196.

Snape, D. & Spencer, L. (2003) *The foundations of qualitative research*. In: Ritchie, J. & Lewis, J. (ed.) *Qualitative Research Practice: A Guide for Social Science Researchers and Students*. London: SAGE Publications Ltd, 1-23.

Spil, T., Katsma, C., Stegwee, R. (2007) *Information systems and healthcare XXIII: exploring interoperability of electronic healthcare records by studying demand and supply in the Netherlands,* Communications of the Association for Information Systems 20, 996-1008.

Srivastava, A. & Thomson, S.B. (2009) *Framework analysis: A qualitative methodology for applied policy research*. Journal of Administration & Governance, 4(2) 72-79.

Stapley, S., Peters, T.J., Neal, R.D et al. (2013) *The risk of oesophago-gastric cancer in symptomatic patients in primary care: a large case-control study using electronic records*. Br J Cancer; 108:25–31.

Stacey, D., Bennett, C.L., Barry, M.J., Col, N.F., Eden, K.B., Holmes-Rovner, M., Llewellyn-Thomas, H., Lyddiatt, A., Légaré, F. (2011) *Decision aids for people facing health treatment or screening decisions. Cochrane database of systematic reviews.* Cochrane Database of Systematic Reviews, 1(10).

Stewart, B.W. & Wild, C.P. (2014) World cancer report 2014. Lyon: International Agency for Research on Cancer. Lyon: International Agency for Research on Cancer.

Steyerberg, E.W., Moons, K.G., van der Windt, D.A., Hayden, J.A., Perel, P., Schroter, S., Riley, R.D., Hemingway, H., Altman, D.G. (2013) *Prognosis*

Research Strategy (PROGRESS) 3: prognostic model research. PLoS Med, 10: e1001381. PMID: 23393430.

Strauss, A. & Corbin, J. (1994) "*Grounded Theory Methodology.*" In NK Denzin & YS Lincoln (Eds.) *Handbook of Qualitative Research*. Thousand Oaks: Sage Publications.

Subramanian, J. & Govindan, R. (2007) *"Lung cancer in never smokers: A review".* Journal of Clinical Oncology (American Society of Clinical Oncology), 25(5) 561-570.

Sutherland, H.J., Llewellyn-Thomas, H.A., Lockwood, G.A., Tritchler, D.L., Till, J.E. (1989) *Cancer patients: Their desire for information and participation in treatment decisions*. J R Soc Med, 82:260-263.

Swallow, V., Lambert, H., Santacrose, S., Macfadyen, A. (2011) *Father and mothers developing skills in managing children's long-term medical conditions: How do their qualitative accounts compare?* Child: Care, Health and Development, 37(4) 512-523.

Swallow, V., Newton, J., Van Lottum, C. (2003) *How to manage and display qualitative data using Framework and Microsoft excel.* Journal of Clinical Nursing, 12(4) 610-612.

Tanimola, M., Hamilton, W., Ukoumune, O., Bank, J., Raine, R. (2014) *Patients' views on testing for prostate cancer: A vignette-based study of primary care attendees.* European Journal of Cancer Care, 23:24-33.

Taylor, S. & Todd, P. (1995) *Assessing IT usage: The role of prior experience.* MIS Quarterly, 19(4) 561-570.

Taylor, R., Najafi, F., Dobson, A. (2007) "*Meta-analysis of studies of passive smoking and lung cancer: Effects of study type and continent".* International Journal of Epidemiology, 36(5) 1048-1059.

Taylor, S. & Todd, P. (1995) *Assessing IT usage: The role of prior experience*. MIS Quarterly 19 (4) 561–570.

Tesser, A. & Conlee, M.C. (1973) *Recipient emotionality as a determinant of the transmission of bad news.* Proc Annu Conv Am Psych Assoc, 247-248.

Tesser, A., Rosen, S., Tesser, M. (1971) *On the reluctance to communicate undesirable messages (the MUM effect). A field study.* Psychol Rep, 29:651-654.

Thun, M.J., Hannan, L.M., Adams-Campbell, L.L. (2008) *"Lung cancer occurrence in never-smokers: An analysis of 13 cohorts and 22 cancer registry studies"*. PLoS Medicine, 5(9) 185.

Tidy, C. (2016) Cardiovascular risk assessment. Cardiovascular disease. Available: https://patient.info/doctor/cardiovascular-risk-assessment.Last accessed on 06/01/18.

Tiedemann, A., Lord, S.R., Sherrington, C. (2010) *The development and validation of a brief performance-based fall risk assessment tool for use in primary care.* J Gerontol A Biol Sci Med Sci .65A:896–903.

Tierney, S., Elwers, H., Sange, C., Mamas, M., Rutter, M.K., Gibson, M., Neyses, L., Deaton, C. (2011) *What influences physical activity in people with heart failure? A qualitative study.* International Journal of Nursing Studies, 48(10) 1234-1243.

Toftegaard, B.S., Bro, F., Falborg, A.Z., Vedsted, P. (2016) *Impact of continuing medical education in cancer diagnosis on GP knowledge, attitude and readiness to investigate - a before-after study.* BMC Fam Pract. 26;17

Togher, F.J., Davy, Z., Siriwardena, A.N. (2013) *Patients' and ambulance service clinicians' experiences of prehospital care for acute myocardial infarction and stroke: A qualitative study.* Emergency Medicine Journal, 30(11) 942-948.

Trevana, L.J. (2006) *Systematic review on communicating with patients about evidence.* Journal of Evaluation in Clinical Practice, 12(1) 3.

Trumbo, C. W. (2002). *Information processing and risk perception: An adaptation of the heuristic-systematic model. Journal of Communication, 52*(2), 367-382.

Tzoulaki, I., Liberopoulos, G., Ioannidis, J.P. (2009) *Assessment of claims of improved prediction beyond the Framingham risk score*. Jama, 302(21) 2345-52.

Usher-Smith, J.A., Silarova, B., Ward, A., Youell, J., Muir, K.R., Campbell, J., Warcaba, J. (2017) *Incorporating cancer risk information into general practice: A qualitative study using focus groups with health professionals.* The British Journal of General Practice, 67(656) 218-226.

Usher-Smith, J.A., Emery, J., Kassianos, A.P., Walter, F.M. (2014) *Risk prediction models for melanoma: A systematic review*. Cancer Epidemiol Biomarkers Prev, 23:1450-63.

Usher-Smith, J., Emery, J., Hamilton, W., Griffin, S.J., Walter, F.M. (2015) *Risk prediction tools for cancer in primary care.* Br J Cancer. 113:1645–50.

Usher-Smith, J.A., Walter, F.M., Emery, J., Win, A.K., Griffin, S.J. (2016) *Risk prediction models for colorectal cancer: A systematic review.* Cancer Prev Res (Phila), 9(1) 13-26.

Van De Ven, A. (2007) *Engaged scholarship: A guide for organizational and social research.* Oxford: Oxford Press.

Van Manen, M. (1990) *Researching lived Experience: Human Science for an Action Sensitivity Pedagogy*. London: Althouse Press.

Van Steenkiste, B., Van Der Weijden, T., Stoffers, H.E., Grol, R. (2004) *Barriers to implementing cardiovascular risk tables in routine general practice.* Scand J Prim Health Care, 22:32-37.

Varsi, C., Eksted, T.M., Gammon, D., Ruland, C.M. (2015) *Using the consolidated framework for implementation research to identify barriers and facilitators for the implementation of an internet-based patient-provider* *communication service in five settings: A qualitative study.* Journal of Medical Internet Research, 17(11).

Venkatesh, V. & Davis, F. (2000) *A theoretical extension of the technology acceptance model: Four longitudinal field studies*. Management Science, 46(2) 186-204.

Venkatesh, V., Morris, M., Davis, G., Davis, F. (2003) *User acceptance of information technology: Towards a unified view*. MIS Quarterly, 27(3) 425-478.

Waldron, C.A., van der Weijden, T., Ludt, S., Gallacher, J., Elwyn, G. (2011) *What are effective strategies to communicate cardiovascular risk information to patients? A systematic review.* Patient Educ Couns, 82:169-181.

Waldron, C.A., van der Weijden, T., Ludt, S., Gallacher, J., Elwyn, G. (2011) *What are effective strategies to communicate cardiovascular risk information to patients? A systematic review*. Patient Educ Couns, 82:169-181.

Wardle, J., Pernet, A., Stephens, D. (1995) *Psychological con-sequences of positive results in cervical cancer screening*. Psychology and Health 10, 195-204.

Walker, S., Hyde, C., Hamilton, W. (2013) *Risk of uterine cancer in symptomatic women in primary care: case-control study using electronic records.* Br J Gen Pract; 63: e643-8.

Walker, J.G., Licqurish, S., Chiang, P.P., Pirotta, M., Emery, J.D. (2015) Cancer risk assessment tools in primary care: A systematic review of randomized controlled trials. Ann Fam Med, 13(5) 480-489.

Walker, S. & Hamilton, W. (2017) *Risk of cervical cancer in symptomatic women aged ≥40 in primary care: A case-control study using electronic records.* Eur J Cancer Care (Engl). ;26(3).

Walters, K., Hardoon, S., Petersen, I., Iliffe, S., Omar, R., Nazareth, I., Rait, G. (2016) *Predicting dementia risk in primary care: development and* *validation of the Dementia Risk Score using routinely collected data*. BMC Medicine 14:6.

Wan, Q., Makeham, M., Zwar, N.A., Petche, S. (2012) *Qualitative evaluation of a diabetes electronic decision support tool: Views of users*. BMC Medical Informatics and Decision Making, 12:61.

Ward, D.J., Furber, C., Tierney, S., Swallow, V. (2013) *Using framework analysis in nursing research: A worked example*. Journal of Advanced Nursing, 69(11) 2423-2431.

Welch, H.G. & Black, W.C. (2010) *Over diagnosis in cancer*. J Natl Cancer Inst, 102:605-13.

Wengraf, T. (2001) *Qualitative research interviewing*. London: Sage.

Wensing, M. (2011) Theories in implementation science. Scientific Institute for Quality of Health Care http://www.netzwerk-versorgungsforschung.de/uploads/Wensing_theoryandimplementationscience.pdf. Accessed: 20/08/2015.

Whitaker, K., Ghanouni, A., Zhou, Y., Lyratzopoulos, G., Morris, S. (2017) *Patients' preferences for GP consultation for perceived cancer risk in primary care: A discrete choice experiment*. Br J Gen Pract, 67(659) 388-395.

WHO Media Centre (2017) WHO Media centre (2017) Cancer fact sheet. http://www.who.int/mediacentre/factsheets/fs297/en/. Accessed:07/08/17.

Wiggins, S., Whyte, P., Huggins, M., Adam, S., Theilmann, J., Bloch, M., Sheps, S.B., Schechter, M.T., Hayden, M.R., (1992) *The psychological consequences of predictive testing for Huntington's disease.* The New England Journal of Medicine 20, 1401-1405.

Williams, E.C., Johnson, M.L., Lapham, G.T., Caldeiro, R.M., Chew, L., Fletcher, G.S., McCormick, K.A., Weppner, W.G., Bradley, K.A. (2011) *Strategies to implement alcohol screening and brief intervention in primary* *care settings: A structured literature review*. Psychol Addict Behav, 25(2) 206-14.

Williams, T.G.S., Cubiella, J., Griffin, S.J., Walter, F.M., Usher-Smith, J.A. (2016) *Risk prediction models for colorectal cancer in people with symptoms: A systematic review*. BMC Gastroenterol, 16:63.

Willis, J.W. (2007) *Foundations of Qualitative Research*. Thousand Oaks, CA: Sage.

Wilson, D.K., Purdon, S.E., Wallston, K.A. (1988) *Compliance to health recommendations: A theoretical overview of message framing*. Health Educ Res, 3:161-71.

Wilson, P.W., D'Agostino, R.B., Levy, D., Belanger, A.M., Silbershatz, H., Kannel, W.B. (1998) *Prediction of coronary heart disease using risk factor categories.* Circulation, 97(18) 1837-1847.

World Health Organisation (2010) "Cancer". World Health Organisation.

WHO Media Centre. (2017). WHO media centre (2017) cancer fact sheet. http://www.who.int/mediacentre/factsheets. Accessed:07/08/17. WHO.

World Health Organisation (2017) Programme, early diagnosis of cancer; http://www.who.int/cancer/prevention/diagnosis-screening/en/. Accessed 16/09/17.

World Health Organization (2004) "Gender in lung cancer and smoking research" (PDF). World Health Organization.

Yamada, T. & Alpers, D.H. (2008) Principles of Clinical Gastroenterology. Chichester, West Sussex; Hoboken, NJ: Wiley-Blackwell.

Yamagishi, K. (1997) *When a 12.86% mortality is more dangerous than 24.14%: Implications for risk communication*. Appl Cogn Psychol, 11:495-506.

Yetton, P., Sharma, R., Southon, G. (199) *Successful IS innovation: The contingent contributions of innovation characteristics and implementation process*. Journal of Information Technology, 14(1) 53-68.

Zapata, J. & Shippee-Rice, R. (1999) *The use of folk healing and healers by six Latinos living in new England: A preliminary study*. Journal of Transcultural Nursing, 10:136-142.

Zentner, R.D. (1979) *Hazards in the chemical industry.* Chemical and Engineering News, 25-27.

Zhang, J., Ou, J.X,. Bai, C.X. (2011) *"Tobacco smoking in china: Prevalence, disease burden, challenges and future strategies*". Respirology, 16(8) 1165-1172.

Zikmund-Fisher, B.J., Smith, D.M., Ubel, P.A., Fagerlin, A. (2007) *Validation of the subjective numeracy scale: Effects of low numeracy on comprehension of risk communications and utility elicitations.* Med Decis Making, 27:663-71.

APPENDICES

Appendix 1: Copies of conference abstracts

Appendix 1.1: Abstract accepted for oral presentation at the Society for Academic Primary Care (SAPC) at the University of Leicester on 15th March 2016

Title of the abstract:	Exploring Service User and practitioner perspectives of QCancer use in primary care consultations
Author(s):	**Akanuwe, J.;** Siriwardena, A.; Black, S. & Owen, S.
Institution:	Community and Health Research Unit, University of Lincoln
Contact Details (email)	**11357484@students.lincoln.ac.uk**
Please indicate your preferred option: Parallel, Poster or Workshop.	Parallel or Poster (No Preference)

Introduction: QCancer is a novel cancer risk assessment tool that combines risk factors and symptoms to estimate an individual's risk of developing cancer within two years. This study explored the perspectives of service users and primary care practitioners about using QCancer in the primary care consultation.

Methods: We used qualitative methods to conduct individual and focus group interviews with service users recruited from the public and primary care practitioners (GPs and nurses) recruited from general practices in Lincolnshire (a large rural county in England) until data saturation was achieved. The qualitative data were transcribed verbatim and analysed using the Framework approach.

Results: Thirty-six participants, 19 service users and 17 practitioners, were interviewed. They expressed a range of views about the implications of quantifying cancer risk using QCancer including potential conflict with

current cancer guidelines or that high risk symptoms would need referral for further investigation whatever the quantified risk.

Participants, both service users and providers, agreed that QCancer was useful for consultations for cancer in: quantifying risk; supporting decision-making; identifying, raising awareness of and modifying health behaviours; improving processes and speed of assessment and treatment; and personalising care.

Participants also raised the need to address communication issues related to use of QCancer such as tailoring visual representation of risk; openness and honesty; informing and involving patients in use of QCancer and providing time for listening, informing, explaining and reassuring in the context of a professional approach. Participants also identified potential challenges to uptake of QCancer in general practice including: additional time required, unnecessary worry generated by false positives, potential for over-referral, practitioner scepticism about using the new tool, and the need for evidence of effectiveness before introducing QCancer in patient consultations.

Conclusion: Service users and primary care practitioners perceived that QCancer would support and individualise decision making, help identify and modify health behaviours, increase knowledge, improve the processes and speed of cancer assessments and treatments and facilitate personalised care of cancer. Communication needs of users and potential barriers for both users and practitioners will need to be considered in planning for QCancer use in general practice consultations.

Number of words: 348

Appendix 1.2: Abstract accepted for oral presentation at the College of Social Science Research Conference at the University of Lincoln on 4th July 2016

Title: Exploring service user and practitioner perspectives of QCancer use in primary care consultations

Authors: Akanuwe, J.; Siriwardena, A.; Black, S. & Owen, S.

Introduction: This study explored perspectives of service users and primary care practitioners about using QCancer, a cancer risk assessment tool, in primary care consultations.

Methods: Individual and focus group interviews with data analysed using the Framework approach.

Results: 36 participants, 19 service users and 17 practitioners, were interviewed until data saturation was achieved. Participants expressed a range of views about the implications of quantifying cancer risk using QCancer including potential conflict with current cancer guidelines and, high risk symptoms would need referral for further investigation whatever the quantified risk. Participants agreed that QCancer would be useful in a number of ways including helping to identify and raise awareness for modifying health behaviours and personalising patient care. Participants discussed communication needs when using QCancer, which will add to knowledge in terms of how best to improve communication of cancer risk during the consultation. Potential challenges to uptake of QCancer were also identified.

Conclusion: Participants perceived that QCancer would be potentially useful but communication needs of users and potential barriers for both users and practitioners need to be considered when planning QCancer use in general practice consultations.

Appendix 1.3 Abstract accepted for oral presentation at the Cancer Research UK Early Diagnosis Research Conference, London, 2017

Which conference theme does your research fit under?	☐ Cancer screening ☐ Patient factors in timely presentation and diagnosis ☐ Optimising clinical practice and systems √ ☐ Risk assessment and risk stratification √ ☐ Inequalities ☐ Cancer data to achieve new insights in cancer control ☐ Health economics
Abstract title	Informing use of QCancer in the primary care consultation - perspectives of service users and practitioners

Introduction: Earlier detection of cancer may help reduce the current high level of cancer mortality in the UK. Cancer risk assessment tools such as QCancer, which predict the absolute risk of cancer in symptomatic individuals, may help identify those at high risk needing investigation for possible cancer. Little is known about the views of service users and primary care practitioners on the use of QCancer in primary care consultations. The aim of this study was to explore the perspectives of service users and primary care practitioners on use of QCancer and how communication with patients might be enhanced when using QCancer in primary care consultations.

Methods: The study was conducted in Lincolnshire, a large rural county in the East Midlands, using a qualitative research design. This involved individual interviews with service users recruited from the public, and both individual and focus group interviews with primary care practitioners including general practitioners and practice nurses. Data were recorded, transcribed verbatim and analysed using the Framework approach. Ethics approval was granted by the University of Lincoln School of Health and Social Care Ethics Committee.

Results: We interviewed 36 participants (19 service users and 17 practitioners) until data saturation was achieved. Four main themes emerged: the implications of quantifying cancer risk, usefulness of QCancer, communicating cancer risk, and barriers to implementation in primary care consultations.

Participants expressed a range of views about the implications of quantifying cancer risk using QCancer. These included: potential conflict with current cancer risk guidelines and the need to refer patients with symptoms suggestive of cancer whatever their quantified risk.

Participants agreed that QCancer would help to: quantify cancer risk; support clinical decision making; inform efforts to modify health behaviours, improve processes and speed of assessments, diagnosis and treatment; and, enable practitioners to personalise patient care.

To enhance patient-practitioner communication of cancer risk, both service users and primary care practitioners suggested the following: tailoring a visual representation of risk; being honest and open with patients; involving patients in the use of QCancer; and allowing time for listening explaining, informing and reassuring patients.

Potential challenges to the uptake of QCancer were also identified including: the additional time required for its use and communication; unnecessary worry caused by investigation of false positives; potential for over-referral; and practitioner scepticism with the need to establish the effectiveness of QCancer against current practice before introducing it more widely.

Conclusion: Participants perceived the potential usefulness of QCancer but felt that communication needs of users and potential barriers should be considered when planning to implement QCancer. Before rolling out the tool, further research is needed to pilot and evaluate the impact of QCancer on outcomes such as rates of investigations, referrals, diagnoses as well as patient and practitioner experiences of using the tool.

Word count- 457	
Lead investigator	Joseph Akanuwe (PhD Student)
Other investigators	Professor Niro Siriwardena Dr Sharon Black Professor Sara Owen
Nominated presenter	Joseph Akanuwe
Host institution / organisation	Community and Health Research Unit (CaHRU), School of Health and Social Care, University of Lincoln
Research funded by	Self-funded
Expected completion date for results	PhD due for completion in 2016
We will be offering a limited number of bursaries to early career researchers (those studying for a Masters or PhD or who have finished their PhD within the last 4 years). If you are an early career researcher and your abstract is accepted, would you like to be considered for a bursary for the conference? **Yes**	
Contact information (telephone number, email)	Email: jakanuwe@lincoln.ac.uk Tel: 01522835448

Appendix 1.4 Abstract accepted for poster presentation at the Society for Academic Primary Care (SAPC) Regional Conference in Lincoln, 2017

Trent Regional SAPC Spring Meeting

UNIVERSITY OF
LINCOLN

Title of the abstract:	A systematic scoping review of the use of cancer risk assessment tools for early detection of cancer risk in primary care
Author(s):	Akanuwe JNA, Siriwardena AN, Black S, Owen S.
Institution:	Community and Health Research Unit, School of Health and Social Care, University of Lincoln, UK
Contact Details (email)	jakanuwe@lincoln.ac.uk
Please indicate your preferred option: Parallel, Poster or Workshop	Parallel or Poster (No Preference)

Abstract: maximum 350 words

Introduction: Cancer risk assessment tools are designed to predict cancer risk using risk factors and symptoms of individuals. These tools could prompt investigations and referral for specialist attention, leading to early diagnosis and treatment and a potential reduction in the high mortality of cancer in the UK.

While cancer risk assessment tools are thought to accurately predict the risk of specific cancers, this is based on statistical testing of data from databases rather than using the tools on actual patients. More needs to be known about the use and implementation in practice of cancer risk assessment tools to aid primary care detection of cancer. We aimed to scope the evidence relating to the use of cancer risk assessment tools for early detection of cancer in primary care.

Methods: Using the framework proposed by Arksey and O'Malley, we conducted a systematic scoping review of the literature published in the English language from 2004 to 2015 to ensure relevance to current practice. Our search strategy included specific search terms which were used to search six electronic databases: Medline; CINAHL; Scopus; Cochrane; Science Direct and Psych INFO. A narrative synthesis was used to analyse the papers identified.

Results: We retrieved 481 papers from the initial database search. After sifting titles and abstracts, 72 full text papers remained, of which 48 studies were excluded because these did not meet the inclusion criteria. The remaining 24 studies were included in the review. These included randomised controlled trials (2); cohorts (11), survey (2); case control (3); qualitative (3), critical reviews (1) and other unspecific designs (2). This review found limited evidence on novel cancer risk assessment tools being used; perceptions of users and outcomes of using the tools. While there was also some evidence pointing to the usefulness of cancer risk assessment tools, there was limited evidence on how best to communicate cancer risk to patients when using a cancer risk assessment tool.

Conclusion: The evidence available on the use of cancer risk assessment tools in primary care was limited. Further research is needed to explore how best cancer risk can be communicated to patients when using a cancer risk assessment tool in primary care consultations.

Appendix 1.5 Abstract accepted for oral presentation at the Society for Academic Primary Care (SAPC) ASM Conference (12-14 July 2017 at the University of Warwick

Exploring service user and practitioner perspectives of using cancer risk prediction tools in primary care gp consultations

Authors: Joseph Akanuwe, Dr Sharon Black, Prof Sara Owen & Prof Niro Siriwardena

Introduction: The UK has one of the highest cancer mortality rates in Europe. The high mortality may be due to late presentation or detection of symptoms in primary care. Cancer Risk Assessment Tools e.g. RAT and QCancer combine risk factors and symptoms to estimate an individual's risk of developing cancer within two or more years.

The tools are integrated in the GP IT systems e.g SystmOne, EMIS and Vision+, and GPs are encouraged to use them. However, evidence about the use of cancer risk assessment tools is limited. For example, there is limited evidence on how best cancer risk information can be communicated to patients. Knowledge about the facilitators and barriers to implementation of the tools is also not clear. We aimed to explore the views of service users and primary care practitioners about how best to communicate cancer risk information to patients when using cancer risk assessment tools in patient consultations. The facilitators and barriers to implementation of the tools were also explored.

Methods: We used individual and focus group interviews to collect qualitative data from 36 participants (19 service users recruited from the public and 17 practitioners) recruited from Lincolnshire general practices. The data were transcribed verbatim and analysed using the Framework approach.

Results: Participants identified ways to better communicate risk information including tailoring a visual representation of risk; providing time for informing, listening, explaining, and reassuring in a professional manner; being open and honest and involving patients when using cancer risk assessment tools.

The facilitators to implementation identified included: aiding decision making; improving processes, speed of assessment and treatment; identifying and modifying health risk behaviours and personalising care. The barriers to implementation included: additional consultation time, worry or anxiety, practitioner scepticism and the need to establish effectiveness of cancer risk assessment tools as compared to existing practice.

Conclusion: We found ways to better communicate cancer risk information to patients. Facilitators and barriers to implementation of cancer risk assessment tools were also identified. Further research is needed to establish effectiveness of cancer risk assessment tools and the experiences of patients and practitioners on using the tools.

Appendix 2: Recruitment and data collection documents

Appendix 2.1: Service user and practitioner invitation letters

Service user invitation letter - version 2 - 28/08/2014

Room 3208, Bridge House Brayford Campus, University of Lincoln
Lincoln
LN6 7TS

Dear Sir/Madam,

INVITATION TO PARTICIPATE IN A QUALITY IMPROVEMENT STUDY, TO EXPLORE THE USE OF CANCER RISK ASSESSMENT TOOLS

The protocol for the above research project was reviewed and approved by the School of Health and Social Care Ethics Committee at the University of Lincoln. We now wish to invite you to participate in this study which involves interviews with members of the public and practitioners in general practices to explore the feasibility of implementing cancer risk assessment tools for early diagnosis of cancer in primary care.

Please find attached a participant information sheet which highlights details of the research project. If you decided to participate, you will be expected to complete and sign a consent form when you meet with the researcher for a face-to face interview. Participation is entirely voluntary, but we would be grateful if you would respond positively and participate in this quality improvement feasibility study which could be beneficial in terms of early diagnosis of cancer.

Yours faithfully,
Joseph Akanuwe
Principal Investigator

Practitioner invitation letter - version 2 - 28/08/2014

UNIVERSITY OF LINCOLN

Room 3208, Bridge House Brayford Campus, University of Lincoln
Lincoln, LN6 7TS

Through:
The Lincolnshire West Clinical Commissioning Group

Dear Madam/Sir,

INVITATION TO PARTICIPATE IN A QUALITY IMPROVEMENT STUDY, TO EXPLORE THE USE OF CANCER RISK ASSESSMENT TOOLS

The protocol for the above project was reviewed by the University of Lincoln Ethics Committee and given a favourable outcome. We now wish to invite you to participate in this study which will involve interviews with individuals recruited from the public and separately with general practitioners in Lincolnshire general practices to explore the feasibility of implementing cancer risk assessment tools for early diagnosis of cancer in primary care.

Please find attached a participant information sheet which highlights details of the research project. Also attached is a participant consent form which we would like you to complete and sign if you decide to participate in the study. Participation is entirely voluntary, but we would be grateful if you would respond positively and participate in this feasibility study which could be beneficial in terms of early diagnosis of cancer.

Yours faithfully,

Joseph Akanuwe
Principal Investigator

Appendix 2.2: Service user and practitioner information sheets

Service user information sheet - Version 2 - 28/08/2014

EXPLORING THE USE OF NOVEL CANCER RISK ASSESSMENT TOOLS IN PRIMARY CARE CONSULTATIONS

We would like to invite you to take part in a research study involving a face-to-face interview with the researcher. Before you decide whether to participate it is important that you understand why the research is being conducted and what it would involve for you. Please take time to read the following information carefully. You might like to talk to others about it at this stage.

What is the purpose of the study?

Cancer related deaths are high in the UK compared to other European countries. This may partly be due to late identification of cancer symptoms and delayed referral to hospital consultants. Some cancer risk assessment tools have been designed for early detection of cancer risk in primary care. These would have the potential to save lives and improve patients' quality of life. However, little is known about how these tools can be used in patient consultations. We need to answer questions like, how acceptable would patients find their health professional using a tool to detect the risk of cancer? In addition, if a risk of cancer is identified, what would be the best way to communicate the risk information to patients? We need your help to answer these questions.

Why have I been selected?

You have been invited as a member of the public who may have an interest in the delivery cancer services and we feel your participation in the study would be valuable in terms of providing relevant data for the research.

Do I have to take part?

It is up to you to decide whether to take part or not. Please contact the researcher (contact details at the end of the information sheet), if you would like more information and have any questions. If you are interested in taking part, you will be asked to complete and sign a consent form on the day of the interview. Even if you decide to take part, you are still free to withdraw at any time without giving a reason.

What will happen if I take part?

The researcher will contact you with a research pack and you will be asked to contact the researcher if you decide to take part after reading the research pack:

- 24 hours prior to the interview, the researcher will contact you to remind you and confirm your willingness to participate in the study.
- The interview will last for about 30 minutes to 1 hour.
- At the interview, you will be asked to sign a consent form to indicate that you understand what the research is about and how your information will be used and stored.
- With your permission, the interview will be audio-recorded; this will be transcribed and written up without your name so you cannot be identified as having taken part. The original audio recordings will be discarded securely after the audio recorded data has been transcribed.

What will I have to do?

We want to know about your perceptions or views around the communication of cancer risk and diagnosis. As well as answering our questions about the use of assessment tools to detect cancer risk in consultation with your health professional and how any cancer risk might be discussed, you will also be given the opportunity to talk about any other issues which you feel may be important to the research.

Are there any benefits in taking part?

We cannot promise the study will help you personally but the information we collect will help to determine whether it is useful and practical to implement cancer risk assessment tools in general practices in Lincolnshire; this will support early detection of cancer in primary care.

What happens after the study?

We will contact you with the results; the data collected from you will be destroyed securely when the study is fully completed, and the findings have been published or disseminated.

What if there are any problems?

We don't expect there to be any problems, but if there are, we will deal with these promptly. If you have any complaints about the way you have been dealt with during the study, these can be forwarded to:

Dr Zowie Davy
Head of Research Ethics
University of Lincoln
Lincoln
LN6 7TS
Email: zdavy@lincoln.ac.uk Tel: 01522 837748

Will my taking part in the study be kept confidential?

As researchers, we will follow ethical and legal practice to handle information about you in confidence. All data will be anonymous.

Where do I go for more information?

You can keep this information sheet. Talk to others about the study if you wish including the clinical team (doctors and nurses) who look after you. If you wish to take part or have questions or want more information on the study, please contact the researcher whose contact details are stated below.

Joseph Akanuwe
Email: 11357484@students.lincoln.ac.uk
Mobile: 07508864099

Practitioner information sheet - version 2 - 28/08/2014

EXPLORING THE USE OF NOVEL CANCER RISK ASSESSMENT TOOLS IN PRIMARY CARE CONSULTATIONS.

We would like to invite you to take part in a research study involving a face-to-face interview with the researcher. Before you decide whether to participate it is important that you understand why the research is being conducted and what it would involve for you. Please take time to read the following information carefully. You might like to talk to others about it at this stage.

What is the purpose of the study?

Cancer related deaths are high in the UK compared to other European countries. This may partly be due to late identification of cancer symptoms and delayed referral to hospital consultants. Some assessment tools have been designed to help practitioners detect the risk of cancer developing within two years. These would have the potential to save lives and improve patients' quality of life. However, what is not known is how to help health professionals use these tools in their consultation with patients. We need to answer questions like, how acceptable would patients find their Practitioner using a tool to detect the risk of cancer? In addition, if a risk of cancer is identified, what would be the best way to communicate the level of risk to patients of having a diagnosis of cancer? We need your help to answer these questions.

Why have I been selected?

You have been invited because you may have an interest in the delivery of cancer services, your general practice is within the study setting, and we feel your participation in the study would be valuable in terms of providing relevant data for the research.

Do I have to take part?

It is up to you to decide whether to take part or not. Please contact the researcher (contact details at the end of the information sheet), if you would like to take part, or if you have any questions about the research. Even if you decide to take part, you are still free to withdraw at any time without giving a reason.

What will happen if I take part?

The researcher will contact you with a research pack and you will be asked to contact the researcher if you decide to take part after reading the research

- 24 hours prior to the interview, the researcher will contact you to remind you and confirm your willingness to participate in the study.
- The interview will last for about 30 minutes to 1 hour.
- At the interview, you will be asked to sign a consent form to indicate that you understand what the research is about and how your information will be used and stored.
- With your permission, the interview will be audio-recorded; this will be transcribed and written up without your name so you cannot be identified as having taken part. The original audio recordings will be discarded securely after the audio recorded data has been transcribed.

What will I have to do?

We want to know about your perceptions, as a practitioner. As well as answering our questions about the use of assessment tools to detect cancer risk in consultation with your patients and how any cancer risk might be discussed with your patients, you will also be given the opportunity to talk about any other issues which you feel may be important to the research.

Are there any benefits in taking part?

We cannot promise the study will help you personally or your general practice in particular, but the information we collect will help to determine whether it is useful and practical to implement cancer risk assessment tools in general practices in Lincolnshire; this will support early detection of cancer in primary care.

What happens after the study?

We will contact your general practice with the results for forwarding to you; the data collected from you will be destroyed securely when the study is fully completed, and the findings have been published or disseminated.

What if there are any problems?

We don't expect there to be any problems, but if there are, we will deal with these promptly. If you have any complaints about the way you have been dealt with during the study, these can be forwarded to:

Dr Zowie Davy
Head of Research Ethics
University of Lincoln
Lincoln
LN6 7TS
Email: zdavy@lincoln.ac.uk Tel: 01522 837748

Will my taking part in the study be kept confidential?
As researchers, we will follow ethical and legal practice to handle information about you in confidence. All data will be anonymous.

Where do I go for more information?

You can keep this information sheet. Talk to others about the study if you wish including the other members of the clinical team (doctors and nurses) in your general practice. If you wish to take part please contact the researcher whose contact details are stated below, to arrange a date for a face-to-face interview with the researcher.

Joseph Akanuwe
Email: 11357484@students.lincoln.ac.uk
Mobile: 07508864099

Thank you for taking the time to read this information.

Appendix 2.3: Service user and practitioner consent forms

UNIVERSITY OF
LINCOLN

Service user consent form - version 2 - 28/08/2014

EXPLORING THE USE OF CANCER RISK ASSESSMENT TOOLS IN PRIMARY CARE CONSULTATIONS.

Name of Researcher: Joseph Akanuwe

1. I confirm that I have read and understand the information sheet dated 28/08/2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that the data collected during the study, will be anonymised and may be looked at by individuals from the research project team, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
4. I understand that anonymised quotes from the data may be used for written publications and I consent to this. ☐
5. I consent to being audio recorded during the interview ☐
6. I agree to take part in the above study. ☐
7. I would like a summary of the findings of the study to be posted to me. ☐

If you have any concerns about the way the research is being carried out, please contact either of the Co-Chairs of the School of Health and Social Care Ethics Committee, Dr Paul Linsley (plinsley@lincoln.ac.uk) or Dr Zowie Davy (zdavy@lincoln.ac.uk). Their postal address is: Bridge House, Brayford Pool, University of Lincoln, Lincoln LN6 7TS.

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Practitioner consent form - version 2 - 28/08/2014

UNIVERSITY OF LINCOLN

EXPLORING USE OF CANCER RISK ASSESSMENTS TOOLS IN PRIAMRY CARE CONSULTATIONS

Name of Researcher: Joseph Akanuwe

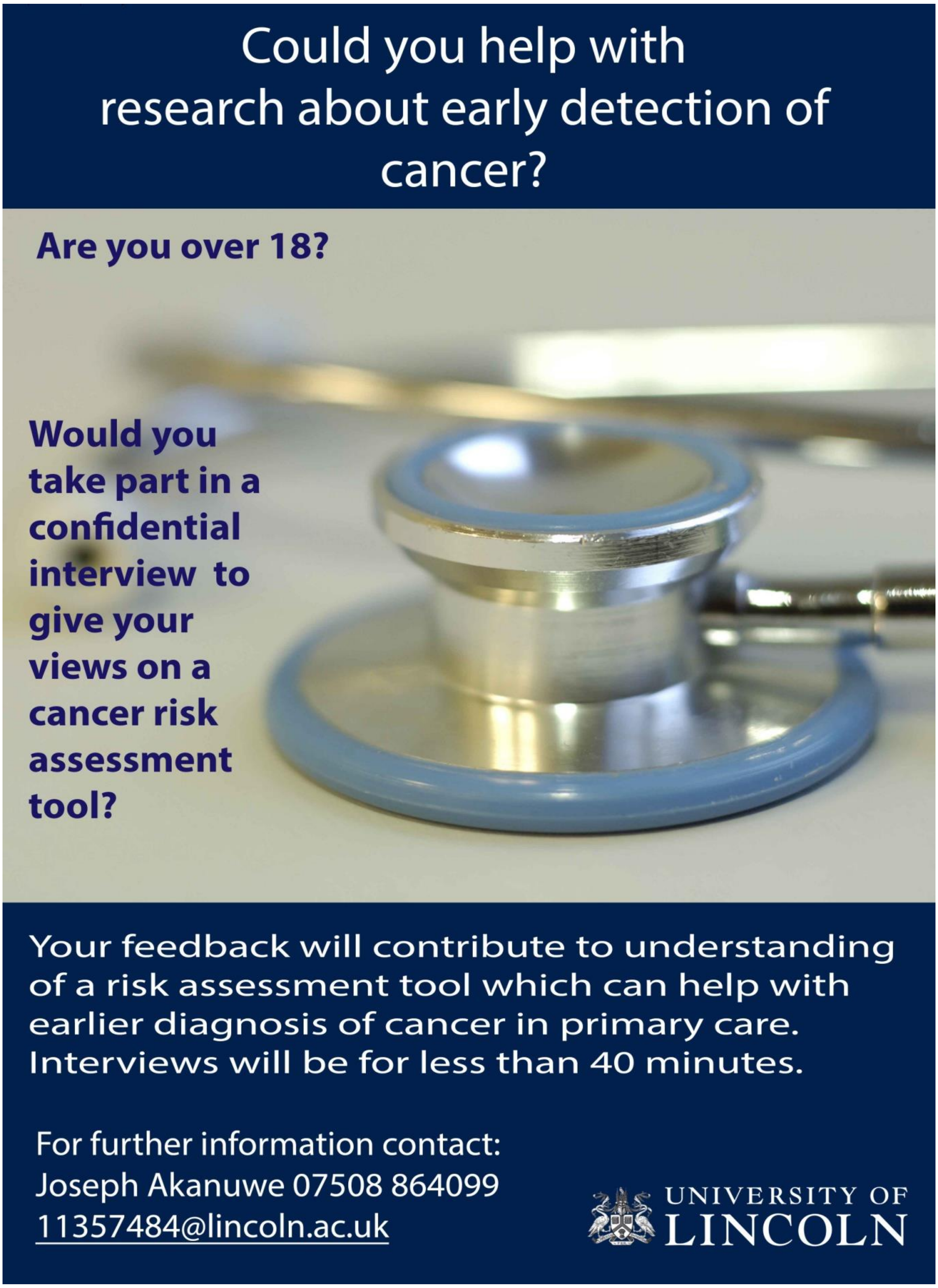
1. I confirm that I have read and understand the information sheet dated 28/08/2014 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that the data collected during the study, will be anonymised and may be looked at by individuals from the research project team, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
4. I understand that anonymised quotes from the data may be used for written publications and I consent to this. ☐
5. I consent to being audio recorded during the interview ☐
6. I agree to take part in the above study. ☐
7. I would like a summary of the findings of the study to be posted to me. ☐

If you have any concerns about the way the research is being carried out, please contact either of the Co-Chairs of the School of Health and Social Care Ethics Committee, Dr Paul Linsley (plinsley@lincoln.ac.uk) or Dr Zowie Davy (zdavy@lincoln.ac.uk). Their postal address is: Bridge House, Brayford Pool, University of Lincoln, Lincoln LN6 7TS.

________________	_________________	___________________
Name of Participant	Date	Signature
________________	_________________	___________________
Name of Researcher	Date	Signature

Appendix 2.4 Flyer for recruitment of service users

Flyer - version 2 - 28/08/2014



Could you help with research about early detection of cancer?

Are you over 18?

Would you take part in a confidential interview to give your views on a cancer risk assessment tool?

Your feedback will contribute to understanding of a risk assessment tool which can help with earlier diagnosis of cancer in primary care. Interviews will be for less than 40 minutes.

For further information contact:
Joseph Akanuwe 07508 864099
11357484@lincoln.ac.uk

UNIVERSITY OF LINCOLN

Appendix 2.5 Interview guides for service users and practitioners

Service user interview guide- version 2 - 28/08/2014

1. Introduce myself.
2. Brief participant about QCancer.
3. Ask politely if participant has ever been affected by cancer directly or indirectly. This will help shape the interviewing process in a way as to prevent distress to participants, especially for individuals recruited from the public.

I will like to begin by asking you a few questions about yourself. Your personal data will not be known to anyone outside the research team and will be stored securely and confidentially.

Demographic data
Age: ....
Gender: ....
Ethnicity: ....
Postcode: ....

I will now like to ask you to share with me what you know about cancer risk

Knowledge of cancer risk

1. Could you tell me what you might think are the possible risks around getting cancer?

Prompt: What things do you know of that are linked to cancer?

I will like us to talk about how the different risks of cancer are communicated between the GP and the patient.

Communication of cancer risk

2. Do you want to know what your risk of cancer might be?

Prompt:

a. Are you aware of any public health messages around cancer?
b. What public health measures are you aware of?
c. Has your GP ever discussed this?
d. What did your GP ever discuss about your risk of cancer?

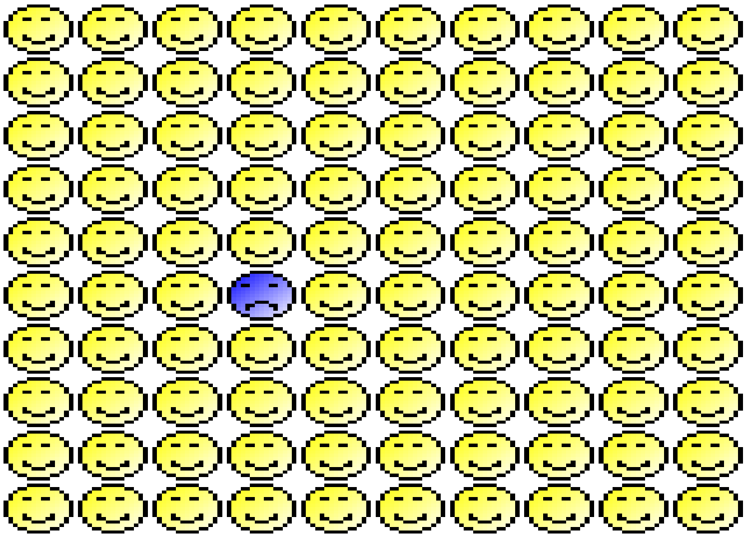
3. Do you think GPs should discuss different risks around cancer with you if you were attending with concern around e.g lung or bowel cancer?

   a. How long should a consultation be?
   b. What information would you need?
   c. Would you want anyone with you?
   d. What else would you like conveyed?

I am now going to show you a cancer risk assessment tool called QCancer. This tool could be used by GPs to assess patients' risk of cancer as in the examples I am about to show you.

<u>Questions around QCancer</u>

Vignette (example) 1: Imagine a 47-year-old man who lives in the Postcode - LN6 7TS. He is an Ex-smoker and a Non-drinker who has symptom of blood on coughing. By entering these details in the QCancer calculator for men, this individual has a 1% risk of having a cancer as yet undiagnosed, and therefore a 99% chance that he is clear. In other words, in a group of 100 people with the same risk factors, 1 is likely to have a cancer as yet undiagnosed and 99 will not. This is shown by the chart below.



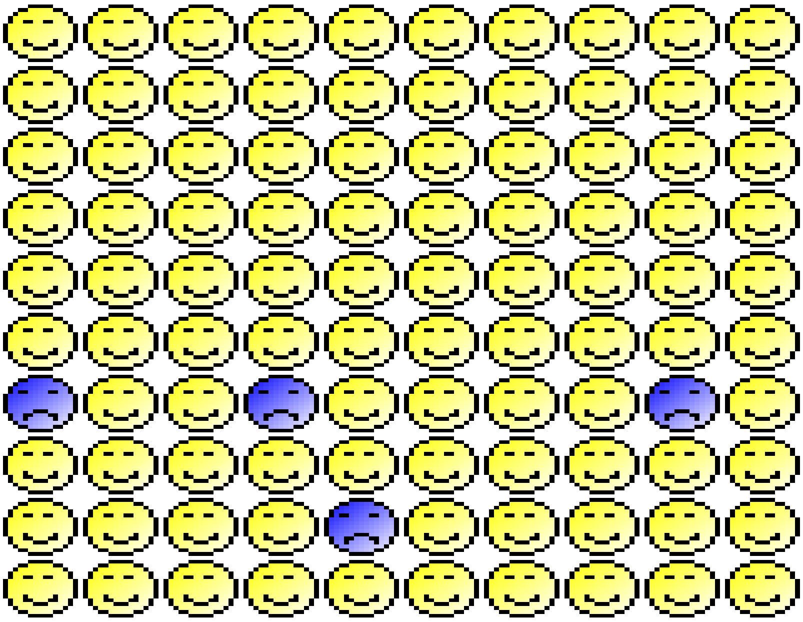
1 man (blue sad face) is at risk of a cancer which has not been diagnosed whilst 99 men (yellow smiley faces) do not have a risk. That is, 1% risk of cancer not yet diagnosed within 2 years

……………………………………………………………………………………………………

Now I will like to ask you a few questions about the QCancer examples I have just shown you.

4. If you were told that you had a 1% estimated risk of cancer:
    a. How would you feel about this level of risk?
    b. What would you want to be told further about this level of risk?
    c. What would your actions be after being told about this level of risk?

Vignette (Example 2): Imagine a 56-year-old male; who lives in the Postcode –LN6 7TS. He is an Ex-smoker and also a Non-drinker but has the symptom of blood on coughing. Again, using the QCancer calculator for men, in this example the older man has a 4% risk of having a cancer as yet undiagnosed, and correspondingly, a 96% chance that he is clear. In other words, in a group of 100 people with the same risk factors, 4 are likely to have a cancer as yet undiagnosed and 96 will not, as shown by the chart below.



4 men (blue sad faces) at risk of a cancer not yet diagnosed, 96 men (yellow smiley faces) not at risk. That is, 4 % Risk of a cancer as yet undiagnosed.

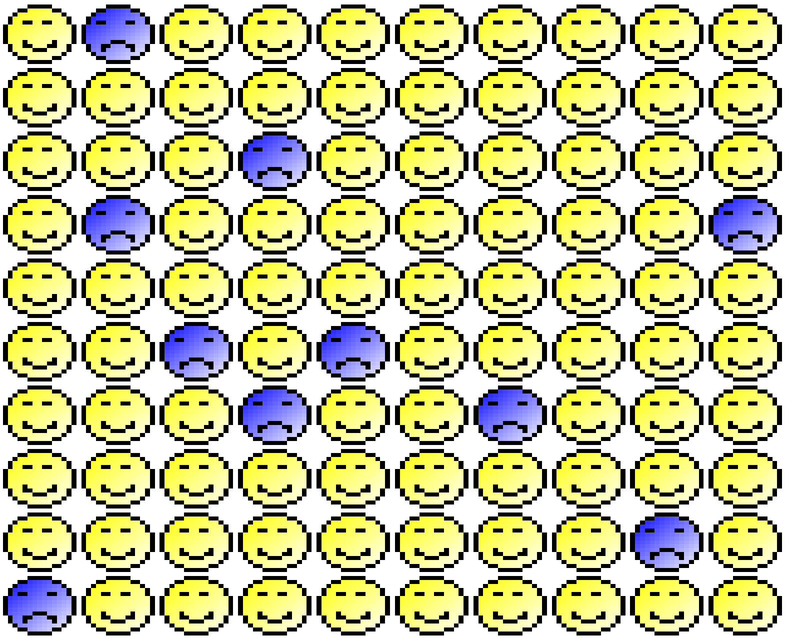
……………………………………………………………………………………………………

Now I will like to ask you a few questions about the QCancer examples I have just shown you.

5. If you were told that you had a 4% estimated risk of cancer:

a. How would you feel about this level of risk?
b. What would you want to be told further about this level of risk?
c. What would your actions be after being told about this level of risk?

Vignette (Example 3: Imagine a 66-year-old man, living in the Postcode- LN6 7TS. He is an Ex-smoker and Non-drinker but with the symptom of blood on coughing. Using QCancer calculator for men, in this example there is a 10% risk of this older man having a cancer as yet undiagnosed, and correspondingly, a 90% chance that he is clear. In other words, in a group of 100 people with the same risk factors, 10 are likely to have a cancer as yet undiagnosed and 90 will not, as shown by the chart below.



10% Risk of a cancer as yet undiagnosed

....

Now I will like to ask you a few questions about the QCancer examples I have just shown you.

6. If you were told that you had a 10% estimated risk of cancer:

a. How would you feel about this level of risk?
b. What would you want to be told further about this level of risk?
c. What would your actions be after being told about this level of risk?

Could we look at some more questions about QCancer please?

7. How useful do you think it might be for you if a GP were to use QCancer as a tool for assessing your risk of cancer?
Prompt: Could you mention more examples of how QCancer might be useful?

8. How do you think the GP should use this tool in the consultation?
Prompts: For example, should the GP inform you they are going to use it?

9. How would you feel about your GP using the tool with you?
Prompts:

a. For example, seeing the results on the computer screen.
b. Or explaining the results to you.

10. What information would you like to be given about risk of cancer?
Prompts: How should that information be given to you (would you prefer written or verbal information or both)?

11. What ethical issues do you feel will arise if the GP uses QCancer without telling the patient?
Prompts: What do you think about patient choice in relation to the use of QCancer?

12. How can the use of QCancer by GPs in consultation help individual patients?
Prompt:

a. Could you tell me some examples of how it might help?
b. How can the use of QCancer help with the modification of risk factors?

Is there anything else you would like to say that I have not asked you already? This is the end of our discussion. Thank you for your time. I will like to assure you that appropriate measures will be taken to ensure that the data collected from you are stored securely and your privacy and confidentiality will not be compromised.

Primary care practitioner interview guide 1- version 2 - 28/08/2014

I will like to begin by asking you a few questions about yourself and your practice. Your personal data will not be disclosed to anyone outside the research team and will be stored securely and confidentially.

Demographic data
Age: ....
Gender: ....
Ethnicity: ....
Postcode: ....
Practice name: ....
Practice location: ....
Practice size: ....

I will now like to ask you to share with me what you know about cancer risk.

Assessment of risk

1. Could you tell me what you think are the possible risks around getting cancer?
Prompt: What things do you know of that are linked to cancer?

2. How do you currently assess your patients for risk of cancer?
Prompt:
a. Have you used any cancer risk assessment tools?
b. If yes what type of CRATs do you use?
c. If no, please explain why?

I am now going to ask you some questions about communicating cancer risk with your patients.

Communication of cancer risk

3. Do you currently discuss cancer risk with patients and families?
Prompt:
a. When cancer risk is discussed.

b. How cancer risk is discussed.
c. What things are discussed?

4. As a GP, how do you feel about discussing the risk of cancer with your patients?
Prompt:
a. How long do you feel a consultation should last?
b. What information would you give your patients?
c. How would you convey this?
e. What support might patients want?
f. Would you want anyone with your patients?

I will like to ask you about how best QCancer may be implemented.

Implementation of QCancer

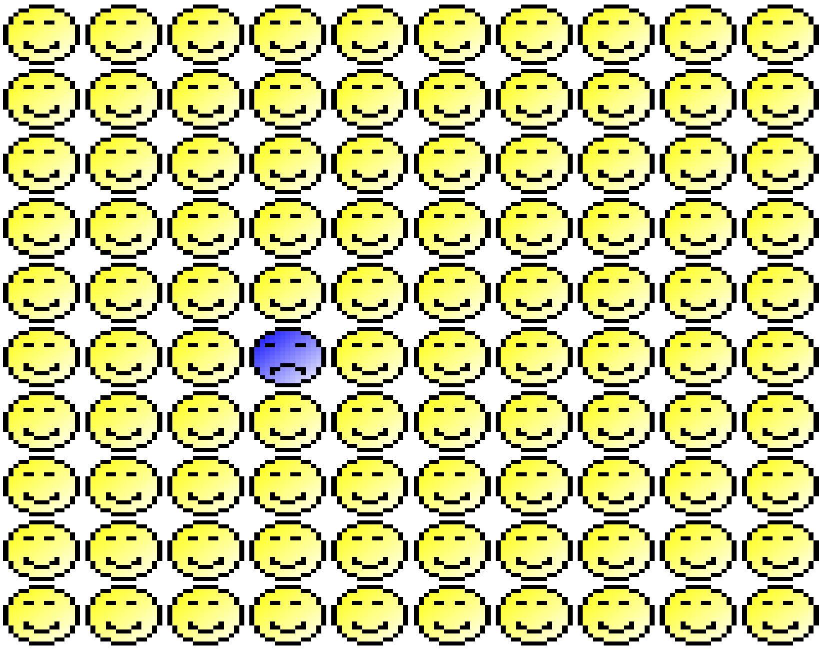
5. How do you feel QCancer might be implemented as a cancer risk assessment tool in your practice?
Prompt on:
a. When should the tool be used?
b. How should it be used?
c. With whom should it be used?
d. What internal and external resources are needed for implementation?
e. What barriers and facilitators may influence implementation?
f. What benefits/disbenefits do you feel such a tool may bring?

I am now going to show you a cancer risk assessment tool called QCancer. This tool will be used by general practitioners to assess patients' risk of cancer as in the examples I am about to show you.

Questions around QCancer

Vignette (example) 1: Imagine a 47-year-old man who lives in the Postcode - LN6 7TS. He is an Ex-smoker and a Non-drinker who has symptom of blood on coughing.

By entering these details in the QCancer calculator for men, this individual has a 1% risk of having a cancer as yet undiagnosed, and therefore a 99% chance that he is clear. In other words, in a group of 100 people with the same risk factors, 1 is likely to have a cancer as yet undiagnosed and 99 will not. This is shown by the chart below.



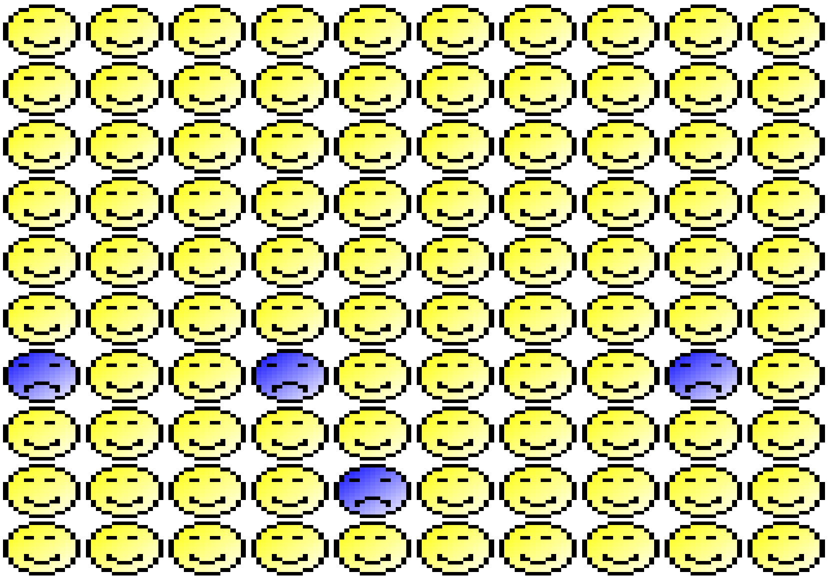
1 man (blue sad face) is at risk of a cancer which has not been diagnosed whilst 99 men (yellow smiley faces) do not have a risk. That is, 1% risk of cancer not yet diagnosed within 2 years

....

Now I will like to ask you a few questions about the QCancer examples I have just shown you.

6. What do you think about a 1%, 2-year cancer risk as estimated by the QCancer tool?
Prompt: What would your actions be?

Vignette (Example 2): Imagine a 56-year-old male; who lives in the Postcode - LN6 7TS. He is an Ex-smoker and also a Non-drinker but has the symptom of blood on coughing. Again, using the QCancer calculator for men, in this example the older man has a 4% risk of having a cancer as yet undiagnosed, and correspondingly, a 96% chance that he is clear. In other words, in a group of 100 people with the same risk factors, 4 are likely to have a cancer as yet undiagnosed and 96 will not, as shown by the chart below.



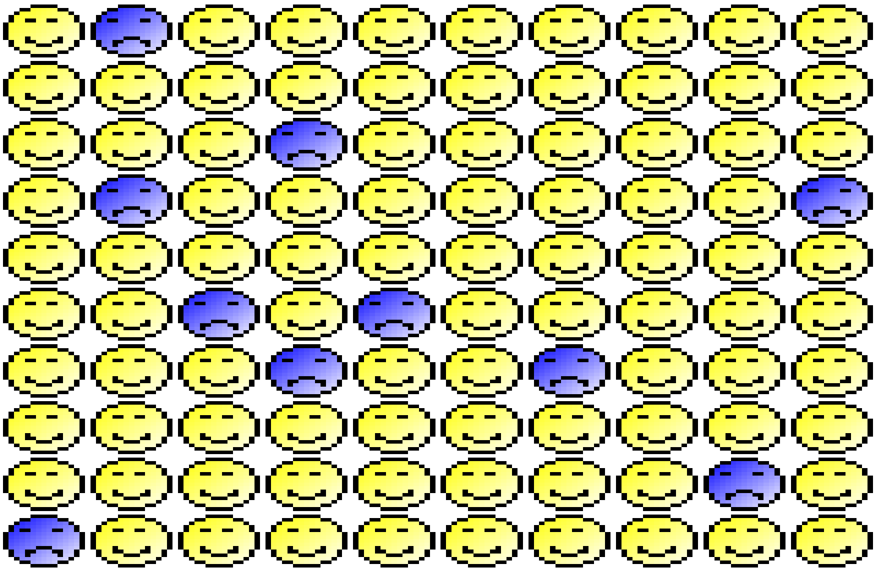
4 men (blue sad faces) at risk of a cancer not yet diagnosed, 96 men (yellow smiley faces) not at risk. That is, 4 % Risk of a cancer as yet undiagnosed.

....

Now I will like to ask you a few questions about the QCancer examples I have just shown you.

7. What do you think about a 4% 2-year cancer risk as estimated by the QCancer tool?
Prompt: What would your actions be?

Vignette (Example 3: Imagine a 66-year-old man, living in the Postcode - LN6 7TS. He is an Ex-smoker and Non-drinker but with the symptom of blood on coughing. Using QCancer calculator for men, in this example there is a 10% risk of this older man having a cancer as yet undiagnosed, and correspondingly, a 90% chance that he is clear. In other words, in a group of 100 people with the same risk factors, 10 are likely to have a cancer as yet undiagnosed and 90 will not, as shown by the chart below.



10% Risk of a cancer yet undiagnosed

....

Now I will like to ask you a few questions about the QCancer examples I have just shown you.

8. What do you think about a 10% 2-year cancer risk as estimated by the QCancer tool?
Prompt: What would your actions be?

<u>Could we look at some more questions about QCancer please?</u>

9. How useful would it be or not be for you as a GP to use QCancer as a tool for assessing your patients' risk of cancer?

10. As a GP, how do you think this tool should be used in your consultation?
Prompts: Should you inform the patient that you are going to use the tool?

11. How best do you feel QCancer as a cancer risk assessment tool should be implemented to help with early diagnosis of cancer?
Prompt on:
a. When should the tool be used?
b. What should it be used for?
c. How should it be used?

d. With whom should it be used?
e. What internal and external resources are needed for implementation?
f. What barriers and facilitators may influence implementation?
g. What benefits will the tool bring?

12. As a GP, how would you feel about using this tool alongside your patient?
Prompts:
a. The patient seeing the results on the computer screen.
b. Helping to convey the results to the patient.

13. What information would you give to your patient about cancer risk, how would you convey this and what other actions may be required?
Prompts:
a. How that information should be given to the patient (written or verbal or both)?
b. How do you think that your use of QCancer in a patient consultation as you've explained it might change depending on the level of risk found?

14. What ethical issues do you think will arise with the use of QCancer?
Prompt: Prompts: What do you think about patient choice in relation to the use of QCancer?

15. How do you think the use QCancer in consultation could help individual patients?
Prompt:
a. Could you tell me some examples?
b. How can the use of QCancer help with the modification of risk factors?

Is there anything else you would like to say that I have not asked you already? This is the end of our discussion. Thank you so much for your time.

As stated in the information sheet, this audio recorded interview will be transcribed and analysed. I will like to assure you that appropriate measures will be taken to ensure that the data collected from you is stored securely and your privacy and confidentiality will not be compromised.

Primary care practitioner interview guide 2 - version:2 - 21/07/2017

Start by Introducing myself to participants/practitioners then tell introduce topic as follows:

You may recall that we met some time ago to discuss your perceptions about implementing cancer risk prediction tools in primary consultations. The themes identified from the information you provided included: ways to best communicate cancer risk information to patients, enablers (facilitators) and barriers to implementation of the tools. I now wish to discuss further your perceptions after using the tools.

Q1. Informed by Fischhoff's framework for risk communication (Fischhoff, 1995)

i. What cancer risk assessment tool/s did you use in patient consultation?
ii. How difficult or easy was it using the tool in patient consultation?
iii. What made it easy or difficult to use the tool in patient consultation?
iv. How did you communicate cancer risk information to patients?
    a. What made it easy or difficult to communicate cancer risk information?
    b. What strategies did you use to help you communicate the risk information effectively?
    c. How did patients respond or react to the way you communicated cancer risk to them?

Prompts on issues relating to the ways identified for communicating risk:

- How did you tailor a visual representation in explaining risk to patients?
- How did you involve patients when you used a cancer risk assessment tools?
- How did you reassure patients when explaining cancer risk to them?

Q2. Informed by constructs from the Consolidated Framework for Implementation Research [CFIR] (Damschroder et al., 2009).

Facilitators/enablers

i. What motivated or encouraged you to use the cancer risk assessment tool/s?

Prompt: ask if the tools were useful in:

- Aiding decision making
- Improving processes, speed of assessment and treatment
- Identifying and modifying health risk behaviours
- Personalising care.

Barriers

i. What challenges did you encounter or experience when using the tool/s?
ii. What strategies do you suggest for addressing the challenges to the implementation of the tool/s?

Prompts on issues relating to challenges/barriers

- How did the tool you used compare or conflict with existing guidelines?
- Was the allocated consultation time adequate to use the tool/s?
- How did patients react to referrals for cancer investigations e.g worry/anxiety?
- Please explain how willing or ready you or other practitioners were in using the tool/s (practitioner scepticism)?

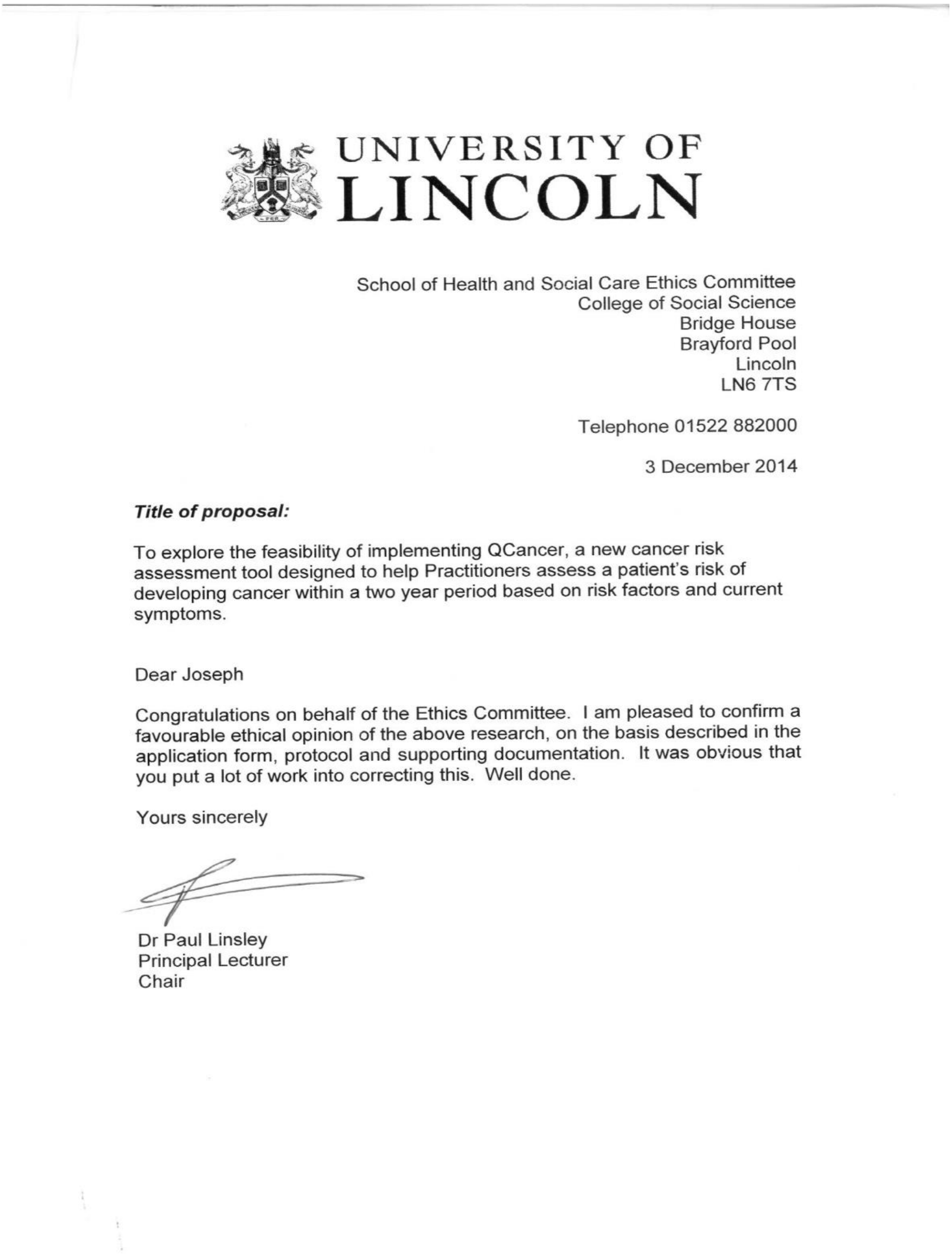
Is there anything you would like to add?

Your views will be kept confidential and the data will be anonymised and used for only the purpose of this research.

Thank you for your time.

Appendix 3 Ethics and governance approval documents

Appendix 3.1 Ethics approval document



UNIVERSITY OF
LINCOLN

School of Health and Social Care Ethics Committee
College of Social Science
Bridge House
Brayford Pool
Lincoln
LN6 7TS

Telephone 01522 882000

3 December 2014

Title of proposal:

To explore the feasibility of implementing QCancer, a new cancer risk assessment tool designed to help Practitioners assess a patient's risk of developing cancer within a two year period based on risk factors and current symptoms.

Dear Joseph

Congratulations on behalf of the Ethics Committee. I am pleased to confirm a favourable ethical opinion of the above research, on the basis described in the application form, protocol and supporting documentation. It was obvious that you put a lot of work into correcting this. Well done.

Yours sincerely

Dr Paul Linsley
Principal Lecturer
Chair

Appendix 3.2 Governance and access document

Lincolnshire Community Health Services NHS
NHS Trust

Our Ref: LCHS Assurance
Your Ref: Research & Innovation Department
Please ask for: Janice Wiseman Lincolnshire Community Health Services
Fen House, Fen Lane, North Hykeham, LN6 8UZ
Telephone: 01522 502023 ext. 233 Calls via Text Relay are welcome
E-mail address: Janice.wiseman@lincs-chs.nhs.uk
Website: www.lincolnshirecommunityhealthservices.nhs.uk
Date: Tuesday 16th December 2014

Mr Joseph Akanuwe Chief Investigator
School of Health and Social Care, Bridge House, Brayford Campus
University of Lincoln
LN6 7TS

Dear Mr Akanuwe

NHS Assurance for Phase 3 – West Lincolnshire Clinical Commissioning Group (CCG)

Study Title: Exploring the Feasibility of Implementing QCancer Use for Early Detection of Cancer in Primary Care

Thank you for submitting your application for the above study. Your application has been reviewed by the Lincolnshire Community Health Services NHS Trust. We provide a research governance function for GP practices in Lincolnshire. We provide assurance that research studies meet nationally agreed research governance criteria to assist GP practices in deciding whether to take part in a research study.

I am pleased to confirm that this application has satisfied the governance criteria for Research sites. This assurance is issued on the basis that the study is conducted in accordance with the following version of the protocol and supporting documents submitted with your application (see below).

Approved documents

Document	Version	Date
Ethics Approval form		
University of Lincoln ethics approval letter		3rd December 2014
Research proposal	2.0	
Interview schedule		
Practitioner invitation letter	2.0	28/08/2014
Practitioner Information Sheet	2.0	28/08/2014
Practitioner Consent Form	2.0	28/08/2014

You are required to notify us of any of the following as these may affect the level of assurance provided:

Any amendments to your study. These must be submitted through IRAS. Unless notified otherwise, and subject to REC approval you may implement amendments 35 days following submission.

- All Serious Adverse Events relevant to the conduct of the research project at GP practices in Lincolnshire.
- Any deviations from the protocol or protocol breaches including any urgent safety measures that are required to be taken to protect research participants against any immediate hazard to their health and safety
- All incidents or complaints in relation to the conduct of the research project at GP practices in Lincolnshire.

Please note this letter does not place any obligations on GP practices, as Independent Contractors, to participate in this study. The agreement by an Independent Contractor to participate in the research study constitutes NHS

Permission for that Independent Contractor; please liaise with Independent Contractors directly to gain agreement.

As part of the Research Governance Framework it is important that the 4 Lincolnshire CCGs are notified of the outcome of the research, therefore we will request a report of your findings. We will also enter your research onto the Lincolnshire CCG research database. We may also request brief updates of your progress from time to time, depending on the duration of the study. Similarly, if at any time details relating to the research project or research team change, please can you let us know. If you have any queries regarding this please contact Janice Wiseman, Research & Innovation Manager, at the above address.

Yours sincerely

Janice Wiseman

Janice Wiseman
Research & Innovation Manager

CC: Lincolnshire Community Health Services NHS Trust Research Team Inbox
Professor Siriwardena, Research Collaborator, University of Lincoln
Dr Karen Windle, Research Collaborator, University of Lincoln
Dr Sarah Amsler, Reader of Educational Research, University of Lincoln

Lincolnshire Community Health Services NHS
NHS Trust

Our Ref: Letter of HR Assurance

Your Ref: Research & Innovation Department
Please ask for: Janice Wiseman, Lincolnshire Community Health Services
Fen House, Fen Lane, North Hykeham, LN6 8UZ
Telephone: 01522 502023 Calls via Text Relay are welcome
Website: www.lincolnshirecommunityhealthservices.nhs.uk

E-mail address: Janice.wiseman@lincs-chs.nhs.uk

Date: Tuesday 16th December 2014

Mr Joseph Akanuwe, Chief Investigator
School of Health and Social Care, Bridge House, Brayford Campus
University of Lincoln, LN6 7TS

Dear Mr Akanuwe

Letter of HR Assurance

Study Title: Exploring the Feasibility of Implementing Cancer Risk Assessment Tools for Early Detection of Cancer in Primary Care

Researcher activity: Carrying out interviews with GPs within the Lincolnshire West CCG in their GP practices.

The information supplied about your role in research in the Lincolnshire West CCG has been reviewed and you do not require an honorary research contract. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You may present this assurance to an independent contractor within West Lincolnshire CCG when negotiating access to conduct research. This assurance is effective from the 16th December 2014 and ends on the 01st February 2016, unless terminated earlier in accordance with the clauses below.

Guidance for Independent Contractors receiving this Letter of HR Assurance

The subject of this assurance is considered to be a legal visitor to your premises. The subject is not entitled to any form of payment or access to other benefits provided by you to employees and this letter does not give rise to any other relationship between the subject and you, in particular that of an employee.

While undertaking research through your premises, the subject will remain accountable to their employer, the Sheffield Teaching Hospitals NHS Trust, but they are required to follow your reasonable instructions or those given on your behalf in relation to the terms of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, the subject is required to co-operate fully with your investigations in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings. The subject must act in accordance with your policies and procedures, which you should make available upon request, and with the Research Governance Framework.

The subject is required to co-operate with you in discharging your duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of themselves and others while on your premises. Although not a contract holder, the subject must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and must act appropriately, responsibly and professionally at all times. If the subject has a physical or mental health condition or disability which may affect their research role and which might require special adjustments to their role, if they have not already done so, they must notify you and their employer prior to commencing their research role with you.

The subject of this assurance is required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times.

They must ensure that they understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore, they should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

As an Independent Contractor, you will not indemnify the subject against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against them and/or their substantive employer.

The subject should ensure that, where they are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. They should also ensure that while on the premises they wear their ID badge at all times, or are able to prove their identity if challenged. As an Independent Contractor, you accept no responsibility for damage to or loss of personal property.

You may terminate the subject's access at any time. We would suggest that this should be either by giving seven days' written notice to the subject or immediately without any notice if they are in breach of any of the terms or conditions described in this letter or if they commit any act that you reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to your interests and/or business or if they are convicted of any criminal offence. The subject must not undertake regulated activity if they are barred from such work. If the subject is barred from working with adults or children, you may immediately terminate their access. Their employer should immediately withdraw them from undertaking this or any other regulated activity and they MUST stop undertaking any regulated activity immediately.

The subject's substantive employer is responsible for their conduct during this research project and may in the circumstances described above instigate disciplinary action against them. If the subjects circumstances change in relation to their health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on their suitability to conduct research, or their role in research changes, they must inform their substantive employer through its normal procedures. They must also inform you.

Yours sincerely

Janice Wiseman

Janice Wiseman
Research & Innovation Manager
CC: Research.Team@lincs-chs.nhs.uk

Chairman: Dr Don White

Appendix 4 Details of codes from the Framework analysis

Appendix 4.1 Data summaries from stage 2-4 of Framework analysis for service users – communicating risk

Participant	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
Service user 1	-Tell them the numbers -Explain what the numbers mean	- Reassurance that it could be something else, not just cancer - Explain other reasons for the risk	2. Reassurance and explanation	"I will like some reassurance and I would like to be told about what other reasons could be causing this level of risk. I'm aware that there are lots of things, so I will want reassurance that it could be something else but not just cancer" (SU1: individual interview)
Service user 2	-Tell them the numbers -Explain what the numbers mean	-take time to inform the patient and explain -allowing them to listen	2. Informing, listening, explaining	"I think it is important to take time to inform the patient by explaining and allowing them to listen. It will be good if they explain the information clearly".
Service user 3	Treat them nicely/with respect	-Being open and honest -Manners and attitude of clinicians -I don't hide anything -I will expect him to give me the information he thought it was, that I needed to know.	3. Being open and honest with patients	"I will like to be told the truth about what this 10% means and whether I've got a chance" (SU3: individual interview). "I would tell you the truth, I don't hide anything, so I will expect him to give me the information he thought it was, that I needed to know." (SU 3: individual interview)
Service user 4	Make them partners	-The word prompt is important because a lot of patients might be embarrassed to tell you something	4. Involving patients when using cancer risk assessment tools	"I think the word prompt is important because a lot of patients might be embarrassed to tell you something but if they are prompted, they can then tell you" (SU4: individual interview).
Service user 5	-Tell them the numbers -Explain what the numbers mean	-Need reassurance about treatment -Explanation about treatment and surviving it -Providing time and listening	2. Providing time for informing, listening, explaining and reassuring in a professional away	"I think with that, if you're looking more likely that you're going to have something then I suppose you would probably want some reassurance, more also about treatment. But whereas before it's coming up which you were worried, I think it's probably now that you need reassurance that is finding it early and treatment, if it can be treated and if they know the risk of having it there's also the possibility of surviving it" (SU5: individual interview).
Service user 6	Make them partners	-Prompting people to communicate their concerns	4. Involving patients	"What I feel is patients should be involved when using the tools, and they should prompt them to discuss their concerns." (SU 6: individual interview)
Service user 7	-Make them partners	-Show and explain how the tool works -Showing the results can be scary but showing can be scarier	4. Involving patients by showing how the tools work	"I'd like them to show me how it works, and I'd like them to explain it to me. Showing the results can be scary but not to be shown the results can be scarier." (SU 7: individual interview).
Service user 8	-Make them partners	-Practitioner engaging with the patient -I think with that I'd be more involved in that consultation -I am more likely to act upon the findings - Seeing from the screen	4. Involving patients by engaging them	"I think because if the practitioner engages with the patient and uses that together with what I'm seeing from the screen together, I think with that I'd be more involved in that consultation, I'm more involved in my own treatment, and therefore I am more likely to act upon the findings of that." (SU 8: individual interview).

Service user 9	-Make them partners	-like to be informed before they use the tool	4.Involving patients by informing them	“Absolutely, yes, I would like to be informed before they use the tool.” (SU 9: individual interview)
Service user 10	-Tell them the numbers -Explain what the numbers mean	-They could just say, this is a tool to help with the assessment for your risk of cancer	2. Informing and explaining in a clear and professional way	“Should use it as part of my consultation with the doctor. But it will be helpful if they could just say, this is a tool to help with the assessment for your risk of cancer.” (SU 10: individual interview
Service user 11	-Tell them the numbers -Explain what the numbers mean	-It is good with visual thing (smiley and sad faces chart)	1.Visual representation	“Yeah very good. It is good with visual thing (smiley and sad faces chart) as compare to others.” (SU 11: individual interview).
Service user 12	-Tell them the numbers -Explain what the numbers mean	-Simplified visual representation of risk e.g. smiley and sad faces -Liking the pictorial representation because it is simple but it's effective -I think it is simple and clear so most people will be able to understand	1.Tailoring a visual representation of risk	“I really like this. I like the pictorial representation; I like the fact that it is simple but it's effective because it draws you really right to the point. You know the happy faces and a mixed of smiley and sad faces can get you an idea. I think it is simple and clear so most people will be able to understand this and take that information on board as opposed to if the doctor just mentions cancer risk it will put you off. But if you look at this and they talk you through this I think that will be really useful” (SU12: individual interview)
	-Tell them the numbers -Explain what the numbers mean	-Listen to patients during consultation -Explain to patient’s understanding	2.Providing time for informing, listening, explaining	“You wouldn't want to feel that you've been rushed, you would want them to take time to talk with you, and if they try to cut this conversation short you would think that they didn't care, and again that could reduce your confidence” (SU12: individual interview
Service user 13		-Want to know why -Want to know as much information as possible	2. providing information and explaining	“Once he says I am at risk of cancer I would want to know why, and I would want to know as much information as he could give me.” (SU 13: individual interview)
Service user 14	Tell them the numbers Explain what the numbers mean	-Avoid speaking in difficult medical terms -Bring it down to the level of the person	2.Informing and explaining in simple terms	“Yes, you wouldn't want them to speak in difficult medical terms; you would want them to bring it down to the level of the person you're speaking to” (SU14: individual interview)
Service user 15	-Tell them the numbers -Explain what the numbers mean	-Discuss the patients' risks with them in a professional way -Help patient understand and feel less worried	2.Taking time to explaining in a professional away	“In my opinion clinicians should discuss the patients' risks with them, but they should take time to do so in a professional and responsible manner in order to help the patient understand and feel less worried about their situation” (SU15: individual interview).
	-Make them partners	-Involve patients -Patients seeing the results on computer screen	4. Involving patients when using cancer risk assessment tools	- “Again, I will like to be involved and I will like to see them using the tool and I like to see the smiley faces on the screen, and I will expect them to then explain to me what the results mean in terms of my risk” (SU15: individual interview).
Service user 16	-Tell them the numbers -Explain what the numbers mean	-Nothing too clinical or too medical. -It should all be basic terminology -Bring it in real terms like this is how treatable it is	2. Explain to patients in a non-technical term	“Nothing too clinical. I won't want anything too medical. You know it should all be basic terminology, they should bring it in real terms like this is how treatable it is, or this is how long it takes.” (SU 16: individual interview

Service user 17	-Treat them nicely/with respect	-If it turns out that you actually at risk -they didn't tell you the right thing	3. Not being honest	"If they decide that you are not at risk and it turns out that you actually at risk, then that is an ethical issue because they didn't tell you the right thing." (SU 17: individual interview)
Service user 18	-Tell them the numbers -Explain what the numbers mean	-Show the patient the graphics -All those yellow smiley faces that will probably make somebody feel at ease. -The blue sad faces could be arranged in rows than scattered	1.Tailoring a visual representation of risk	"Somebody could show the patient the graphics, the yellow smiley faces and blue sad faces. With all those yellow smiley faces that will probably make somebody feel at ease. But if all the blue sad faces could be arranged in rolls so they are concentrated in the same area it will probably make someone more reassured than if they are scattered." (SU 18: individual interview)
Service user 19	-Treat them nicely/with respect	-Be honest and clear and expect the same from the practitioner -Open conversation, open details from both sides	3.Being open and honest with patients	"When I go to the doctor I expect to be honest with him and be clear as best as I can and you would expect the same from the practitioner, open conversation, open details from both sides to avoid misunderstanding" (SU19: individual interview).

Appendix 4.2 Data summaries from stage 2-4 of Framework analysis for practitioners – communicating risk

No	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
1	-Tell them the numbers -Explain what the numbers mean	-Give sufficient time -Provide clear plan -Provide information on how to explain a person’s risk (to both patient and practitioners) -Give both oral and written information about cancer risk to patients	2.Providing time for informing, listening, explaining and reassuring in a professional away	“What I feel is, I would try and give as much time as possible and be as accurate as possible” (P1 [GP]: individual interview).
	-Make them partners -All of the above	- the only time you might do it without informing the patient is when you are uncertain	3. Being open and honest with patients	“I think the only time you might do it without informing the patient is when you are uncertain, you might go back and use it and then call the patient and inform them when you are sure of the risk” (P1 [GP]: Focus Group2).
2	-Tell them the numbers -Explain what the numbers mean	-Convey information based on patient’s understanding -Provide information on how to explain a person’s risk (to both patient and practitioners)	2.Providing time for informing, listening, explaining and reassuring in a professional away	- “I normally give them a chance to ask questions, what they think, what they know about cancer and the kind of support they will need” (P3 [GP]: individual interview). “talking about risk is quite difficult” (P3 [GP]: Focus Group1). - “do the patients actually understand me, what I am trying to tell them?” (P3 [GP]: Focus Group1).
3	-Make them partners -All of the above	-Involve patients (patients to see results on computer screen)	4. Involving patients when using cancer risk assessment tools	“If you don't tell them before using the tool it means you are not being honest. I mean you can't do anything without telling the patient, you need their consent” (P4 [GP]: individual interview).
4	-Tell them the numbers -Explain what the numbers mean	-Simplify presentation of risk -Should be user friendly -Providing a simplified visual representation of risk e.g. smiley and sad faces	1.Tailoring a visual representation of risk	“It’s more a question of more time really, because at the moment we're in crisis, GPs are in crisis, and the future is very bleak for GPs. Because you come in at 5 in the morning and you get back home in the night and it’s a nightmare really. So, we don't want more work” (P6 [GP]: Focus Group1)
	Treat them nicely/with respect	- will be open and honest with patient	3. Being open and honest with patients	“I will be quite open and honest with them that, you've come with these symptoms, some of them are already in, and we can use the tool to work out what it is. If you bear with me I will check your risk and I could put those figures and what is coming out is your risk, and we can try that” (P6 [GP]: Focus Group1).
5	-Tell them the numbers -Explain what the numbers mean	- The graphs and charts to explain their risk	1.Visual representation-graphs/charts	“If they do not understand the graphs and the charts then I will be more than happy to explain it to them and their risk.” (Practitioner 9: individual interview)

Appendix 4.3 Data summaries from stage 2-4 of Framework analysis for practitioners (used the tools)– communicating risk

No	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
1	-Tell them the numbers -Explain what the numbers mean	-Pictorial representation convinced patients - The yellow smiley faces and blue sad faces were easy to understand - The presentation and icon arrays were very user friendly -Showed them the QCancer chart, the yellow smiley and blue sad faces	1.Tailoring a visual representation of risk	"The pictorial representation and multi cancer symptom approach is useful with QCancer" P1 [GP]: Focus Group 3). "I showed them the QCancer chart, the yellow smiley and blue sad faces, and it was easy for them to understand" P1 [GP]: Focus Group3)
	-Treat them nicely/with respect	-Didn't hide anything from patient -Was honest throughout consultation	3.Being open and honest with patients	"I didn't hide anything from the patient, I was honest with them throughout. I think that help to ease their worry" (P1 [GP]: Focus Group3).
	-Tell them the numbers -Explain what the numbers mean	- explained the need to do investigations -They understood and were alright with that	2.Providing time for informing, listening, explaining and reassuring in a professional away	I explained that I needed to do some investigations and possibly to refer them. They understood and were alright with that (P1[GP]: Focus Group3).
	-Make them partners -All the above	-I informed them -Asked for their consent to use the tool. -They agreed -I involved them from the beginning	4.Involving patients when using cancer risk assessment tools	"As I said, I informed them and asked for their consent to use the tool. They agreed and I involved them in the use of the tool from the beginning, when I was about to use the tool" (P1 [GP]: Focus Group3).
2	-Tell them the numbers -Explain what the numbers mean	-Pictorial presentation will convince the patient - The presentation and icon arrays are also very user friendly	1.Tailoring a visual representation of risk	"The Pictorial presentation will convince the patient about their risk as it is yellow smiley faces and blue sad faces are easy to understand. The presentation and icon arrays are also very user friendly" (P2 [GP]: Focus Group 3).
	-Make them partners -All the above	-I also involved them from the beginning -Patient was happy for me to carry on	4.Involving patients when using cancer risk assessment tools	"Yes, I also involved them from the beginning by taking time in explaining what I wanted to do to assess their risk of cancer and the patient I was dealing with was happy for me to carry on" (P2 [GP]: Focus Group3).
Practitioner 3	-Tell them the numbers -Explain what the numbers mean	-took time in explaining -reassured by explaining - it's only a risk and not a cancer diagnosis - They understood and were alright with that	2.Providing time for informing, listening, explaining and reassuring in a professional away	"I reassured the patient by explaining that the risk is only a risk and not a cancer diagnosis. I explained what a 2% risk, meant, which is not a diagnosis of cancer, but a risk. I also explained that, early detection of risk will help with early investigations, diagnosis and early treatment" (P3 [GP]: Focus Group 3).

Appendix 4.4 Data summaries from stage 2-4 of Framework analysis for service users – enablers to implementation

Participant	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
Service user 1	Relative advantage	-Promotes consistent decisions	1.Supporting decision making	-“It will help to make decisions appropriately” (SU1: individual interview).
Service user 2	Relative advantage	-Some examples of what can be used to reduce the risk What to do to identify the risk”	3. Identify and reduce risk	“I guess I would like to be told some examples of what can potentially be used to reduce the risk, what to what to do, how to react and any potential tools that could be used to identify the risk” (SU 2:individual interview)
Service user 3	Relative advantage	-What the risks are and meaning -What to do to reduce the risk	3. Identify the risk and how to reduce them	“What my risks are, what the risks mean, what they will do, what I can do to reduce the risk” (SU 3: individual interview)
Service user 4	Relative advantage	-Earlier detection of cancer symptoms - things can be picked up	2.Improving process and speed of assessment and treatment	- “I think my first worry is that I may have cancer and most of us will like to know early so they can get it sorted. But a lot of things can be picked up, can't they, if they spot check risk if you like” (SU4: individual interview)
Service user 5	Relative advantage	-Information about modifying health behaviours -Identification and modification of cancer risk factors	3. Identifying and modifying health risk behaviours	“I think it might be just raising awareness, so people realise what's happening, and what can go wrong with them and where the risks are and may be, they can reinforce them where someone else like the young person who has given up smoking it might be used to reinforce by saying well you've got a very low risk so if you've given up smoking carry on with that. Rather than saying you've got a very high risk later” (SU5: individual interview)
Service user 6	Relative advantage	-What can be done now -Any medical interventions such as tests and referral for further tests	3.identifying the risk and acting on it	“Well I'd like to be told what can be done now, not in the next 2 years but now. Any medical interventions such as tests and referral for further tests or checks and what will happen after that?” (SU 6: individual interview).
Service user 7	Relative advantage	-structured decision making	1.Supporting decision making	“a structured way of going through risk” (SU7: individual interview)
Service user 8	Relative advantage	-Using their own clinical knowledge and judgment for a decision -Risk assessment tool is to confirm or help them confirm decision	1.Use for confirming decisions	“Well, they are trained professionals, the practitioners, so they will be using their own clinical knowledge and judgment obtained from their training to make a decision, and risk assessment tool is to confirm or help them confirm that.” (SU 8: individual interview)
Service user 9	Relative advantage	-Highlighting individual -It makes you think about the choices that you can make e.g. exercise, correct food, drink, smoke etc	3. Highlighting risk and what to do	“Erh, well, it's highlighting individual risks based on the answers you give, and it can only be seen as benefit, erh as it makes you think about the choices that you can make e.g. exercise, correct food, drink, I don't smoke so that doesn't matter. But I think it's just giving me a snapshot of what could actually happen.” (SU 9: individual interview).
Service user 10	Relative advantage	-Earlier detection of cancer symptoms -Provides structured risk assessment	2.Improving process and speed of assessment and treatment	- “it will help with early diagnosis through early detection of cancer risks” (SU10: individual interview).
		-So, they can change their lifestyles -stop smoking or drinking alcohol	3. Identifying and modifying health risk behaviours	- “to be forewarned is to be forearmed, so they change their lifestyles such as stopping smoking or drinking alcohol” (SU10: individual interview).

Service user 11	Relative advantage	-Show or tell you how the risk could be lowered -what you should do to lower the risk	3. Advice on how patients can lower their risk	“It could be useful if they could show or tell you how the risk could be lowered, what you should do to lower the risk that will be useful.” (SU 11: individual interview).
Service user 12	Relative advantage	-Will help clinicians to know the patient -Promote individualised patient centred care - Care will be more patient-centred	4.Personalising care	“I think it will make the care more patient-centred because you're presenting them with their own risk not a general risk, it's personal to them and it will just make the consultation more patient focused, and I think it will make patients feel more involved in the consultation and just feel more cared for I think” (SU12: individual interview)
Service user 13	Relative advantage	-explain that to the person that they do have a greater risk of cancer - tell them preventive measures	3.Telling patients the risk and prevention measures	“Therefore, you do explain that to the person that they do have a greater risk of cancer. But you tell them the prevention, the prevention; you must give them the prevention, if you can in certain, in cases of cancer, at an early stage.” (SU 13: individual interview).
Service user 14	Relative advantage	-Helps to make decision -Support early detection of cancer risk	1. Support decisions on early detection	“I think it is a good idea. That's useful because it is a preventive medicine; approach isn't it, to help make decisions and support early detection of cancer risk” (SU 14: individual interviews)
Service user 15	Relative advantage	-Advice on how to maintain a healthy lifestyle -How to reduce cancer risk factors	3.Advice on healthy lifestyle	“Again, as with the 1% risk, I would expect to be advised on how to maintain a healthy lifestyle and reduce the factors that contribute to the risk of cancer.” (SU 15: individual interview).
Service user 16	Relative advantage	- A tool they can depend on but use it as a support	1. Use it as a support	“I think it will be a really good idea. I think clinicians are under a lot of pressure and very quick appointments. So, if they've got a tool, they can depend on but use it as a support.” (SU 16: individual interview)
Service user 17	Relative advantage	-It is an assessment and not a diagnostic tool - helpful for assessing and modifying risk over a long period of time	3. modify their risk factors	“I think as it is an assessment and not a diagnostic tool, it will be helpful may be to assess risk over a long period of time, so that people can then modify their risk factors and so instead of QCancer capturing those who will have cancer within 2 years, the tool could be used to assess for the risk for those who develop cancer within a longer period, say 5 years.” (SU 17: individual interview).
Service user 18	Relative advantage	-the tool will help the practitioners to ask the right questions -Adds to clinician's knowledge and skills -Useful if combined with clinical knowledge and skills	1.Supporting decision making	“Yes, it is useful because the tool will help the practitioners to ask the right questions, and I know you have just 5 or 10 minutes with the doctor, and if the use of the risk assessment tools helps with the process then I think they should be used” (SU18: individual interview).
		- can help to identify the individual's risk --Support lifestyle advice and patient motivation to reduce cancer risk -Encourage patients to check risk and seek advice from GP	3. Identifying and modifying health risk behaviours	“It can help to identify the individual's risk, isn't it? Because the input you've given is about your own risk rather than the general population, and if it's done over some years and your risk is increasing they could turn around and say well we need to increase or make more changes in your life style. So, if they were to do it every 5 years and if they see that the risk is increasing then maybe they could start giving me some lifestyle advice” (SU18: individual interview).
Service user 19	Relative advantage	-Promote individualised patient centred care	4.Personalising care	“So, it needs to be about me. I think it’s an excellent idea, the tool. I mean it's dealing with the individual very specifically and there's an opportunity to explain things in more details and delay the inevitable anxiety” (SU19: individual interview).

Appendix 4.5 Data summaries from stage 2-4 of Framework analysis for practitioners – enablers to implementation

No	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
1	Relative advantage	-More accurate and specific information for individual patients -Individualised assessment and care -Reassurance for both low and high cancer risk -Reduced complaints from different patients	4.Personalising patient care	“Patients will go away with a lot more targeted information about their personalised risk of cancer rather than a vague statement” (P1: individual interview).
2	Relative advantage	Promoting understanding and behaviour -Patient education about cancer risk -Support lifestyle advice and patient motivation to reduce cancer risk -Encourage patients to check risk and seek advice from GP	3.Identifying and modifying health risk behaviours	“They don't understand the risks, you know what I mean? I mean like someone who is a smoker, he is smoking, smoking. You can use this tool to help them modify their lifestyle. People who are refusing referral, you can use the tool to estimate their risk to show and explain to them” (P2 [GP]: individual interview
3	Relative advantage	-Will help to improved speed of assessment -Earlier detection and treatment -More rapid investigation and referral -Improved outcomes -Capture of cases missed by two-week wait	2.Improving process and speed of assessment and treatment	“Well as a tool, it's useful, for helping practitioners' ability to spot cancer or the possibility of cancer at an earlier stage than we could do. You know all emphasis is on cancer care, and GPs are sometimes a bit, a bit stuck to know what to pick as symptoms of cancer” (P3 [GP]: Focus Group1).
	Relative advantage	-They could also check and then come to us -You could recheck the cancer risk with the patient to see whether you have the same result	3.Identifying and modifying health risk behaviours	“I am saying they could also check and then come to us, and they could be helping us as well. If what they regard as risk, you know almost the fact that they've come that might suggest they regard whatever number they've got as something we will be able to discuss with them. We go over it and you could recheck. You could recheck the cancer risk with the patient to see whether you have the same result” (P3 [GP]: Focus Group1).
4	Relative advantage	-the tools could aid decision making -Aid at initial consultation -For cancer screening programmes in general practice -Those with suspicion of cancer -For patients with vague or doubtful or borderline symptoms -Empowering patients in decision making -Breaking bad news to patients - Will generate data e.g. for research	1.Supporting decision making	“I think somebody where you thought they have a cancer, probably you wouldn't go on a QCancer, and you would do what you do now. I think with people who are at the borderline, I think for these people you might want to use it” (P4 [GP]: Focus Group2).
5	Relative advantage	-For a differential decision or diagnosis	1.Supporting decision making	- “I think one of the ways I can use this tool is when you have got a differential in your mind, how can you put

				the cancer which may be at the lower end of the spectrum to come on top?” (P5 [GP]: Focus Group1). “GP experience is more important than tools and guidelines” (P5 [GP]: individual interview), “I will recommend that CRATs like QCancer be available to patients to use before coming to their GP.” (P5 [GP]: individual interview)
6	Relative advantage	-Will generate data e.g. for research need more investigations, we need more test	2.Improving process and speed of assessment and treatment	- “With everyone on board because we need more investigations, we need more tests quickly” (P6 [GP]: Focus Group1)

Appendix 4.6 Data summaries from stage 2-4 of Framework analysis for practitioners (used the tools) – enablers to implementation

No	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
1	Relative advantage	-Time saving -Faster consultation, the assessments, investigations and referral processes	2.Improving process and speed of assessment and treatment	"I think when the tools are fully integrated in our IT systems and every practitioner get familiar with using them, it will be time saving in the long term, as the consultation, the assessments, investigations and referral processes will be faster" (P1 [GP]: Focus Group3). "It was easy to assess a patient's risk of cancer by entering their symptoms and risk factors into the QCancer calculator. It was also easy to use the risk generated to explain why they I needed to refer them for investigations and for a more specialised attention in the hospital, where early diagnosis and treatment could be done sooner than later" (P1 [GP]: Focus Group3).
		-QCancer is based on current presentation (Q cancer) and easier to understand -We don't quite understand the RAT yet -The pictorial representation and multi cancer symptom approach is useful with QCancer	4.Ease of use	"QCancer is based on current presentation (Q cancer). But I think, we don't quite understand the RAT yet. The pictorial representation and multi cancer symptom approach is useful with QCancer" (P1 [GP]: Focus Group3).
2	Relative advantage	-The tools will help to guide the clinician to see the broad level of differential diagnosis. - It also facilitates referral of patients -Quantitative risk value to help make decision	1.Supporting decision making	"I think the tools will help to guide the clinician to see the broad level of differential diagnosis. It also facilitates referral of patients by presenting quantitative risk value to help explain risk and make a decision" (P2 [GP]: Focus Group3).
		-The tool helped in using the risks generated to advise patients who need behavioural changes. -Told them to maintain healthier lifestyles by exercising, eating a healthy diet, less alcohol and to stop smoking if they were smoking. -The tools can help to empower patient to take control of their risk factors and live healthier lifestyles	3.Identifying and modifying health risk behaviours	"I also found that using the tool helped in using the risks generated to advise patients who need behavioural changes. Their risk was small, and I told them to maintain healthier lifestyles by exercising, eating a healthy diet, less alcohol and to stop smoking if they were smoking. Yes, as I said, these tools can help to empower patient to take control of their risk factors and live healthier lifestyles" (P2 [GP]: Focus Group3).
3	Relative advantage	-Potential for using the tools for screening in other health categories e.g asymptomatic individuals -Modify or redesigned the tools to suit other conditions in primary care -They could also be modified for asymptomatic patients	3.Identifying and modifying health risk behaviours	"I think there is a potential for using the tools for screening in other health categories. The tools could be modified or redesigned to suit other conditions in primary care. They could also be modified for asymptomatic patients, for example the QCancer 10 years' risk tool, I understand can be used to predict of cancer in asymptomatic individuals" (P3 [GP]: Focus Group3).

Appendix 4.7 Data summaries from stage 2 - 4 of Framework analysis for service users – Barriers to implementation

Participant	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
Service user 1	Compatibility/complexity	-Everybody should use the same sort of guidelines	4.Conflict with existing guidelines	"I think it is good for everybody to have the same sort of guidelines, so to use risk assessment tools everybody should use the same sort of guidelines" (SU1: individual Interview).
Service user 2	Complexity	-It doesn't matter whether it's 1% or 2% -Something is actually not right something should be done	5.Need for referral whatever the risk level	"It doesn't matter whether it's 1% or 2% but so you have peace of mind and something is actually not right something should be done it and it should be assessed." (SU 2: individual interview).
Service user 3	Patient needs & resources	-If not explained well, worried be about having cancer	2.Worry about cancer	"If the level is high and they don't explain well I would be worried that I already have cancer." (SU 3: individual interview)
Service user 4		-People worry when they go for consultations -People have questions to ask	2. People worry at GP consultation	"I think an awful lot of patients go into a consultation, whatever it is, whether it's hospital or GP surgery and there are several questions they want to ask and then they forget or because they are just anxious." (SU 4: individual interview).
Service user 5		-Worry when cancer is mentioned -Cancer as bad news	2.Worry about cancer	"Yeah, when they start talking about cancer then I would worry straight away." (SU 5: individual interview).
Service user 6	Patient needs & resources	-Worry due to investigations -Emotionally I would be quite distraught and worried	2.Worry due to investigations	"I think they may be, have to assess their patients first to see if they were going to promote great anxiety on the patients by using some of these tools. I think emotionally I would be quite distraught and worried, and this is where having another person in there is important, I think. But I think until you've got some sort of appointment and then further tests and so forth, you will be in a state of limbo, I think, you know, not being able to concentrate properly" (SU6: individual interview)
Service user 7	Patient needs & resources	-More time to discuss risk of cancer) -There may be cost e.g time initially with implementation	1.Additional consultation time required	"more time to use the tool in consultations" (SU7: individual interview)
Service user 8	Patient needs & resources	-Worry the risk could be cancer -Some kind of clarification will be good	2. Worry the risk could be cancer	"Again, would worry about that the risk could be cancer, so I think just some kind of clarification about the likelihood of it developing further will be good" (SU 8: individual interviews).
Service user 9	Complexity	to see whether it is cancer	5.Symptoms suggestive of cancer need referral whatever the quantified risk	"to see whether it is cancer or something else" (SU9: individual interview)
Service user 10	Patient needs & resources	-I would be quite frightened	2. Worry about a high-risk level	"I would be quite frightened, I think. At 66 years old and if I was coughing out blood, I don't quite know because I've

		-10% is quite high and I will be worried.		no medical background, but it doesn't sound very good to me. It's quite high, 10%, isn't it? I think it's quite high and I will be worried." (SU 10: individual interview).
Service user 11	Patient needs & resources	–Anxiety due to referral -Misinformation of a person's risk -They can be too worried especially if they don't explain that it is just a risk	2.Worry/anxiety relating to cancer referral & investigations	"Some people may not understand and they can be too worried especially if they don't explain that it is just a risk but it is not guaranteed that they will get cancer, then it is not good enough ethically" (SU11: individual interview).
Service user 12	Reflecting & monitoring	-Need for further investigation of symptoms and risk of cancer	7.Need to establish effective of CRATs	"But I think if you are going to roll something out rather than going to everybody I would start with the doctors, see how the doctors do with it after evaluation and then move on to the practice nurses" (SU12: individual interview).
Service user 13	Complexity	-It doesn't really matter about percentages - the fact is the symptom is there which is quite worrying	5.Symptoms suggestive of cancer need referral whatever the quantified risk	"It doesn't really matter about percentages; I know 1% is less risk. But the fact is the symptom is there, the coughing out of blood, which is quite worrying" (SU13: individual interview).
Service user 14	Patient needs & resources	-It's getting serious at 10% risk -I would not happy at this level of risk	2.Worry about a high-risk level	"Well it's getting serious isn't it, so I would not be very happy at this level of risk, 10%." (SU 14: individual interview)
Service user 15	Patient needs & resources	-Problem is the GPs tend to spend just about 10 minutes -10 minutes may not be enough for detailed discussion with the patient	1.Current consultation time too small	"But the problem is the GPs tend to spend just about 10 minutes which may not be enough for a more detail discussion with the patient, which is unfortunate." (SU 15: individual interview)
Service user 16	Patient needs & resources	-When you hear of cancer, you think of death -All sort of thoughts come to your mind and you worry."	2.Worried about cancer	"I think when you hear of cancer, you hear a lot of noises in your heard. You think you are going to die, and all sort of thoughts come to your mind and you worry." (SU 16: individual interview).
Service user 17	Patient needs & resources	-Potential for over referral -Potential burdening of resources	3.Over-referral & over burdening of services	"It could be useful if the right patients are referred but it could also lead to over referral as some people may have a certain risk but will not have cancer after they have been referred and tested" (SU17: individual interview)
Service user 18	Patient needs & resources	-10 minutes per consultation is short	1.Current consultation time too short	"I think one of the problems with these consultations is the 10 minutes which seems quite short." (SU 18: individual interview).
Service user 19		-There's still going to be anxiety -The more information will help in dealing with that anxiety.	2. Anxiety related to cancer	"It's always gona be there, even if it's understood there's still going to be anxiety there, and the more there is information at the earlier stage the better the chance you've got in dealing with that anxiety." (SU 19: individual interview).

Appendix 4.8 Data summaries from stage 2-4 of Framework analysis for practitioners – Barriers to implementation

No	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
1	Patient needs & resources	-Time and workload pressure -I think we should have 15 minutes' appointments. -That will give us a little bit extra time, which is assuming the patient has only one problem -All that information in, it will be difficult	1.Additional consultation time required	- "the uncertainty and putting all the data manually" (P1 (GP): Focus Group2) - "It should be integrated in our system, SystmOne, rather than every time we have to go on Google to get it. Like you put all that information in, it will be difficult, it should be completely automatic, and think of the investigations, people are more likely to use it" (P1 [GP]: Focus Group2) - "Well I believe if, in the ideal world, you may be aware of that, if there is a push to implement that; I think we should have 15 minutes' appointments. That will give us a little bit extra time, which is assuming the patient has only one problem, but they have multiple problems in one appointment, I think it will be done well if something like cancer risk assessment, communication, organising of the test that follow, 15 minutes will be ideal" (P1 [GP]: individual interview).
	Reflecting & monitoring	-Getting it in real life and then reporting back	7.Need to establish effective of CRATs	"One of the things I think will be really useful is, it's been devised but getting it in real life and then reporting back on that, it will be really useful to know how good a tool it is (P1 [GP]: individual interview)
	Knowledge & beliefs of individuals involved	-They need to tell us. So, for cancers, unless we have those things it will probably be difficult to use the tool	6.Practitioner scepticism about using CRATs	"I think for it to be useful there needs to be some benchmarks for us to really relate with. If you say 7% or 6%, should I worry? I think they need to tell us. So, for cancers, unless we have those things it will probably be difficult to use the tool" (P1 [GP]: Focus Group2).
2	Patient needs & resources	-Which is creating unnecessary anxiety	2.Worry/anxiety relating to cancer referral & investigations	"The thing is if you tell the patient they've got 1% cancer, which is creating unnecessary anxiety" (P2 [GP]: individual interview).
	Reflecting & monitoring	-Need to compare with current practice before and after implementing CRATs	7.Need to establish effective of CRATs	"review, we have to make sure that it is better than what we are already doing" (P2 [GP]: Focus Group2)
3	Patient needs & resources	-Need for sufficient secondary care capacity for rapid assessment	3.Over-referral & over burdening of services	"I think we should not be worried about resources. Now many more people are dying from cancer, so they want more referral and diagnosis earlier. I am not sure using the tool is cheaper but I will say it is good for patient safety because people will be diagnosed earlier if referred earlier and they will be helped earlier" (P3 [GP]: individual interview).

	Knowledge & beliefs of individuals involved	-Initially I was very sceptical about this tool	6.Practitioner scepticism about using CRATs	“Until you said this thing, you know initially I was very sceptical about this tool” (P3 [GP]: individual interview)
4	Patient needs & resources	-Potential for over referral and burden or strain on NHS resources	3.Over-referral & over burdening of services	“But on the other side it will put a strain on the NHS; you know what I mean, on the services there. You know, you don't want to over burden the services as well” (P4 [GP]: individual interview).
5	Patient needs & resources	-Generating unnecessary patient anxiety	2.Worry/anxiety relating to cancer referral & investigations	“You can probably make them more worried” (P5 [Practice Nurse]: Focus Group2).
	Complexity	-Some symptoms need referral whatever the risk percentage -High risk prompts further investigation	5.Symptoms suggestive of cancer need referral whatever the quantified risk	“as I said, if I suspect cancer and I put in the tool 1%, 2% doesn't matter to me” (P5 [GP]: individual interview).
	Knowledge & beliefs of individuals involved	-Some practitioners may be sceptical	6.Practitioner scepticism about using CRATs	“GP experience is more important than tools and guidelines” (P5 [GP]: Focus Group1).
6	Compatibility/complexity	-Current risk assessment is based on practitioners’ knowledge of patients' symptoms, cancer risk factors and NICE guideline Referral also depends on important single risk factors e.g. age	4.Conflict with existing guidelines	“I will be quite confused about using the tool. I mean you know with the NICE guidelines; you couldn't focus on another criterion for any other risk here” (P6 [GP]: Focus Group1).
	Complexity	-Varying perception of risk from 1-10%, e.g. 4%-10% risk of cancer is high and needs referral with investigations for low risk e.g 1%	5.Symptoms suggestive of cancer need referral whatever the quantified risk	“Since they've got symptoms, it is urgent x-ray straight away. I always send my patients for x-ray and say not to worry about the symptom, because I am going to investigate. Because even if he came with 1%, that's the thing. Regardless of what QCancer said I will refer them for investigation with the symptoms. So, it doesn't matter 1% or 0%, I will always do one thing, investigation if the symptoms are suggestive of cancer” (P6 [GP]: Focus Group1).
7	Patient needs & resources	-Increase the length of consultation -Depending on how the consultation starts and runs	1.More consultation time	“Well I think it might increase the length of consultation. Yeah, it depends on the consultation, how it runs and how it starts.” (Practitioner 8: individual interview)

Appendix 4.9 Data summaries from stage 2-4 of Framework analysis for practitioners (used the tools) – Barriers to implementation

Participants	Theory/deductive themes	Subthemes/codes	Key themes	Quotes
Practitioner 1	Knowledge & beliefs of individuals involved	-The tools are useful -For clinical decision making	1.Willingness to use the tools	"Yes, I will use the tools. I think the tools are useful in helping with clinical decision making as we already discussed" (P1 [GP]: Focus Group3).
	Patient/practitioner needs & resources	-The tools are not known to the secondary or hospital setup. -They may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals	4.Need to involve in-hospital specialists in use of the tools	"My concern is that the tools are not known to the secondary or hospital setup. So, I referred some patients, and I am concerned they may not recognise my QCancer referral as they are only used to NICE referral guidelines, that is the two-week waiting or urgent referrals. So, when I am thinking, if they see the patients I referred using QCancer, they will ask - who is this? Is this a new doctor, a new GP?" (P1 [GP]: Focus Group3)
	Reflecting & monitoring	-We will to use these tools for a while and then evaluate. -Need to see effectiveness of the tools they are against existing practice. -Need to assess the impact of using these tools on investigations, referral, diagnosis etc	5.Need to establish effectiveness of CRATs	"The only thing is, as I have said before, we will need to use these tools for a while and then evaluate to see how effective they are against existing practice. I mean we have to assess the impact of using these tools on investigations, referral, diagnosis etc" (P1 [GP]: Focus Group3)
Practitioner 2	Patient/practitioner needs & resources	-Have no problem using the tools -believed it will be good to use the tools	1.Willingness to use the tools	"I have no problem using the tools, and I believe it will be good to use cancer risk assessment tools to facilitate early diagnosis of cancer, and as you know, early diagnosis will help with early treatment" (P2 [GP]: Focus Group3).
		-Problem of accessing the tools as they are not integrated in our IT system. - It was not easy downloading or googling the tools during patient consultation.	2.Need to integrate the tools into general practice system	"There was a problem of accessing the tools as they are not integrated in our IT system. It was not easy downloading or googling the tools during patient consultation, but that was the only option as I wanted to use the QCancer tool to check whether the patient was at risk of cancer, as the symptoms were a bit unclear" (P2 [GP]: Focus Group3).
		-Problem is the RAT is not clear. -The RAT is more complicated to use than the QCancer. -We don't quite understand how to use that tool. We need to have proper education or training on using these tools.	3.Need for training on using the tool in consultation	"One problem is that the RAT is not very clear. The RAT is looking more complicated to use than the QCancer. We don't quite understand how to use that tool. I think we need to have proper education or training on using these tools. The other day I met a lady from the Macmillan Cancer I support, and I asked them to see if they could come and give us a training session or talk on how to use the cancer risk assessment tools in patient consultations. I think we need to follow that up because the tools look good to use" (P2 [GP]: Focus Group3).

Practitioner 3	Patient/practitioner needs & resources	-Happy to use the tools -Will use the QCancer which is easier to use	1.Willingness to use the tools	“Me too, I am happy to use the tools especially the QCancer, which is easier to use” (P3 [GP]: Focus Group3).
		-The tools are not linked with the current NHS system	2.Need to integrate the tools into general practice system	“The tools are not linked with the current NHS system, so you can’t really use them in patient consultation, unless you google and then use, all that, while the patient is waiting” (P3 [GP]: Focus Group3).