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Is variation in patients' experiences of cancer care associated with their subsequent survival

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Is variation in patients' experiences of cancer care associated with their subsequent survival

Thesis presented in accordance with the requirements for the degree of

Doctor of Philosophy

By

Saleh Alessy

At the Department of Cancer Epidemiology, Population and Global Health,

School of Cancer and Pharmaceutical Sciences, Faculty of Life Sciences &

Medicine, King's College London

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1. **Alessy, S. A**., Lüchtenborg, M., & Davies, E. (2019). How have Patients' Experiences of Cancer Care Been Linked to Survival? A Systematic Review. Patient Experience Journal, 6(1), 63-80.
2. **Alessy, S. A**., Davies, E. A., Rawlinson, J., Baker, M., & Lüchtenborg, M. (2019). How representative are colorectal, lung, breast and prostate cancer patients responding to the National Cancer Patient Experience Survey (CPES) of the cancer registry population in England? A population-based case control study. *BMJ open*, *9*(12).
3. **Alessy, S. A**., Lüchtenborg, M, Rawlinson, J., Baker, M., & Davies, E. A. Being assigned a Clinical Nurse Specialist is associated with better experiences of cancer care: English population-based study using the linked National Cancer Patient Experience Survey and Cancer Registration Dataset (**under review)** in The European Journal of Cancer Care
4. **Alessy, S. A**.,, Rawlinson, J., Baker, M., & Davies, E. A. Factors influencing cancer patients' experiences of care in USA, United Kingdom, and Canada: A systematic review and development of a conceptual framework (**in progress**)
5. **Alessy, S. A**., Davies, E. A., Rawlinson, J., Baker, M., & Lüchtenborg, M. Variation in cancer patients' survival in relation with their reported care experiences with Clinical Nurse Specialist: Population-based cohort study from the national linked English Cancer Patient Experience Survey and Cancer Registration Data (**in progress**)
6. **Alessy, S. A**., Asery A. T., Al-zahrani A., & Davies, E. A. Developing a roadmap for cancer patient experience initiatives in Saudi Arabia: lessons from healthcare settings in the United States and England, UK (**In press),** European Journal for Person Centered Healthcare, 2020, Vol 8 Issue 4
7. **Alessy, S. A**., & AlWaheidi, S. (2020). Moving cancer prevention and care forward in Saudi Arabia. *Journal of Cancer Policy*, *26*, 100250.
8. **Alessy, S. A.,** Davies EA, Jazieh AR. Cancer care during the COVID-19 pandemic: a perspective from Saudi Arabia. Ecancermedicalscience. 2020 Jul 17;14:1076. doi: 10.3332/ecancer.2020.1076. PMID: 32863870; PMCID: PMC7434509.

List of conference posters and presentations

1. How Have Patients' Experiences of Cancer Care Been Linked to Survival: A Systematic Review; (**poster presentation**), PHE Cancer Services, Data and Outcomes Conference 2018, Manchester
2. The representativeness of patients responding to the CPES of the wider cancer population in England: Initial analysis from CPES-NCRAS dataset; **(oral presentation),** in the Cancer Epidemiology and Population Health monthly seminar, King's College London, September 2018
3. How representative are patients responding to the CPES of the wider cancer population in England? Analyses for breast, prostate, lung and colorectal cancer; **(oral presentation),** PHE Public Health Research and Science Conference, April 2019, Manchester
4. Comparison of the linked cancer registry and cancer patient experience survey datasets in England and the United States (US); (**poster presentation**), published in the BMJ Quality Conference Proceedings of 9TH Annual Patient Safety Forum, April 2019, Jeddah, Saudi Arabia
5. How representative are patients responding to the CPES of the wider cancer population in England? Analyses for breast, prostate, lung and colorectal cancer; **(oral presentation),** The 2019 NCRI Conference, November 2019, Glasgow, UK
6. Cancer and COVID Experience from Saudi Arabia (**oral presentation**), Comprehensive Cancer Centre: Programme Seminar, May 2020, London
7. The importance of being given the name of a Clinical Nurse Specialist for experiences of cancer care: Population-based study using linked CPES-NCRAS Dataset, accepted in (World Cancer Congress, Oman,2020). <u>cancelled because of COVID-19</u>
8. The importance of being given the name of a Clinical Nurse Specialist for experiences of cancer care: Population-based study using linked CPES-NCRAS Dataset; (**E-poster**) The 2020 NCRI Virtual Showcase conference, November 2020
9. The importance of being given the name of a Clinical Nurse Specialist for experiences of cancer care: Population-based study using linked CPES-NCRAS Dataset; (**oral presentation)** in the Cancer Epidemiology and population Health seminar, King's College London, January 2020
10. Cancer patients' experiences and their survival: analyses from CPES-NCRAS dataset; (**oral presentation)** in the monthly meeting of NCRAS analyst, Public Health England, January 2021
11. Alessy, S. A., Alhajji, M., Rawlinson, J., Baker, M., & Davies, E. A. Factors influencing cancer patients' experiences of care in USA, United Kingdom, and Canada: A systematic review (**accepted**) in NCRI Festival: Making cancer research better together, November 2021.

List of abbreviations

AOPSS	Ambulatory Oncology Patient Satisfaction Survey
ASMR	Age-standardised mortality rate
CAHPS	The Consumer Assessment of Healthcare Providers and Systems
SEER-CAHPS	Data linkage between CAHPS and Surveillance, Epidemiology, and End Results datasets
CAS	Cancer Analysis System
CI	Confidence interval
CNS	Clinical Nurse Specialist
COSD	Cancer Outcomes and Services Dataset
COVID-19	Coronavirus 2019
CPES	National Cancer Patient Experience Survey
CPES-NCRAS	National Cancer Registration and Analysis Service
DCO	Death Certificate Only
DID	Diagnostic Imaging Dataset
ER	Emergency Presentation
GP	General practitioner
HES	Hospital Episode Statistics
HR	Hazard ratio
ICD-10	International Statistical Classification of Diseases and Related Health Problems 10th Revision
IMD	The Index of Multiple Deprivation
LSOA	Lower Layer Super Output Areas
LCNS	Lung Cancer Nurse Specialist
NCRAS	National Cancer Registration and Analysis Service
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NLCA	The National Lung Cancer Audit
NDRS	National Disease Registration Service
ONS	Office of National Statistics
OR	Odds Ratio
PROM	Patient Reported Outcomes Measures
RTDS	The Radiotherapy Data Set
SACT	The Systemic Anti-Cancer Therapy dataset
SEER	Surveillance, Epidemiology, and End Results (USA cancer registry)
SQL	Structured Query Language
TNM	Tumour Node Metastasis classification
UK	United Kingdom
USA	United States of America

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I could not have completed my PhD were it not for the very important people in my life. I owe an immense debt of gratitude to my mother who has an exceedingly warm and kind heart, and to my father who taught me the rewards of hard work. I am deeply indebted to my recent born baby, Taim, and my infinitely patient wife, my unflagging companions in this journey, and to my brothers and sisters. I thank all of them for encouraging me, supporting me, and believing in me. I could not have completed this endeavour without them.

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Abstract

Background

Colorectal, lung, breast, and prostate cancers are the most common cancers in England. Cancer prognosis and cancer survival are widely used performance measures of cancer care. Patient experience is a key aspect of healthcare quality and widely considered as the third pillar of healthcare quality alongside patient safety and clinical effectiveness. Improving cancer patients' experiences and their subsequent survival were emphasised in the recent cancer care strategies in England. Previous research has identified sociodemographic variation in cancer patients' experiences in England. An important but as yet unanswered question is whether the variation seen in cancer patients' experiences is also associated with their subsequent survival.

Aims:

This PhD thesis consists of five projects:

Project 1: A systematic review to examine how patients' experiences have been linked to survival.

Project 2: A population-based case control study to assess the representativeness of Cancer Patient Experience Survey (CPES) responders.

Project 3: A cross sectional study to assess how Clinical Nurse Specialists (CNS) influence patients' experiences with cancer care.

Project 4: A systematic review to assess what factors influence cancer patients' experiences.

Project 5: A population-based cohort study to assess the association between patients' experiences with CNS care and their subsequent survival.

Methods:

I used a mixture of different analyses to carry out the five projects in this thesis. Two systematic reviews were carried out for projects 1 and 5. The rest of the thesis analyses focused on colorectal, lung, breast and prostate cancer patients responding

to CPES during 2010–2014 using the linked NCRAS-CPES at Public Health England. I assessed the representativeness of CPES using a population-based case-control design and assessed the role of CNS in cancer care using a population-based cross-sectional study. In the final project, I conducted a population-based cohort study to assess the association between cancer patients' experiences with CNS and their subsequent survival.

Results:

Project 1: systematic review

This review included 16 studies and showed that satisfaction with care and psychosocial support were the aspects of experience associated with survival. Positive, negative or no association between experience and survival were reported across the studies included in the review.

Project 2: representativeness of CPES responders

Compared with controls, CPES responders across all cancers were found to be younger, more likely to have a White ethnic background, to be resident in less deprived areas and diagnosed with earlier stage disease. Median survival for responders was also higher for the CPES responders than the general cancer population across all cancers.

Project 3: role of CNS in patients' experiences

Across all cancer types, patients who reported being given the name of a CNS reported better experiences across several aspects of care. Experiences of being involved in treatment decisions was most strongly associated with reporting being given a CNS name across all cancers.

Project 4: factors influencing patients' experiences

This review included 38 studies from several countries and showed that there are several factors affecting cancer patients' experiences at patient, disease, and healthcare system levels. Cancer type, prognosis, and patients' demographic characteristics were consistently linked with variation in patients' experiences across many countries.

Project 5: patients' experiences with CNS and their subsequent survival

Overall, there was variation in cancer patients' survival in relation to their reported communication experiences with CNS. Among the three compared groups (excellent experience, non-excellent experience, and no CNS name given), patients who reported not being given a CNS name had the worst survival. In the adjusted Cox regression analysis, the results show that among those who reported not being given a CNS name, the highest risk of death was in those with colorectal, breast and prostate cancers only (colorectal HR: 1.40; 95% CI: 1.32–1.84; breast HR: 1.34; 95% CI: 1.25-1.44; prostate HR: 1.09; 95% CI: 0.99–1.13). However, this association seemed to disappear among lung cancer patients when accounting for cofounders. The possibility that reverse causation might have explained this finding was considered where possible.

Conclusion:

This thesis has established new knowledge by assessing the literature that has explored the associations between cancer patients' experiences and their subsequent survival. It has also highlighted the complexity of such a relationship and discussed the appropriate theoretical and methodological approach to assess it. Findings from this thesis on the importance of CNS in improving cancer patients' experiences and the factors affecting these are important for cancer charities, patient representatives and health professionals and managers using CPES findings to assess and improve care, as well policy makers. This thesis also established methodological approaches that might be useful for future research on patient experience in cancer care settings.

Chapter 1 : Introduction

This chapter describes the burden of cancer in England focusing on the four most common cancers, i.e., colorectal, lung, breast and prostate cancer. The chapter also provides a short history of patient experience and how it has emerged as a key aspect of healthcare quality within the cancer care setting in England. The PhD aims and thesis outline are provided at the end of this chapter.

Parts of the literature review presented in this chapter resulted in the following publication: Alessy, S., Asery, A., Al-Zahrani, A., & Davies, E. (2020). Developing a roadmap for cancer patient experience initiatives in Saudi Arabia: lessons from health care settings in the United States and England. European Journal for Person Centered Healthcare (in press).

1.1 Cancer epidemiology in England

Cancer is a major public health challenge and over 300,000 cancer cases were diagnosed in England during 2017 (Office for National Statistics, 2019). Cancer incidence and prevalence in England are both projected to increase substantially in the coming decades reflecting the growing and ageing population (Mistry et al., 2011; Maddams et al., 2012). Colorectal, lung, breast, and prostate cancers account for more than half (53%) of all annual cancer cases (Office for National Statistics, 2019). In addition, these four cancers are the most common causes of cancer deaths accounting for around half (45%) of all cancer deaths in England (Cancer Research UK, 2020). Cancer survival in the United Kingdom (UK) continues to lag behind several western industrialized countries (Arnold et al., 2019). Colorectal, lung, breast, and prostate cancers are a major health burden in England in terms of both morbidity and mortality.

1.1.1 Colorectal cancer

Colorectal cancer (as coded in the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) as C18 – C20), is cancer that starts in either the colon or the rectum. It is the fourth most common cancer among males and females in England (Cancer Research UK, 2020). A total of 34,825 cases were diagnosed in 2017, accounting for 11.4% of all cancer new cases in England (Office for National Statistics, 2019). In addition, colorectal cancer is the second leading cause of cancer death in England. A total number of 7,509 of deaths in males and over 6,057 in females were attributable to colorectal cancer in England in 2017, with age-standardised mortality rates (ASMR) of 32.9 and 20.8 per 100,000, respectively (Cancer Research UK, 2020).

1.1.2 Lung cancer

Lung cancer (C33 to C34) is a cancer that starts in the tracheal and lung tissues. It is the third most common cancer in England and the second most common cancer in both males and females (Office for National Statistics, 2019). A total number of 38,906 cases were diagnosed during 2017, accounting for 12.7% of all cancer new cases in England (Office for National Statistics, 2019). Although lung cancer is not the most common cancer in terms of incidence, it is the leading cause of cancer death in both males and females in England. A total number of 15,229 cancer deaths in males and 12,959 in females were attributable to lung cancer in England in 2017, with the ASMR being 65.8 per 100,000 males and 46.1 per 100,000 females (Cancer Research UK, 2020).

1.1.3 Breast cancer

Breast cancer(C50) is defined as an abnormal cell growth of breast tissue. Breast cancer is the most common cancer among females in England. In 2017, a total number of 46,109 cases were registered, accounting for almost one third of all female cancer diagnoses and 15% of all cancer cases in England in that year (Office for

National Statistics, 2019). Breast cancer is the fourth most common cause of cancer death in England. In 2017, the total number of breast cancer deaths in females in England was 9,502 with the ASMR of 33.3 per 100,000 females (Cancer Research UK, 2020).

1.1.4 Prostate cancer

Prostate cancer, (C61) in ICD-10, is defined as an abnormal cell growth in the prostate gland. It is the most common cancer among males in England with 41,201 cases registered in 2017, accounting for 13.5% of all cancer diagnoses. In addition, prostate cancer is the second most common cause of cancer deaths among males in England. A total of 10,146 deaths in England in 2017 were attributable to prostate cancer with the ASMR being 47.7 per 100,000 males (Cancer Research UK, 2020).

1.2 Cancer care in England

Improving cancer outcomes has been emphasised in several major The National Health Service (NHS) Cancer Plans. The Calman–Hine report was the first comprehensive cancer report that outlined the principles for the clinical organisation for care delivery in the UK (Calman and Hine, 1995; Haward, 2006). The first national cancer care strategy, published in 2000 (Department of Health, 2000), introduced an investment plan to improve cancer prevention, reform cancer care delivery, and emphasise cancer research (Exarchakou et al., 2018). In 2007, the Cancer Reform Strategy focused on the progress made since the first plan to improve cancer care services in England (Department of Health, 2007). The current healthcare strategy ‘Achieving world-class outcomes: a strategy for England 2015 – 2020’ emphasizes the importance of improving both cancer patients’ experiences and their cancer outcomes (The Independent Cancer Taskforce, 2015a). The increasing emphasis on patients’ perspectives on cancer care systems in England draws on the growing UK and international literature on cancer patient experience as an area of research and as an indicator of healthcare quality (Davies and Cleary, 2005; Madden and Davies, 2010; Davies et al., 2011, 2008; Ziebland et al., 2013; Coulter et al., 2009; Cleary, 2016; Anhang Price et al., 2014).

1.3 History of patient experience research

Improvements in scientific, clinical and epidemiological knowledge along with advances in healthcare technology in recent decades have offered a significant opportunity to deliver more effective and patient-centred care. This shift in the focus of the healthcare system has resulted in increasing attempts to gather patients' feedback with the aim of understanding their experiences. Efforts to investigate and understand patients' experiences are not new and can be traced back to at least 1960, when several researchers in the United States and United Kingdom tried to understand the experience of ill people within the healthcare system (Ziebland et al., 2013). Later in the 1990s, Cleary and others in the United States introduced the methodology for assessing patient experience by using patient surveys (Ziebland et al., 2013). The UK and USA literature on patient experience has continued to grow driven in part by three significant factors: (1) the launch of the Commonwealth Fund Patient Centred-Care Program in the United States of America (USA) (Beatrice et al., 1998), (2) the establishment of the Picker Institute in the UK (Jenkinson et al., 2002), and (3) the publication of the Institute of Medicine (IOM) report ' Crossing the quality chasm' in the USA (Institute of Medicine, 2001).

The Commonwealth Fund Patient Centred-Care Program grant was launched in 1986 to explore patient experience with care and ways of improving patient-centred care. The results of program grants and recommendations led to the establishment the Picker Institute and publication of the book, 'Through the Patient Eyes' (Gerteis, 1993), which summarized the grant findings and presented practical frameworks to improve the patient experience. Following that, several survey tools were developed to understand patient experience of care. These include The Picker Care Experience

Survey (Jenkinson et al., 2002), two national surveys of cancer patient experience in England in collaboration with Picker Europe between 1999-2004 (Madden and Davies, 2010), and The Consumer Assessment of Healthcare Providers and Systems (CAHPS) (Goldstein et al., 2005), which recently added a modified version that has been developed for cancer care (Evensen et al., 2017).

In addition, the IOM report on how to improve patient-centred care played a key role in drawing attention to the importance of understanding patient experience and developing a shift in the healthcare system to focus on what matters to patients (Institute of Medicine, 2001). These combined factors have led to the development of understanding, enhancement and implementation of patient-centred care to date. Presently, patient experience surveys are widely used in healthcare systems across many countries including those in the United States, England, Turkey, Australia, The Netherlands, Norway, Sweden, Canada, Denmark, Ireland, Japan and Hong Kong (Coulter et al., 2009).

1.4 Definitions of patient experience

Previous literature has identified confusion over and overlap between the concept of patient experience and that of patient satisfaction. Although the two concepts are closely linked, they differ in the purpose and measurement. Patient satisfaction refers to whether patients' expectations are met, while patient experience refers to what happened or is reported about the interaction between patients and the healthcare system (Wolf et al., 2014; Agency for Healthcare Research & Quality, 2017). Patient experience definitions vary widely from one healthcare system to another with no unique or common definition (Wolf et al., 2014; LaVela and Gallan, 2014). For example, Wolf and colleagues point out that 'patient experience reflects occurrences and events that happen independently and collectively across the continuum of care' (Wolf et al., 2014). The Agency for Healthcare Research and Quality in the USA defines patient experience as ‘the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities’ (Agency for Healthcare Research & Quality, 2017).

NHS in England, however, defines patient experience as ‘what the process of receiving care feels like for the patient, their family and carers’ (NHS Institute for Innovation and Improvement, 2013). Each one of these patient experience definitions was developed in relation to different health system structures and patient expectations and consists of a differing set of patient experience aspects (LaVela and Gallan, 2014). The second chapter discusses, in detail, these aspects within several cancer care settings and how they have been used in research.

1.5 Cancer patient experience surveys in England

1.5.1 The 2000 and 2004 surveys

The NHS Cancer Plan published in 2000 (Department of Health, 2000), along with the increasing emphasis on improving patient experience in England resulted in several initiatives to evaluate cancer care from patients’ perspectives. Two national surveys of patient experience were conducted in England in collaboration with Picker Europe between 1999-2004 (Madden and Davies, 2010) to assess cancer patient experience. The first survey was carried out between 1999–2000 by the National Patient Survey Programme and the other in 2004 by the National Audit Office. Both surveys assessed patients’ experiences with cancer care and led to improvement in several aspects of patients' experiences (Richards and Coulter, 2007; Madden and Davies, 2010).

1.5.2 National Cancer Patient Experience Survey (CPES)

Since 2010, the National Cancer Patient Experience Survey (CPES) has been conducted annually with the specific aim of collecting new information that could be used to improve patients' experiences of NHS cancer care (Quality Health, 2019). The survey, as a tool to measure cancer patients' experiences, has been so far used in England (Quality Health, 2019), Scotland (Cunningham and Wells, 2017), Wales (Bracher et al., 2016), and at a cancer care setting in Australia (Lacey et al., 2016). In England, the survey has been conducted on behalf of the Department of Health (by Quality Health until 2019, and by Picker Institute Europe since 2020) to cover the entire cancer patients care pathway. Detailed survey data are published annually at the national level, as well as fed back to individual hospital trusts to help them and other users achieve better care for patients. The high response rate, large scale, and standardised approach results from CPES findings have so far informed policy makers about disparities in patients' experiences (Poots et al., 2018). Information on the scope of CPES, its administration, sampling frame, and response rate are described in the general methodology for this thesis in chapter 3.

1.6 Cancer patients' experiences data linkage

Cancer patient experience datasets in the USA and UK have been recently linked with data on patient demographic and disease characteristics at cancer registry level to maximize the value of patient experience datasets (S. Alessy et al., 2019). Currently, several years of collated surveys data for CPES in England and CAHPS in the USA are linked to population-based cancer registry data. The aim of linking these data with those on demographic and disease characteristics is to help provide better analyses of how patients' experiences may be related to aspects of their disease course and to prioritise policies for improving experience as well as allowing international comparison(Carneiro et al., 2017; Chawla et al., 2015). Detailed information on the methodology for the CPES data linkage is provided in chapter 3.

1.7 Thesis aims

Research in cancer care settings has shown variation in patients' care experiences. An important but as yet unanswered question is whether the variation in experiences is associated with the risk of cancer mortality. **This thesis therefore consists of five projects to assess whether variation in cancer patients' experiences is associated with their survival (**Figure 1-1**).**

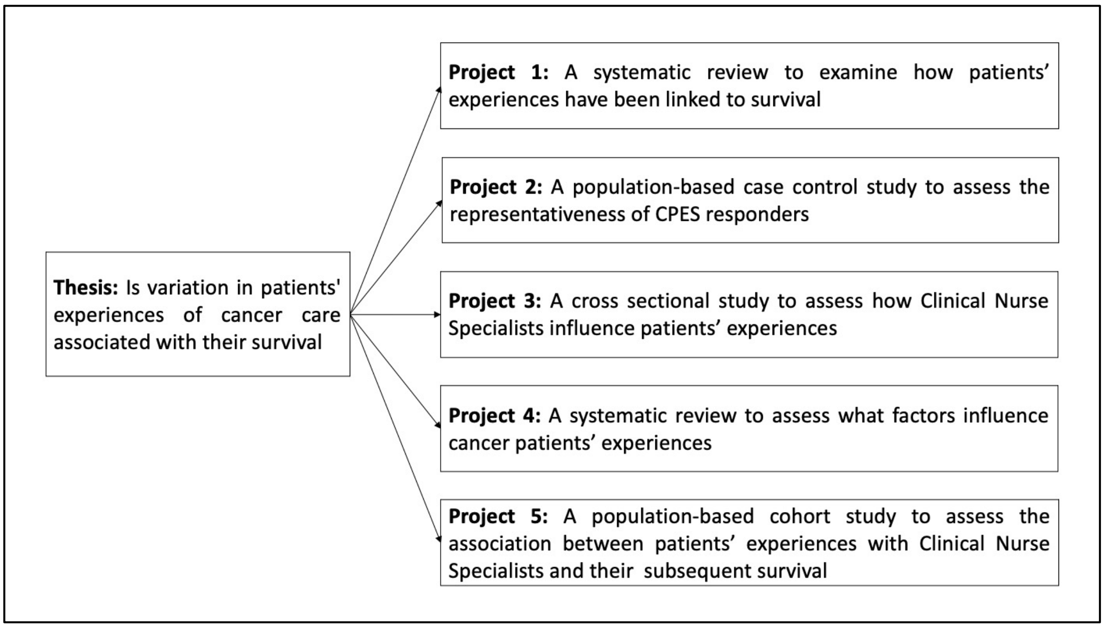


Figure 1-1: PhD aims

1.7.1 Patients representatives' involvement in this thesis

To maximise the impact of this thesis and to understand the findings and implications from the perspective of cancer patients' in the community, analyses in this thesis were continuously shared with two patient representatives: Janette Rawlinson and Matthew Baker. They had both already conducted work on the CPES and have worked with researchers and cancer charities in UK to improve patients' experiences and participation in research. I therefore invited them to contribute to the methodological design and manuscript writing for most of the studies and abstracts generated from this thesis. Throughout the PhD, they have provided me with constructive discussion and feedback both on the interpretation of findings and on how this work can be used by the wider audience of policy makers and user representatives using CPES findings. In addition, findings from this thesis were continuously shared with the two patient representatives to be discussed at the National Cancer Research Institute (NCRI) Consumer Forum that aims to bring mutual learning and exchanging knowledge and expertise between the patient representatives.

1.8 Outline of thesis

This chapter introduced the burden of cancer in England, provided a brief history of cancer patient experience and its concepts, and reviewed the literature growing in this area. The next chapter will discuss how patients' experiences with cancer care have been linked to cancer survival. Chapter 3 explains the data sources and general methodology used in the thesis. Chapter 4 examines the representativeness of CPES responders compared to the general cancer registry population in England. Chapter 5 assesses whether being given the name of a CNS is associated with better patients' experiences where CNS are involved in the care pathway. A systematic review of the factors influencing cancer patients' experiences followed up by the conceptual association diagram for the possible a relationship between patients' care experiences and their survival are discussed in chapter 6. Chapter 7 examines the possible association between patients' reported experiences with CNS and their cancer survival. Finally, a general discussion of the thesis is provided in chapter 8.

Chapter 2 : Systematic Review

This chapter provides an overview of how patients' experiences of cancer care have been linked to cancer survival in the literature. This chapter also describes how the relationship has been tackled in the literature and what type of biases and confounders may be present in such a relationship.

The systematic review in this chapter resulted in the following publication:
Alessy, Saleh A.; Lüchtenborg, Margreet; and Davies, Elizabeth A. (2019) 'How have Patients' Experiences of Cancer Care Been Linked to Survival? A Systematic Review,' Patient Experience Journal: Volume. 6: issue. 1, Article 9. Available at:
https://pxjournal.org/journal/vol6/iss1/9

2.1 Introduction

As explained in the previous chapter, measures of patients' perspectives on their health care have emerged over the last few decades both as a research area and as a component of healthcare quality. Patient-centred care is now recognised as an essential component of high quality healthcare (Institute of Medicine, 2001). Patient experience is an important measure of and interpretation of how patient-centred care principles and practice are perceived by patients receiving health care (Wolf et al., 2014). A considerable international literature on patient experience has grown in response to the increasing emphasis on and measurement of patients' experiences in healthcare systems (Ziebland et al., 2013; Coulter et al., 2009; Garratt et al., 2008). The link between patient experience and health outcomes has also been investigated in many different healthcare settings (Manary et al., 2013). Several studies across a range of health conditions and different populations have documented associations between patient experience and care effectiveness (Fenton, 2012; Boulding et al., 2011), patient safety (Doyle et al., 2013), or mortality (Meterko et al., 2010).

Cancer outcomes are influenced by cancer type, stage of disease, and comorbid conditions at diagnosis, as well as the quality of cancer care the patient receives (Malin et al., 2006). The possibility of an association between patient experience and survival, however, has not often been investigated in a cancer care setting. As shown in the previous chapter, variation by sociodemographic and healthcare system aspects in patients' experiences with cancer care have been documented in several studies from the United States (Ayanian et al., 2010; Halpern et al., 2017, 2018; Mollica et al., 2018; Lines et al., 2019) and Canada (Fitch et al., 2019; Coronado et al., 2017; Chadder et al., 2018). In addition, several studies published from CPES since 2010 have documented similar variations in cancer patients' experiences in England (El Turabi et al., 2013; Lyratzopoulos et al., 2012; Saunders et al., 2014; Bone et al., 2014; Saunders et al., 2015; Pham, Gomez-Cano, et al., 2019; Salika et al., 2018; Gomez-Cano et al., 2019; Pinder et al., 2016; Griffiths et al., 2013). Some of the factors associated with poorer experiences such as higher socioeconomic deprivation and access to care are also associated with poorer outcomes, raising the question of whether an independent association exists between patients' experiences of cancer care and their survival.

2.2 Aims

Several systematic reviews have so far focused on cancer patient experience. Sanders and others conducted a review to investigate the available instruments used to measure the experience that cancer patients have of health care (Carla Saunders et al., 2016). They found a lack of studies measuring cancer patient experience in a systematic and consistent way (Carla Saunders et al., 2016). Mollica and colleagues performed a scoping review of cancer patient experience, considering only the core domains of CAHPS – a patient experience measure used widely in the USA, and summarized the literature and identified possible future directions for research

(Mollica, Lines, et al., 2017). Their review identified a gap in the research literature regarding the relationship between cancer care experience and survival. Thus, the aim of this systematic review was to search the medical literature to determine how patients' experiences of cancer care have been linked to survival.

I envisaged that this would:

1. Inform the development of a conceptual framework to analyse my PhD data
2. Inform my methodology to account for any possible biases
3. Inform directions for future research in this area

2.3 Method and approach

Patient experience is a new term that refers to different dimensions of the interaction between patients and the healthcare system and has not yet been recognized as a subject heading in health science databases. Previous systematic reviews on patient experience have therefore used different dimensions to extract different types of literature (Mollica, Lines, et al., 2017; Doyle et al., 2013). I decided to use the patient experience dimensions presented by Doyle and colleagues since they combined aspects identified and used by the Institute of Medicine (IOM), Picker Institute, and National Institute for Health and Care Excellence (NICE) (Doyle et al., 2013).

I first identified possible words and terms that might denote literature on dimensions of patient experience (Table 2-1 and Table 2-2). I used cancer survival as the outcome, and a range of different terms to extract possible relevant literature (Table 2-1). I limited this review to Medline due to the complexity of duplicating the same terms in other databases and assumed that most of quantitative articles investigating survival would be indexed in Medline. After combining these terms together, and using the Medline database, I identified 1,830 papers that were published between January 1998 and March 2018. I first read titles and abstracts for all 1830 articles and excluded 1683 as not at all relevant, and then shortlisted the remaining 156 to 26 full text articles (Figure 2-1) adapted from (Liberati et al., 2009).

Table 2-1: Patient experience terms used in combination with cancer (neoplasm) and cancer survival terms

Cancer patient experience aspects terms	Cancer term	Survival terms
Patient centred care Physician-patient relations Patient preference Patient participation Patient satisfaction Quality of health care Patient experience Surveys and questionnaires Decision making Health care surveys Continuity of patient care Communication Social support Empathy	Neoplasm	Treatment outcome Survival Disease-Free Survival Survival Analysis Survival Rate Mortality Prognosis

Table 2-2: Full electronic search strategy for patient experience terms used in Medline database

Patient-Centered Care/ OR Physician-Patient Relations/ Patient Preference/ or Patient Participation/ Patient Satisfaction/ Or ‘Quality of Health Care’/ or ‘patient* experience*’.mp./ OR ‘Surveys and Questionnaires’/ Decision Making/ or Health Care Surveys/ OR ‘Continuity of Patient Care’/ Communication/ Patient Preference/ Social Support/ Empathy/ AND Neoplasms/ AND treatment outcome/ OR Survival/ or Disease-Free Survival/ or Survival Analysis/ or Survival Rate/ OR Mortality/ OR Prognosis/

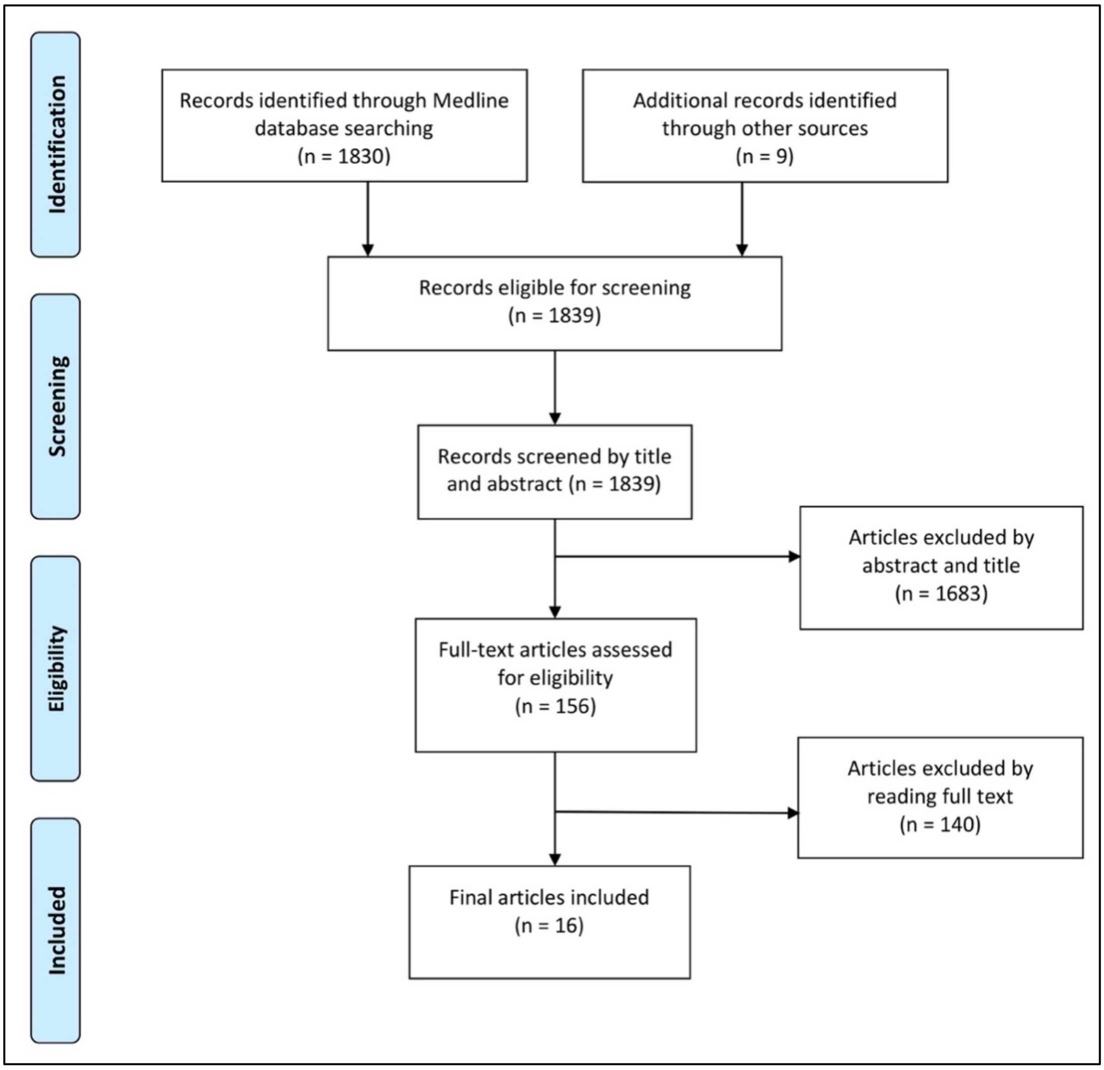


Figure 2-1: Systematic review flowchart

In addition, since patient experience is an emerging research field, I considered eligible papers that have been referred to in the following popularly cited articles that linked patients' experiences to their health outcomes (Fenton, 2012; Boulding et al., 2011), in the scoping review about cancer experience with care (Mollica, Lines, et al., 2017), and in a popular systematic review that linked patients' experiences to clinical safety and effectiveness across many health conditions including several types of cancer (Doyle et al., 2013). Following that, I used Google Scholar features, 'Cited by' and 'Related Articles', to review the citation histories of these popular articles to consider any additional papers that had linked patients' experiences to cancer survival (Figure 2-1). By doing so, I found an additional nine articles that met the inclusion criteria.

I chose the preliminary shortlist of eligible research papers and these were read independently by my 1st PhD supervisor and discussed with my 2nd PhD supervisor to determine the final eligible articles. In addition, although many assessment tools were available, I chose the Effective Public Health Practice Project Assessment Tool (Thomas et al., 2004) to assess the quality of the included quantitative studies due to the variety in design of included studies (Table 2-3).

I included studies that linked any aspect of patient experience with cancer survival. This included studies where the experience was reported by patients, doctors, GPs, or extracted from healthcare systems records. Patient Reported Outcomes Measures (PROM) studies were excluded on the basis that they do not ask questions about patients' experiences, but rather about their symptoms and outcomes. All types of studies such as cross sectional, cohort and case control studies that used validated tools or specifically developed interviews to measure or assess patient experience dimensions and linked those to a measure of cancer survival were included. The studies were categorised into four groups, based on their main aims and how they linked patients' experiences to cancer survival: **(1) preferences for information about cure or treatment, (2) psychosocial support (3) a care system or team intervention, and (4) patient satisfaction**.

2.4 Results

2.4.1 Studies characteristics

A total of 16 journal articles met the inclusion criteria including 11 observational studies (Gupta et al., 2015; Gupta, Lis, et al., 2013; Gupta et al., 2014; Gupta, Rodeghier, et al., 2013; Lis et al., 2015; Gupta et al., 2012; McCarthy et al., 2008; Gleason et al., 2009; Rose et al., 2004; Burns et al., 2005; Cunningham et al., 2000), one quantitative content analysis (Buis and Whitten, 2011), two clinical trials (Daly et al., 2013; Guo et al., 2013), and two consecutive case series (Lis, Gupta, and Grutsch, 2006; Lis, Gupta, Granick, et al., 2006). The included studies varied widely in methods, population and findings. Table 2-4 summarizes the study aims, study population, methods, patient experience aspects, and study outcomes.

2.4.1.1 Preferences for information about cure or treatment

Two studies - one cohort (Rose et al., 2004) and one cross sectional (Gleason et al., 2009) - focused on patients' expectations for cancer cure, their treatment preferences, relations with oncologists and how they perceived the quality of their care . Gleason and colleagues examined whether lung, colorectal, breast, lymphoma, head and neck, liver, and leukaemia cancer patients' expectations for cure influence their decisions to follow treatment recommendations and whether these are affected by the oncologist–patient alliance (Gleason et al., 2009). The authors found that patients who expected a cure were more likely to report an intention to follow oncologists' treatment recommendations (Gleason et al., 2009).

Additionally, Rose and colleagues focused on the difference between older and middle aged late-stage cancer patients in terms of care preferences, relations with oncologist, perceived quality of life and estimation of survival (Rose et al., 2004). This study concluded that both middle-aged and older patients and their physicians had different perspectives regarding perceived quality of life, physician estimation for patient survival, and patient's estimation of their survival (Rose et al., 2004). In addition, the majority of patients in both groups had treatment goals of relieving pain or discomfort (Rose et al., 2004).

2.4.1.2 Psychosocial support

Four studies, one clinical trial (Guo et al., 2013), two observational studies (Burns et al., 2005; Cunningham et al., 2000), and one qualitative study (Buis and Whitten, 2011) focused on psychosocial support and patient survival. Burns and colleagues investigated whether emotional support was predictive of survival among patients with incurable breast, lung, and gastrointestinal, prostate, and haematological cancer. They found that survival (follow-up 36 months) was significantly shorter among those with two to three confidants - the people with whom patients been able to share feelings - compared to those with no or one confidant (p=0.031). They also found that younger patients tend to share their feelings with more confidents than older patients, which might explain these findings. The same study also found emotional support to be an independent prognostic indicator of survival (Burns et al., 2005).

Guo and colleagues determined the benefits of psychosocial interventions for breast, lung, cervical, endometrial cancer patients who were undergoing radiotherapy (Guo et al., 2013). Although no significant difference between cases and controls in terms of survival was found, the psychological intervention significantly reduced symptoms of anxiety ($p < 0.05$) and depression ($p < 0.05$), as well as improved elements of quality of life such as global health status ($p < 0.05$) in the intervention group (Guo et al., 2013). In addition, a qualitative analysis by Buis and colleagues analysed 3717 posts on the internet, made by patients with lung, pancreatic, melanoma, and thyroid cancers, to determine how emotional and informational support contents differ in online communities for cancers with high and low five-year survival (Buis and Whitten, 2011). Within the posts containing social support content, high-survival cancer communities had more content including emotional support (75%) than low-survival communities (66%). By contrast, low-survival communities had more informational content (46%) than high survival communities (36%) (Buis and Whitten, 2011). Finally, Cunningham and colleagues focused on the variation in psychological responses to the diagnosis of life-threatening cancer and whether this was related to survival in several types of cancers (Cunningham et al., 2000). Even though this study had a limited sample size (n=22), patients who had a lower psychological score had a statistically significant lower median survival of 1.29 years while those with higher psychological score had a median survival of 2.85 years. The authors attributed this to psychological self-help activities such as relaxation, meditation, and spiritual activities (Cunningham et al., 2000).

2.4.1.3 Health care system and team intervention

Two studies, one cross sectional study (McCarthy et al., 2008), and one non-randomised clinical trial (Daly et al., 2013), focused on the cancer care system, or team interventions and their association with cancer survival. McCarthy and colleagues investigated various aspects of the performance of breast, colorectal, lung and prostate cancer services and whether they were related to survival at the hospital level or specialist services level (McCarthy et al., 2008). They combined five different datasets including those on waiting times, compliance with standards, cancer patient experience survey, routinely collected hospital measures, and cancer survival outcomes (McCarthy et al., 2008). Their analysis showed that higher breast cancer one-year survival (p=0.04) and lung cancer five-year survival (p=0.014) at cancer network level was associated with higher overall dissatisfaction scores (McCarthy et al., 2008). However, a limitation in these findings was that they were based on correlation analysis and factors such as cancer stage at diagnosis and treatment episodes were not considered.

In addition, Daly and colleagues conducted a non-randomized clinical trial to evaluate the effects of interdisciplinary cancer support team on quality of life and quality of care among patients with advanced colorectal, lung, and gynaecologic cancers (Daly et al., 2013). The study found no significant difference between cases and controls in quality of care; but that the five-year survival probability had the most significant effect on quality of care outcomes (P = 0.04) (Daly et al., 2013).

2.4.1.4 Patient satisfaction

Eight studies, including five cross sectional studies (Gupta, Lis, et al., 2013; Gupta et al., 2014; Lis et al., 2015; Gupta et al., 2012, 2015), two consecutive case series (Lis, Gupta, and Grutsch, 2006; Lis, Gupta, Granick, et al., 2006), and one prospective cohort study (Gupta, Rodeghier, et al., 2013), were conducted at The Cancer Treatment Centres of America Hospitals, and focused on the association between patient satisfaction and survival. This research assessed different types of patient satisfaction including satisfaction with service quality and with quality of life. After controlling for variables such as cancer stage at diagnosis, previous treatment history, and treatment location, patients who had higher satisfaction with their service quality had a lower risk of mortality than those with low satisfaction scores in the following cancers: colorectal (hazard ratio (HR) = 0.74; 95% CI: 0.58–0.95; p = 0.02) (Gupta, Lis, et al., 2013), pancreatic (HR= 0.63; 95% CI: 0.51–0.79; P = 0.001), (Gupta et al., 2012) breast (HR= 0.71; 95 % CI 0.57–0.87; p=0.001) (Gupta et al., 2014), and non-small cell lung (HR = 0.71; 95% CI: 0.60–0.85; P < 0.001) (Gupta, Rodeghier, et al., 2013).

Later, Gupta and colleagues added self-rated health as an independent variable and examined the same association in non-small cell lung (Lis et al., 2015) and prostate cancers independently (Gupta et al., 2015). They found that self-rated-health was significant in predicting survival in non-small cell lung cancer (HR = 0.75; 95% CI:

0.57 to 0.99; p=0.04) and prostate cancer (HR= 0.25; 95 % CI: 0.11-0.58; p=0.001) (Gupta et al., 2015). Thus, self-rated-health confounded the relationship between patient satisfaction and survival in non-small cell lung cancer (Lis et al., 2015) and replaced patient satisfaction in prostate cancer (Gupta et al., 2015) as a predictor of survival. In two other studies conducted at the same cancer centre, Lis and colleagues assessed whether patient satisfaction with quality of life can predict survival in advanced colorectal and pancreatic cancers (Lis, Gupta, and Grutsch, 2006; Lis, Gupta, Granick, et al., 2006). After controlling for cancer stage at diagnosis (in both) and previous treatment history (only in colorectal), baseline patient satisfaction with quality of life a prognostic factor for survival in advanced colorectal cancer (p=0.0003) (Lis, Gupta, Granick, et al., 2006), but not in pancreatic cancer (p=0.053) (Lis, Gupta, and Grutsch, 2006).

Overall, findings from these studies support the importance of assessing the relationship between patient satisfaction, self-rated health, and quality of life measures in cancer patient experience. Yet, the inconsistency in the results is puzzling. It might be a result of differing effects of type of cancer, pathways of possible influence for patient experience, care offered at different treatment centres, and different measuring instruments used in the studies. All of these possibilities emphasise the need for a systematic and consistent way to assess the association between cancer patient experience and subsequent survival.

2.5 Discussion:

The aim of this review was to systematically review the literature to determine how cancer patient experience has been linked to cancer survival. I hoped to develop an informed analysis plan for the recently available linked patient experience and patient survival databases in England. Overall, this review revealed a variety of different methods and perspectives on how cancer patients' experiences were linked to survival across different types of cancer. Patients' satisfaction, psychosocial support, and satisfaction with quality of life were the most common aspects of patient experience found to be associated with survival in the literature. The studies included in my review showed a positive, negative or lack of association between cancer patient experience and subsequent survival. Thus, these studies suggest a relation may exist between patients' experiences of cancer care and survival, while also emphasising the importance of applying the appropriate methodological consideration when analysing the linked data in this PhD thesis.

Previous systematic reviews have identified several gaps in the cancer patient experience research field. Sanders and others found a lack of studies measuring cancer patient experience in systematic and consistent ways (Carla Saunders et al., 2016). I found a wide range of methods, settings, and populations used to measure cancer patient experience and to link it to subsequent survival. Moreover, Mollica and colleagues conducted a review to summarize the cancer patient experience literature, indicate research gaps, and provide future research directions (Mollica, Lines, et al., 2017). They identified a gap in research examining relationships between cancer experience and survival. My review contributes to closing this gap by finding that cancer patients' experiences have been linked to survival in a number of studies in different ways, and by revealing a complex and challenging relationship to unpick. In addition, Doyle and colleagues demonstrated a positive association between patient experience and patient safety and clinical effectiveness across a wide range of disease areas including several types of cancer (Doyle et al., 2013). Several studies included in my review suggested a positive association between cancer patient experience and patient survival. However, my review shows a clear heterogeneity of studies across all aspects of linking cancer patient experience with subsequent survival, and not all gave a clear overall indication of the magnitude of any observed association.

My findings show the difficulty of determining the association between patient experience and survival. While the findings are novel ones for the cancer care setting, several studies in other health care settings have raised concerns that any possible association between patient experience and health outcomes may be biased by patient characteristics, affected by reverse causation, confounded by factors within the healthcare system or related to the patient's health situation (Xu et al., 2015; Anhang Price et al., 2014; Manary et al., 2013). These issues were found in several studies included in this review. For example, the conclusion that cancer survival can be predicted by measuring patient self-rated health or patient satisfaction with services quality or with quality of life was contradicted by findings within studies conducted by the same research group (Lis, Gupta, Granick, et al., 2006; Gupta, Lis, et al., 2013; Gupta et al., 2014; Gupta, Rodeghier, et al., 2013; Lis, Gupta, and Grutsch, 2006; Lis et al., 2015; Gupta et al., 2012, 2015). Despite the different cancer types in these studies, such a contradiction in the final conclusion demonstrates the importance of using appropriate methodological approaches in my PhD when assessing the presence of any association between patient experience and health outcomes in cancer setting.

The present review has several strengths. First, it is, to my knowledge, the first study that examines how cancer patient experience has been linked to cancer survival. Second, using the methods presented by Doyle and colleague (Doyle et al., 2013), I extended the patient experience dimensions to include those presented by the Picker Institute, and NICE to catch all dispersed terms. In addition, since the association between patient experience and health outcome is an emerging field and not well established in the literature, I included relevant articles from similar systematic reviews and popular studies in the field to make sure I included all relevant studies in the field.

However, this review is subject to several limitations. It was limited to English language articles in Medline and did not include other medical databases such as CINAHL, which might have included some eligible studies. This exclusion was due to the complexity and lack of uniformity of the MeSH terms for patient experience dimensions in different medical literature databases. It remains an area for future research to review the currently used MeSH terms for referencing patient experience studies, given the importance of measuring these elements in current research. Second, some of the studies included in my review had several methodological limitations within them including small sample sizes, absence of control groups and no consideration of reverse causation. For example, several of the patient satisfaction studies I included reported contradictory results across several types of cancer and lacked an appropriate reverse causation analysis using systematic and consistent instruments. However, I decided to include them since the main aim of this study was to examine how patients' experiences have been linked to survival in the literature, not to draw a conclusion on the strength and direction of association between cancer patient experience and cancer survival. Finally, I cannot exclude the possibility of publication bias for significant positive or negative association findings.

2.6 Conclusion:

The possible association between patient experience with cancer care and subsequent outcomes continues to emerge as an important topic. The availability of the UK (Carneiro et al., 2017), Canada (Canadian Institute for Health Information, 2017), and USA (Chawla et al., 2015) datasets that contain information on both cancer patients' experiences and their survival status will now enable researchers to explore such an association. This review highlights the methodological considerations of determining a possible relationship between cancer patient experience and subsequent survival. While future research is recommended to examine the strength and direction of this association, the conceptual model and methodological consideration, developed based upon the results of this review, will hopefully be relevant when studying or drawing a conclusion about any future association.

2.7 Summary

This chapter provided an overview on how patients' experiences of cancer care have been linked to cancer survival in literature. The chapter also described some possible biases and confounders that were presented from the included studies, which needs to account for in the PhD analysis. Next chapter describes the general methodology used in this thesis.

Table 2-3: Quality assessment for the included quantitative studies using the Effective Public Health Practice Project Assessment Tool

Citation	Selection bias	Study design	Confounder	Blinding	Data collection	Dropouts	Analysis	Overall rating
Rose, J. H., et al (2004).	strong	moderate	strong	strong	strong	moderate	strong	strong
Gleason, et al (2009).	moderate	weak	weak	strong	moderate	N/A	strong	moderate
Burns, C. M., et al (2005).	moderate	moderate	strong	N/A	strong	strong	strong	strong
Cunningham al (2000).	weak	moderate	moderate	strong	strong	weak	strong	moderate
Daly, et al (2013).	moderate	strong	strong	strong	strong	strong	strong	strong
Buis, et al (2011).	Not applicable as this method of assessment is not applicable on qualitative study							
Guo, Z., et al (2013).	strong	strong	strong	strong	strong	strong	strong	strong
McCarthy, et al (2007).	moderate	weak	moderate	N/A	strong	N/A	moderate	moderate
Lis, et al (2015).	moderate	weak	weak	moderate	moderate	weak	moderate	weak
Gupta, et al (2012).	moderate	weak	weak	moderate	moderate	weak	moderate	weak
Gupta, et al (2014).	moderate	weak	weak	moderate	moderate	weak	moderate	weak
Lis, et al (2006).	weak	moderate	weak	moderate	moderate	weak	moderate	moderate
Lis, et al (2006).	weak	moderate	moderate	moderate	moderate	weak	moderate	moderate
Gupta, et al (2013).	weak	moderate	weak	moderate	moderate	weak	moderate	moderate
Gupta, et al (2015).	moderate	weak	weak	moderate	moderate	weak	moderate	weak
Gupta, et al (2013).	moderate	weak	moderate	moderate	moderate	weak	moderate	moderate

Table 2-4: Summary of included studies

Citation	Study type, sample size, country	Study aim	Patient experience aspect and method used	Primary Outcomes and method used	Result on association and notes
Buis, et al (2011).	3717 posts made by patients in online cancer support forums, USA.	How emotional and informational support content differs in online communities for cancers with high and low 5-year relative survival rates.	Quantitative content analysis of emotional and informational support needs expressed were recorded by two independent coders.	Analysis of whether the cancer communities with high or low 5-year survival rate made more posts about needs for emotional or informational support using descriptive statistics and chi-square test.	The relationship between more emotional support comments and 5-year survival rate was significant. Within the posts containing social support content, high-survival rate communities contained more emotional support (75%) content than low-survival communities (66%). In addition, low-survival rate communities had more informational content (46%) than high survival rate communities (36%).
Rose, J. H., et al (2004).	Prospective cohort study, 1416 patients, USA.	To evaluate relationships among physician and cancer patient survival estimates, patients' perceived quality of life, care preferences, and outcomes, and how they vary across middle-aged and older patient groups.	Assessing patient’s survival estimate, physician’s survival estimates and patient’s perceived quality of life. Care practice was measured by assessing discussion about aggressive care and therapeutic intervention. Patient’s preference was measured by assessing their preference for cardiopulmonary resuscitation.	Outcome was measured by readmission to hospital and death in 6- month timeframe.	Patients’ preferences for treatment to extend their lives, did not translate to longer survival in both older and middle-aged patients. In contrast, physicians were less optimistic about patients’ survival in both age groups. In addition, the majority of patients in both groups preferred treatment goal of reducing pain and discomfort.

Gleason, et al (2009).	Cross sectional, study of 101 patients, USA.	To examine whether cancer patients' expectations for cure prior to interacting with their oncologist influence their decisions to follow treatment recommendations.	(1) To assess expectations for cure, patients and companions were asked four questions independently: if they expected the cancer to be cured, or will not worsen but not cured, or symptoms will be relieved, but cancer will not be cured, or if they do not know what to expect. (2) Oncologist patient alliance assessed by KAAS scale, which measures rapport, trust, closeness with oncologist, level of information, clarity, responsiveness, amount of hope provided by oncologist, and how organized is the oncologist.	Patient decision to follow oncologist's treatment recommendation assessed by self-report at phone interview and categorised as no intention, some intention, and intention to follow treatment recommendations.	Patients who expected a cure were more likely to report an intention to follow oncologist's treatment recommendation when their alliance with the oncologist was not strong and when their companions did not believe they will be cured. In addition, this study concludes that a complex interaction of patient and companion, or oncologist and patient alliance and expectations influence patients' decisions.
Burns, C. M., et al(2005).	Cross sectional study, 163 patients, Australia	To investigate whether emotional support was predictive of survival duration among patients diagnosed with incurable cancers.	Emotional support was assessed by a specific survey consisting of three items: sharing feelings with others, if yes, with whom, is there anyone else to share feeling with.	Cancer survival was assessed at 6, 12, 18, 24, 30, 30, 36 months from study entry.	Number of confidents (0-1, 2-3, 4+) at entry time was predictive of survival duration after adjusting for primary cancer site and other variables. Specifically, using two or three confidants as the reference group, the relative risk of a shorter survival was: 0.44 for patients with 0-1 confidants and 0.60 for those with four or more confidants. Emotional support appeared to be an independent prognostic indicator of survival after accounting for sex, age, cancer type, and treatment modality.

Cunningham, et al (2000).	Prospective study, 22 patients, Canada	To describe the individual variation in psychological responses to the predicament of life-threatening cancer, and to relate this variability to survival duration, using a case-oriented, correlative approach.	Variation in patient's response to the psychotherapy sessions assessed by three main methods: notes taken by investigators, written homework, and individual interview conducted by two investigators for two and half-hour weekly for 1 year. The session consisted of three components: support, homework, and group psychotherapy.	Survival rate after following up for about five years.	Although the sample size is limited for this study (n=22) the study concluded that after controlling for the severity of disease there was a strong association between longer survival and psychological factors. Those who had lower psychological score had a median survival of 1.29 years while those with higher psychological score had a median survival of 2.85 years. The physiological factors related to the involvement of cancer patients in psychological self-help activities such as relaxation, meditation, and spiritual activities at home.
Daly, et al (2013).	Non-randomized Clinical trial, 511 patients, USA.	To evaluate the effect of an interdisciplinary cancer support team (CST) on quality of care and quality of life in patients with advanced cancers.	To measure the effect of the interdisciplinary cancer support team (CST) intervention, which consists of advanced practice nurse, social workers, spiritual care counsellor. A quasi-experimental design was used to measure the quality of care and quality of life outcomes.	Quality of end-of-life care using the National Quality Forum (NQF) standards. Survival expectation was in the regression analysis as part of the end of life measures.	There was no significance difference in survival between patients receiving interdisciplinary cancer support team (CST) and usual care on the quality-of-care indicators. In addition, patients with higher survival expectancy in the intervention arm had the greatest improvement in health-related quality of life scores compared to other groups.
Guo, Z., et al (2013).	Randomized clinical trial, 178 patients, China.	To determine the benefits of psychosocial interventions for cancer patients who received radiation therapy.	Psychological intervention delivered by a clinician, a nurse and a radiation therapist and consisted of Psychoeducation, cognitive-behavioural therapy, and supportive–expressive therapy.	Depression assessed by Zung self-rating depression scale, anxiety assessed by self-rating anxiety scale, quality of life assessed with (EORTC QLQ-C30), and survival analysis.	The psychological intervention significantly reduced the level of depression and anxiety, improved the elements of quality of life such emotional and physical functioning. There was no difference in the survival between the two groups.

McCarthy, et al. (2007)	Cross sectional study, England, five independent national data sets.	To examine whether cancer service performance across a range of quality indicators including patient satisfaction was more related more the hospital level, or specialist services level within the hospital across different tumour types.	Satisfaction with care from National Cancer Patient Survey dataset and in hospital mortality and population-level survival from National Cancer Registry.	The different data sets were compared at both cancer network and hospital levels. In addition, 1- 5-year relative survival was calculated for patients diagnosed in England between 1996 and 2001 (followed up to the end of 31 December 2002).	Variation was statistically significant across hospitals and networks in all measures. Breast cancer 1-year survival (p=0.04) and lung cancer 5-year survival (p=0.014) were associated with higher dissatisfaction scores.
Lis, et al (2015).	Cross sectional study, 778 patients, USA	To examine whether better self-rated health (SRH) confounds the relationship between patients' satisfaction and their survival in non-small cell lung cancer.	Patients' satisfaction assessed by a paper-based questionnaire developed by the authors in 2006.	Patient survival measured between the date a patient completed the survey and the date of their death from any cause or the date of last contact or last known to be alive.	Patients who were satisfied with their care had lower risk of mortality (hazard ratio = 0.75; 95% CI: 0.57 to 0.99; p=0.04) compared to those who were not satisfied. Also, patients who had better self-rated health had a significantly lower risk of mortality (HR = 0.61; 95% CI: 0.46 to 0.81; p =0.001). On multivariate analysis, only self-rated health was significant (hazard ratio = 0.67; 95% CI: 0.50 to 0.89; p = 0.007). Thus, it confounded the association between patients' satisfaction and survival.
Gupta, et al (2012).	Cross sectional study, 496 patients, USA	To evaluate the relationship between patient satisfaction with cancer care, service quality and survival in pancreatic cancer patients.	Patients' satisfaction assessed by a paper-based questionnaire developed by the authors in 2006.	Patient survival between the date a patient completed the survey and the date of their death from any cause or the date of last contact or last known to be alive.	Patients who had higher satisfaction with care services had lower risk of mortality (hazard ratio = 0.63; 95% confidence interval: 0.51–0.79; P = 0.001) than those who had lower satisfaction score after controlling for stage, treatment history, and treatment centre.

Gupta, et al (2014).	Cross sectional study, 1521 patients, USA.	To evaluate the relationship between patient-reported satisfaction with service quality and their survival of breast cancer.	Patients satisfaction assessed by a paper-based questionnaire developed by the authors in 2006.	Patient survival between the dates a patient completed the survey and the date of their death from any cause or the date of last contact or last known to be alive.	Patients who had higher satisfaction with care services had lower risk of mortality (hazard ratio = 0.71; 95 % CI 0.57–0.87; p =0.001) than those who had lower satisfaction score after controlling for stage, treatment history, and treatment centre.
Lis, et al (2006).	A consecutive case series, 177 patients, USA.	To evaluate the association between patient satisfaction with quality of life and survival in colorectal cancer patients undergoing care in a community hospital comprehensive cancer centre.	Quality of life assessed by QLI scale, which covers health and physical, social and economic, psychological and spiritual, and family. Each one of these areas has questions about satisfactions.	Patient survival between the dates a patient first visited the hospital and the date of their death from any cause or the date of last contact or last known to be alive. The survival data were obtained from the hospital cancer registry.	Patient's satisfaction with quality of life provided a prognostic information in colorectal cancer care. Specifically, health and physical subscale was significantly associated with survival (p=0.0003), with median survival being 20.6 months for high scores and 8.3 for low score after taking in account the stage of the disease at diagnosis and the treatment history.
Lis, et al . (2006).	A consecutive case series, 55 patients, USA.	To evaluate the association between patient satisfaction with quality of life and survival in pancreatic cancer patients undergoing care in a community hospital comprehensive cancer centre.	Quality of life assessed by QLI scale, which covers health and physical, social and economic, psychological and spiritual, and family. Each one of these areas has associated questions about satisfaction.	Patient survival between the dates a patient first visits the hospital and the date of their death from any cause or the date of last contact or last known to be alive. The survival data obtained from the hospital cancer registry.	No quality of ife subscale was found to be statistically significant after controlling for stage at diagnosis.

Gupta, et al (2013).	Cross sectional study, 702 patients, USA	To evaluate the relationship between patient-reported experience with service quality and survival colorectal cancer patients.	Patients satisfaction assessed by a paper-based questionnaire developed by the authors in 2006.	Patient survival between the dates a patient completed the survey and the date of their death from any cause or the date of last contact or last known to be alive.	Patients who had higher satisfaction with their service quality had a lower risk of mortality (hazard ratio = 0.74; 95% CI: 0.58–0.95; p = 0.02) than those who had lower satisfaction scores after controlling for stage, treatment history, gender, age, and treatment centre.
Gupta, et al (2015).	Cross sectional study, 917 patients, USA.	To investigate whether self-rated health can supersede patients' satisfaction as a predictor of survival in prostate cancer patients.	Patients satisfaction assessed by a paper-based questionnaire developed by the authors in 2006.	Patient survival between the dates a patient completed the survey and the date of their death from any cause or the date of last contact or last known to be alive.	On multivariate analysis, those who had better self-rated health had a lower risk of mortality (hazard ratio = 0.25; 95 % CI: 0.11-0.58; p = 0.001) compared to those who had lower self-rated health. In addition, patient satisfaction was significant in the same analysis model (hazard ratio = 0.76; 95 % CI: 0.40-1.5; p = 0.40). Thus, self-rated health replaced patient satisfaction as a predictor for survival.
Gupta, et al (2013).	Prospective cohort study, 986 patients, USA.	To evaluate the relationship between self-reported satisfaction with service quality and overall survival in non-small cell lung cancer.	Patients satisfaction assessed by a paper-based questionnaire developed by the authors in 2006.	Patient survival between the dates a patient completed the survey and the date of their death from any cause or the date of last contact or last known to be alive.	Patients who had higher satisfaction with their service quality with their service quality had lower risk of mortality (hazard ratio = 0.71; 95% CI: 0.60–0.85; P < 0.001) than those who had lower satisfaction score after controlling for stage at diagnosis, treatment history, gender, and age.

Chapter 3 : General methods

This chapter gives details of the various data sources I used in this thesis including the CPES data, the cancer registry datasets, and how these two datasets were linked at patient and tumour levels. This chapter also explains how information on patients' demographic, treatment, mortality, and tumour characteristics were obtained. Details of the ethical approval, data access, and data quality are also given.

3.1 Defining my study cohort

This PhD thesis focuses on all patients with colorectal (C18-20), lung (C33-34), female breast (C50), and prostate (C61) cancers (ICD-10) who responded to CPES during 2010-2014. As this work started in 2017, I initially used the most recent cancer data available at the time, so-called closedown 2016, to carry out the analyses to assess how representative CPES data is of all English cancer patients in chapter 4. This task included defining a general cancer population cohort from the English cancer registry. As soon as cancer registration [closedown 2017 data] became available in 2019, I used it for the analyses assessing the role of CNS in patients' experiences and the association between the patients' experiences with their survival (chapter 5 and 7). Different analyses in this thesis required a slightly different inclusion of patients based on their year of diagnoses. More specific information about the cohort defined and used for each analysis is therefore provided within the methodology section in each chapter.

3.2 CPES sampling and administrative process

CPES is conducted each year in England with the specific aim of collecting new information that is designed to monitor national progress on cancer care quality, assist commissioners and cancer care providers with cancer care planning, and inform charities and stakeholder groups supporting cancer patients (Quality Health, 2019). The survey was conducted by Quality Health on behalf of the Department of Health up until 2019, and covers the following aspects of cancer care: seeing the GP, diagnostic tests, finding out what was wrong, deciding on best treatment, communication with CNS, support for cancer patients, operations, hospital doctors, ward nurses, hospital care and treatment, communication, home care and support, hospital day and outpatient care, outpatient appointments with doctors, care from GP, and overall NHS care (Quality Health, 2019).

The survey sampling frame includes all adult patients (aged 16 and over) with a primary diagnosis of cancer who have been admitted to an NHS hospital as an inpatient or as a day case patient and have been discharged during the sampling time frame of the year the survey was carried out (three consecutive months of each year Figure 3-1). The first iteration of the survey in 2010, used January - March as the time frame to draw the survey sample, while the iterations for years 2012-2014 used September - November as the sampling frame. The survey is conducted by post, with two reminders being sent to non-responders. Response rates to the survey were stable between 64% - 68% in the four iterations of the survey used in this thesis (2010 and 2014). As a final step before the survey is sent, duplicate records and all patients who are known to have died between the time of drawing the sample and survey distribution are removed (Figure 3-1) (Quality Health, 2019).

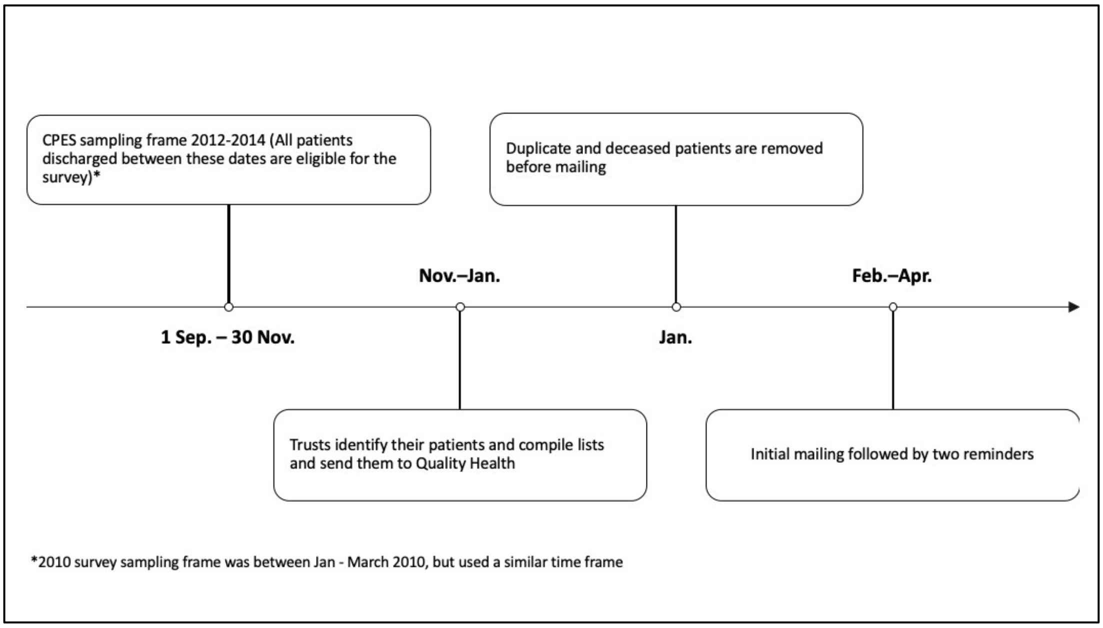


Figure 3-1: CPES administrative process (based on CPES published reports)

3.3 The National Cancer Registration and Analysis Service

The National Cancer Registration and Analysis Service (NCRAS), hosted by Public Health England, is the population-based cancer registry for England (Henson et al., 2019). NCRAS collects, quality assures and analyses data on cancer patients' entire care pathway with high completeness and validity (Figure 3-2 and Figure 3-3). This data has been collected, at national level, on all diagnosed cancer in England since 1971. Researchers and policy makers can use cancer registration data in cancer epidemiology, public health planning, service monitoring, research, and quality of treatment outcomes (Henson et al., 2019).

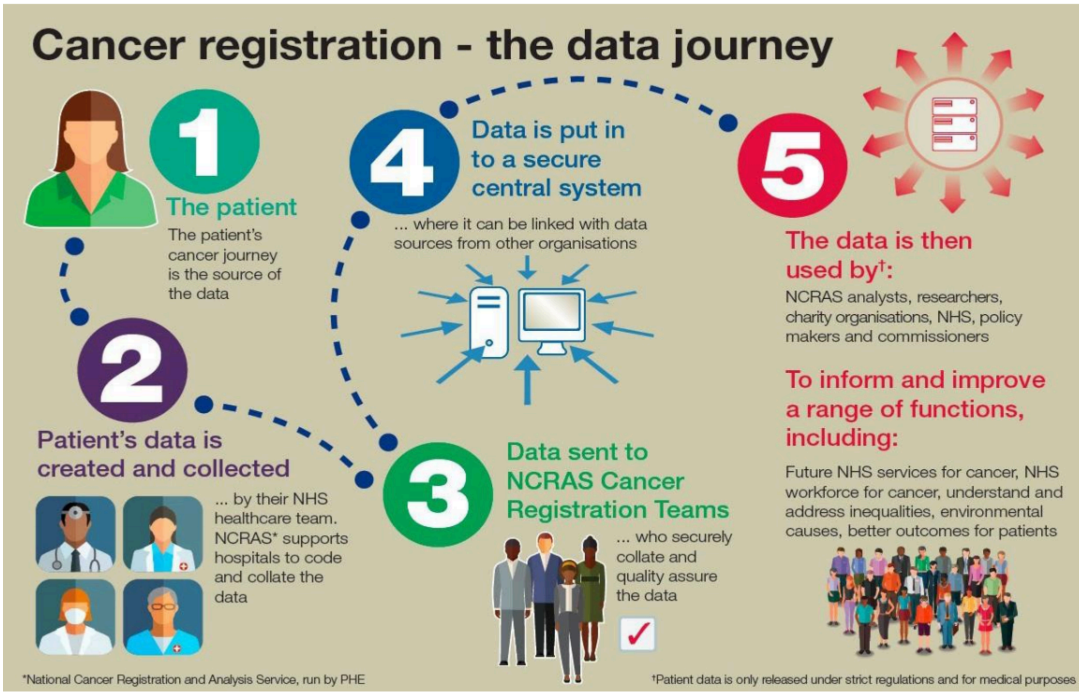
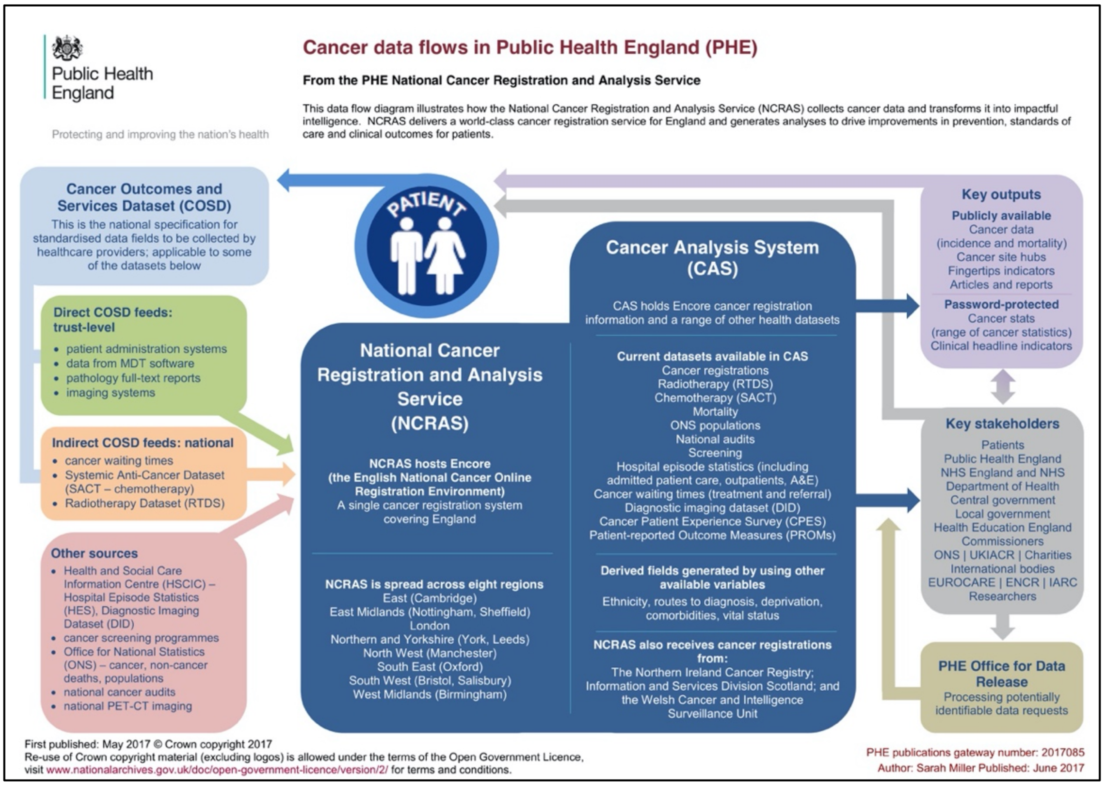


Figure 3-2: Cancer data journey to NCRAS (adapted from Public Health England, 2020)

The wide range of cancer data, received from 162 health care providers across the NHS, is accessible through the Cancer Analysis System (CAS). Moreover, NCRAS has increasingly been focussing on linking data from different data sources to the cancer registry. And there are currently several linked datasets available within CAS (Figure 3-3). These datasets are: Office of National Statistics death data (ONS), Hospital Episode Statistics (HES), Radiotherapy Data Set (RTDS), Systemic Anti-Cancer Therapy (SACT), national cancer audits, cancer screening data, Cancer Waiting Times (CWT, treatment and referral), Diagnostic Imaging Dataset (DID), Patient Reported Outcomes Measures(PROMs) dataset , and CPES (Henson et al., 2019; Miller, 2017; Public Health England, 2020)



Public Health England

Protecting and improving the nation's health

Cancer data flows in Public Health England (PHE)

From the PHE National Cancer Registration and Analysis Service

This data flow diagram illustrates how the National Cancer Registration and Analysis Service (NCRAS) collects cancer data and transforms it into impactful intelligence. NCRAS delivers a world-class cancer registration service for England and generates analyses to drive improvements in prevention, standards of care and clinical outcomes for patients.

Cancer Outcomes and Services Dataset (COSD)
This is the national specification for standardised data fields to be collected by healthcare providers; applicable to some of the datasets below

Direct COSD feeds: trust-level
- patient administration systems
- data from MDT software
- pathology full-text reports
- imaging systems

Indirect COSD feeds: national
- cancer waiting times
- Systemic Anti-Cancer Dataset (SACT – chemotherapy)
- Radiotherapy Dataset (RTDS)

Other sources
- Health and Social Care Information Centre (HSCIC) – Hospital Episode Statistics (HES), Diagnostic Imaging Dataset (DID)
- cancer screening programmes
- Office for National Statistics (ONS) – cancer, non-cancer deaths, populations
- national cancer audits
- national PET-CT imaging

PATIENT

National Cancer Registration and Analysis Service (NCRAS)

NCRAS hosts Encore (the English National Cancer Online Registration Environment)
A single cancer registration system covering England

NCRAS is spread across eight regions
East (Cambridge)
East Midlands (Nottingham, Sheffield)
London
Northern and Yorkshire (York, Leeds)
North West (Manchester)
South East (Oxford)
South West (Bristol, Salisbury)
West Midlands (Birmingham)

Cancer Analysis System (CAS)
CAS holds Encore cancer registration information and a range of other health datasets

Current datasets available in CAS
Cancer registrations
Radiotherapy (RTDS)
Chemotherapy (SACT)
Mortality
ONS populations
National audits
Screening
Hospital episode statistics (including admitted patient care, outpatients, A&E)
Cancer waiting times (treatment and referral)
Diagnostic imaging dataset (DID)
Cancer Patient Experience Survey (CPES)
Patient-reported Outcome Measures (PROMs)

Derived fields generated by using other available variables
Ethnicity, routes to diagnosis, deprivation, comorbidities, vital status

NCRAS also receives cancer registrations from:
The Northern Ireland Cancer Registry; Information and Services Division Scotland; and the Welsh Cancer and Intelligence Surveillance Unit

Key outputs
Publicly available
Cancer data (incidence and mortality)
Cancer site hubs
Fingertips indicators
Articles and reports
Password-protected
Cancer stats (range of cancer statistics)
Clinical headline indicators

Key stakeholders
Patients
Public Health England
NHS England and NHS
Department of Health
Central government
Local government
Health Education England
Commissioners
ONS | UKIACR | Charities
International bodies
EUROCARE | ENCR | IARC
Researchers

PHE Office for Data Release
Processing potentially identifiable data requests

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PHE publications gateway number: 2017085
Author: Sarah Miller Published: June 2017

Figure 3-3: Data flows to NCRAS: (adapted from Miller, 2017)

3.4 CPES - NCRAS data linkage

CPES for the years 2010 to 2014 has been linked with the English population cancer registry in CAS (Carneiro et al., 2017; S. Alessy et al., 2019). This new linked dataset will be referred to as 'CPES-NCRAS' throughout this thesis. A partnership team from Cancer Research UK, Macmillan Cancer Support, and NCRAS carried out the data linkage to allow for further analysis and research exploring patient experience of cancer care. Linkage to the cancer registration data and associated datasets extends the possibilities of cancer patient experience research (Carneiro et al., 2017). The survey was first linked to the cancer registry by matching NHS number - the individual identifier used for each patient - in both datasets. Following that, where patients had multiple tumour records in the cancer registry, the ICD-10 3- and 4-digits diagnosis codes from both datasets and the time frames from diagnosis to discharge were used to match both datasets at the patient-tumour level. As a result, over 75% of the CPES

2010-2014 cohort were successfully linked for each year of the survey waves (National Cancer Registration and Analysis Service, 2015). The CPES-NCRAS dataset can therefore now be linked to different sets of patients' information that flow to the cancer registration.

Furthermore, due to technical issue with data linkage, around 15,000 records from CPES 2010 -2014 were not successfully linked to NCRAS, which would have been a great addition to this PhD project. As the data matching was prepared by an external group and I had no access to those data, I was not able to assess the experiences and representativeness of this population. However, other research groups who used data directly from Quality Health have explored the experiences of the entire CPES population resulting in several published studies. All these studies are described and discussed in chapter 6 in this thesis.

Table 3-1: Sampling frame, response rate, and number of linked records within the cancer registry dataset for CPES 2010 -2014

Survey year	**2010**	**2011/2012**	**2013**	**2014**
Sampling time frame	1st Jan- 30th March,2010	1st Sep - 30th Nov,2011	1st Sept - 30th Nov,2012	1st Sept - 30th Nov,2013
Response time frame (from initial mail to 2nd reminder)	16th Jun - 31st Aug, 2010	03rd Feb -19th April, 2012	28th Jan - 30th April, 2013	14th Feb - 24th April, 2014
Number of NHS trusts	158	160	155	153
Sampled patients	101,064	113,808	116,490	109,760
Patients responded	67,713	71,793	68,737	70,141
Response rate	67%	68%	64%	64%
Linked records all cancers (matched by NHS number and ICD10 Code)	51,821	55,786	54,355	56,426
Colorectal linked records	7,823	8,420	7,969	7,710
Lung linked records	3,131	3,624	3,724	3,487
Breast linked records	13,129	13,553	12,808	13,361
Prostate linked records	5,580	5,676	5,481	6,206

3.5 Data source:

3.5.1 Age and sex

Age at diagnosis and sex are reported to the cancer registry by the hospital trust where the patients were diagnosed with cancer. For the purposes of different analyses in this thesis, age was categorised differently, and more information about these categorisations are provided in the methodology for each chapter.

3.5.2 Geographical area of residence

Area of residence is based on each patient's postcode of residence taken at the time of cancer diagnosis from the National Statistics Postcode Lookup, provided by the ONS (Office for National Statistics, 2020). Cancer registration is linked to the National Statistics Postcode Lookup by postcode which is updated annually. England is divided into nine areas of residence which are: East Midlands, East of England, London, North East, North West, South East, South West, West Midlands, and Yorkshire & Humber.

3.5.3 Ethnicity

Ethnicity should refer to a sense of self-defined belonging to a community of people who share the same culture. There were two available sources of ethnicity data in the cancer registration data in NCRAS. The first dataset is derived from Cancer Outcomes and Services Datasets, and supplemented through the linkage with the inpatient and outpatient HES records (NHS Digital, 2018). HES ethnicity data has achieved high completeness (over 90%) in recent years, being collected through patient self-reports during their hospital visits (NHS Digital, 2018). In addition, patients are invited to report their ethnicity in the CPES questionnaire using HES ethnic categories. A recent study compared patients' self-reported ethnicity in CPES to the one they reported in HES and found high levels of concordance in this information (Saunders et al., 2013). For the purpose of consistency, HES-recorded ethnicity was used in this thesis. The 16-group classification for ethnicity was collapsed into two different methods according to the analysis methodology in this thesis.

Table 3-2: The differing ethnic groups categorisation used in different analyses within this thesis

16-Ethnicity groups in HES	**Collapsed for analysis in chapter 4**	**Collapsed for analysis in chapter 5 and 7**
British Irish Any other White background	White	White
White and Black Caribbean White and Black African White and Asian Any other mixed background	Mixed	Non-white
Indian Pakistani Bangladeshi Any other Asian background	Asian	
Caribbean African Any other Black background	Black	
Chinese	Chinese	
Any other ethnic group	Other Ethnic Groups	

3.5.4 Socioeconomic Deprivation

The Indices of Multiple Deprivation (IMD) is the official measure of relative deprivation for all populations in England and is produced by the Office for National Statistics (Office for National Statistics, 2015). IMD provides measures of deprivation for the 32,844 Lower Layer Super Output Areas (LSOAs) in England, which are small areas of a similar population size (around 1,500 residents), equivalent to around 650 households (Office for National Statistics, 2015). It provides an overall measure of seven measured domains: income deprivation; employment deprivation; education, skills and training deprivation; health deprivation and disability; crime; barriers to housing and services; and living environment deprivation. The income domain in IMD is calculated based on the proportion of the population living in a LSOA with low income based on four indicators: adults and children in Income Support families; adults and children in income-based Jobseeker’s Allowance families; adults and children in income-based Employment and Support Allowance Families; and adults and children in Pension Credit (Guarantee) families (Office for National Statistics, 2015).

A patient’s socioeconomic deprivation score is area- based and assigned based on the postcode of residence at diagnosis. The deprivation score is derived from a quintile distribution of the LSOAs using the income domain of the IMD, with a score of 1 indicating the least deprived through 5 (most deprived) based on the quintile of distribution across the country that their LSOA falls within (Office for National Statistics, 2015). Four versions of IMD are currently available for use in the cancer registry (2004, 2007, 2010, 2015). I applied the closest match of IMD to the year of diagnosis (IMD 2004 for diagnosis years 1999 to 2002; IMD 2007 for diagnosis years 2003 to 2006; IMD 2010 for diagnosis years 2007 to 2009; IMD 2015 for diagnosis years 2010 to 2013). Both socioeconomic status and area of residence are based on patients’ postcodes, but the socioeconomic status is calculated using a different approach as described above. As both indicators have been shown in previous CPES literature to independently influence reported patients’’ experiences (Saunders et al., 2015, 2014), I therefore decided to use both in the regression analysis in thesis. Data completeness on socioeconomic deprivation was nearly 100% for the study cohort. However, a small number of patients (n=174) had a missing postcode when the cancer registry data was updated [closedown 2017 data] for the analysis in chapter 5 and 7.

3.5.5 Vital status data

Dates of death for all deceased cancer patients are obtained from death records through the NCRAS data link with ONS (Henson et al., 2019). Patients who were still alive were censored on their last updated live status date in the cancer registration (between 5th and 10th January 2018) when assessing the representativeness of CPES responders, and for the rest of the thesis between 5th and 10th February 2019 as the latest live status update became available in the cancer registry. A small number of patients were found to have data quality issues with their vital status. Methods for excluding these patients are provided in the methodology section in each chapter.

3.5.6 Stage at diagnosis

NCRAS collects information on each cancer stage based on internal pathological and clinical information provided by hospitals using the Tumour Node Metastasis (TNM) classification (Henson et al., 2019). The TNM staging system was produced by the Union for International Cancer Control and is now widely used by cancer registries around the world (Union for International Cancer Control, 2020). Stage at diagnosis data completeness has greatly improved in the English cancer registry since 2012 (Henson et al., 2019) (Figure 3-4). Disease stage was extracted for all cancers. Prior to 2013, stage recording in the cancer registry had varied between the eight former local cancer registries. Stage is categorised in this thesis as (I, I, III, IV, and Unknown).

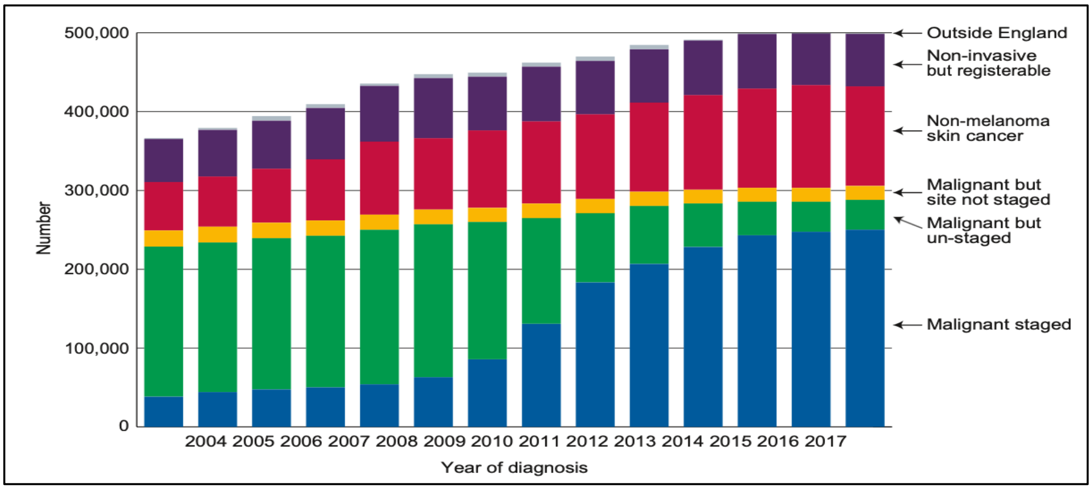

Figure 3-4: Improved data for stage at diagnosis over time at NCRAS, adapted from Public Health England, 2020

3.5.7 The National Lung Cancer Audit

The National Lung Cancer Audit (NLCA) has collected data from lung cancer multidisciplinary teams (MDTs) (National Lung Cancer Audit, 2015). The independent audit started collecting national data in 2005, organised by the Health and Social Care Information Centre until 2013(LUCADA). Since 2014, the commissioned work for the NLCA is carried out by the Royal College of Physicians and based on enhanced cancer registration records. The audit collects data on patients' demographic, diagnosis, pathology, treatment details, and on aspects of the care pathway. Both LUCADA and NLCA data are held within the cancer registry at NCRAS. As the LUCADA data has better data completeness for lung cancer stage than the cancer registry for 2005-2014, I supplemented lung cancer stage information where this was missing in the cancer registrations records with stage information from the NLCA. In addition, I used information on the allocation of a CNS to patients from the LUCADA data in the analysis in chapter 5. Details on the numbers of cases used are provided in the methodology section of each chapter.

3.5.8 Route to diagnosis

Route to diagnosis refers to the interactions between the patient and the health care system including primary and secondary care that lead to the diagnosis of cancer. To develop this dataset, administrative HES data are linked with data from the cancer screening programs, Cancer Waiting Times data, and cancer registration data (Elliss-Brookes et al., 2012; Henson et al., 2019). This has resulted in a categorization of all cancer diagnoses in England into one of eight routes to diagnosis (screen detected, two-week referral, general practice referral, other outpatient, inpatient elective, emergency presentation, death certificate only, and unknown). This data is now available for all cancer cases diagnosed in England since 2006 (Elliss-Brookes et al., 2012; Henson et al., 2019). These data were used in the analyses in chapters 5 and 7, and numbers and categorisation are provided in the methodology section in these chapters.

3.5.9 Treatment data

An overall descriptive analysis of treatment episodes was needed in chapter 7 to further investigate some of my findings. Treatment data has historically been recorded as part of cancer registration and continues to be today. However, since the data completeness is variable and detail on treatments was lacking, several independent datasets are usually used to assess treatment in cancer patients. Details on surgical resections can be obtained from inpatient HES data. Radiotherapy and systemic anticancer therapy data have been collected in separate datasets, RTDS and SACT, respectively. As RTDS was launched in 2010, and SACT in 2012, they do not cover most the patient cohorts used in this thesis. I therefore extracted treatment episodes data from the cancer registration treatment dataset- so called Av.Treatment Table - on treatment before 2013. All treatment episodes were extracted for patients for the period beginning 30 days before diagnosis until 180 days after their diagnosis as per the cancer registry guidelines.

3.6 Ethical approval, data access, and data extraction

The CPES-NCRAS linked dataset sits at NCRAS within Public Health England and is accessible through CAS. NCRAS has approval from the Confidentiality Advisory Group of the National Health Service Health Research Authority to carry out surveillance using the data they collect on all cancer patients under section 251 of the NHS Act 2006. I have been granted a studentship agreement with NCRAS at Public Health England which allowed me to access the cancer registry data. Following this, a formal request for the release of cancer registration data required for the project was sent to the National Disease Registration Service (NDRS). Based on the analysis and data variables needed, I was granted level two access to CAS. This has given me formal permission to access identifiable data such as NHS numbers, postcodes and date of birth, excluding patients' names and addresses. Hence, separate ethical approval from an NHS or university committee was not required for the analyses carried out throughout this thesis.

A PHE secure laptop and a pass allowing me to access the NCRAS working area were also provided to me during my studentship between 2017-2021. As part of a studentship agreement, I carried out most of the analyses for this thesis at PHE, in a secure data environment, located in the PHE building at Wellington House, London, UK. As Coronavirus disease (COVID-19) affected working practices globally, a separate permission was granted to me to access and analyse data for this project from my home address in London beginning from March 2020. All the cancer registration data at NCRAS are stored in an Oracle database (Henson et al., 2019). Structured Query Language (SQL) scripts were used to link data and extract them from the cancer registrations tables for the entire work in this thesis.

This project aligns with the most updated UK Government's Data Ethics Framework in terms of the responsible use of patients' data (Government Digital Service, 2020).

During this project, I have attended several training sessions on data privacy and kept high standards of the data overarching principles. These as outlined in the UK Government’s Data Ethics Framework are accountability, fairness, and transparency. As mentioned earlier in this thesis, patient representatives were involved in this project and gave constructive feedback on how the patients community might benefit from this project. This project was also given oversight by my line manager at PHE, and all data analyses were carried out according to the standard operating procedures available at NCRAS.

Data quality assessments

3.6.1 DCO

Death Certificate Only (DCO) registration refers to cases where a cancer registration is based on information from the patient’s death certificate alone. These cases are incomplete for date of diagnosis and have limited details on characteristics of the cancer. The DCO percentage serves as an indicator of data completeness and case ascertainment in cancer registries. As the cancer registration in England continues to improve, DCO registrations have decreased and now account for less than 1% of all cancer registrations in recent years (Henson et al., 2019). By its nature of being based on patients responding to CPES, no DCO cases were found in the CPES-NCRAS linked data. A small number of cases were found in the general cancer population cohort when assessing the representativeness of CPES (chapter 4). All these DCO cases were excluded at source.

3.6.2 Multiple surveyed population

Based on CPES sampling and administration, it is possible that CPES asked information about the most recent visit. Patients who longer survival may have had several admissions and be reporting their experiences about more than one hospital attendance. Evidently, some patients appeared to have responded to more than one survey for the same or different cancer site when the merged 2010-2014 CPES cancer registry dataset was inspected. Some patients would have been surveyed several times because they had been admitted to hospital during the sampling frame for more than one survey year. Different study designs in this thesis required different methodological approaches to those patients who had completed multiple surveys. Thus, more details on how many duplicates were handled or removed is described in the methodology section each chapter.

3.7 Summary

This chapter has described the various data sources and general methodology I used in this thesis. This includes an overview of CPES administration, cancer registration practices, data linkage, approval for the study, and data extraction. This chapter also described how information on patients' demographic, treatment, mortality, and tumour characteristics were obtained and categorised. The next chapter uses these data to assess the representativeness of CPES responders compared with the general cancer population in England.

Chapter 4 : The representativeness of CPES responders

This chapter assesses the representativeness of CPES responders compared with the cancer registry population in England. This chapter also provides a discussion about possible reasons behind the limited representativeness of CPES responders to the wider cancer population.

The work in this chapter has resulted in the following journal publication: Alessy, S.A., Davies, E.A., Rawlinson, J., Baker, M. and Lüchtenborg, M., 2019. How representative are colorectal, lung, breast and prostate cancer patients responding to the National Cancer Patient Experience Survey (CPES) of the cancer registry population in England? A population-based case control study. BMJ open, 9(12). https://bmjopen.bmj.com/content/9/12/e034344

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4.1 Introduction

Patient experience surveys now play a major role internationally in assessing patients' care experiences, monitoring services, and improving care quality and outcomes. CPES has invited a large sample of patients who received cancer care for all cancer types annually since 2010 to report their experiences (Department of Health, 2010). These data are fed back to local NHS Cancer Services, reported nationally and used for policy development and research. Studies published from different years of CPES indicate that experiences have been improving across many domains but that systematic differences in cancer patient experience by sociodemographic factors remain (El Turabi et al., 2013; Bone et al., 2014; Saunders et al., 2015; Pinder et al., 2016; Saunders et al., 2014).

Although population-based health experience surveys provide a valuable patient perspective on many aspects of health services, they are prone to selection biases that might result from missing the experiences of ethnic minorities, people living in the more deprived areas, and the youngest and oldest age groups (Hu et al., 2016; Etter and Perneger, 1997; Abel et al., 2016). In addition, there has been a concern that patients with the poorest prognosis are missed, because they are too ill or die before they can complete the survey (Abel et al., 2016; Brønserud et al., 2019). Analysis of early cancer experience surveys in England in 2000 and 2004, for example, showed limited inclusion of lung cancer patients (Madden and Davies, 2010), and analysis of CPES data for 2010 raised a concern about the number of patients in the initial sampling frame for some cancer types who died before they could receive they survey (Abel et al., 2016; Brønserud et al., 2019).

NCRAS collects data on all incident cancer diagnoses in England (Henson et al., 2019). Focusing on the four most common cancers in England (colorectal, lung, breast and prostate), I aimed to compare the survey responders' demographic and tumour stage at diagnosis and their median survival time to determine the extent to which they represent the cancer registry population. I hoped this would inform the rest of the PhD analysis, as well as future English surveys.

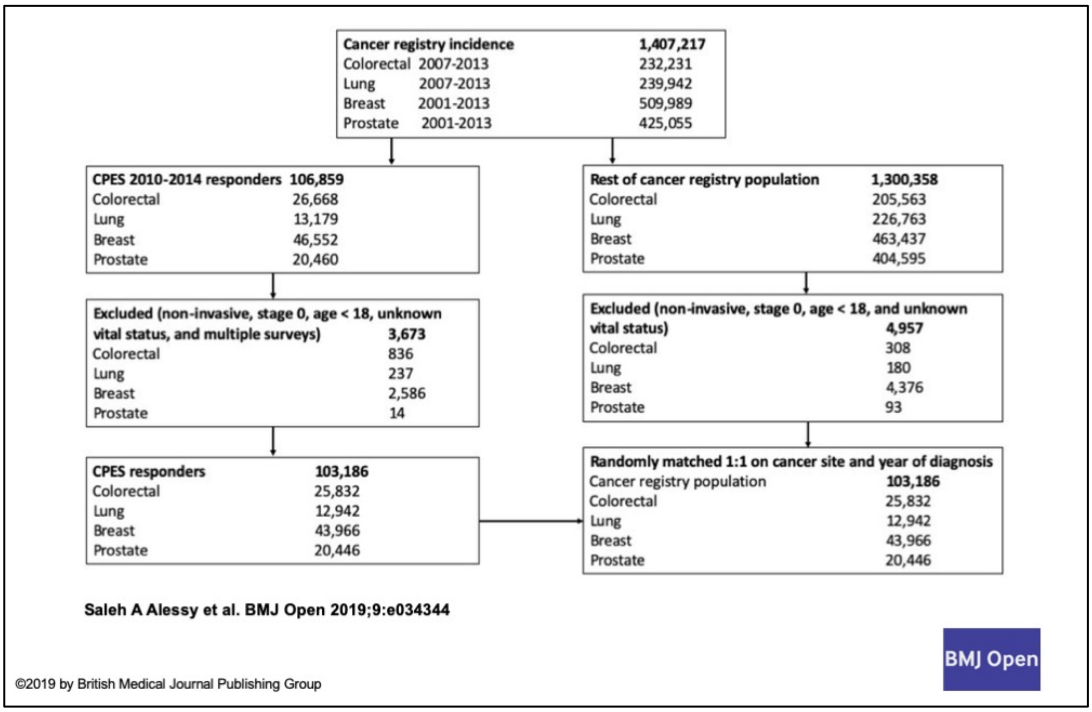
4.2 Methods

4.2.1 Dataset and participants

CPES-NCRAS dataset was previously described in chapter 3. For the analysis presented here, I focussed on the four iterations of the survey between 2010 and 2014. Several methodologies were available in the literature on comparing patient experience survey responders to cancer registry population considering factors such as patients' clinical characteristics and population data collection methods (Kemp et al., 2015; Catalano et al., 2013; Li et al., 2018). In England, NCRAS collects data on all cancers diagnosed. This includes demographic information, date of diagnosis, treatment, and vital status through the Office for National Statistics (ONS)(Henson et al., 2019).

The survey, however, includes only patients discharged in a recent three months period from hospital, regardless of their date of diagnosis. Specifically, the survey sampling frame includes all adult patients with a primary diagnosis of cancer who have been discharged from an NHS hospital either as an inpatient or day patient during a three-month period in each year. Patients are invited to complete the survey by post, with two reminders being sent to non-responders. In my initial analysis, I found that for lung and colorectal cancer at least 95% of survey responders had their cancer diagnosed between 2007 and 2013, while 95% of responders with breast and prostate cancers were diagnosed between 2001 and 2013 (Figure 4-2). Thus, I extracted data for all patients diagnosed in those time periods with colorectal, lung, female breast, and prostate cancers from the cancer registration data [2016 closedown] (Henson et al., 2019).

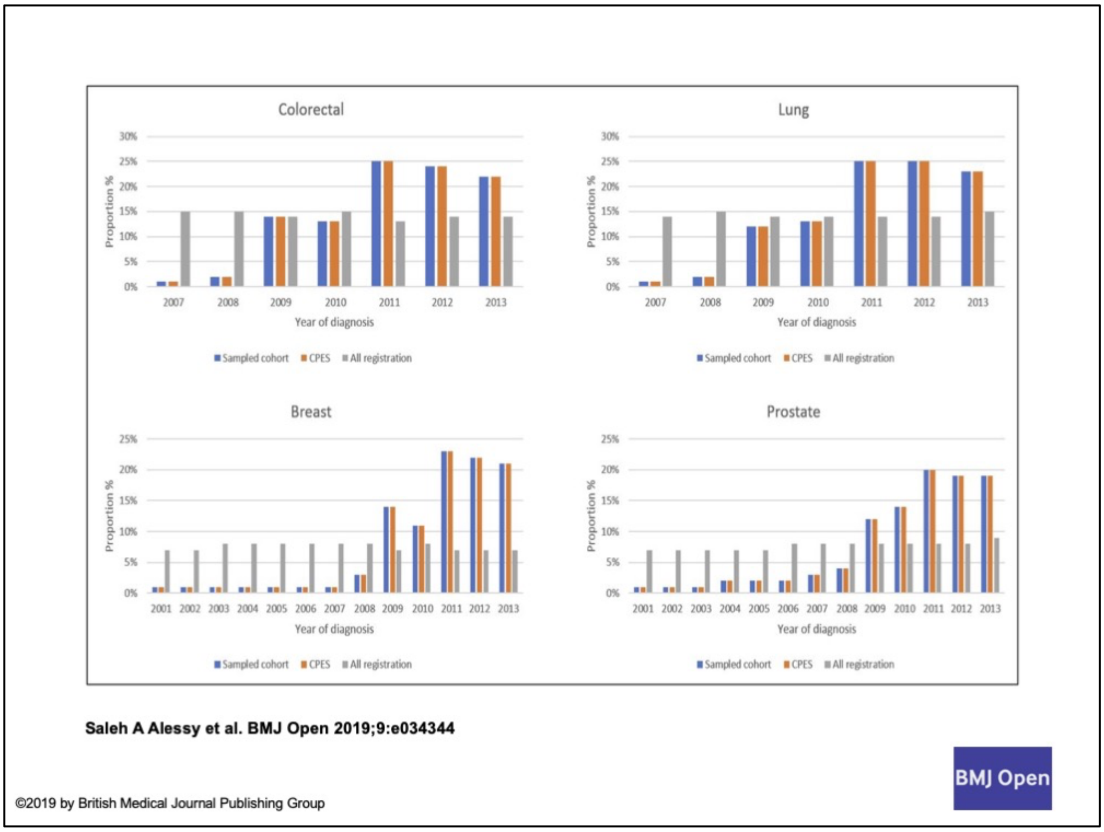
Cancer in situ (stage 0), patients aged less than 18 years, and diagnoses based on DCO only (not found among CPES responders) were excluded. I also excluded cases with unknown vital status. In addition, some patients have responded to the survey more than once for the same type of cancer. Therefore, out of all 3673 cases excluded in CPES cohort, 3,442 were excluded because they were multiple records (Figure 4-1).



Saleh A Alessy et al. BMJ Open 2019;9:e034344

Figure 4-1: Flowchart for study participants

I first removed all CPES responders from the cancer registry population. In order to make a fair comparison in terms of the follow-up time, diagnosis date, and data completeness which changed over time, I randomly selected one patient who was not a CPES responder for each CPES responder, matched on cancer type and time of diagnosis (same yearly quarter), (n=103,186), (Figure 4-2). To assess the robustness of my method, I repeated it by taking another random sample from the cancer registry. I then compared the two random samples and found there were no differences with regard to sex, age, ethnicity, and socioeconomic deprivation, geographical area of residence, disease stage, and survival.



Saleh A Alessy et al. BMJ Open 2019;9:e034344

Figure 4-2: Distribution of year of diagnosis within the National Cancer Patient Experience Survey (CPES) responders compared with the sample chosen from the cancer registry for colorectal, lung, breast and prostate cancers

For all patients, I included demographic data (sex, age, ethnicity, socioeconomic deprivation, and geographical area of residence) and their survival and disease stage at diagnosis. Source of information on the demographic variables has been described in the general methodology chapter. I collapsed the 16-group ethnicity classification into six categories: White, Asian, Black, Chinese, Mixed, and Other. Information on disease stage was extracted from the cancer registry system for all cancers, and for lung cancer missing stage information was supplemented from the NLCA dataset (n= 107,280), which has a higher completeness of lung cancer stage data (Health and Social Care Information Centre, 2014).

4.2.2 Data analysis

A total of 206,372 patients were included in the analysis. I first compared the distribution of the patient characteristics (age, sex, socioeconomic deprivation, ethnicity, geographical areas) and disease stage among CPES responders and the cancer registry population using univariable and multivariable logistic regression. χ^2 Tests were performed to estimate the p-values for trend and heterogeneity excluding missing value categories, where p-values for trend were estimated by fitting the categorical variables linearly. I calculated survival time from the date of diagnosis until date of death. Patients who were still alive were censored on their last updated live status date in the cancer registration (between 5th and 10th January 2018). Where the date of death and date of diagnosis were the same, I added 0.1 day to cancer registry population survival time before selecting the comparison sample from it (breast: (n=2,108), prostate: (n=3,140), lung: (n=5,436), and colorectal: (n=2,617)). Finally, I compared median patient survival (in years) between the two groups using the Mann-Whitney test. All analyses were performed using Stata Software, version 15 (StataCorp, Texas, USA).

4.3 Results

Table 4-1 to Table 4-4 show the odds of being in the CPES group based on patient characteristics and tumour stage at diagnosis. Males were more likely to have responded to CPES than females among colorectal cancer patients but not among lung cancer patients (colorectal: adjusted OR 1.06, 95% CI: 1.02 - 1.10; lung: adjusted OR 0.96, 95% CI: 0.91 – 1.01). CPES responders were significantly younger than their registry counterparts across all cancers (median age: colorectal 68 vs. 74 years, $p < 0.001$; lung 68 vs. 73 years, $p < 0.001$; breast 58 vs. 64 years, $p < 0.001$; prostate 67 vs. 71 years, $p < 0.001$) (Figure 4-3). Patients with a non-White ethnic background were less likely to be in the CPES cohort across all cancers, although this was most statistically significant among people with an Asian background (colorectal: adjusted OR 0.67, 95% CI: 0.57 - 0.80; lung: adjusted OR 0.73, 95% CI: 0.57 - 0.94; breast: adjusted OR 0.67, 95% CI: 0.61 - 0.74; prostate: adjusted OR 0.79, 95% CI: 0.65 - 0.96). In addition, breast and prostate cancer patients from a black ethnic background were less likely to be in the CPES cohort (breast: adjusted OR 0.81, 95% CI: 0.72 - 0.92; prostate: adjusted OR 0.82, 95% CI: 0.71 - 0.95), while patients from a Chinese ethnic background were less likely to be in the CPES cohort among breast cancer patients only (adjusted OR 0.67, 95% CI: 0.50 - 0.88).

Table 4-1: Odds of colorectal cancer patients diagnosed between 2007 and 2013 having responded to CPES according to case-mix; adapted with permission from (Alessy, Davies, et al., 2019)

Variable	CPES (n=25,832)		Cancer Registry (non-CPES) (n=25,832)		Univariable		Mutually adjusted*	
Sex	N	%	N	%	OR	95% CI	OR	95% CI
Female	10,636	41.2	11,394	44.1		reference		reference
Male	15,196	58.8	14,438	55.9	1.13	1.09 - 1.17	1.06	1.02 - 1.10
Heterogeneity test					χ2 (1) =45.4; p < 0.001		χ2 (1) =9.2; p = 0.002	
Age Group								
<30	75	0.3	135	0.5	0.86	0.65 - 1.14	0.96	0.72 - 1.28
30-44	721	2.8	688	2.7	1.63	1.46 - 1.81	1.71	1.53 - 1.91
45-59	4,431	17.2	3,133	12.1	2.19	2.08 - 2.32	2.24	2.12 - 2.37
60-74	13,370	51.8	9,801	37.9	2.12	2.03 - 2.20	2.13	2.04 - 2.21
75-89	7,013	27.1	10,880	42.1		reference		reference
90+	222	0.9	1,195	4.6	0.29	0.25 - 0.33	0.31	0.27 - 0.36
Trend test					χ2 (1) =1291.4; p < 0.001		χ2 (1) =1281.3; p< 0.001	
Ethnicity								
White	22,563	87.3	20,836	80.7		reference		reference
Mixed	43	0.2	46	0.2	0.86	0.57 - 1.31	0.87	0.56 - 1.33
Asian	260	1.0	330	1.3	0.73	0.62 - 0.86	0.67	0.57 - 0.80
Black	199	0.8	224	0.9	0.82	0.68 - 0.99	0.84	0.69 - 1.03
Chinese	35	0.1	30	0.1	1.08	0.66 - 1.76	0.98	0.60 - 1.62
Other	4	0.0	7	0.0	0.53	0.15 - 1.80	0.53	0.15 - 1.87
Unknown	2,728	10.6	4,359	17.0	0.58	0.55 - 0.61	0.65	0.61 - 0.69
Heterogeneity test					χ2 (5) =20.0; p = 0.001		χ2 (5) =22.8; p< 0.001	
Area of residence								
South East	4,116	15.9	4,367	16.9		reference		reference
East Midlands	2,573	10.0	2,215	8.6	1.23	1.15 - 1.32	1.07	0.99 - 1.15
East of England	3,075	11.9	3,053	11.8	1.07	1.00 - 1.14	0.91	0.85 - 0.98
London	2,373	9.2	2,591	10.0	0.97	0.91 - 1.04	1.08	1.00 - 1.16
North East	1,578	6.1	1,457	5.6	1.15	1.06 - 1.25	1.14	1.04 - 1.24
North West	3,222	12.5	3,659	14.2	0.93	0.88 - 1.00	0.92	0.86 - 0.99

South West	3,268	12.7	3,117	12.1	1.11	1.04 - 1.19	1.02	0.95 - 1.09
West Midlands	3,060	11.8	2,823	10.9	1.15	1.08 - 1.23	1.04	0.96 - 1.11
Yorkshire and The Humber	2,567	9.9	2,550	9.9	1.07	1.00 - 1.14	0.99	0.92 - 1.07
Heterogeneity test					χ2 (8) =89.5; p <0.001		χ2 (8) =46.3; p <0.001	
Deprivation								
1- (most affluent)	5,988	23.2	5,404	20.9		reference		reference
2	6,370	24.7	5,659	21.9	1.02	0.97 - 1.07	1.01	0.96 - 1.07
3	5,500	21.3	5,430	21.0	0.91	0.87 - 0.96	0.92	0.87 - 0.97
4	4,551	17.6	4,938	19.1	0.83	0.79 - 0.88	0.84	0.79 - 0.89
5- (most deprived)	3,423	13.3	4,401	17.0	0.7	0.66 - 0.74	0.69	0.65 - 0.73
Trend test					χ2 (1) =184.1; p < 0.001		χ2 (1) =164.9; p < 0.001	
Stage								
I	2,155	8.3	2,473	9.6		reference		reference
II	4,404	17.0	3,687	14.3	1.37	1.27 - 1.47	1.48	1.37 - 1.60
III	6,381	24.7	3,784	14.6	1.94	1.80 - 2.08	1.93	1.80 - 2.08
IV	3,726	14.4	4,845	18.8	0.88	0.82 - 0.95	0.91	0.84 - 0.98
Not known	9,166	35.5	11,043	42.7	0.95	0.89 - 1.02	1.08	1.01 - 1.15
Trend test					χ2 (1) =14.2; p < 0.001		χ2 (1) =12.5; p < 0.001	

Abbreviations: CI= confidence interval, OR= odds ratio; *multivariable model including all factors; Unknown stage and ethnicity categories were not included in tests for heterogeneity and trend.

Table 4-2: Odds of lung cancer patients diagnosed between 2007 and 2013 having responded to CPES according to case-mix; adapted with permission from (Alessy, Davies, et al., 2019)

Variable	CPES (n=12,942)		Cancer Registry (non-CPES) (n=12,942)		Univariable		Mutually adjusted*	
Sex	N	%	N	%	OR	95% CI	OR	95% CI
Female	5,968	46.1	5,793	44.8		Reference		reference
Male	6,974	53.9	7,149	55.2	0.95	0.90 - 0.99	0.96	0.91 - 1.01
Heterogeneity test						χ2 (1) =4.7; p =0.02		χ2 (1) =2.6; p =0.10
Age Group								
<30	13	0.1	16	0.1	0.58	0.28 - 1.21	0.73	0.34 - 1.56
30-44	148	1.1	119	0.9	0.89	0.70 - 1.14	1.05	0.81 - 1.35
45-59	2,144	16.6	1,406	10.9	1.09	1.01 - 1.18	1.19	1.10 - 1.28
60-74	7,681	59.3	5,513	42.6		Reference		reference
75-89	2,922	22.6	5,397	41.7	0.39	0.37 - 0.41	0.38	0.36 - 0.41
90+	34	0.3	491	3.8	0.05	0.04 - 0.07	0.05	0.04 - 0.07
Trend test						χ2 (1) =1165.7; p < 0.001		χ2 (1) =1174.2; p < 0.001
Ethnicity								
White	11,566	89.4	10,287	79.5		Reference		reference
Mixed	23	0.2	19	0.1	1.08	0.59 - 1.98	0.75	0.40 - 1.39
Asian	128	1.0	151	1.2	0.75	0.59 - 0.96	0.73	0.57 - 0.94
Black	80	0.6	82	0.6	0.87	0.64 - 1.18	0.82	0.59 - 1.14
Chinese	19	0.1	14	0.1	1.21	0.60 - 2.41	1.00	0.48 - 2.09
Other	4	0.1	5	0.1	0.71	0.19 - 2.65	0.57	0.15 - 2.18
Unknown	1,122	8.7	2,384	18.4	0.42	0.39 - 0.45	0.49	0.45 - 0.54
Heterogeneity test						χ2 (5) =6.8; p =0.23		χ2 (5) =7.4; p = 0.1
Area of residence								
South East	1,631	12.6	1,903	14.7		Reference		reference
East Midlands	1,266	9.8	1,070	8.3	1.38	1.24 - 1.53	1.35	1.21 - 1.51
East of England	1,475	11.4	1,368	10.6	1.26	1.14 - 1.39	1.17	1.05 - 1.30
London	1,320	10.2	1,359	10.5	1.13	1.02 - 1.25	1.36	1.21 - 1.52
North East	1,034	8.0	944	7.3	1.28	1.14 - 1.43	1.27	1.13 - 1.44
North West	1,808	14.0	2,229	17.2	0.95	0.86 - 1.04	0.94	0.85 - 1.04

South West	1,349	10.4	1,229	9.5	1.28	1.16 - 1.42	1.21	1.09 - 1.35
West Midlands	1,354	10.5	1,302	10.1	1.21	1.10 - 1.34	1.18	1.06 - 1.32
Yorkshire and The Humber	1,705	13.2	1,538	11.9	1.29	1.18 - 1.42	1.25	1.12 - 1.39
Heterogeneity test					χ2 (8) =104.9; p < 0.001		χ2 (8) = 86.7; p < 0.001	
Deprivation								
1- (most affluent)	2,047	15.8	1,726	13.3		Reference		reference
2	2,603	20.1	2,251	17.4	1.04	0.96 - 1.13	1.00	0.91 - 1.09
3	2,662	20.6	2,595	20.1	0.92	0.84 - 1.00	0.85	0.78 - 0.93
4	2,733	21.1	2,880	22.3	0.83	0.77 - 0.90	0.75	0.68 - 0.82
5- (most deprived)	2,897	22.4	3,490	27.0	0.77	0.71 - 0.84	0.65	0.60 - 0.71
Trend test					χ2 (1) =73.4; p < 0.001		χ2 (1) =135.5; p < 0.001	
Stage								
I	2,170	16.8	1,422	11.0		Reference		reference
II	1,672	12.9	765	5.9	1.43	1.28 - 1.60	1.40	1.25 - 1.56
III	3,759	29.0	2,333	18.0	1.06	0.97 - 1.15	1.00	0.91 - 1.09
IV	4,210	32.5	6,170	47.7	0.45	0.41 - 0.48	0.42	0.38 - 0.45
Not known	1,131	8.7	2,252	17.4	0.33	0.30 - 0.36	0.36	0.33 - 0.40
Trend test					χ2 (1) =696.9; P < 0.001		χ2 (1) =713.7; p < 0.001	

Abbreviations: CI= confidence interval, OR= odds ratio; *multivariable model including all factors; Unknown stage and ethnicity categories were not included in tests for heterogeneity and trend.

Table 4-3: Odds of breast cancer patients diagnosed between 2001 and 2013 having responded to CPES according to case-mix; adapted with permission from (Alessy, Davies, et al., 2019)

Variable	CPES (n=43,966)		Cancer Registry (non-CPES) (n=43,966)		Univariable		Mutually adjusted*	
Age Group	N	%	N	%	OR	95% CI	OR	95% CI
<30	257	0.6	221	0.5	1.06	0.88 - 1.27	1.05	0.88 - 1.27
30-44	5,907	13.4	3,921	8.9	1.37	1.31 - 1.43	1.34	1.28 - 1.41
45-59	17,517	39.8	12,761	29.0	1.25	1.21 - 1.29	1.23	1.19 - 1.27
60-74	15,991	36.4	14,520	33.0		Reference		reference
75-89	4,175	9.5	10,825	24.6	0.35	0.34 - 0.37	0.34	0.33 - 0.35
90+	119	0.3	1,718	3.9	0.06	0.05 - 0.08	0.06	0.05 - 0.08
Trend test					χ2 (1) =3984.3; p < 0.001		χ2 (1) =3857.5; p < 0.001	
Ethnicity								
White	36,329	82.6	33,022	75.1		Reference		reference
Mixed	146	0.3	138	0.3	0.96	0.76 - 1.21	0.74	0.58 - 0.94
Asian	912	2.1	964	2.2	0.86	0.78 - 0.94	0.67	0.61 - 0.74
Black	576	1.3	539	1.2	0.97	0.86 - 1.09	0.81	0.72 - 0.92
Chinese	100	0.2	104	0.2	0.87	0.66 - 1.15	0.67	0.50 - 0.88
Other	30	0.1	24	0.1	1.14	0.66 - 1.94	0.84	0.48 - 1.45
Unknown	5,873	13.4	9,175	20.9	0.58	0.56 - 0.60	0.63	0.60 - 0.65
Heterogeneity test					χ2 (5) =11.7; p =0.03		χ2 (5) =76.1; p < 0.001	
Area of residence								
South East	7,040	16.0	8,010	18.2		Reference		reference
East Midlands	4,264	9.7	3,741	8.5	1.30	1.23 - 1.37	1.16	1.10 - 1.23
East of England	5,135	11.7	5,025	11.4	1.16	1.11 - 1.22	1.00	0.94 - 1.05
London	5,069	11.5	5,320	12.1	1.08	1.03 - 1.14	1.15	1.09 - 1.21
North East	2,417	5.5	2,118	4.8	1.30	1.21 - 1.39	1.14	1.07 - 1.23
North West	4,787	10.9	6,080	13.8	0.90	0.85 - 0.94	0.88	0.84 - 0.93
South West	5,364	12.2	5,016	11.4	1.22	1.16 - 1.28	1.11	1.05 - 1.17
West Midlands	5,250	11.9	4,509	10.3	1.32	1.26 - 1.39	1.20	1.14 - 1.27
Yorkshire and The Humber	4,640	10.6	4,147	9.4	1.27	1.21 - 1.34	1.11	1.05 - 1.18
Heterogeneity test					χ2 (8) =372.0; p < 0.001		χ2 (8) =178.5; p < 0.001	
Deprivation								

1- (most affluent)	10,154	23.1	9,883	22.5		Reference		reference
2	10,510	23.9	9,905	22.5	1.03	0.99 - 1.07	1.04	0.99 - 1.08
3	9,452	21.5	9,204	20.9	1	0.96 - 1.04	1.00	0.96 - 1.04
4	7,835	17.8	8,080	18.4	0.94	0.91 - 0.98	0.95	0.91 - 0.99
5- (most deprived)	6,015	13.7	6,894	15.7	0.85	0.81 - 0.89	0.84	0.80 - 0.88
Trend test					$\chi2$ (1) =60.4; p < 0.001		$\chi2$ (1) =73.6; p < 0.001	
Stage								
I	11,956	27.2	12,939	29.4		Reference		reference
II	14,047	31.9	10,685	24.3	1.42	1.37 - 1.47	1.54	1.49 - 1.60
III	3,983	9.1	2,377	5.4	1.81	1.71 - 1.92	1.90	1.79 - 2.02
IV	1,385	3.2	2,159	4.9	0.69	0.65 - 0.75	0.84	0.78 - 0.91
Not known	12595	28.6	15,806	36.0	0.86	0.83 - 0.89	1.06	1.02 - 1.10
Trend test					$\chi2$ (1) =63.7; p < 0.001		$\chi2$ (1) =157.3; p < 0.001	

Abbreviations: CI= confidence interval, OR= odds ratio; *multivariable model including all factors; Unknown stage and ethnicity categories were not included in tests for heterogeneity and trend.

Table 4-4: Odds of prostate cancer patients diagnosed between 2001 and 2013 having responded to CPES according to case-mix; adapted from (Alessy, Davies, et al., 2019)

Variable	CPES (n=20,446)		Cancer Registry (non-CPES) (n=20,446)		Univariable		Mutually adjusted*	
Age Group	N	%	N	%	OR	(95% CI)	OR	95% CI
<44	36	0.2	43	0.2	0.68	0.44 - 1.07	0.71	0.45 - 1.12
45-59	2,999	14.7	2,106	10.3	1.11	1.04 - 1.18	1.15	1.08 - 1.23
60-74	13,499	66	10,511	51.4		Reference		reference
75-89	3,870	18.9	7,241	35.4	0.42	0.40 - 0.44	0.41	0.39 - 0.43
90+	42	0.2	545	2.7	0.06	0.04 - 0.08	0.06	0.04 - 0.08
Trend test					χ2 (1) =1501.4; p < 0.001		χ2 (1) =1542.7; p < 0.001	
Ethnicity								
White	17,205	84.1	15,132	74.0		Reference		reference
Mixed	48	0.2	42	0.2	1.01	0.66 - 1.52	0.96	0.62 - 1.46
Asian	204	1.1	235	1.1	0.76	0.63 - 0.92	0.79	0.65 - 0.96
Black	396	1.9	449	2.2	0.78	0.68 - 0.89	0.82	0.71 - 0.95
Chinese	58	0.3	63	0.3	0.81	0.57 - 1.16	0.83	0.58 - 1.20
Other	24	0.1	8	0.1	2.64	1.19 - 5.87	2.29	1.02 - 5.16
Unknown	2,511	12.3	4,517	22.1	0.49	0.46 - 0.52	0.49	0.46 - 0.51
Heterogeneity test					χ2 (5) =27.7; p < 0.001		χ2 (5) =16.6; p = 0.005	
Area of residence								
South East	2,802	13.7	3,677	18.0		Reference		reference
East Midlands	2,015	9.9	1,712	8.4	1.54	1.42 - 1.67	1.47	1.35 - 1.60
East of England	2,378	11.6	2,613	12.8	1.19	1.11 - 1.29	1.14	1.05 - 1.24
London	1,959	9.6	2,316	11.3	1.11	1.03 - 1.20	1.21	1.11 - 1.31
North East	989	4.8	907	4.4	1.43	1.29 - 1.59	1.42	1.27 - 1.58
North West	3,737	18.3	2,508	12.3	1.96	1.82 - 2.10	2.04	1.89 - 2.19
South West	2,721	13.3	2,504	12.2	1.43	1.33 - 1.53	1.34	1.24 - 1.45
West Midlands	2,215	10.8	2,217	10.8	1.31	1.21 - 1.42	1.26	1.16 - 1.36
Yorkshire and The Humber	1,630	8.0	1,992	9.7	1.07	0.99 - 1.17	1.05	0.96 - 1.14
Heterogeneity test					χ2 (8) =470.1; p < 0.001		χ2 (8) =459.8; p < 0.001	
Deprivation								

1- (most affluent)	5,198	25.4	5,019	24.5		Reference		Reference
2	5,228	25.6	4,886	23.9	1.03	0.98 - 1.09	1.01	0.95 - 1.07
3	4,159	20.3	4,261	20.8	0.94	0.89 - 1.00	0.94	0.88 - 1.00
4	3,278	16.0	3,463	16.9	0.91	0.86 - 0.97	0.90	0.84 - 0.96
5- (most deprived)	2,583	12.6	2,817	13.8	0.89	0.83 - 0.95	0.83	0.78 - 0.90
Trend test						χ2 (1) =24.3; p < 0.001		χ2 (1) =40.5; p < 0.001
Stage								
I	3,081	15.1	3,044	14.9		Reference		Reference
II	3,032	14.8	2,560	12.5	1.37	1.27 - 1.47	1.20	1.12 - 1.30
III	2,279	11.1	1,791	8.8	1.93	1.08 - 2.07	1.26	1.16 - 1.37
IV	2,103	10.3	2,156	10.5	0.88	0.82 - 0.94	1.14	1.05 - 1.24
Not known	9951	48.7	10,895	53.3	0.95	0.89 - 1.02	1.08	1.01 - 1.14
Trend test						χ2 (1) =0.1; p =0.7		χ2 (1) =12.9; p < 0.001

Abbreviations: CI= confidence interval, OR= odds ratio; *multivariable model including all factors; Unknown stage and ethnicity categories were not included in tests for heterogeneity and trend

In addition, living in more deprived areas was associated with reduced odds of being in the CPES group across all cancers: colorectal (adjusted OR 0.69, 95% CI: 0.65 - 0.73 for most vs. least deprived), lung (adjusted OR 0.65, 95% CI: 0.60 - 0.71 for most vs. least deprived), breast (adjusted OR 0.84, 95% CI: 0.80 - 0.88 for most vs. least deprived), and prostate (adjusted OR 0.83, 95% CI: 0.78 - 0.90 for most vs. least deprived). Generally, CPES responders were more likely to be resident in areas other than the South East or North West. However, among prostate cancer patients, responders to the CPES were most likely to be resident in the North West (adjusted OR 2.04, 95% CI: 1.89-2.19 for North West vs. South East).

In general, when comparing cancer stage at diagnosis between the two cohorts, CPES responders were more likely to be diagnosed with stage II and III disease and less likely to be diagnosed with stage IV disease. The proportions of missing stage information were lower among CPES responders across all cancers. CPES responders with colorectal and breast cancers were more likely to be diagnosed with stage II (colorectal: adjusted OR 1.48, 95% CI: 1.37-1.60; breast: adjusted OR 1.54, 95% CI: 1.49-1.60), and III (colorectal: adjusted OR 1.93, 95% CI: 1.80-2.08; breast: adjusted OR 1.90, 95% CI: 1.79-2.02) while CPES responders with lung cancer patients were more likely to be diagnosed with stage II (adjusted OR 1.40, 95% CI: 1.25-1.60). Survey responders had a significantly higher median survival compared with the cancer registry population across all cancers, with the largest difference in lung cancer and colorectal cancer (colorectal: 4.8 vs 3.2 years, $p<0.001$; breast: 5.7 vs 5.4 years, $p<0.001$; and prostate: 5.7 vs 5.2 years, $p<0.001$; lung: 2.0 vs 0.3 years, $p<0.001$) (Figure 4-4).

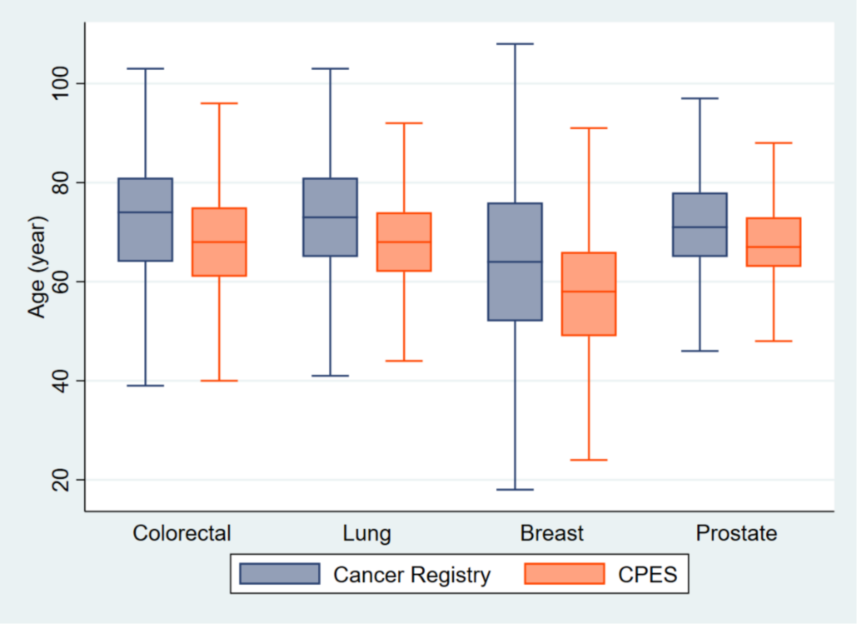


Figure 4-3: Comparison of median age between CPES responders and the cancer registry population across all cancers

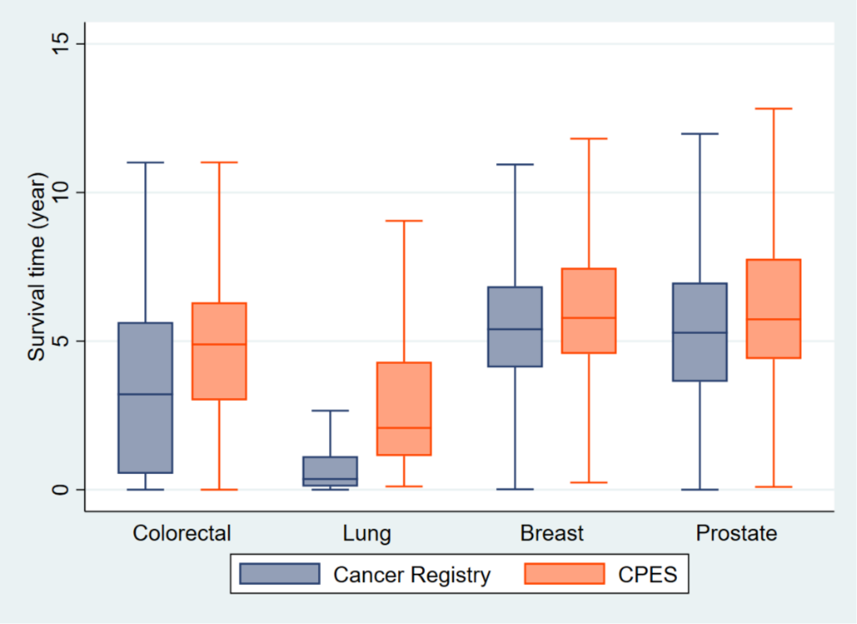


Figure 4-4: Comparison of median survival between CPES responders and the cancer registry population across all cancers

4.4 Discussion

4.4.1 Summary of main findings

This study examined how representative CPES responders for the four main cancers are compared with the cancer registry population with respect to individual characteristics and tumour stage at diagnosis. Overall, survey responders were younger, more likely to have a White ethnic background, to be living in less deprived areas, and diagnosed at stage II and III across all cancer types. There was a small difference by sex among patients with colorectal cancer with males being more likely to be in the CPES responder group than females, but not for those with lung cancer. Median survival was generally higher in CPES responders, although the magnitude varied across different cancers and was most pronounced in lung and colorectal cancer patients.

4.4.2 Comparison with other findings

My findings concerning the limited representativeness of the survey responders compared with the cancer registry population are consistent with several previous studies (Madden and Davies, 2010; Abel et al., 2016). Abel and colleagues examined those selected into the initial CPES sampling frame and found non-responders were more likely to be older, from more deprived areas, or diagnosed with poor prognosis cancers. These patients were more likely to have died in the two to three month period between the initial sampling and the mail out of the survey and so never received the survey (Abel et al., 2016).

The variation in median survival between the survey responders and the cancer registry population in my study, especially for lung cancer, is very likely related to this issue but may also represent patients who received the survey but were too ill to complete and return it. Abel et al’s findings are important when comparing CPES responders vs. non-responders (Abel et al., 2016). However, their study focussed on internal representativeness only, whereas I sought to address the question of how representative the CPES responders are of all patients diagnosed with one of the four most common cancers, and not only those who have had an inpatient experience. Although my findings are similar and align with theirs, my present study is important when comparing the responders to the wider cancer population with these cancer types. This is particularly important when using CPES findings to inform cancer care policy for all English patients whether they have a hospital admission or not.

My findings are also consistent with a recent published study that assessed the representativeness of lung cancer patients responding to CPES (Nartey et al., 2020). The study compared the sociodemographic and clinical characteristics for all CPES responders who were diagnosed between 2009 and 2015 to all lung cancer patients in the National Lung Cancer Audit who were diagnosed in the same time frame. Although the study used a different approach, it arrived at the same conclusion that CPES responders were more likely to be from less deprived groups and had better overall survival (Nartey et al., 2020).

It is of interest that CPES responders were more likely to be diagnosed with stage II or III disease compared to stage I. This may reflect a higher intensity of treatment which means they were more likely to be included in the sampling frame. Moreover, the low inclusion of patients with lung cancer patients as a proportion of the incidence is consistent with another study which found that the initial 2000 and 2004 patient experience surveys did not represent patients registered with lung cancer in South East England (the response rate for lung patients was between 6% -28% in 2000 and 2004, respectively)(Madden and Davies, 2010). It is also of interest that there was a small difference by sex among patients with colorectal cancer with males being more likely to be in the CPES responder group than females, but not for those with lung cancer. This association was attenuated in the full multivariable adjusted model, which might reflect the impact of other demographic or clinical factors included in the model.

4.4.3 Strengths and limitations of the study

To my knowledge, this study is the first to compare CPES responders directly to the cancer registry population using the CPES-NCRAS data linkage. One strength of my study is the large sample size, which allowed for detailed comparison of demographic and tumour stage at diagnosis between CPES responders and cancer registration patients for the four different cancer types. While most of the CPES responders for every survey year were recently diagnosed patients admitted and discharged from cancer care, CPES has a backward tail of patients diagnosed in previous years, representing long term survivors. The cancer registry population on the other hand is the annual cumulative incidence of all cancers diagnosed. I randomly selected one patient who was not a CPES responder for each CPES responder matched on cancer site and period of diagnosis (same yearly quarter) to eliminate survival time bias, and to achieve a similar level of stage and ethnicity data completeness for both groups.

I recognize that this study has several limitations. Although data completeness for stage and ethnicity at NCRAS has vastly improved since 2012 (Henson et al., 2019), a proportion of patients had missing information on disease stage and ethnicity. In addition, I extracted ethnicity information from the same data source to get a similar ethnicity completeness. Yet, ethnicity and stage completeness were slightly higher for the CPES group compared to the cancer registry population, which might be explained by CPES responders being more often admitted to hospital and therefore appearing more in the HES records. In addition, while CPES is based on NHS hospital discharges, it misses private patients who would be on cancer registration system. Besides that, there are patients who might have missed reminders sent by post because they were ill or may have moved to be in nursing homes or were staying with relatives. These limitations however are still important to investigate in recent CPES rounds after the implementation of the online response option.

4.4.4 Study implications

CPES aims to capture patients' experiences across many aspects of their care pathway and has successfully guided cancer policy, the monitoring and improvement of experiences and the development of cancer services across England (The Independent Cancer Taskforce, 2015a). The survey dataset is now linked to the cancer registry data, enabling researchers to explore more complex questions such as possible associations between cancer patients' experiences and their clinical outcomes. As I have shown, the representativeness of the dataset to the population of cancer patients is limited in some areas and varies between the four cancer types.

When using results generated from this dataset, cancer policy makers, cancer care providers, patient advocates, charities, and health researchers should therefore be aware of several limitations. First, my exploration of this dataset found that most of the survey responders were diagnosed close to the survey sampling frame period. This is because the CPES sampling frame is based on a recent period of hospital treatment, so the patients recruited may not represent the care experience or perspective for all cancer patients. Second, patients responding to the survey were more likely to be diagnosed with earlier stage disease, and to have a higher median survival. This leads to an under-representation of the experiences of patients with poor prognosis, which disproportionally affects certain cancer types. Patients excluded from the survey because of the sampling frame very likely have greater health needs including those for supportive and palliative care which the survey cannot capture.

In addition, there are notable differences in responders by cancer type by comparison with the cancer incidence registered every year in England. For example, out of all lung cancer incident cases diagnosed between 2011 and 2013 (n= 107,431), only 9% were captured in CPES (n= 9,381) compared with 22% (n= 28,781) for breast cancer (n= 128,552) (Office for National Statistics, 2019). As a consequence, the number of responses for individual cancer types may be too low to be reported and considered at a local level or to show improvement. This is particularly problematic for lung cancer - the most common cancer in males and females combined and the biggest killer of all the cancers (Office for National Statistics, 2019). Work is therefore needed to recruit more patients with poor prognosis cancers in particular, so that cancer services can be designed based on these patients' experiences and comments rather than on data from a mix of patients with other cancers.

Moreover, solutions to capture the under-represented groups might involve additional surveys that seek to capture experiences in the early part of the referral, investigation and diagnosis pathway from a larger number of patients. An alternative is to expand the current sampling frame or move to continuous sampling throughout the year for patients with poor prognosis cancers. For example, CAHPS has made efforts and initiatives to capture under-represented patients' voices (Anhang Price and Elliott, 2018). Another example of a study including under-represented patients is one carried in Denmark which aimed to capture lung cancer patient-reported outcomes (PROs) at a nationwide level (Brønserud et al., 2019). Future efforts should assess the feasibility of adopting similar methods for CPES as well as on the reasons behind the low response rates among patients with advanced stage disease, older patients, and those from non-White ethnic backgrounds.

4.5 Summary

This chapter demonstrates that while CPES has been a valuable tool for the large-scale reporting of patient experience, it does not necessarily represent all cancer patients in terms of patient and tumour stage at diagnosis for the four main cancers. These limitations need to be acknowledged by cancer policy makers, charities, cancer services, and patient representatives using the findings and by researchers interpreting results from the survey and the linked registry dataset. In addition, my findings are particularly important to inform my analysis for the rest of this thesis. Future research should examine the feasibility of applying either supplementary focussed or more continuous surveys for the under-represented groups of patients to capture their missing care experiences. The next chapter will examine the role of the Clinical Nurse Specialist (CNS) in cancer patients' experiences.

Chapter 5 : The Clinical Nurse Specialist (CNS) role in patients’ experiences of cancer care

This chapter assesses whether being given the names of a Clinical Nurse Specialist (CNS) is associated with reporting better cancer care experiences. This chapter also provides a discussion about possible reasons behind this association, and what the implications may be for cancer care in England.

5.1 Introduction

Patient experience is widely considered to be an important aspect of cancer care quality (Institute of Medicine, 2013; The Independent Cancer Taskforce, 2015a; Cleary, 2016; Wolf, 2018). Previous research in England and Europe has shown that hospital care quality varies in relation to inpatient nurse staffing and education and improves with higher levels of each across many care settings (Rafferty et al., 2007; Keogh, 2017; Aiken et al., 2014, 2012). CNS now play a key role in improving the quality of information provided to patients, co-ordinating their care, as well as assessing needs and providing emotional support (National Cancer Action Team, 2010; The Lancet, 2011; Challinor et al., 2020). Specifically in relation to cancer care, findings from CPES 2010 show that English cancer patients' experiences of care coordination and emotional support are better in NHS hospitals with large numbers of CNS (Griffiths et al., 2013).

CPES has been conducted annually since 2010 with the aim of assessing and improving patients’ experiences of NHS cancer care. The survey asks patients about a wide range of care aspects including whether they have been given the name of a CNS (Quality Health, 2019). Research using different years of CPES data has so far shown variation in cancer patients’ experiences by socio-demographic and health system factors (El Turabi et al., 2013; Bone et al., 2014; Saunders et al., 2015; Pinder et al., 2016; Griffiths et al., 2013; Salika et al., 2018). This variation included patients’ reports of being involved in decisions about treatment (El Turabi et al., 2013), their care coordination (Griffiths et al., 2013), of being treated with respect and dignity (Griffiths et al., 2013), and their overall care experience (Pinder et al., 2016). An important question is therefore whether being assigned a CNS has a direct impact on patients' care experiences at an individual level.

Linking the CPES dataset to the English population cancer registry has allowed for further studies to assess the potential association between patients' experiences and aspects of their cancer diagnosis, treatment and outcomes (Carneiro et al., 2017). Using the NCRAS-CPES linked dataset and focusing on the four most common cancers - colorectal, lung, breast and prostate cancers – I aimed to 1) compare the characteristics of patients who reported being given the name of a CNS with those who did not and 2) examine whether being given the name of a CNS is associated with more positive reports of experiences in care areas where CNS play a key role. These are: being involved in treatment decisions, perceiving care to be more co-ordinated, reporting being treated with respect and dignity, and having a more positive overall care experience. A more detailed understanding of the experiences of patients who have been assigned to CNS care can provide new evidence to support cancer policies.

5.2 Methodology

5.2.1 Data source

Information on CPES administration, sampling, and data linkage has been introduced in chapter 3. I extracted data on all individuals with invasive colorectal, lung, female breast, and prostate cancers who responded to CPES between 2010 and 2014 from the linked NCRAS-CPES dataset (n= 114,898). Some patients were surveyed more than once in different iterations of CPES. Therefore, I took the first survey record for each patient and removed additional responses (n=6293). I also excluded cases with a missing socioeconomic deprivation score for area of residence (n=174), inconsistent registration dates (n=1230), and patients who did not respond or provide informative answers about whether they have been given a CNS name (i.e. ‘I do not know’), or who did not report their care experiences (n= 6,311) (Figure 5-1).

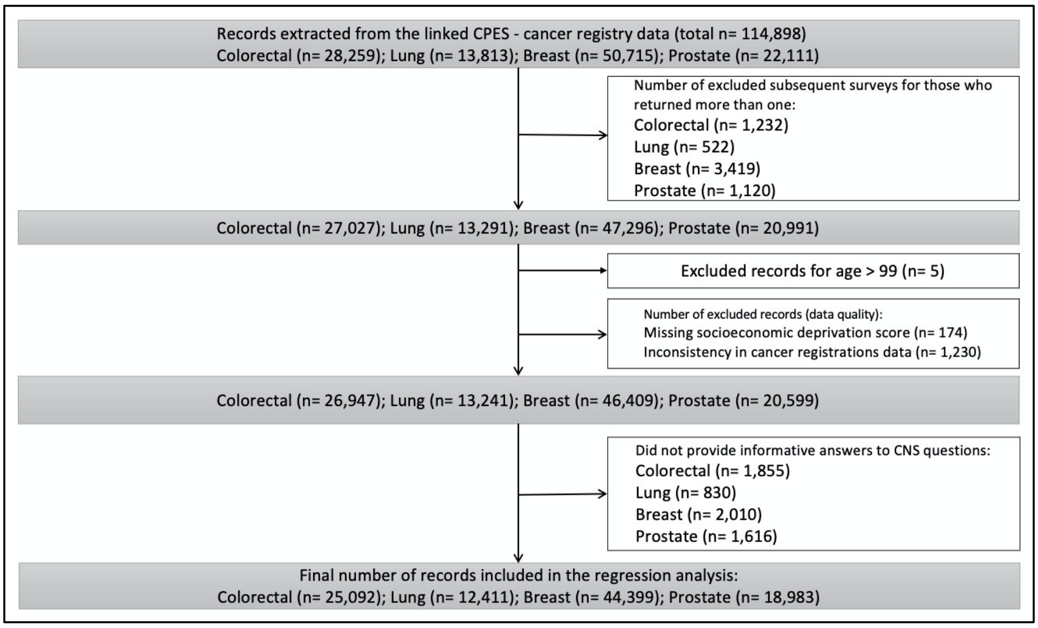


Figure 5-1: Flowchart for study participants

CPES contains four questions on aspects of CNS care. I focused my analysis on the survey question about patients being given the name of a CNS: ‘Were you given the name of a CNS who would be in charge of your care?’. Patients’ answers in CPES included ‘Yes’, ‘No’, or ‘I do not know’. Since CNS are actively involved with patients across the cancer care pathway, I selected four questions from CPES representing different aspects of patients’ experiences of cancer services where CNS are involved. I hypothesized a priori that patients who have been given a CNS name would report better experiences in response to questions on 1) Involvement in treatment decision, 2) Treatment with respect and dignity, 3) Overall care coordination, and 4) Overall care experience (see Table 5-1 for the questions selected for study). For the purposes of the analysis, I categorised patients’ responses into two main categories: ‘excellent’ and ‘non – excellent’ experience in line with other reports, (Pinder et al., 2016; Salika et al., 2018; El Turabi et al., 2013). An additional sensitivity analysis was undertaken for the effect of adding the response ‘most of the time’ to the ‘excellent’ experience category in treatment with respect and dignity aspect and adding the response ‘very good’ to ‘excellent’ experience category in overall care experience aspect.

Table 5-1: CPES questions on aspects of cancer care categorised into excellent and not excellent experience

Cancer care aspects	Question as phrased in CPES	Experience categories based on CPES answers		Notes
		Excellent	Not excellent	
Involvement in treatment decision	Were you involved as much as you wanted to be in decisions about your care and treatment?	Yes, definitely	Yes, to some extent No, but I would like to have been more involved'	I excluded patients who did not provide informative answers: “There was only one treatment option” or “Not sure / can't remember”
Treatment with respect and dignity	Were you treated with respect and dignity by the doctors and nurses and other hospital staff?	Always	Most of the time Some of the time Never	‘Most of the time’ was categorised as an excellent experience in the sensitivity analysis
Overall care coordination	Sometimes people with cancer feel they are treated as “a set of cancer symptoms”, rather than a whole person. In your NHS care over the last year did you feel like that?	No	Yes, often Yes, sometimes	No sensitivity analysis was needed for this question
Overall care experience	Overall, how would you rate your care?	Excellent	Very good Good Fair Poor	This question is only available in CPES 2012 - 2014; ‘very good’ was categorised as an excellent experience in the sensitivity analysis

5.2.2 Patient characteristics

For all patients, I included information on demographic and tumour characteristics at diagnosis that previous research has linked to variation in reported experiences of care (Saunders et al., 2015; Salika et al., 2018; Pinder et al., 2016; El Turabi et al., 2013), or shown to be associated with access to CNS. These include sex, age, socioeconomic deprivation of area of residence, ethnicity, geographical region of residence in England, route to diagnosis and disease stage.

Data on sex, age, geographical region of residence, deprivation of area of residence and TMN disease stage were available in the cancer registry dataset for all patients with cancer. For lung cancer, I extracted additional stage information from NLCA (n=2,888), which includes more detailed clinical and multi-disciplinary team data (National Lung Cancer Audit, 2015). Although ethnicity data are collected in the survey, the response categories were slightly different in each survey year. I therefore used self-recorded ethnicity information within cancer registration data which is in turn derived initially from COSD and supplemented form HES data (NHS Digital, 2018). Due to the limited numbers in each ethnic category, I collapsed the 16-group classification into two categories: all White background (i.e., British, Irish and other White background), and non-White.

Socioeconomic deprivation is measured using the income domain of the IMD. Detailed information on socioeconomic deprivation measurement has been introduced in chapter 3. Individual patients are assigned a score of 1 (least deprived) through 5 (most deprived) based on the quintile of distribution that their LSOA of residence at time of diagnosis falls within. Route to diagnosis data are available for all cancer cases diagnosed in England since 2006 and are derived by linking HES data, Cancer Waiting Times data, cancer screening programs data, and cancer registration data (Elliss-Brookes et al., 2012; Henson et al., 2019). The categories used are emergency presentation, general practice referral, screening, two-week referral, and elective referral.

5.2.3 Data analysis

A total number of 100,885 cases were included in the analysis (colorectal n=25,092; lung n=12,411; breast n=44,399; prostate n=18,983). I tabulated the distribution of patient characteristics (age, sex, socioeconomic deprivation, ethnicity, geographical areas) and disease stage at diagnosis between patients reporting that they were given the name of a CNS and those who did not (Table 5-2). Chi-square test was performed to estimate the p-values for differences between groups. To assess whether being given the name of a CNS influenced patients' experiences of being involved in treatment decisions, their feeling about care coordination, being treated with respect and dignity, and their overall care experience with NHS cancer care, I compared responses between patients who reported being given the name of a CNS and those who did not using univariable and multivariable logistic regression. I first performed explanatory univariable analyses for all included variables across all cancers, and assessed whether there is an interaction between stage at diagnosis and route to diagnosis as shown in previous studies (Pham, Gomez-Cano, et al., 2019; Salika et al., 2018). Finally, Cohen's Kappa coefficient test was used to assess the interrater reliability of lung cancer patients' reports of being given the name of a CNS in CPES with the clinical data from the NLCA on whether or not they had been assigned a CNS. All analyses were performed using Stata Software, version 15.1 (StataCorp, Texas, USA).

5.3 Results

Patients' demographic and cancer stage characteristics are shown in Table 5-2. Overall, 90.5% of colorectal, 92.2% of lung, and 93.9% of breast cancer patients reported being given the name of a CNS compared to only 86.4% of prostate cancer patients. There were slight variations by demographic and cancer stage characteristics across all cancers between patients who reported being given the name of a CNS compared with those who did not (Table 5-2).

Patients' reported experiences with four aspects of cancer care according to having been given the name of a CNS are shown in (Table 5-3). After adjusting for these variables in univariable and multivariable logistic regression analyses, being given the name of a CNS was strongly associated with reporting better experiences across all aspects of care (being involved in treatment decisions, perceiving care as more coordinated, reporting being treated with respect and dignity, and reporting a positive overall experience with NHS care) for all cancers (Table 5-4 and Table 5-5).

All the included variables in the univariable logistic regression analyses were independently associated with the reported experiences although the strength of the association varied. These were, sex, age, socioeconomic deprivation of area of residence, ethnicity, geographical region of residence in England, route to diagnosis and disease stage at diagnosis. Due to the large number of produced tables, these numbers were only inspected, but were not included in this thesis. I only reported only final models by care experience aspects and cancer type, which are provided in (Table 5-4 and Table 5-5).

Experience of being involved in the treatment decision was the aspect of care most improved (rated excellent) if patients reported being given the name of a CNS (colorectal: adjusted OR 2.69, 95% CI: 2.45 – 2.96; lung: adjusted OR 2.41, 95% CI:

2.07 - 2.78; breast: adjusted OR 2.68, 95% CI: 2.47 - 2.92; prostate: adjusted OR 2.11, 95% CI: 1.92 - 2.32) (Table 5-4 and Table 5-5). Across all cancers, this was followed by overall care experience, care coordination, and being treated with respect and dignity. In a sensitivity analysis, the association between having been given the name of a CNS and having excellent care experiences was stronger across all cancers for the respect and dignity and overall care experience aspects (Table 5-4 and Table 5-5).

Table 5-6 shows the number of lung cancer patients who reported being given the name of a CNS in comparison to the assignment of a CNS recorded by NLCA. Most of the patients who reported having been given the name of a CNS were also recorded as having been allocated a CNS (Kappa = 0·80; very good agreement; P-value <0.001; 95%CI = (0.79 - 0.82).

Table 5-2: Patient demographics and tumour stage at diagnosis for CPES responders with colon, lung, breast and prostate cancers according to reporting being given the name of a CNS

Reporting being given a CNS name	**Colorectal cancer**				**Lung cancer**				**Breast cancer**				**Prostate cancer**			
	Yes	**%**	**No**	**%**	**Yes**	**%**	**No**	**%**	**Yes**	**%**	**No**	**%**	**Yes**	**%**	**No**	**%**
	22,716	90.5	2,376	9.5	11,449	92.2	962	7.8	41,681	93.9	2,718	6.1	16,405	86.4	2,578	13.6
Variable	**N**	**%***	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Sex																
Male	13,514	59.5	1,367	57.5	6,178	54.0	505	52.5	-	-	-	-	16,405	100	2,578	100
Female	9,202	40.5	1,009	42.5	5,271	46.0	457	47.5	41,681	100	2,718	100	-	-	-	-
χ2 and P value	*χ2 =3.4; p=0.06*				*χ2 =0.7; p=0.3*				-				-			
Age Group																
< 45	707	3.1	74	3.1	138	1.2	20	2.1	5,690	13.7	470	17.3	30	0.2	4	0.2
45 - 59	3,924	17.3	448	18.9	1,932	16.9	159	16.5	16,494	39.6	1,188	43.7	2,517	15.3	333	12.9
60 - 74	11,966	52.7	1,118	47.1	6,918	60.4	525	54.6	15,402	37.0	811	29.8	11,093	67.6	1,564	60.7
75 - 99	6,119	26.9	736	31.0	2,461	21.5	258	26.8	4,095	9.8	249	9.2	2,765	16.9	677	26.3
χ2 and P value	*χ2 =28.9; p<0.001*				*χ2 = 21.9; p<0.001*				*χ2 =71.8; p<0.001*				*χ2 =133.6; p<0.001*			
Ethnicity																
White	19,969	87.9	2,059	86.7	10,290	89.9	827	86.0	34,759	83.4	2,265	83.3	13,978	85.2	2,163	83.9
Non - white	650	2.9	73	3.1	299	2.6	39	4.1	2,038	4.9	162	6.0	635	3.9	116	4.5
Unknown	2,097	9.2	244	10.3	860	7.5	96	10.0	4,884	11.7	291	10.7	1,792	10.9	299	11.6
χ2 and P value	*χ2 = 3.1; p=0.2*				*χ2 =15.3; p<0.001*				*χ2 =8.1; p=0.01*				*χ2 =3.5; p=0.1*			
Area																
East Midlands	2,176	9.6	292	12.3	1,089	9.5	100	10.4	3,755	9.0	445	16.4	1,478	9.0	355	13.8
East of England	2,763	12.2	260	10.9	1,318	11.5	102	10.6	4,957	11.9	236	8.7	1,975	12.0	248	9.6
London	2,140	9.4	190	8.0	1,143	10.0	121	12.6	4,732	11.4	311	11.4	1,480	9.0	322	12.5
North East	1,431	6.3	107	4.5	973	8.5	46	4.8	2,417	5.8	71	2.6	837	5.1	88	3.4
North West	2,833	12.5	246	10.4	1,554	13.6	163	16.9	4,693	11.3	181	6.7	3,159	19.3	347	13.5
South East	3,658	16.1	374	15.7	1,437	12.6	127	13.2	6,600	15.8	504	18.5	2,296	14.0	337	13.1
South West	2,998	13.2	229	9.6	1,228	10.7	79	8.2	5,077	12.2	398	14.6	2,170	13.2	353	13.7
West Midlands	2,549	11.2	387	16.3	1,162	10.1	127	13.2	4,819	11.6	428	15.7	1,730	10.5	303	11.8
Yorkshire & Hum	2,168	9.5	291	12.2	1,545	13.5	97	10.1	4,631	11.1	144	5.3	1,280	7.8	225	8.7
χ2 and P value	χ2 =127.2; p<0.001				χ2 =50.8; p<0.001				χ2 =406.3; p<0.001				χ2 = 152.4; p<0.001			
IMD																
1- most affluent	5,356	23.6	508	21.4	1,789	15.6	168	17.5	9,630	23.1	692	25.5	4,230	25.8	664	25.8
2	5,622	24.7	600	25.3	2,318	20.2	174	18.1	10,033	24.1	620	22.8	4,204	25.6	659	25.6

3	4,822	21.2	505	21.3	2,363	20.6	195	20.3	8,984	21.6	577	21.2	3,360	20.5	503	19.5
4	3,962	17.4	426	17.9	2,436	21.3	204	21.2	7,362	17.7	503	18.5	2,571	15.7	455	17.6
5- most deprived	2,954	13.0	337	14.2	2,543	22.2	221	23.0	5,672	13.6	326	12.0	2,040	12.4	297	11.5
χ2 and P value	*χ2 = 7.2; p=0.1*				*χ2 = 4.2; p=0.3*				*χ2 = 13.8; p=0.008*				*χ2 =8.0; p=0.09*			
Route to Diagnosis																
ER	2,709	11.9	607	25.5	1,442	12.6	125	13.0	493	1.2	67	2.5	553	3.4	146	5.7
GP	5,638	24.8	558	23.5	2,883	25.2	263	27.3	2,931	7.0	286	10.5	6,868	41.9	917	35.6
Screening	3,322	14.6	164	6.9	-	-	-	-	12,457	29.9	609	22.4	-	-	-	-
2-week referral	8,263	36.4	700	29.5	5,272	46.0	358	37.2	22,867	54.9	1,277	47.0	6,381	38.9	723	28.0
Elective Referral	2,427	10.7	265	11.2	1,707	14.9	195	20.3	852	2.0	79	2.9	1,545	9.4	282	10.9
Unknown	357	1.6	82	3.5	145	1.3	21	2.2	2,081	5.0	400	14.7	1,058	6.4	510	19.8
χ2 and P value	*χ2 =468.5; p<0.001*				*χ2 =39.2; p<0.001*				*χ2 =594.6; p<0.001*				*χ2 =608.2; p<0.001*			
Stage																
I	1,945	8.6	142	6.0	1,823	15.9	262	27.2	11,760	28.2	559	20.6	2,499	15.2	305	11.8
II	3,958	17.4	330	13.9	1,478	12.9	112	11.6	13,258	31.8	790	29.1	2,624	16.0	237	9.2
III	5,677	25.0	489	20.6	3,396	29.7	206	21.4	3,727	8.9	237	8.7	2,012	12.3	154	6.0
IV	3,076	13.5	465	19.6	3,777	33.0	237	24.6	1,221	2.9	169	6.2	1,690	10.3	280	10.9
Unknown	8,060	35.5	950	40.0	975	8.5	145	15.1	11,715	28.1	963	35.4	7,580	46.2	1,602	62.1
χ2 and P value	*χ2 = 117.6; p<0.001*				*χ2 =150.9; p<0.001*				*χ2 =196.0; p<0.001*				*χ2 =280.7; p<0.001*			

Abbreviations: CNS = Clinical Nurse Specialist; IMD = indices of multiple deprivation; GP = general practitioner; ER = emergency presentation; χ2= Chi square test, with unknown ethnicity, route to diagnosis, and stage as a category.

***** column percentage

Table 5-3: Level of patients' reported experiences with four aspects of cancer care for CPES responders with colon, lung, breast and prostate cancers according to reporting being given the name of a CNS

Care aspect	Involvement in treatment decision				Treatment with respect and dignity				Overall care coordination				Overall care experience			
Level of experience	**Non-Excellent**		**Excellent**		**Non-Excellent**		**Excellent**		**Non-Excellent**		**Excellent**		**Non-Excellent**		**Excellent**	
Reporting being given a CNS name	**N***	**%****	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Colorectal Cancer	5,688	25.0	17,036	75.0	3,729	18.6	16,313	81.4	4,061	16.9	19,925	83.1	8,052	44.3	10,143	55.7
No	951	45.7	1,128	54.3	488	29.8	1,152	70.2	660	29.2	1,602	70.8	1,041	63.1	609	36.9
Yes	4,737	22.9	15,908	77.1	3,241	17.6	15,161	82.4	3,401	15.7	18,323	84.3	7,011	42.4	9,534	57.6
χ2 and P value ‡	χ2 =523.1; p<0.001				χ2 = 146.6; p<0.001				χ2 =266.3; p<0.001				χ2 =260.9; p<0.001			
Lung cancer	3,057	26.9	8,289	73.1	1,112	16.4	5,672	83.6	2,510	21.1	9,396	78.9	4,071	43.9	5,204	56.1
No	367	44.3	462	55.7	134	23.3	440	76.7	291	31.9	622	68.1	398	61.5	249	38.5
Yes	2,690	25.6	7,827	74.4	978	15.7	5,232	84.3	2,219	20.2	8,774	79.8	3,673	42.6	4,955	57.4
χ2 and P value	χ2 =136.4; p<0.001				χ2 =22.1; p<0.001				χ2 =69.2; p<0.001				χ2 =87.7; p<0.001			
Breast cancer	10,850	26.1	30,653	73.9	5,603	15.7	29,974	84.3	9,297	21.5	33,881	78.5	13,119	40.5	19,277	59.5
No	1,201	48.4	1,282	51.6	486	27.7	1,268	72.3	1,006	38.2	1,630	61.8	1,236	64.2	688	35.8
Yes	9,649	24.7	29,371	75.3	5,117	15.1	28,706	84.9	8,291	20.5	32,251	79.5	11,883	39.0	18,589	61.0
χ2 and P value	χ2 =675.7; p<0.001				χ2 = 198.8; p<0.001				χ2 =459.6; p<0.001				χ2 =478.6; p<0.001			
Prostate cancer	4,374	24.5	13,477	75.5	1,320	15.0	7,489	85.0	3,142	17.4	14,911	82.6	6,512	46.2	7,588	53.8
No	935	40.1	1,399	59.9	202	20.5	785	79.5	594	24.3	1,854	75.7	1,068	61.0	682	39.0
Yes	3,439	22.2	12,078	77.8	1,118	14.3	6,704	85.7	2,548	16.3	13,057	83.7	5,444	44.1	6,906	55.9
χ2 and P value	χ2 =351.2; p<0.001				χ2 =26.2; p<0.001				χ2 =92.7; p<0.001				χ2 =177.1; p<0.001			

***** The total responses across the different questions are not the same because patients did not respond to all four questions. Further description on this can be found in the methodology section.; **χ2**: Chi square test; ****** Row percentage

Table 5-4: Odds ratio of having excellent care experiences according to reporting being given the name of a CNS for colorectal and lung cancer patients

	Colorectal Cancer				**Lung cancer**			
	Univariable		**Multivariable**		**Univariable**		**Multivariable**	
Cancer care aspects	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Involvement in treatment decision	2.83	2.58 - 3.10	2.69	2.45 - 2.96	2.31	2.00 - 2.66	2.41	2.07 - 2.78
Treatment with respect and dignity	1.98	1.77 - 2.21	1.93	1.72 - 2.17	1.62	1.33 - 2.01	1.68	1.36 - 2.08
Overall care coordination	2.21	2.01 - 2.44	2.12	1.92 - 2.35	1.88	1.59 - 2.14	1.91	1.63 - 2.21
Overall care experience	2.32	2.09 - 2.58	2.19	1.96 - 2.43	2.15	1.83 - 2.54	2.15	1.81 - 2.53
Sensitivity analysis‡								
Treatment with respect and dignity	2.88	2.34 – 3.56	2.88	2.31 - 3.58	2.09	1.42 - 3.09	2.19	1.47 - 3.27
Overall care experience	3.02	2.68 - 3.42	2.83	2.49 - 3.21	2.93	2.42 - 3.54	2.87	2.37 - 3.49

Univariable model = having been given the name of a CNS is the exposure and having an excellent care experience is the outcome. **Multivariable model =** Adjusted for sex (only in lung and Colorectal cancers), age, ethnicity (missing as a covariate), area, socioeconomic deprivation, route to diagnosis (missing as a covariate), and stage (missing as a covariate). ‡**Sensitivity analysis** = Excellent care experience with being treated with respect & dignity = 'always' and 'most of the time' vs· all other categories; Excellent overall experience with care = 'excellent' and 'very good' vs· all other categories.

Table 5-5: Odds ratio of having excellent care experiences according to reporting being given the name of a CNS for breast and prostate cancer patients

	Breast cancer				**Prostate cancer**			
	Univariable		**Multivariable**		**Univariable**		**Multivariable**	
Cancer care aspects	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**	**OR**	**95% CI**
Involvement in treatment decision	2.85	2.62 - 3.09	2.68	2.47 - 2.92	2.34	2.14 - 2.57	2.11	1.92 - 2.32
Treatment with respect and dignity	2.15	1.92 - 2.39	2.03	1.80 - 2.27	1.54	1.30 - 1.82	1.51	1.26 - 1.78
Overall care coordination	2.40	2.21 - 2.60	2.24	2.06 - 2.44	1.64	1.48 - 1.81	1.57	1.41 - 1.75
Overall care experience	2.81	2.55 - 3.09	2.63	2.39 - 2.90	1.98	1.79 - 2.20	1.86	1.68 - 2.07
Sensitivity analysis‡								
Treatment with respect and dignity	2.56	2.07 – 3.16	2.36	1.90 - 2.92	2.65	1.86 - 3.77	2.82	1.95 - 4.09
Overall care experience	3.51	3.14 - 3.92	3.26	2.91 - 3.66	2.51	2.21 - 2.83	2.42	2.13 - 2.75

Univariable model = having been given the name of a CNS is the exposure and having an excellent care experience is the outcome. **Multivariable model =** Adjusted for sex (only in lung and Colorectal cancers), age, ethnicity (missing as a covariate), area, socioeconomic deprivation, route to diagnosis (missing as a covariate), and stage (missing as a covariate). ‡**Sensitivity analysis** = Excellent care experience with being treated with respect & dignity = ‘always’ and ‘most of the time’ vs· all other categories; Excellent overall experience with care = ‘excellent’ and ‘very good’ vs· all other categories.

Table 5-6: Comparison of the agreement between reporting being given the name of a CNS in CPES and indication of being assigned a CNS in the cancer registry data for lung cancer patients

Reporting being given a CNS name in CPES	**Being allocated a CNS from cancer registry data**				Kappa ‡**
	No	Yes	Missing	Total	Kappa = 0.80;
No	50	631	281	962	P-value = <0.001;
Yes	174	9,506	1,769	11,449	95% CI = (0.79 - 0.82)
Total	224	10,137	2,050	12,411	

‡ Kappa test did not include missing data

** Very good agreement

5.4 Discussion

5.4.1 Summary of main findings

This study used four years of linked CPES and cancer registration data for 100,885 patients to examine whether being given the name of a CNS is associated with reporting more positive care experiences for patients with breast, colorectal, lung and prostate cancers. A strong association emerged between being given the name of a CNS and reporting being more involved in treatment decisions, perceiving care as more coordinated, being treated with dignity and respect, and better overall experiences with NHS cancer care across all four cancer types.

5.4.2 Comparison with other findings

Few large population studies on the role of the CNS in cancer care have considered its possible influence across the cancer care pathway. A previous study using 2010 CPES data alone revealed that numbers of CNS per NHS hospital trust varied across England (Griffiths et al., 2013). It also showed patients' experiences of care coordination and emotional support were better in hospital trusts that had higher numbers of CNS. While I have not assessed the relationship of experience to the numbers of CNS in each trust, my case-mix adjusted analysis now shows better individual patient experiences with involvement in treatment decisions, perceived care coordination, being treated with dignity and respect, and overall care experience with NHS cancer care when patients themselves report being given the name of a CNS.

A recent Swedish study found that the implementation of a new oncology nursing role led to improvements in patients' perceptions of health-related information, supportive care resources, and care coordination of care (Westman et al., 2019). My findings are therefore consistent and suggest that it is the presence of CNS that is important in improving patients' experiences. In addition, my findings also align with a previous mixed method study which assessed whether prostate cancer patients who saw a CNS had different experiences than who did not (Tarrant et al., 2008). Although the study was limited to three hospitals across the UK, patients who reported being seen by a CNS had better experiences with receiving treatment information and shared-treatment decision (Tarrant et al., 2008). Moreover, a recent Cochrane review highlighted the role of specialist breast care nurses in supporting women with breast cancer(Brown et al., 2021). In particular, the evidence from this review suggests that specialist breast care nurses play a crucial role in improving cancer patients' health-related and cancer-specific quality of life, controlling patients' depression and anxiety, and improving satisfaction with care (Brown et al., 2021).

Furthermore, previous research has highlighted variation in access to CNS both by region of residence and by cancer type (Leary et al., 2011; Trevatt et al., 2008). My study also revealed variation in being given the name of a CNS by cancer type and geographical region. Although among CPES responders 93% of lung cancer patients reported being given a CNS, only around 71% of lung cancer patients overall in England were assessed by a lung CNS in 2017 (Royal College of Physicians, 2019). While this could not be verified for the other cancers due to the lack of independent reliable data on CNS assignment, the difference for lung cancer may reflect the fact that the survey data are less representative of all lung cancer patients than for the other three cancers (S. A. Alessy, Davies, et al., 2019).

5.4.3 Strengths and limitations of the study

To my knowledge, this study is the first to use linked cancer experience and cancer registration data to examine the role of the CNS in affecting patients' experiences across many aspects of cancer care. One strength of my study is the large sample size and the different cancer types studied. This allowed for detailed case-mix adjustment of the role of the CNS across different aspects of cancer care in a diverse cancer population.

I recognize that my study has some limitations. First, studies using survey data are prone to recall bias. Some patients in this study might therefore have reported not having been given the name of a CNS when in fact they had, an error which would have resulted in what is termed 'non-differential misclassification bias'. This therefore might have led to the assumption that being given a CNS name, which is the independent variable in this study, is not a good measure of actual allocation and so of exposure to a CNS for cancer patients. Indeed, initially I had hypothesised that the CNS name question was likely to be a good indication of CNS allocation as it shows an important aspect of cancer care from patients' perspectives. I was also able to validate the survey reports in the case of lung cancer patients by using independent clinical data collected by the NLCA. A large percentage (83%) of patients who reported having been given a CNS name had also been recorded as being assigned to one according to the NLCA. My results also align with previous studies findings on the allocation of lung cancer CNS in England (Stewart et al., 2018, 2020). Finally, the two patient representatives advising on the study who themselves have conducted some work on CPES and agreed on the relevance of the finding to clinical care.

Second, although CPES had a good response rate (64% - 68%) between 2010 and 2014, it needs to be borne in mind that the survey only samples a section of the wider cancer population and studies have shown that patients with the poorest prognosis are not always well represented (Abel et al., 2016; S. A. Alessy, Davies, et al., 2019). In addition, although NCRAS data completeness for stage and ethnicity has improved since 2012 (Henson et al., 2019), a proportion of patients had missing information on disease stage, ethnicity, and route to diagnosis. For lung cancer stage, missing information was extracted with information available from the NLCA. Finally, a small percentage of patients had unknown route to diagnosis data, which varied between cancers. This is largely due to the unavailability of these data for some patients in this cohort who had been diagnosed before 2006- when the coverage of these data began (Elliss-Brookes et al., 2012).

5.4.4 Study implications

Improving patients' experiences of cancer care has been a high priority in the NHS cancer strategy (The Independent Cancer Taskforce, 2015a). CNS play an vital role in cancer patients' care pathways by eliciting and managing their concerns, promoting their wellbeing, providing physical and emotional support, coordinating care services, and informing and advising them (Macmillan Cancer Support, 2014; Whittaker et al., 2017; Dempsey et al., 2016). There is, however, currently concern about the challenges facing CNS in cancer care because of restrictions on funding and an ageing workforce (Whittaker et al., 2017). Whilst the CNS workforce is continuing to grow, more are now employed on band 5 and 6 than in previous years, suggesting they are less experienced and skilled, which might impact the quality of care and hence cancer patients' experiences (Macmillan Cancer Support, 2017). Moreover, some variability still exists in the number of CNS vacancy posts across England (Macmillan Cancer Support, 2017). This variability will therefore require careful workforce planning to ensure recruitment and retention to the CNS workforce in order to maintain the level of patient experience reported in this study.

The study showed that CNS may play a crucial role in improving patients' experiences in several important aspects across the cancer care pathway. These findings are particularly important as excellent experiences have been shown to benefit patient safety and outcomes (Keating et al., 2002; Brown et al., 2012; S. A. Alessy, Lüchtenborg, et al., 2019; Doyle et al., 2013). One way of interpreting my findings is that giving patients a named CNS enables a trusted relationship to grow more quickly in the initial period after diagnosis. This could prevent or offset the effect of seeing different clinicians at subsequent appointments and re-explaining concerns, which patients often describe as a frustrating experience. Future research should focus on how well CPES captures experiences of the work done by CNS, the extent of equity in access to care, and on determining whether it is CNS availability, the size of the cancer centre or its ability to foster organisational cultures that empower both CNS and the whole cancer team that lead to the improved experiences of care.

5.5 Summary

This chapter demonstrates evidence of the positive impact of a CNS on patients' experiences across several important aspects of the cancer care pathway. If this association is causal, then removing CNS from cancer care will diminish cancer care quality and outcomes. My findings can be used by cancer policy makers, charities, cancer services, and patient representatives as evidence of the significant role CNS play in cancer care. Future research should focus on determining where and how CNS play the most vital role, as reflected in improved patient experiences, and how to ensure equity of access to their care. As this chapter focused on assessing the role of CNS in patients' experiences, the next chapter will provide an overview on other factors influencing cancer patients' experiences of care across diverse cancer populations. The chapter also introduces a conceptual framework that was developed to underpin the analysis to assess and understand the possible association between patients' experiences and their subsequent survival.

Chapter 6 : Factors influencing cancer patients' experiences of care: A systematic review and development of a conceptual framework

This chapter provides an overview on factors influencing cancer patients' experiences of care across diverse cancer populations. The chapter also describes a conceptual framework that was developed to underpin the analysis to assess and understand the possible association between patients' experiences and their subsequent survival.

6.1 Introduction:

Cancer patient experience is developing as a measure of cancer care quality to guide service improvements and as a research field in its own right. Recently there has been an increase in research that attempts to explore the possible association between patents' ratings of care satisfaction, or their experiences of care with their subsequent outcomes (Fenton, 2012; S. A. Alessy, Lüchtenborg, et al., 2019; Doyle et al., 2013). However, as shown in chapter 2, this association seems to be complex and needs careful and appropriate methodological consideration before conclusions can be drawn. One challenge is finding data that have been collected for the purpose of measuring patients' experiences along with information on patients' care outcomes (Manary et al., 2013; Xu et al., 2015; Anhang Price et al., 2014). Three cancer patient experience surveys are currently being used at a national population level to assess patients' experiences with cancer care: CPES in UK (Quality Health, 2019), CAHPS in USA (Chawla et al., 2015), and Ambulatory Oncology Patient Satisfaction Survey (AOPSS) in Canada (Chadder et al., 2018; Bridge et al., 2019). CAHPS and CPES datasets have been linked to cancer registration to enable researchers to explore such an association (Chawla et al., 2015; Carneiro et al., 2017; S. Alessy et al., 2019).

Cancer outcomes are influenced by cancer type, stage of disease, and comorbid conditions at diagnosis, as well as the quality of cancer care the patient receives (Malin et al., 2006). Previous research has also shown that cancer patients' experiences are influenced by either one or a combination of these factors (Pinder et al., 2016; Pham, Gomez-Cano, et al., 2019; Gomez-Cano et al., 2019; Saunders et al., 2014; Mollica et al., 2018; Lines et al., 2019). In addition, conceptual frameworks are important in epidemiological studies to determine any possible association that may exist and which confounders to account for prior to performing data analysis. These frameworks need to be developed by considering the current literature carefully and by avoiding any possible biases in predicting the direction of an association.

Since this PhD began in 2017, a growing body of literature on cancer patients' experiences has emerged from USA, Canada, and England. While this literature was important for the development of this PhD, the extent to which various factors influence cancer patients' experiences of care has not been assessed systematically due to the very recent development of this field. I therefore systematically reviewed the available literature to identify all studies that have been published from CAHPS, CPES, and AOPSS to assess factors shown to influence cancer patients' experiences of care. This review had two aims – the first was to synthesize the evidence on factors affecting cancer patients' experiences and the second was to develop a conceptual framework based upon this evidence that would help in assessing the association between cancer patients' experiences and their subsequent survival. Once this was completed, my aim was to set out the hypotheses for their being several mechanisms whereby cancer patient experience might be associated with cancer patient survival into causal and non-causal pathways. These could then be tested using the linked patient experience and population cancer registry datasets.

6.2 Methodology:

6.2.1 Search strategy

I searched PubMed and Web of Science databases, with no year restrictions, to identify all studies that used CPES, or CAHPS (focusing only on cancer care), or AOPSS datasets, with the date of last search as 8th of June 2020. Mesh terms and keywords used for searching the database are listed in (Table 6-1). I also used these exact terms in Google Scholar's advanced search feature "with the exact phrase" to identify published conference proceedings or any other possible study using these surveys that might not be indexed in PubMed or Web of Science. Moreover, I considered further articles for review that were mentioned in: the scoping review about cancer experience with care (Mollica, Lines, et al., 2017), the popular systematic review on patients' experiences (Doyle et al., 2013), and my previous systematic review (chapter 2 in this thesis), published as (S. A. Alessy, Lüchtenborg, et al., 2019).

Table 6-1: MeSH terms used in PubMed and Web of Science to retrieve all studies published from CPES, CAHPS, and AOPSS

Database	National Cancer Patient Experience Survey	Consumer Assessments of Healthcare Providers and Systems	Ambulatory Oncology Patient Satisfaction Survey
PubMed	"CPES" OR "National Cancer Patient Experience Survey" OR "Cancer Patient Experience Survey" AND (cancer)	"Consumer Assessments of Healthcare Providers and Systems" or "SEER-CAHPS" or "HCAHPS" AND (Cancer)	"Ambulatory Oncology Patient Satisfaction Survey" OR "AOPSS "AND (cancer)
Web of Science	(TI= ("CPES”) OR TI= ("National Cancer Patient Experience Survey”) OR TI= ("Cancer Patient Experience Survey”) AND TS=(cancer)) Databases= WOS, MEDLINE, SCIELO Timespan=All years Search language=English	AB= ("Consumer Assessments of Healthcare Providers and Systems”) OR AB= ("SEER- CAHPS”) OR AB=("CAHPS”) AND TS=(cancer)	AB= ("Ambulatory Oncology Patient Satisfaction Survey”) OR AB=("AOPSS”) AND TS=(cancer)

6.2.2 Eligibility criteria

The goal of this study is to identify what factors have been reported as being associated with cancer patients’ experiences of care. I therefore included all studies that identified factors related to variation or differences in cancer patients’ experiences. Studies of patient reported outcomes measures or quality of life were not included on the basis that they do not ask questions about patients’ experiences, but rather about symptoms, activities or care outcome. In addition, I excluded studies that only focused on patient satisfaction or compared hospital performance, rather than assessed patients’ experiences. Finally, several published conference proceedings were also found as original journal articles with slightly different titles. Where the research findings were found to be duplicated, I only kept the articles published in journals.

6.2.3 Review process

This study was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Liberati et al., 2009). I searched databases, screened articles, and chose the potential articles for full text read. The full text into tables and these summaries were then obtained and assessed independently by my 1st supervisor (Dr Elizabeth Davies). The final included articles were discussed and decided by both of us. Finally, I extracted all study details, which were then independently reviewed by (ED). Out of the 277 studies retrieved from my search, 38 studies met the inclusion criteria and were relevant for final synthesis (Figure 6-1).

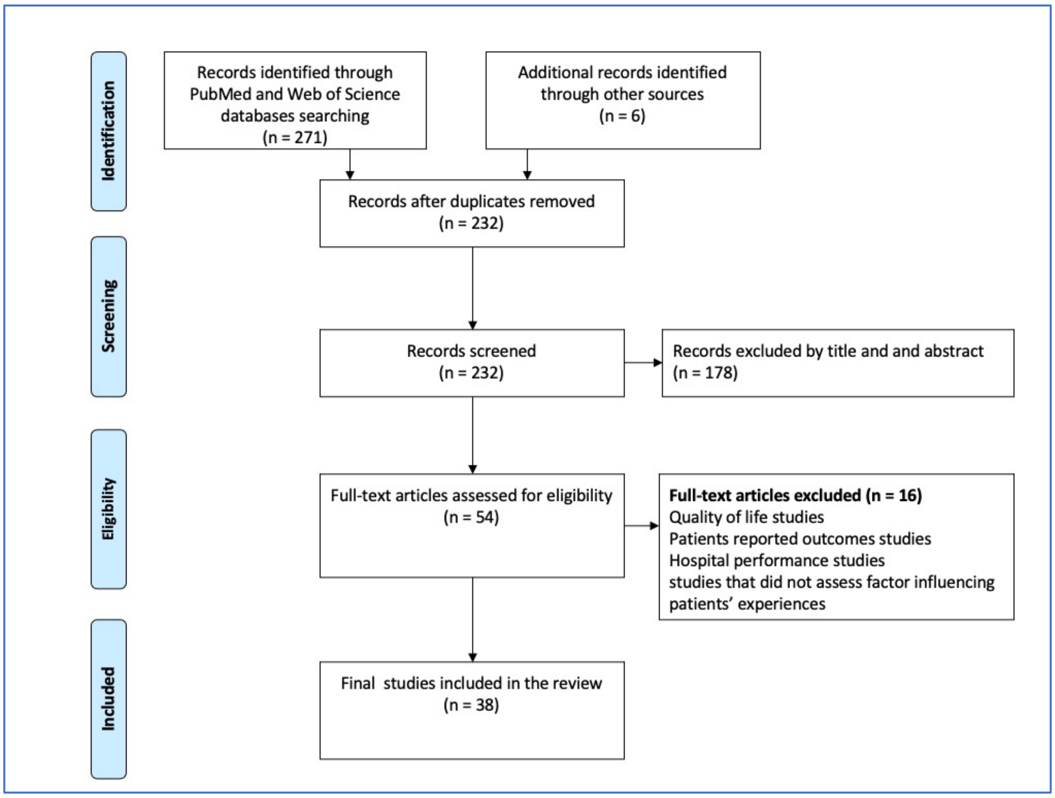


Figure 6-1: Flow chart of study inclusion process according to PRISMA guidelines

6.3 Results:

6.3.1 Study characteristics

Most of the final included studies were from the United Kingdom due the availability of cancer patient experience datasets since 2010, with several recently published studies from Canada, USA, and Australia. Authors' names, the study aim, design, and findings summary were extracted for each study (Table 6-2). Most of the included studies were quantitative studies (n= 34 observational studies), but there were four qualitative studies. Several factors were found to affect cancer patients' experiences consistently across diverse cancer populations. These included patient demographic characteristics (age, sex, ethnicity, residency area, socioeconomic status), health status, cancer type, cancer prognosis, patients' presentation to cancer care, treatment facility location, and patient interaction with health providers. In addition, other factors such as health plan, hospital size, and survey responders' characteristics were also found to influence patients' experiences, but the extent varied between different populations. I summarized all factors influencing patients' experiences into three main categories: 1) **patients' cancer types and demographic characteristics**; 2) **patients' interactions with the healthcare system**; and 3) **survey administration**. When studies crossed more than one category, I categorised them based on the main aim as stated in the study objective.

6.3.1.1 Patients' cancer types and demographic characteristics

A total of 22 studies linked variation in patients' experiences to their demographic characteristics or disease characteristics. A full list of these studies' citations and summaries can be found in Table 6-2 at the end of the results section. Published studies from several rounds of CPES documented variation in patients' experiences with primary care, involvement in treatment decisions, health provider communication, and overall care experience by their sex, age, and ethnicity

(Lyratzopoulos et al., 2012; Bone et al., 2014; El Turabi et al., 2013; Saunders et al., 2015; Stephens et al., 2015; Mc Grath-Lone et al., 2015; Pinder et al., 2016; Trenchard et al., 2014; Cunningham and Wells, 2017; Hulbert-Williams et al., 2017). These studies showed that overall, younger patients report less positive experiences than older ones (Bone et al., 2014; Saunders et al., 2015; Mc Grath-Lone et al., 2015), females report less positive experiences than males (Bone et al., 2014), and non-white patients report less positive experiences than those from the white population (Bone et al., 2014; Pinder et al., 2016; Saunders et al., 2015; Trenchard et al., 2016). Similar variation in cancer patients' experiences by their sex, age, and ethnicity were also found in studies from USA (Shirk et al., 2016; Halpern et al., 2017), and Canada (Loiselle, 2019).

Furthermore, residence area and socioeconomic status were also shown to influence patients' experiences. For example, patients from the London area tend to report less positive experiences than those from other areas of England (Saunders et al., 2014). In addition, cancer patients in rural areas in the United States report better experiences with timely care than those in urban areas (Mollica et al., 2018), and patients who are enrolled in both Medicare and Medicaid (and who therefore tend to be more deprived) tend to report better care experiences with prescription drug plans and health plans than patients enrolled in Medicare-only (Lines et al., 2019). Moreover, Halpern and colleagues assessed care experiences among patients with cancer in the year before death, and found better mental health and a longer time before death were associated with better experiences (Halpern et al., 2017). In another study, Halpern et al also found that better reported health status and better mental health were associated with reporting a better care experience (Halpern et al., 2018).

Variation in patients' experiences of cancer care are not limited to patient sociodemographic characteristics but are also documented by cancer site and disease prognosis. For example, prostate cancer patients tend to report the worst experiences of being referred for emotional support in Canada (Coronado et al., 2017). In terms of experience with cancer diagnosis, patients who were diagnosed at advanced stage were more likely to report worse care experiences in England (Salika et al., 2018), and in USA (Farias et al., 2020). Moreover, patients with multiple myeloma and pancreatic cancer were more likely to report negative experiences in England (Lyratzopoulos et al., 2012; Richard and Shaw, 2016), while thyroid, vulvar, and multiple myeloma cancer patients were more likely to report negative experiences in Australia (Lacey et al., 2016). In addition, patients with cancer of unknown primary (CUP) in England were more likely to prefer more written information about their type of cancer and tests received compared to those with metastatic disease of known primary (non-CUP) (Wagland et al., 2017).

6.3.1.2 Surveys administration

Four studies from the UK assessed how CPES sampling and administration processes influence reported patients' experiences (Abel et al., 2016; S. A. Alessy, Davies, et al., 2019; Nartey et al., 2020; Pham, Abel, et al., 2019). Abel and colleagues found that patients with brain and pancreatic cancers had the highest risk of post-sampling mortality meaning that they had initially been included in CPES sampling but died before the survey mail out could be carried out (Abel et al., 2016). These findings about the CPES representativeness limitations were also confirmed by two other studies that compared the survey responders to the general cancer population of the same cancer in England (S. A. Alessy, Davies, et al., 2019; Nartey et al., 2020). These studies found that patients who are included in CPES tend to be less deprived, more likely to be from white background, and are those with the better cancer prognoses (S. A. Alessy, Davies, et al., 2019; Nartey et al., 2020). In addition, Pham and others assessed the differences in patients' experiences reported in the 2015 CPES online or via mail services (Pham, Abel, et al., 2019). The study found that patients who responded online were more likely to report an overall satisfied experience of care than those who responded through mail (Pham, Abel, et al., 2019).

6.3.1.3 Interactions with healthcare system

Twelve studies (Eight from the UK, three from the USA, and one from Canada) linked variation in patients' experiences to their interactions with healthcare system or care providers (Griffiths et al., 2013; Clucas, 2016; Mendonca et al., 2016; Catherine Saunders et al., 2016; Abel et al., 2017; Mollica, Enewold, et al., 2017; Salika et al., 2018; Mollica et al., 2019; Pham, Gomez-Cano, et al., 2019; Singer et al., 2019; Fitch et al., 2019; Gomez-Cano et al., 2019). First, patients' presentation pathway to cancer care were associated with their reported care experiences (Mendonca et al., 2016; Pham, Gomez-Cano, et al., 2019; Abel et al., 2017; Salika et al., 2018). For example, studies using CPES datasets showed that patients who present to cancer care through emergency care or those who have multiple consultations with primary care prior to referral tend to report negative experiences with cancer care (Mendonca et al., 2016; Pham, Gomez-Cano, et al., 2019; Abel et al., 2017; Salika et al., 2018). In contrast, patients report better experiences when they are diagnosed at an earlier stage or present to care through the 'screening-detection' route of diagnosis (Salika et al., 2018; Pham, Gomez-Cano, et al., 2019).

Moreover, patient care coordination within the health care system and patient communication with healthcare providers were found to influence their experiences. Specifically, studies from the UK, Canada, and the USA showed several elements of care that are perceived by patients to be key aspects in improving their care experiences (Gomez-Cano et al., 2019; Fitch et al., 2019; Mollica, Enewold, et al., 2017; Clucas, 2016). These are: effective communication, better patient-provider relationship, being treated with respect and dignity as a person, care that takes patients' needs into considerations, and better care administration and coordination (Gomez-Cano et al., 2019; Fitch et al., 2019; Mollica, Enewold, et al., 2017; Clucas, 2016). Furthermore, better experiences in terms of patient-provider relationship was also found to improve adherence to office visits for colorectal cancer surveillance in USA (Mollica, Enewold, et al., 2017).

Finally, patients' experiences with care were also associated with hospital size and treatment received. For instance, patients reported better experiences in hospitals where there were more cancer specialist nurses (Griffiths et al., 2013), or in hospitals that had higher CPES response rates (Catherine Saunders et al., 2016). Additionally, patients who received radiation therapy were more likely to report their overall care better than those not receiving treatment (Mollica et al., 2019), and patients who had shorter hospital stays (less than 6 days) were more likely to report better experiences than those who stayed longer (Singer et al., 2019).

Table 6-2: Summary of included studies

Author and year	Study design	Aim	Summary
Lyratzopoulos et al., 2012	A cross-sectional study using 2010 CPES data in England for patients with 24 different cancers.	To examine variation in patients' experiences with the number of pre-referral consultations with a general practitioner.	Three or more visits to the General Practitioner (GP) before hospital referral was considered s a negative experience of care. The study found wide variation in patients' experiences with GP visits by patients' cancer types and demographic characteristics. Higher probability of three or more pre-referral consultations was found among young patients (aged 16-24 years), those from black ethnic minorities, women, and among patients with pancreatic, stomach, and lung cancers.
El Turabi et al., 2013	A cross-sectional study using 2010 CPES data in England for patients with 38 primary cancers.	To examine how experiences with involvement in decisions about treatment varied by patients' characteristics and cancer type	Patients' experiences of involvement in decision making varied by their demographic characteristics and cancer types. Younger patients, those from ethnic minorities, and those with ovarian, myeloma, bladder and rectal cancers reported worse experiences compared with other patient groups.
Griffiths et al., 2013	A cross-sectional study using the 2010 CPES data for patients with 14 different cancers	To assess whether variation in the provision of cancer specialist nurses is associated with better reported patients' experiences.	Cancer patients' experiences of care coordination and emotional support was better in trusts with more specialist nurses. Specifically, patients in these trusts reported better experiences with being treated and cared for well, being provided with enough emotional support, and being supported with the control of chemotherapy side effects.
Bone et al., 2014	A cross-sectional study using the 2012 CPES data in England for all cancer patients included.	To explore inequalities in cancer patients' experiences by patient, clinical and trust-level factors.	This study showed inequalities in cancer patients' experiences by their gender, age, ethnicity and disability. After adjusting for patient, clinical and trust-level factors, female, non-white, younger patients, and patients with long-standing conditions (particularly those with learning disabilities or mental health conditions), were less likely to rate their overall care as excellent or very good
Saunders et al., 2014	A cross-sectional study using the 2012 CPES data and the Adult Inpatients survey in England for all cancer patients.	To explore why cancer patients treated in London hospitals reported worse experiences of care compared with patients treated in all other English regions.	Patients with cancer treated by London hospitals reported worse care experiences. The differences were not explained by patient case-mix or whether the hospital was a teaching hospital. The study showed evidence of poorer experiences reported in London when comparing 10 of 16 experience aspects in both the CPES and the Adult Inpatients Surveys.

Saunders et al., 2015	A cross-sectional study using all patients included in 2012 CPES data.	To understand variation in cancer patients' experiences among patients with different cancers.	Younger and very old patients, those from ethnic minorities, and women were more likely to report worse care experiences across CPES questions. Specifically, patients with multiple myeloma, ovarian, anal, hepatobiliary and renal cancer reported notably worse experiences than patients with gynaecological, haematological, gastrointestinal and urological malignancies respectively.
Stephens et al., 2015	A cross-sectional study using all patients included in the CPES 2013 data.	To assess factors associated with variation in patients' experiences of being involved in cancer research.	There was little variation by gender in whether patients reported a conversation about taking part in research. There was a clear decline in being asked to participate in cancer research for patients aged over 75. Skin and urological cancer patients were less likely to be asked to participate in cancer research.
Mc Grath-Lone et al., 2015	A mixed method study using the 2012-13 CPES data in England.	To investigate variation in cancer patients' experiences with being asked to participate in cancer research.	The study identified barriers to research participation at staff, patient and trust level. Specifically, staff were less likely to discuss research with older patients. Asian and black patients were less likely to take part in research, while patients treated at specialist or teaching trusts had higher levels of discussion and participation in cancer research.
Abel et al., 2016	A cross-sectional study using the CPES data for all cancer patients in England included in the 2010 survey.	To assess if CPES sampling processes, post-sampling mortality and non-response can influence the CPES representativeness.	The overall response rate to CPES was 67%, being >70% for the most affluent patients and those diagnosed with colon or breast cancer, and <50% for Asian or Black patients. Patients with brain and pancreatic cancers had the highest risk of post-sampling mortality meaning that they had initially been included in the survey sampling but died and were removed before the survey was distributed.
Clucas, 2016	A cross-sectional study using CPES data in England for all cancer patients included in the 2012 survey.	To explore whether communication behaviours from hospital staff are associated with cancer patients' experiences for being treated with respect.	Effective communication from hospital staff was associated with better patients' experiences. Providing care with emotional support was associated with better reported experiences of being treated with respect although this varied by gender, ethnicity, age, comorbidity, treatment response, time since first treated, employment status, and type of cancer.
Lacey et al., 2016	A cross-sectional study using CPES in care settings in Victoria, Australia for patients with 19 cancer types.	To assess and understand variations in the number of general practitioner visits prior to a cancer diagnosis.	Certain cancer types were more frequently associated with multiple GP visits, with 34% of all patients having visited a GP at least three times before being referred to hospital. Adjusting for age, sex, language, and socio-economic deprivation, the highest number of GP visits were more likely to be made by patients with pancreatic, thyroid, vulvar, and multiple myeloma cancers, whereas the lowest number were by among patients with breast, cervical, and endometrial cancers.

Mendonca et al., 2016	A cross-sectional study using CPES data for all patients in England completing the survey in 2012 and 2013	To examine whether visiting a GP (3+ visits) prior to diagnosis is associated with negative experiences of other cancer services using 12 CPES questions.	There was a negative association between multiple pre-diagnostic consultations with a GP and the experience of subsequent cancer care. Patients with 3+ pre-referral consultations reported worse care experiences in several CPES questions including involvement in the treatment decision, communication with clinical nurse specialist and being given information about treatment and care.
Pinder et al., 2016	A cross-sectional study using the CPES data in England for all cancer patients included in the survey in 2012 and 2013	To explore reported experience of interacting with medical and nursing staff for cancer patients from ethnic minority backgrounds.	This study showed that patients from ethnic minority backgrounds reported lower satisfaction with and less positive experiences of care overall. Specifically, after adjusting for demographic factors, patients from ethnic minorities remained less positive in terms of lower confidence in, and less understanding of healthcare professionals (including clinical nurse specialists, doctors and ward nurses).
Saunders et al., 2016	A cross-sectional study using the CPES data for all cancer patients in England completing the survey in 2010	To explore possible associations between hospital-level survey response rates and patients' experiences.	Hospitals that had higher CPES response rates also had more positive experience scores, which was partly explained by patient case-mix. In the multivariable analysis, associations between individual patient experience and hospital-level response rates were statistically significant in terms of managing late appointments, surgery admission delay, and providing correct documentation to patients.
Shirk et al., 2016	A cross-sectional study using HCAHPS data from 2009 through 2011 for patients with genitourinary cancers	To determine whether there is an association between patients' experiences and cancer surgical outcomes.	This study found a limited association between patients' experiences and cancer surgical outcomes with variation by patient age, race, income, comorbidity, and cancer type. The study showed that patients' experiences may be viewed as an independent quality domain rather than a mechanism by which to improve surgical outcomes.
Trenchard et al., 2014	A cross-sectional study using the CPES data for all patients in England completing the survey in 2012	To examine variation in patients' experiences with information provision and communication by their ethnic sub-categories.	Ethnic inequalities in cancer patients' experiences of information provision and communication were evident both between and within broad ethnic categories. Asian patients were less likely than White patients to receive an understandable explanation of treatment side effects. Specifically, Asian patients with Bangladeshi ethnicity were less likely to receive an understandable answer to their important questions.
Richard and Shaw, 2016	A cross-sectional study using the CPES for all patients in England completing the survey in 2014	To examine whether myeloma patients reported worse experiences of diagnosis compared to all other cancer patients.	Myeloma patients reported worse experiences of diagnosis in the following care aspects: time prior to seeing a specialist, receiving information about diagnostic tests, and understanding at the time of diagnosis than the average for all other cancers. In addition, Myeloma patients reported longer times waiting for a diagnosis than the average for all other cancers, and were less likely to feel that they received the information they needed about the tests and subsequent diagnosis.

Abel et al., 2017	A cross-sectional study using the 2010 CPES data linked to route to diagnosis data for patients with the 18 most common cancers in England.	To examine the experiences of patients who were diagnosed through emergency route with any previous or multiple primary care consultations.	Around a third of patients who were diagnosed through the emergency route never had any prior GP consultation. These were more likely to be male, older (≥85 years), living in the deprived areas, and to be diagnosed with brain cancer. In addition, among emergency presenters with prior consultations, 41% reported 3+ GP visits, and these were more likely to be female, younger, and non-white and to be diagnosed with multiple myeloma.
Coronado et al., 2017	A cross-sectional study using the AOPSS data in Canada for all cancer patients included in the survey between 2012 and 2016.	To examine variation in patients' experiences with patient-provider communication, during the diagnosis and treatment planning phases of cancer care	This study showed variation in patients' experiences with patient-provider communication. Most respondents (92%) reported that their care provider told them of their cancer diagnosis in a sensitive manner and felt that they were provided with enough information about their cancer treatment. Across all cancers, prostate cancer patients reported the worst experiences with being referred for emotional support even though they reported having anxieties and fears upon diagnosis.
Cunningham and Wells, 2017	Qualitative analysis examining all cancer patients' experiences reported in the first Scottish CPES in 2014.	To understand patients' experiences of care, identify valued aspects and areas for improvement.	Although the majority of patients' comments on their care were positive, there were a significant number of negative comments, especially about diagnosis care. The number of negative comments about care experiences varied by gender, age, employment status, and cancer type.
Halpern et al., 2017	Cross-sectional study using the SEER-CAHPS data between 1998 and 2011 for patients with all cancer types in the dataset.	To assess factors influencing cancer patients' experiences among individuals within one year before death.	Patients with higher general or mental health status were significantly more likely to report excellent experiences across all the measures examined. Sex, ethnicity, clinical characteristics, and education status were associated with patients' experiences. Individuals in fee-for-service Medicare plans were more likely to report better experiences with health plans, getting care quickly, and getting needed care.
Hulbert-Williams et al., 2017	A cross-sectional study using the CPES data for all patients in England included in the 2013 survey.	To assess whether there is variation in care experiences for patients based on their sexual orientation.	Around 0.8% of CPES responders in 2013 identified themselves as lesbian, gay or bisexual. After adjusting for age, gender and concurrent mental health comorbidity, less positive cancer experiences were reported by patients who identified themselves as lesbian, gay and (especially) bisexual.
Mollica et al., 2017	A cross-sectional study using the SEER-CAHPS dataset for colorectal cancer patients diagnosed between 1999-2009.	To examine the association between experiences of care and adherence to surveillance guidelines among Medicare Fee-For-Service beneficiaries.	Most of the 314 responders were highly satisfied with their care experience. This study showed that in a multivariable framework, better experiences with patient-provider relationships improved adherence to office visits for colorectal cancer surveillance.

Halpern et al., 2018	A cross-sectional study using the SEER-CAHPS dataset for breast, colorectal, lung, and prostate cancer patients completed CAHPS (1998 – 2011).	To examine experience of care among cancer patients and assess associations of patients' characteristics with their experience.	Higher self-reported health status was associated with better experiences of cancer care with limited differences in patients' experiences by sex or years since diagnosis. This association was significant for breast, colorectal, and prostate cancer patients. Better mental-health status was associated with better experience for lung cancer patients only. College-educated and Asian survivors reported lower care experiences.
Mollica et al., 2018	A cross-sectional study using the SEER-CAHPS (1998 - 2013) dataset for patients with breast, lung, colorectal, or prostate cancers.	To examine whether there is variation in patients' experiences by their place of residence at cancer diagnosis (urban vs rural).	Rural cancer patients were more likely to report better experiences with timely care than those in urban areas. Ethnic-minority rural patients were more likely to report negative experiences with accessing needed care as quickly. Black and Hispanic respondents from rural areas rated getting needed care lower than their counterparts residing in urban areas.
Salika et al., 2018	A cross-sectional study using the 2010 CPES data inked to information on diagnostic route for colorectal cancer patients.	To examine how different pathways to diagnosis of colorectal cancer may be associated with patients' experiences of care.	Screening-detected patients reported the best experiences of care, while emergency presenters reported the worst experiences. In 18 CPES questions about care experience, emergency presenters were more likely to report a negative experience for most questions, including those about diagnosis information and sufficient explanation before operations. Screen-detected patients were least likely to report negative experiences except for support from primary care.
Alessy et al., 2019	Population-based case-control study using 2010 - 2014 CPES data linked with cancer registration data in England for colorectal, lung, breast, and prostate cancers.	To assess the representativeness of CPES responders compared with the wider English cancer registry population In England.	CPES responders with colorectal, breast, lung and prostate cancers do not necessarily represent all patients with these cancers in terms of demographic characteristics and tumour stage at diagnosis. Across all cancer types, survey responders were younger, more likely to have a White ethnic background, to be resident in less deprived areas, and diagnosed with earlier stage disease although this varied between cancers. Survey responders also had higher median survival than the cancer registry population across all four cancers.
Mollica et al., 2019	A cross-sectional study using the SEER-CAHPS data between 1998 – 2011 for prostate cancer patients.	To examine the association between treatment received (surgery, radiation, or no treatment) and patients overall experiences with care.	This study assessed patients' experiences among localized prostate cancer patients (n=507) receiving surgery, radiation, or no treatment. Respondents who received radiation were more likely to report their overall care as better than those not receiving treatment. Overall care rating was not different between patients who received surgery and patients received no treatment at all.

Lines et al., 2019	A cross-sectional study using the SEER-CAHPS date between 2005-2013.	To understand the effects of poverty on self-reported care experiences among seniors diagnosed with cancer.	Patients who were enrolled in both Medicare and Medicaid tended to be poorer, have more functional and cognitive limitations, and have more medical needs compared with beneficiaries enrolled in Medicare or Medicaid alone. Cancer patients who were enrolled in both Medicare and Medicare reported better care experiences with prescription drug plans and health plans than patients enrolled in Medicare-only.
Loiselle, 2019	A cross-sectional study using AOPSS data (2013–2017) for patients with 14 different cancers.	To understand patients' needs and preferences as part of their care experiences.	This study showed that 60% of patients reported they wanted to actively seek information about their cancer, while around 40% did not want seek information about their cancer. Men were more likely to avoid asking about cancer information than women.
Pham, Abel, et al., 2019	A cross-sectional study using the 2015 CPES data for all cancer patients in the dataset.	To examine predictors of postal or online response mode, and associations with patient reported experience	Around 8% of CPES responders completed the survey online in 2015. Online and postal CPES responders tend to differ in their characteristics and rating of their care experiences. In the adjusted analysis, male, younger (<55 years), least deprived, and non-white patients were more likely to respond online. Patients responding online were more likely to report an overall satisfied experience of care.
Pham, Gomez-Cano, et al., 2019	A cross-sectional study using the 2014 CPES data linked with data on diagnostic route and tumour stage at diagnosis for breast, prostate, colon, lung, and rectal cancers.	To examine whether diagnostic route (e.g. emergency presentation) is associated with cancer patients’ experiences independently of tumour stage.	Diagnostic route was associated with reported care experiences independently from cancer stage. In the adjusted analysis, emergency presenters had the highest likelihood of reporting a negative experience while screening-detected had the lowest for patients. Patients with advanced stage reported more negative experiences with little confounding between stage and diagnostic route, with no evidence for cancer-stage or cancer-route interactions.
Singer et al., 2019	A cross-sectional study using clinical data linked to HCAHPS survey data between 2014 and 2018 for lung cancer patients.	To determine whether length of hospital stay affects HCAHPS scores.	Length of hospital stay (6+ days) after having lung resection for cancer was negatively associated with overall satisfaction scores (driven from several HCAHPS experience questions). Increasing length of stay was also associated with worse experiences with provider communication. In the adjustment analysis, increasing length of stay was associated with worse patient satisfaction in the aspects of communication with physicians and nurses (less likely to report that doctors gave understandable explanations and that nurses listened carefully).

Farias et al., 2020	Cross-sectional study using the SEER-CAHPS data for breast cancer patients who completed CAHPS survey between 1997 and 2011.	To identify whether there is variation in patients’ experiences by their ethnicity and whether that is associated with stage at diagnosis.	Ethnic minorities reported poorer experiences with care preceding a diagnosis of breast cancer. In the adjusted analysis, black patients reported lower mean scores for getting care quickly, getting needed prescription drugs, getting needed care, and lower ratings of their overall health care compared to white patients. These worse experiences were more likely to be reported by patients with earlier stage breast cancer.
Fitch et al., 2019	Qualitative analysis examining cancer patients’ experiences reported in AOPSS in Canada between 2012 and 2016.	To explore patients’ experiences of their care and identify identified aspects of care patients thought were important	Out of 6232 patients’ comments, four themes were identified: characteristics of a "positive" experience, personal care, interaction with health care providers, and service delivery. Respondents reported that being treated as a person with respect and dignity, clear communication with staff, access to relevant and timely information, and care that takes their needs into account are important aspects of their experiences.
Nartey et al., 2020	A cross-sectional study using CPES data from 2010 - 2015 in England for lung cancer patients.	To assess the representativeness of lung cancer patients responding to CPES in England.	There is a low representativeness of lung cancer patients who responded to CPES between 2010 - 2015 compared with the general lung cancer patients in England. Only 7 % of all lung cancer patients were included in CPES. Older patients, those from more socioeconomically deprived areas, those with the worse performance status, multiple comorbidities, and patients diagnosed via emergency presentation were under-represented in CPES.
Gomez-Cano et al., 2019	A cross-sectional study using 2015 data CPES in England for all cancer patients included in CPES.	To examine which aspects of care experience are the key drivers of overall satisfaction with cancer care.	Overall, out of 68340 patients who responded to CPES in 2015, 86% were highly satisfied with their cancer care. The strongest predictors of overall satisfaction with cancer care in England across all frameworks were responses to two questions on experience: the care administration and the coordination.
Wagland et al., 2017	Qualitative analysis examining patients’ experiences reported in CPES 2013 for patients with cancer of unknown primary and those with metastatic disease of known primary in England.	To explore differences in patients’ experiences between patients with cancer of unknown primary (CUP) and those with metastatic disease of known primary (non-CUP).	In a matched analysis for 2992 patients, there was a significant difference in care experiences between patients with cancer of unknown primary (CUP) and those with metastatic disease of known primary (non-CUP). CUP patients were more likely to report that they wanted more written information about their type of cancer and tests received, to receive their diagnosis from a GP and have seen allied health professionals, but less likely to have understood explanations of their condition or had surgery

Abbreviations: CPES = Cancer Patient Experience Survey; CHAPS or HCHAPS = Hospital Consumer Assessment of Healthcare Providers and Systems; AOPSS = Ambulatory Oncology Patient Satisfaction Survey; GP= General practitioner.

6.4 Discussion:

6.4.1 Summary of main findings

Understanding how patients' experiences vary between different populations can help policy makers to prioritise policies and initiatives to improve patients' experiences of care. The patient experience research field is emerging in many countries (Wolf, 2018) and large amounts of data are now being collected on patients' experiences in many differing healthcare systems (Coulter et al., 2014). My study showed that a wide range of factors can influence cancer patients' experiences including patients' demographic characteristics, their health status, cancer type and prognosis, and their interactions with the healthcare system, as well as the reporting methods. Patients' demographic and cancer characteristics were the factors found to be associated in the most pronounced way with variation in patients' experiences across all the studies included in this review.

Several systematic reviews have previously focused on cancer patients' experiences (Carla Saunders et al., 2016; Mollica, Lines, et al., 2017; S. A. Alessy, Lüchtenborg, et al., 2019). Saunders and colleagues highlighted the variation in the emerging patients' experiences measures worldwide. My review summarised evidence on what factors impact patients' experiences gathered from specifically designed surveys. In addition, Mollica and colleagues conducted a scoping review explaining the landscape of cancer patients' experiences research in USA and introducing the SEER-CAHPS linked dataset. My review also examined evidence generated from recently published studies from SEER-CAHPS linked dataset, revealing variation in cancer patients' experiences in USA. Although the structure of cancer care in USA is different from the UK and Canada, there were several consistent factors affecting patients' experiences across these systems such as patients' ethnicity and their cancer type.

Figure 6-2 below summarises and syntheses the findings drawn from the included studies. The figure also shows which factors were associated with better or negative care experiences and where. How these findings influenced my final chapter analysis is explained in detail in the theoretical framework below and in the methodology section in chapter 7.

Patient characteristics, living area, health plan, and cancer type

Factors associated with reporting negative care experiences:

Patient characteristics and living area

- Being younger or very old, or female
- Being from an ethnic minority group (Black Asian, and Hispanic)
- Living in more a deprived area
- Receiving care in hospitals in London

Health status and cancer type

- Having learning disabilities, poorer mental health or poorer health status
- Being diagnosed with prostate, myeloma, or pancreatic cancer
- Being diagnosed with cancer of unknown primary

Factors associated with reporting better care experiences:

Patient characteristics and living area

- Being resident in rural areas of the United States
- Being enrolled in both Medicare and Medicaid in the United States

Health status and cancer type

Having better mental health or health status

Lyratzopoulos et al., 2012; Bone et al., 2014; El Turabi et al., 2013; Saunders et al., 2015; Stephens et al., 2015; Mc Grath-Lone et al., 2015; Pinder et al., 2016; Trenchard et al., 2014; Cunningham and Wells, 2017; Hulbert-Williams et al., 2017; Trenchard et al., 2016; Shirk et al., 2016; Halpern et al., 2017; Loiselle, 2019; Mollica et al., 2018; Lines et al., 2019; Halpern et al., 2018; 2017; Richard and Shaw, 2016; Lacey et al., 2016; Wagland et al., 2017; Saunders et al., 2014

Clinical processes and interactions with healthcare providers

Factors associated with reporting negative care experiences:

- Presenting through an emergency care route
- Having multiple consultations with primary care prior to referral to a cancer care setting
- Being diagnosed with advanced cancer

Factors associated with reporting better care experiences:

- Presenting through the screening-detection route of diagnosis
- Being diagnosed at an earlier stage
- Being treated in hospitals with higher CPES response rates
- Being treated in hospitals with more cancer clinical nurse specialists
- Effective communication with care providers
- Better patient-provider relationship
- Being treated as a person with respect and dignity
- Care that takes patients' needs into considerations
- Better care administration and coordination
- Receiving radiation therapy
- Having a shorter hospital stay (less than 6 days)

Griffiths et al., 2013; Clucas, 2016; Mendonca et al., 2016; Saunders et al., 2016; Abel et al., 2017; Mollica et al., 2017; Salika et al., 2018; Mollica et al., 2019; Pham, Gomez-Cano, et al., 2019; Singer et al., 2019; Fitch et al., 2019; Gomez-Cano et al., 2019

Survey administration

Factors influencing reported care experiences:

- Patients with poorer prognoses including brain, pancreatic, and lung cancers were less well represented in CPES in England
- More deprived patients, those from ethnic minorities, with poorest prognosis were less represented in CPES
- Responding online to CPES was associated with better experience compared to responding through mail

Abel et al., 2016; Alessy et al., 2019; Nartey et al., 2020; Pham, Abel, et al., 2019

Figure 6-2: An evidence synthesis on factors affecting caner patients' experiences

6.4.2 Strengths and limitations

To my knowledge, this is the first systematic review to assess together all factors influencing patients' experiences and to focus on cancer patients. In addition, this is the first systematic review to focus on studies that specifically aim to measure patients' experiences and have been published from large patient experience datasets recently available in USA (Chawla et al., 2015), England, (S. Alessy et al., 2019), and Canada (Chadder et al., 2018). However, while this review is comprehensive in terms of searching several databases, some studies that used other tools to assess patients' experiences were not included. These studies however have been previously covered in chapter 2 and in other systematic reviews (Carla Saunders et al., 2016; Mollica, Lines, et al., 2017; S. A. Alessy, Lüchtenborg, et al., 2019).

6.4.3 Implications

Findings from this review which are important for policy makers and patient experience researchers include the fact that cancer patients' experiences are influenced by several factors or a combination of them. Efforts to improve patients' experiences or survivorship programs among individuals with cancer should therefore carefully consider what might affect patients' experiences in order to prioritise or propose improvement initiatives. In addition, this review shows that cancer care experience programmes should not be designed as "one size fits all". Rather, these programmes should take into account patients' characteristics, their different cancers, and the different trajectories they take through their care journeys. For example, patients in England who present to cancer care through emergency presentation tended to report poorer care experiences compared to patients presenting to care with screen-detected good prognosis cancer (Salika et al., 2018). Patients' characteristics and their different cancers were also found to influence their experiences across countries with the patients from ethnic minorities and those with advanced stage reporting poorer experiences. The study findings are also important for the patient experience research field. Specifically, my findings can inform researchers and survey designers to understand the heterogeneity in patients' experiences and inform data analysts about these differences prior to analysing patient experience large datasets.

6.5 Theoretical framework

Based on this systematic review and the previous systematic review (chapter 2), I have developed a conceptual analysis framework to underpin analyses from patient experience linked datasets. The framework has been developed continuously since the beginning of my PhD project based on the updated literature as it emerged, and then extended by this final systematic review. A summary synthesis of literature that guided the development of this framework can be found in (Figure 6-2).

The final framework aims to help in assessing the more detailed associations between cancer patients' experiences and their subsequent survival (Figure 6-3, below). It has set out the hypotheses that there are several mechanisms whereby cancer patient experience might be associated with cancer patient survival in causal and non-causal pathways. It takes into account an adapted version of a framework on how patient experience might be linked with care outcomes, which was designed by Anhang Price and colleagues (Anhang Price et al., 2014). The framework also takes into account the methodology presented by Xu et al, which cautions against linking patient experience to care outcomes without applying the appropriate methodology to account for possible confounders (Xu et al., 2015). The framework may be further tested using linked experience survey with population cancer registry datasets.

As described in the results section of this chapter, cancer patients' experiences are influenced by many factors at both patient and healthcare levels. All elements that have been shown to affect patients' experiences, in a negative or positive direction, have been considered in the framework. Cancer patients' experiences and their care pathway are made up of several different aspects. These are: patient characteristics, tumour presentation and diagnosis, clinical process of care, patient behaviours, care utilisation, and cancer outcomes.

I developed the framework considering all these aspects assigning all the factors that have been found to influence patients' experiences under each component. In addition, my previous systematic review (Chapter 2) and other relevant literature (Xu et al., 2015; Anhang Price et al., 2014; Manary et al., 2013) showed how different elements of patients' experiences might affect their outcomes. I therefore hypothesised the direction of the possible association between each component of the framework (Figure 6-3). The direct arrow represents the direction of the association as presented in the literature while the dotted arrow represents possible associations that I assume but are not well documented in the literature.

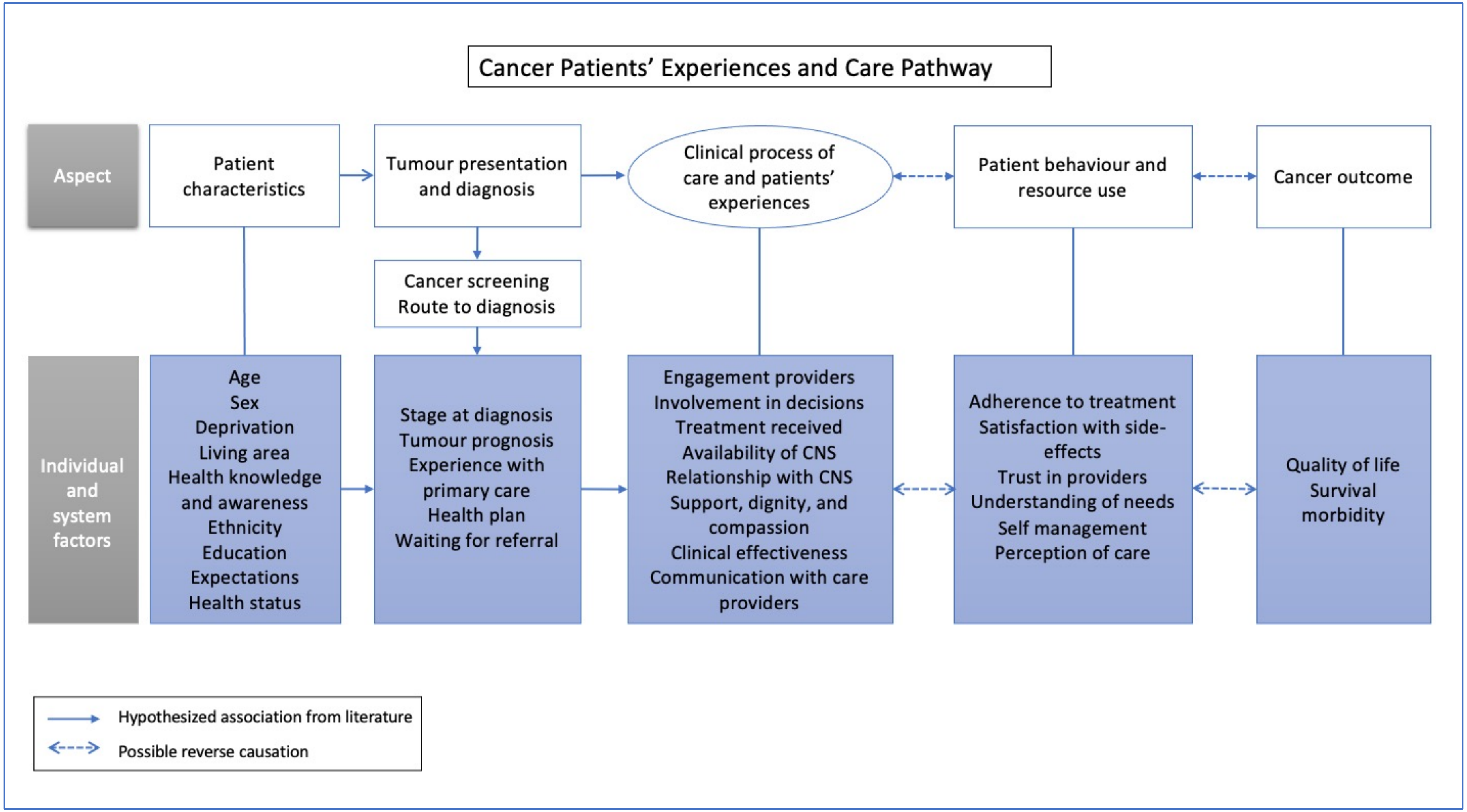


Figure 6-3: Conceptual framework illustrating pathways by which patients' experiences may be associated with cancer stage and survival.

Moreover, patient's experiences may be reflected in patient behaviours that influence survival. For example, a patient's involvement in their treatment decision or engagement with CNS might lead to better adherence to treatment and improved chance of survival. It is also hypothesized that cancer patient experience is associated with cancer survival via reverse causation pathway (see two heads arrow in Figure 6-3). This assumes that some patients might rate their experience with care based on knowledge or experience of their disease progression. Specifically, since patient experience data are collected after treatment, patients may rate their experience based on their current health status, or any side effects from treatment and not directly on their actual experience with cancer care at an earlier point in the care pathway.

It is also conceivable that cancer patients with worse outcomes report more negative experiences of care as their judgment or views are coloured by their health status and disappointment that treatment has not been successful. Similarly, patients who receive different kinds of treatment or more treatment might report more positive or negative care experiences in retrospect. While there are few research studies on this area in the field of patient experience (Shirk et al., 2016), several published articles document or warn against the risk of reverse causation when assessing the association between patients' satisfaction and their outcomes (Fenton, 2012; Jerant et al., 2019; Meterko et al., 2010; Anhang Price et al., 2014). Evidently, this was shown in chapter 2, where the association between patient survival and patient self-rated health or patient satisfaction with service quality or with quality of life was contradicted by findings within studies conducted by the same research group (Lis, Gupta, Granick, et al., 2006; Gupta, Lis, et al., 2013; Gupta et al., 2014; Gupta, Rodeghier, et al., 2013; Lis, Gupta, and Grutsch, 2006; Lis et al., 2015; Gupta et al., 2012, 2015).

6.6 Summary:

This systematic review has revealed that many factors are influencing cancer patients' experiences. The proposed framework appears appropriate to guide my first analyses using patient experience data linked with cancer registration and outcomes datasets. The systematic review and the developed framework are designed to theoretically guide my analyses assessing the possible association between cancer patient experience and their survival. These will include applying stratification and adjustment analyses considering factors affecting patients' experiences and the availability of them in the CPES-NCRAS dataset. Extensive details about the methods used to account for these methodological considerations, the reasoning behind including them, and how this framework guided my analysis are presented in the next chapter. It will discuss whether patients' experiences with CNS in England are associated with their subsequent survival.

Chapter 7 : The association between patients' experience with CNS and their subsequent survival in England

This chapter uses a population-based cohort drawn from the CPES-NCRAS dataset to assess the variation observed in cancer patients' survival in relation to the experiences they reported with CNS. The novelty of this project and its methodology are extensively described in the methods section of this chapter. Here the findings are first presented and discussed, and their implications considered towards the end of the chapter.

7.1 Introduction:

Cancer survival in the UK is lower compared with several high-income countries (Arnold et al., 2019). Variabilities in underlying health systems, cancer policy, and clinical practice are known to be important drivers of cancer survival (Arnold et al., 2019). Patient experience is widely considered as a central pillar of cancer care quality (Institute of Medicine, 2013; The Independent Cancer Taskforce, 2015a; Cleary, 2016; Wolf, 2018; Anhang Price et al., 2014). Patient experience has also been shown to be associated with patient safety, care effectiveness, and health outcomes in many care settings including cancer (Fenton, 2012; Doyle et al., 2013; S. A. Alessy, Lüchtenborg, et al., 2019; Jerant et al., 2019). Previous research in England and Europe has also shown that hospital care quality varies in relation to inpatient nurse staffing and education, and improves with higher levels of each across many care settings (Rafferty et al., 2007; Keogh, 2017; Aiken et al., 2014, 2012).

Clinical Nurse Specialists (CNS) play a key role in co-ordinating cancer patients care, contributing to the cancer multidisciplinary team (MDT), as well as in providing information and emotional support (National Cancer Action Team, 2010; The Lancet, 2011; Westman et al., 2019; Wallace et al., 2019; Challinor et al., 2020; Young et al., 2020). CPES asks patients about a wide range of care aspects including their experiences with CNS (Quality Health, 2019). My previous findings presented in chapter 5 showed that patients who have been assigned a CNS tend to report better experiences with care across several aspects of the cancer care pathway. An important question therefore is whether variation in cancer patients’ care experiences with CNS are also associated with their survival. The linked CPES-NCRAS data has enabled studies of the potential association between patients’ experiences and cancer care outcomes (Carneiro et al., 2017). CNS care has been shown to play a role in improving cancer patients’ experiences with other care aspects such as care co-ordination, involvement in treatment decision, and overall care experience. Using the CPES-NCRAS linked dataset and focusing on the four most common cancers - colorectal, lung, breast and prostate cancers - this study aimed to examine whether having a better care experience with CNS is associated with better cancer survival in England.

7.2 Methodology:

7.2.1 Study design and participants

In this population-based cohort study, I extracted data on all individuals with a primary, invasive tumour of the colorectum, lung, female breast, and prostate. CPES sampling, data linkage, extraction, and representativeness of the dataset have been previously explained in Chapters 3 and 4. Patients are asked in CPES to report their experiences on four aspects of CNS care. These are - as ordered in CPES - 1) being given a CNS name, 2) the ease of contacting their CNS, 3) feeling that a CNS had listened to them, and 4) the degree to which explanations given by a CNS were understandable. Patients who reported not being given a CNS name were asked not to report their experiences in the rest of the three CNS experience questions in the survey. For the purposes of the analysis, I first identified the group of patients who were not given the name of a CNS. For patients who were given a CNS name and reported their experiences in the remaining three questions, I categorized their responses into two main categories: ‘excellent’ and ‘non – excellent’ experience in line with other reports, (Pinder et al., 2016; Salika et al., 2018; El Turabi et al., 2013) (Table 7-1).

Table 7-1: CPES questions about patients' experiences with clinical nurse specialist categorized into excellent and not-excellent experience

Cancer care aspects	Exact question in CPES	Experience categories based on CPES answers*	
		Excellent	**Not excellent**
Ease of contacting a CNS	How easy is it for you to contact your clinical Nurse Specialist?	• Easy	• Sometimes easy, sometimes difficult • Difficult
CNS listening carefully to patients	The last time you spoke to your Clinical Nurse Specialist, did she/he listen carefully to you?	• Yes definitely	• Yes, to some extent • No
Patients understanding a CNS answers	When you have important questions to ask your Clinical Nurse Specialist, how often do you get answers you can understand?	• All or most of the time	• Some of the time • Rarely or never

*Patients who reported that they did not try to ask or contact their CNS were excluded from the analysis

7.2.2 Procedures:

A total number of 114,898 records were extracted from the CPES-NCRAS dataset. Some patients were surveyed more than once throughout different iterations of CPES. Therefore, I took the first survey record for each patient and removed additional responses (n=6,293). In addition, I excluded cases with a missing socioeconomic deprivation score for their area of residence (n=174), and patients with registered date of death before treatment and/or diagnosis dates (n=1,230). I also excluded patients who did not indicate whether they had been given a CNS name, and those who did not report their experiences for at least one of the CNS questions, including patients who reported 'I do not know' or 'I did not ask questions' (n= 7,825) (Figure 7-1).

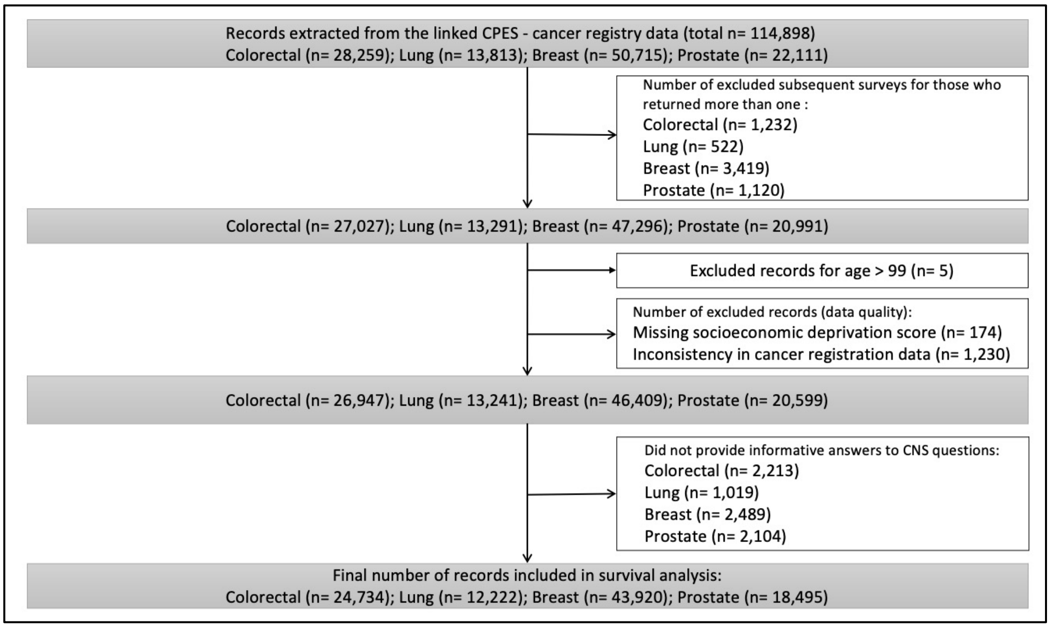


Figure 7-1: Study participant flowchart

7.2.3 Start of follow up

One important initial task was to eliminate potential 'immortal time' bias on patient's survival. This is the possibility that there has been a period of the follow-up time – so called 'immortal time' - when a participant of a cohort has not been properly considered at risk for the outcome of interest (Lee and Nunan, 2020). In this study, for example, those patients who completed the survey had, by definition, to be alive to receive, complete and return it. Patients could, however, have been alive for variable lengths of time before they received the survey and those who had already survived longer might contribute in different ways to the survey. If I calculated survival simply from the original date of diagnosis to the date of death, I would therefore be introducing 'immortal time' that had occurred before CPES was completed.

I therefore first carefully considered the time between the patient's diagnosis and their actual response to the survey. Prior to sending the survey to patients, the survey administrators – Quality Health - removed data on any patient within the dataset they had received who was found to have already died. Ideally, the date at which the study observation begins for the patient cohort in this study is the date patients completed their own survey. As this is not recorded, I moved the start of follow-up to the survey mail out date provided to me by Quality Health. This approach accepts that patients were at risk of death at the last point they are known to be alive (survey mail out). I also calculated the 'immortal time' between the date of diagnosis and the point where the survival analysis started (survey mail out) in days to adjust for it in the cox model analysis (Figure 7-2). Patients who were still alive were censored on their live status date in the cancer registration (updated between 5th and 10th February 2019).

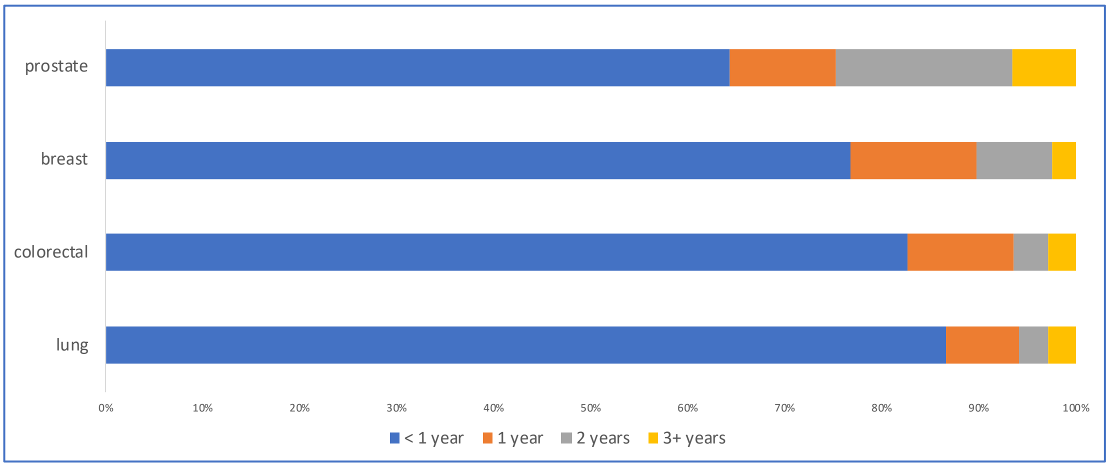


Figure 7-2: Time between date of cancer diagnosis and start of follow-up in the cohort by cancer type

7.2.4 Patients' information and data analysis

Based on the framework presented in the previous chapter and the patient information available in the CPES-NCRAS dataset, several factors were considered as potential confounders of any relationship between patient experience and survival. These factors are those that have already been linked to variation in patients' experiences (Saunders et al., 2015; Salika et al., 2018; Pinder et al., 2016; El Turabi et al., 2013), and shown to be associated with cancer survival (Palser et al., 2013; Office for National Statistics, 2018; Exarchakou et al., 2018). Therefore, my decision on which covariables to include initially in the regression analysis was based on my previous analysis of this dataset, variables discussed in the previous chapters that are known to influence patients' experiences, and variables known to be linked to cancer patient survival by previous English research.

First, sex, age, and stage of cancer at diagnosis have been documented as strong predicators of their cancer survival due to a biological or risk exposure association (Radkiewicz et al., 2017). As shown in the previous chapter, all of these factors have also been linked to variations in cancer patients' experiences in several settings. Specifically, younger cancer patients, women, and patients diagnosed with advanced cancer stage were more likely to report negative care experiences. Second, I have shown in the previous chapter that many studies from CPES and from other USA settings documented variations in patients' experiences by their area of residence, ethnicity, and socioeconomic deprivation. Patients living in rural or socioeconomically deprived areas, and those from ethnic minority groups, were more likely to report negative care experiences (Pinder et al., 2016; Mollica et al., 2018; Saunders et al., 2014). These factors have also been shown to independently explain variations in cancer patients' survival in England, especially for those from black ethnic minority groups or those living in the most deprived areas who have a worse cancer survival (Palser et al., 2013; Office for National Statistics, 2018; Exarchakou et al., 2018). Routes to cancer diagnosis has also been shown to independently influence cancer patients' experiences in England (Pham, Gomez-Cano, et al., 2019), with few studies also revealed an association between emergency diagnosis and lower patients survival (Palser et al., 2013).

For all patients, I included sex, age (categorized as < 45, 45-59, 60-74, 75-99), socioeconomic deprivation (with 1 being the least deprived and 5 being the most deprived), ethnicity (white vs all non-white), area of residence (the nine English areas), route to diagnosis (Emergency presentation, GP, screening, two-week referral, elective referral), time between date of diagnosis and survey mail-out (in days), and stage at diagnosis. I also included descriptive data on the proportion of patients receiving each type of cancer treatment (surgery, chemotherapy, radiotherapy). Information on these data sources and how they are collected in the cancer registry have been previously explained in the general methodology of this thesis (Chapter 3).

I first tabulated the distribution of patient characteristics (age, sex, socioeconomic deprivation, ethnicity, geographical areas), their tumour characteristics (disease stage at diagnosis), and their route to diagnosis according to their reported experience with CNS. χ^2 tests were obtained to test for differences between groups with (unknown values) for ethnicity, route to diagnosis, and stage categories included in these tests. I used Kaplan-Meier survival function to compare overall patients' survival in relation to their experiences with CNS for all cancers and obtained log-rank test.

I then used univariable and multivariable Cox proportional hazards regression analyses to estimate hazard ratios (HR) with 95% confidence intervals (95% CI) by patient experience for each cancer. As previously explained, the three categories for patients' experiences were (excellent, non-excellent, and no CNS name was given), using the "excellent" experience as the reference group. I included all three aspects of patients' experiences with CNS that are reported in CPES: the ease of contacting their CNS, feeling that a CNS had listened to them, and the degree to which explanations given by a CNS were understandable. The covariables that were used in survival analyses were sex, age, socioeconomic deprivation, ethnicity, geographical areas, patients' route to diagnosis, and disease stage at diagnosis. I evaluated the assumption of proportional hazards using Schoenfeld residuals.

Assessing health outcomes based on survey responses is problematic due to the possibility of reverse causation where the current patient's health status might influence the patient's response to the outcome measured by the survey. This type of reverse causation has been warned against in the literature that investigated the association between patients' satisfaction and their health outcomes (Fenton, 2012). In this study, it might well be argued that patients could rate their experiences with care based on their prognosis and/or extent of their current disease progression. Specifically, patients who have worse cancer prognosis might rate their experience as negative based on their disease prognosis, how they feel about this, the treatment they have to undergo and the impact of both on their life in general, rather than on the actual care their received. A potential way to assess the impact of this issue is to eliminate patients with the worst outcomes in a sensitivity analysis (Gunter et al., 2017; VanderWeele et al., 2016). Therefore, I ran a multivariable Cox proportional hazards regression model after eliminating patients with the worst outcomes (lowest 25th quartile of survival time). All the analysis was done using Stata Software, version 15.1 (Stata Corp, Texas, USA).

7.3 Results:

The final study cohort included 99,371 patients (colorectal n = 24,734; lung n = 12,222; breast n = 43,920; prostate n = 18,495) who responded to CPES between 2010-14. By cancer type, Table 7-2 to Table 7-5 show the distributions of patients sex, age, ethnicity, socioeconomic deprivation, geography of residence, their route to diagnosis and their disease stage at diagnosis according to their reported experience with CNS. As shown in Table 7-2 to Table 7-5, more than 89% of patients reported an excellent care experience across all cancers with the two following care aspects: feeling that a CNS had listened to them; and that the explanations given by CNS had made sense. However, the proportions of patients indicating excellent experiences with ease of contacting their CNS varied from 72% to 78% between cancer types. Chapter 5 of this thesis provided in-depth analysis of patients' experiences with being given a CNS name. That analysis showed a slight variation in patients reporting being given a CNS name between cancers, but with a strong association emerged between being given the name of a CNS and reporting better care experiences.

Overall, the Kaplan-Meier curves showed variation in patients' survival in relation to their reported communication experiences with CNS between the three compared groups (excellent experience, non-excellent experience, and no CNS name given) (Figure 7-4 & Figure 7-3). The differences were highly statistically significant (all log-rank tests P< 0.001).

Table 7-6 shows the results of the Cox proportional hazards regression analysis after applying and testing three different explanatory models for the association between experience and survival. After adjusting for age and sex in model 1 of the Cox regression analysis, the results show that among those who reported not being given a CNS name, the highest risk of death was in those with colorectal, breast and prostate cancers (colorectal HR: 1.78; 95% CI: 1.68–1.88; breast HR: 1.94; 95% CI:

1.82–2.08; prostate HR: 1.58; 95% CI: 1.48–1.69). These estimates were slightly sensitive to further statistical adjustment in model 2 after adding stage to the previous model. The association, however, was attenuated in some parts of the analysis when fully adjusting in Model 3 for all covariates (Table 7-6). The association remained strong among colorectal and breast cancers only (colorectal HR: 1.40; 95% CI: 1.32–1.84; breast HR: 1.34; 95% CI: 1.25-1.44) (Model 3) (Table 7-6). Among lung cancer patients, those who reported not being given a CNS name had a lower risk of death compared with other groups, but this association was attenuated after partial adjustment in model 2, and in the full adjustment in model 3 (HR: 0.92; 95% CI: 0.84–0.98) (Table 7-6).

Patients' experiences with the degree to which explanations given by a CNS were understandable was the aspect of communication with CNS that was most strongly associated with the risk of death, followed by experience of feeling that a CNS had listened to them (Table 7-6). Among colorectal, breast, and prostate cancers, those who reported non-excellent experiences with understanding CNS explanations had higher risk of death compared with patients who reported excellent experiences (colorectal HR: 1.22; 95% CI: 1.12–1.30; breast HR: 1.23; 95% CI: 1.14-1.31; prostate HR: 1.26; 95% CI: 1.15–1.39) (Model 3) (Table 7-6).

In the sensitivity analysis (model 4), I eliminated patients in the lowest 25% quartile of survival time (in days) to investigate whether the association between patients' experiences and their survival might be prone to reverse causation (Table 7-6). My hypothesis being that patients with better cancer prognosis might be more likely to be assigned to a CNS, and those with the poorest prognosis might be more likely to be referred to a palliative care nurse. The association was only sensitive to this adjustment among breast cancer patients who reported not being given a CNS name (HR: 1.05; 95% CI: 0.85–1.09) (Table 7-6).

Finally, I compared the proportion of patients receiving treatment according to their experience with being given a CNS name or not as reported in CPES. Overall, there was a wide variation between the two groups in terms of the proportion of patients receiving surgery, chemotherapy, and radiotherapy among lung cancer patients, and in surgery among prostate cancer patients (Figure 7-5).

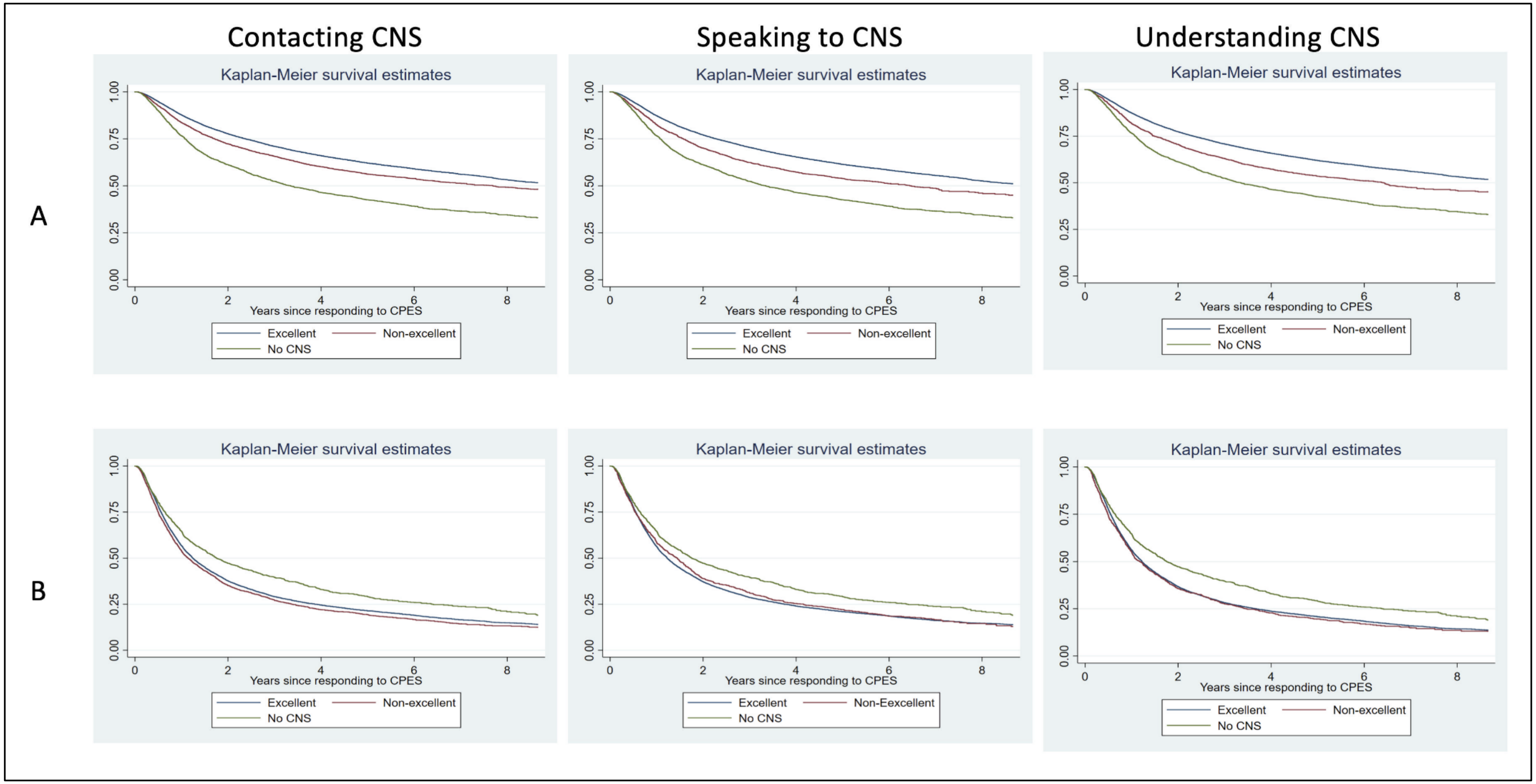


Figure 7-3: Kaplan-Meier survival estimates of death from any cause in (A) colorectal and (B)lung cancer patients according to their care experience with Clinical Nurse Specialist (CNS)

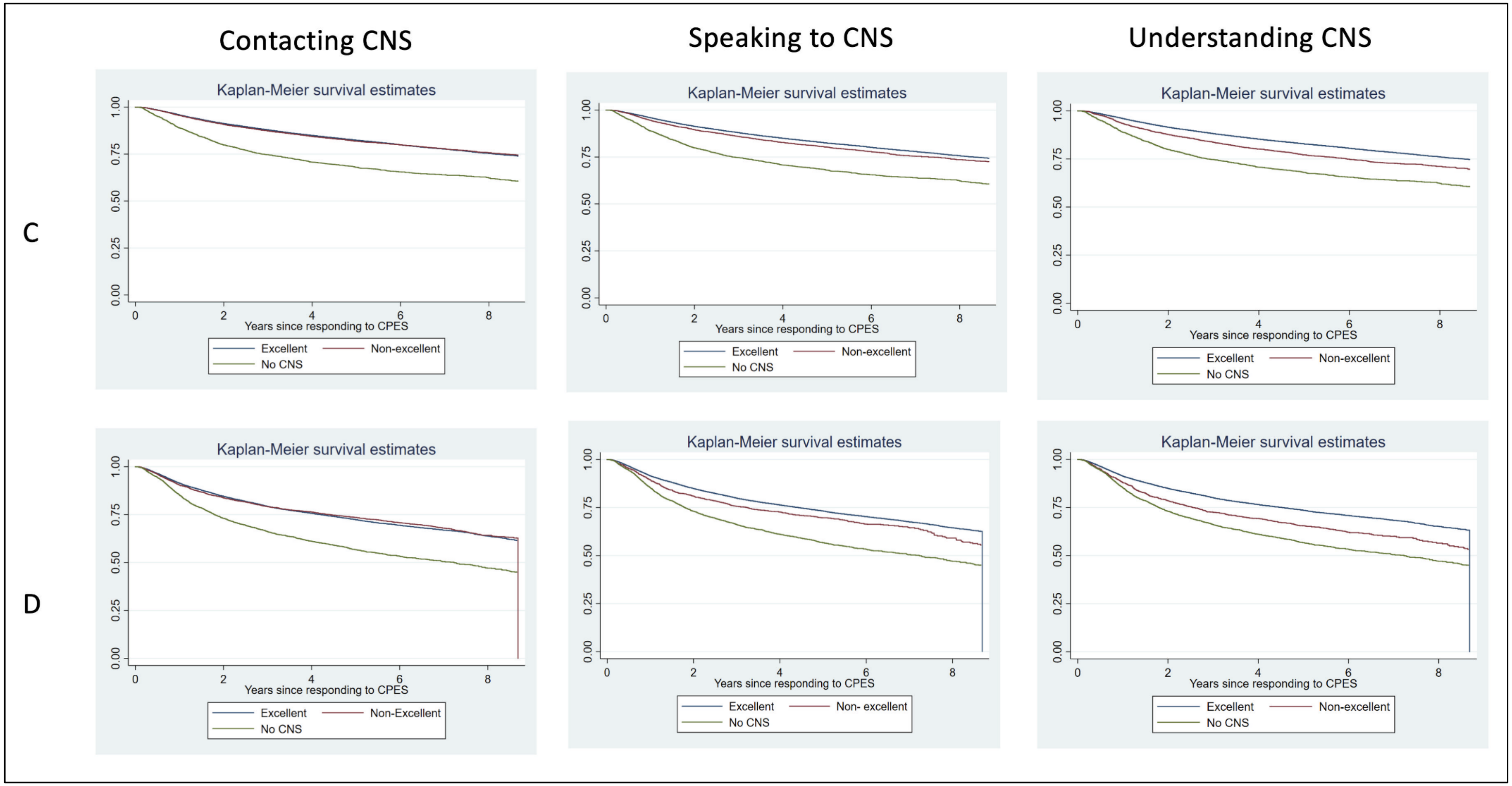


Figure 7-4: Kaplan-Meier survival estimates of death from any cause in (C) breast and (D) prostate cancer patients according to their care experience with Clinical Nurse Specialist (CNS)

Table 7-2: Characteristics of colorectal cancer patients reporting their care experiences with cancer clinical nurse specialists (CNS)

Type of experience	**CNS name**		**Contacting CNS**				**Speaking to CNS**				**Understanding CNS**			
Level of care experience	**Not given (n=**2388**)**		**Excellent (n=**16,107) (78.6%)		**Non-excellent (n=**4,392) (21.4%)		**Excellent (n=**20,532) (92.8%)		**Non-excellent (n=**1,585) (7.2%)		**Excellent (n=**18,612) (92.1%)		**Non-excellent (n=**1,597) (7.9%)	
Variable	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
Sex														
Male	1,373	57.5	9,720	60.3	2,517	57.3	12,326	60.0	848	53.5	11,187	60.1	898	56.2
Female	1,015	42.5	6,387	39.7	1,875	42.7	8,206	40.0	737	46.5	7,425	39.9	699	43.8
χ2 and P value*			χ2 =17.5; p<0.001				χ2 =29.8; p<0.001				χ2 = 3.8; p=0.001			
Age Group														
< 45	74	3.1	456	2.8	212	4.8	635	3.1	69	4.4	580	3.1	87	5.4
45 - 59	448	18.8	2,684	16.7	908	20.7	3,468	16.9	374	23.6	3,274	17.6	331	20.7
60 - 74	1,123	47.0	8,606	53.4	2,280	51.9	10,897	53.1	794	50.1	9,991	53.7	768	48.1
75 - 99	743	31.1	4,361	27.1	992	22.6	5,532	26.9	348	22.0	4,767	25.6	411	25.7
χ2 and P value			χ2 =138.6; p<0.001				χ2 =93.9; p<0.001				χ2 =82.7; p<0.001			
Ethnicity														
White	2,070	86.7	14,220	88.3	3,805	86.6	18,083	88.1	1,360	85.8	16,406	88.1	1,366	85.5
Non - white	73	3.1	437	2.7	150	3.4	573	2.8	68	4.3	514	2.8	80	5.0
Unknown	245	10.3	1,450	9.0	437	9.9	1,876	9.1	157	9.9	1,692	9.1	151	9.5
χ2 and P value			χ2 =13.5; p<0.001				χ2 =16.3; p=0.003				χ2 =30.0; p<0.001			
Area														
East Midlands	294	12.3	1,506	9.3	397	9.0	1,955	9.5	158	10.0	1,768	9.5	154	9.6
East of England	261	10.9	1,962	12.2	544	12.4	2,495	12.2	194	12.2	2,270	12.2	190	11.9
London	191	8.0	1,453	9.0	505	11.5	1,909	9.3	188	11.9	1,714	9.2	191	12.0
North East	107	4.5	1,142	7.1	189	4.3	1,342	6.5	75	4.7	1,223	6.6	83	5.2
North West	247	10.3	2,086	13.0	528	12.0	2,589	12.6	185	11.7	2,370	12.7	195	12.2
South East	375	15.7	2,442	15.2	846	19.3	3,251	15.8	296	18.7	2,937	15.8	275	17.2
South West	232	9.7	2,190	13.6	530	12.1	2,741	13.3	168	10.6	2,524	13.6	169	10.6
West Midlands	389	16.3	1,754	10.9	482	11.0	2,279	11.1	195	12.3	2,043	11.0	197	12.3
Yorkshire & Humber	292	12.2	1,572	9.8	371	8.4	1,971	9.6	126	7.9	1,763	9.5	143	9.0

χ2 and P value			χ2 =260.9; p<0.001				χ2 =171.9; p<0.001				χ2 =167.5; p<0.001			
IMD														
1 – most affluent	509	21.3	3,692	22.9	1,126	25.6	4,847	23.6	356	22.5	4,407	23.7	337	21.1
2	605	25.3	4,033	25.0	1,070	24.4	5,097	24.8	370	23.3	4,654	25.0	343	21.5
3	507	21.2	3,444	21.4	904	20.6	4,351	21.2	342	21.6	3,940	21.2	351	22.0
4	427	17.9	2,815	17.5	756	17.2	3,587	17.5	285	18.0	3,237	17.4	309	19.3
5 – most deprived	340	14.2	2,123	13.2	536	12.2	2,650	12.9	232	14.6	2,374	12.8	257	16.1
χ2 and P value			χ2 =22.7; p<0.001				χ2 =13.2; p=0.10				χ2 =34.8; p<0.001			
Route to Diagnosis														
ER	609	25.5	1,888	11.7	524	11.9	2,421	11.8	212	13.4	2,177	11.7	227	14.2
GP	560	23.5	3,933	24.4	1,147	26.1	5,052	24.6	430	27.1	4,542	24.4	431	27.0
Screening	165	6.9	2,445	15.2	566	12.9	3,070	15.0	182	11.5	2,852	15.3	169	10.6
Two-week referral	704	29.5	5,869	36.4	1,586	36.1	7,473	36.4	569	35.9	6,744	36.2	557	34.9
Elective Referral	266	11.1	1,733	10.8	483	11.0	2,205	10.7	156	9.8	2,000	10.7	178	11.1
Unknown	84	3.5	239	1.5	86	2.0	311	1.5	36	2.3	297	1.6	35	2.2
χ2 and P value			χ2 =495.7; p<0.001				χ2 =497.5; p<0.001				χ2 = 501.5; p<0.001			
Stage														
I	142	5.9	1,437	8.9	322	7.3	1,770	8.6	120	7.6	1,615	8.7	113	7.1
II	332	13.9	2,896	18.0	604	13.8	3,632	17.7	209	13.2	3,221	17.3	234	14.7
III	489	20.5	4,037	25.1	1,104	25.1	5,143	25.0	397	25.0	4,741	25.5	394	24.7
IV	465	19.5	1,990	12.4	762	17.3	2,679	13.0	294	18.5	2,386	12.8	276	17.3
Unknown	960	40.2	5,747	35.7	1,600	36.4	7,308	35.6	565	35.6	6,649	35.7	580	36.3
χ2 and P value			χ2 =225.1; p<0.001				χ2 =170.; p<0.001				χ2 =156.6; p<0.001			

*Patients who were not give a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS, and understanding CNS); **Abbreviations**: CNS = Clinical Nurse Specialist; % for Column percentage; IMD = indices of multiple deprivation; GP = general practitioner; ER = emergency presentation. ** All χ2 tested for differences between three groups (Excellent, non-excellent, and not having CNS) across all variables in the table.

Table 7-3: Characteristics of lung cancer patients reporting their care experience with cancer clinical nurse specialists (CNS)

Type of experience	**CNS name**		**Contacting CNS**				**Speaking to CNS**				**Understanding CNS**			
Level of care experience	**Not given** (n=966)		**Excellent** **(n=**7,888) (75.9%)		**Non-excellent** (n=2,510) (24.1%)		**Excellent** **(n=**10,128) (91.0%)		**Non-excellent** (n=1,000) (9.0%)		**Excellent** **(n=**8,886) (89.5%)		**Non-excellent** (n=1,040) (10.5.%)	
Variable	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
Sex														
Male	507	52.5	4,356	55.2	1,293	51.5	5,541	54.7	476	47.6	4,856	54.6	539	51.8
Female	459	47.5	3,532	44.8	1,217	48.5	4,587	45.3	524	52.4	4,030	45.4	501	48.2
χ2 and P value*						χ2 =11.7; p=0.003				χ2 =19.4; p<0.001				χ2 =4.2; p<0.12
Age Group														
< 45	20	2.1	84	1.1	43	1.7	122	1.2	16	1.6	103	1.2	24	2.3
45 – 59	159	16.5	1,272	16.1	523	20.8	1,679	16.6	227	22.7	1,528	17.2	208	20.0
60 – 74	525	54.3	4,821	61.1	1,469	58.5	6,150	60.7	561	56.1	5,438	61.2	582	56.0
75 – 99	262	27.1	1,711	21.7	475	18.9	2,177	21.5	196	19.6	1,817	20.4	226	21.7
χ2 and P value						χ2 =65.6; p<0.001				χ2 =49.7; p<0.001				χ2 =46.5; p<0.001
Ethnicity														
White	831	86.0	7,122	90.3	2,222	88.5	9,107	89.9	890	89.0	8,009	90.1	905	87.0
Non - white	39	4.0	171	2.2	96	3.8	259	2.6	32	3.2	222	2.5	48	4.6
Unknown	96	9.9	595	7.5	192	7.6	762	7.5	78	7.8	655	7.4	87	8.4
χ2 and P value						χ2 =35.0; p<0.001				χ2 =16.1; p=0.003				χ2 =30.6; p<0.001
Area														
East Midlands	101	10.5	714	9.1	243	9.7	963	9.5	95	9.5	809	9.1	104	10.0
East of England	102	10.6	878	11.1	292	11.6	1,146	11.3	127	12.7	1,008	11.3	115	11.1
London	121	12.5	733	9.3	320	12.7	993	9.8	126	12.6	861	9.7	141	13.6
North East	46	4.8	747	9.5	133	5.3	873	8.6	75	7.5	782	8.8	78	7.5
North West	163	16.9	1,131	14.3	312	12.4	1,392	13.7	126	12.6	1,221	13.7	146	14.0
South East	127	13.1	923	11.7	380	15.1	1,246	12.3	144	14.4	1,094	12.3	134	12.9
South West	79	8.2	857	10.9	262	10.4	1,084	10.7	103	10.3	953	10.7	96	9.2
West Midlands	129	13.4	837	10.6	224	8.9	1,052	10.4	81	8.1	931	10.5	91	8.8
Yorkshire & Humber	98	10.1	1,068	13.5	344	13.7	1,379	13.6	123	12.3	1,227	13.8	135	13.0
χ2 and P value						χ2 =141.6; p<0.001				χ2 =70.1; p<0.001				χ2 =72.2; p<0.001
IMD														
1 – most affluent	168	17.4	1,215	15.4	429	17.1	1,599	15.8	148	14.8	1,427	16.1	145	13.9
2	174	18.0	1,582	20.1	514	20.5	2,030	20.0	211	21.1	1,810	20.4	178	17.1

3	196	20.3	1,611	20.4	512	20.4	2,084	20.6	210	21.0	1,810	20.4	211	20.3
4	205	21.2	1,695	21.5	520	20.7	2,152	21.2	214	21.4	1,881	21.2	234	22.5
5 – most deprived	223	23.1	1,785	22.6	535	21.3	2,263	22.3	217	21.7	1,958	22.0	272	26.2
χ2 and P value						χ2 =9.2; p=0.32				χ2 =5.2; p=0.73				χ2 =18.6; p=0.01
Route to Diagnosis														
ER	126	13.0	978	12.4	327	13.0	1,256	12.4	145	14.5	1,124	12.6	142	13.7
GP	265	27.4	1,944	24.6	689	27.5	2,512	24.8	298	29.8	2,213	24.9	297	28.6
Screening	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Two-week referral	359	37.2	3,667	46.5	1,113	44.3	4,710	46.5	415	41.5	4,123	46.4	449	43.2
Elective Referral	195	20.2	1,206	15.3	344	13.7	1,522	15.0	128	12.8	1,313	14.8	142	13.7
Unknown	21	2.2	93	1.2	37	1.5	128	1.3	14	1.4	113	1.3	10	1.0
χ2 and P value						χ2 =51.3; p<0.001				χ2 =59.5; p<0.001				χ2 =49.8; p<0.001
Stage														
I	262	27.1	1,276	16.2	324	12.9	1,582	15.6	168	16.8	1,338	15.1	156	15.0
II	112	11.6	1,011	12.8	319	12.7	1,284	12.7	149	14.9	1,141	12.8	143	13.8
III	208	21.5	2,360	29.9	767	30.6	3,010	29.7	303	30.3	2,642	29.7	309	29.7
IV	239	24.7	2,568	32.6	881	35.1	3,383	33.4	296	29.6	3,010	33.9	333	32.0
Unknown	145	15.0	673	8.5	219	8.7	869	8.6	84	8.4	755	8.5	99	9.5
χ2 and P value						χ2 =173.2; p<0.001				χ2 = 159.4; p<0.001				χ2=164.6; p<0.001

*Patients who were not give a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS, and understanding CNS); **Abbreviations**: CNS = Clinical Nurse Specialist; % for Column percentage; IMD = indices of multiple deprivation; GP = general practitioner; ER = emergency presentation. ** All χ2 tested for differences between three groups (Excellent, non-excellent, and not having CNS) across all variables in the table

Table 7-4: Characteristics of breast cancer patients reporting their care experience with cancer clinical nurse specialists (CNS)

Type of experience	**CNS name**		**Contacting CNS**				**Speaking to CNS**				**Understanding CNS**			
Level of care experience	**Not given** (n=2,721)		**Excellent** (**n=**27,740) (72.1%)		**Non-excellent** (n=10,736) (28.9%)		**Excellent** (**n=**37,056) (90.6%)		**Non-excellent** (n=3,852) (9.4%)		**Excellent** (**n=**34,898) (91.4%)		**Non-excellent** (n=3,303) (8.6%)	
Variable	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
Age Group														
< 45	470	17.3	3,506	12.6	1,894	17.6	4,960	13.4	680	17.7	4,786	13.7	640	19.4
45 – 59	1,189	43.7	10,574	38.1	4,761	44.3	14,494	39.1	1,774	46.1	13,978	40.1	1,397	42.3
60 – 74	812	29.8	10,687	38.5	3,369	31.4	13,857	37.4	1,155	30.0	12,857	36.8	1,000	30.3
75 – 99	250	9.2	2,973	10.7	712	6.6	3,745	10.1	243	6.3	3,277	9.4	266	8.1
χ2 and P value						χ2 =515.5; p<0.001				χ2 =257.8; p<0.001				χ2 =166.4; p<0.001
Ethnicity														
White	2,268	83.4	23,244	83.8	8,774	81.7	30,910	83.4	3,162	82.1	29,159	83.6	2,617	79.2
Non - white	162	6.0	1,219	4.4	707	6.6	1,764	4.8	260	6.7	1,622	4.6	311	9.4
Unknown	291	10.7	3,277	11.8	1,255	11.7	4,382	11.8	430	11.2	4,117	11.8	375	11.4
χ2 and P value						χ2 =84.4; p<0.001				χ2 =37.2; p<0.001				χ2 =147.7; p<0.001
Area														
East Midlands	446	16.4	2,374	8.6	932	8.7	3,259	8.8	373	9.7	3,002	8.6	323	9.8
East of England	236	8.7	3,321	12.0	1,239	11.5	4,412	11.9	439	11.4	4,154	11.9	393	11.9
London	312	11.5	2,841	10.2	1,607	15.0	4,025	10.9	645	16.7	3,839	11.0	537	16.3
North East	71	2.6	1,860	6.7	428	4.0	2,244	6.1	155	4.0	2,129	6.1	132	4.0
North West	181	6.7	3,284	11.8	1,119	10.4	4,198	11.3	417	10.8	3,974	11.4	334	10.1
South East	504	18.5	4,202	15.1	1,869	17.4	5,876	15.9	607	15.8	5,459	15.6	529	16.0
South West	398	14.6	3,387	12.2	1,229	11.4	4,535	12.2	422	11.0	4,300	12.3	340	10.3
West Midlands	429	15.8	3,297	11.9	1,126	10.5	4,347	11.7	383	9.9	4,072	11.7	353	10.7
Yorkshire & Humber	144	5.3	3,174	11.4	1,187	11.1	4,160	11.2	411	10.7	3,969	11.4	362	11.0
χ2 and P value						χ2 =751.5; p<0.001				χ2 =568.8; p<0.001				χ2 =550.4; p<0.001
IMD														
1 – most affluent	692	25.4	6,329	22.8	2,536	23.6	8,489	22.9	903	23.4	8,106	23.2	679	20.6
2	620	22.8	6,673	24.1	2,565	23.9	8,958	24.2	897	23.3	8,474	24.3	750	22.7
3	579	21.3	5,948	21.4	2,388	22.2	8,033	21.7	797	20.7	7,577	21.7	660	20.0
4	504	18.5	4,952	17.9	1,846	17.2	6,532	17.6	696	18.1	6,090	17.5	630	19.1
5 – most deprived	326	12.0	3,838	13.8	1,401	13.0	5,044	13.6	559	14.5	4,651	13.3	584	17.7
χ2 and P value						χ2 =24.0; p=0.02				χ2 =20.8; p=0.008				χ2 = 78.5; p<0.001

Route to Diagnosis														
ER	67	2.5	323	1.2	118	1.1	439	1.2	40	1.0	393	1.1	42	1.3
GP	286	10.5	1,857	6.7	871	8.1	2,578	7.0	316	8.2	2,427	7.0	280	8.5
Screening	609	22.4	8,317	30.0	2,935	27.3	11,102	30.0	1,051	27.3	10,389	29.8	846	25.6
Two-week referral	1,277	46.9	15,295	55.1	6,061	56.5	20,366	55.0	2,153	55.9	19,270	55.2	1,867	56.5
Elective Referral	79	2.9	597	2.2	200	1.9	757	2.0	78	2.0	725	2.1	71	2.1
Unknown	403	14.8	1,351	4.9	551	5.1	1,814	4.9	214	5.6	1,694	4.9	197	6.0
χ2 and P value						χ2 =649.2; p<0.001				χ2 = 626.4; p<0.001				χ2 =637.3; p<0.001
Stage														
I	560	20.6	7,923	28.6	2,663	24.8	10,549	28.5	940	24.4	9,821	28.1	773	23.4
II	791	29.1	9,012	32.5	3,394	31.6	11,879	32.1	1,195	31.0	11,355	32.5	978	29.6
III	237	8.7	2,503	9.0	1,025	9.5	3,353	9.0	323	8.4	3,142	9.0	343	10.4
IV	170	6.2	779	2.8	318	3.0	1,042	2.8	140	3.6	931	2.7	139	4.2
Unknown	963	35.4	7,523	27.1	3,336	31.1	10,233	27.6	1,254	32.6	9,649	27.6	1,070	32.4
χ2 and P value						χ2 =281.8; p<0.001				χ2 =260.8; p<0.001				χ2 =290.4; p<0.001

*Patients who were not give a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS, and understanding CNS); **Abbreviations**: CNS = Clinical Nurse Specialist; % for Column percentage; IMD = indices of multiple deprivation; GP = general practitioner; ER = emergency presentation. ** All χ2 tested for differences between three groups (Excellent, non-excellent, and not having CNS) across all variables in the table.

Table 7-5: Characteristics of prostate cancer patients reporting their care experience with cancer clinical nurse specialists (CNS)

Type of experience	**CNS name**		**Contacting CNS**				**Speaking to CNS**				**Understanding CNS**			
Level of care experience	**Not given** (n=2,600)		**Excellent** (**n=**10,271) (72.0%)		**Non-excellent** (n=3,991) (28.0%)		**Excellent** (**n=**14,279) (91.2%)		**Non-excellent** (n=1,370) (8.8%)		**Excellent** (**n=**12,587) (90.8%)		**Non-excellent** (n=1,278) (9.2%)	
Variable	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
Age Group														
< 45	4	0.2	17	0.2	10	0.3	29	0.2	1	0.1	25	0.2	3	0.2
45 – 59	333	12.8	1,529	14.9	713	17.9	2,185	15.3	245	17.9	2,002	15.9	231	18.1
60 – 74	1,572	60.5	6,946	67.6	2,752	69.0	9,677	67.8	920	67.2	8,596	68.3	825	64.6
75 – 99	691	26.6	1,779	17.3	516	12.9	2,388	16.7	204	14.9	1,964	15.6	219	17.1
χ2 and P value			χ2 =217.4; p<0.001				χ2 =161.9; p<0.001				χ2 =188.6; p<0.001			
Ethnicity														
White	2,182	83.9	8,770	85.4	3,392	85.0	12,194	85.4	1,143	83.4	10,723	85.2	1,084	84.8
Non - white	118	4.5	385	3.7	166	4.2	540	3.8	71	5.2	471	3.7	72	5.6
Unknown	300	11.5	1,116	10.9	433	10.8	1,545	10.8	156	11.4	1,393	11.1	122	9.5
χ2 and P value			χ2 =5.1; p=0.26				χ2 =10.6; p=0.03				χ2 = 16.0; p<0.001			
Area														
East Midlands	358	13.8	899	8.8	358	9.0	1,255	8.8	146	10.7	1,086	8.6	138	10.8
East of England	252	9.7	1,200	11.7	516	12.9	1,687	11.8	164	12.0	1,469	11.7	166	13.0
London	324	12.5	861	8.4	438	11.0	1,262	8.8	146	10.7	1,125	8.9	137	10.7
North East	88	3.4	585	5.7	149	3.7	756	5.3	50	3.6	654	5.2	68	5.3
North West	347	13.3	2,035	19.8	706	17.7	2,777	19.4	252	18.4	2,438	19.4	224	17.5
South East	340	13.1	1,389	13.5	624	15.6	1,981	13.9	201	14.7	1,788	14.2	163	12.8
South West	358	13.8	1,461	14.2	468	11.7	1,962	13.7	138	10.1	1,734	13.8	140	11.0
West Midlands	306	11.8	1,049	10.2	434	10.9	1,497	10.5	159	11.6	1,310	10.4	147	11.5
Yorkshire & Humber	227	8.7	792	7.7	298	7.5	1,102	7.7	114	8.3	983	7.8	95	7.4
χ2 and P value			χ2 =234.4; p<0.001				χ2 =186.9; p<0.001				χ2 =176.5; p<0.001			
IMD														
1 – most affluent	669	25.7	2,641	25.7	1,041	26.1	3,691	25.8	319	23.3	3,302	26.2	252	19.7

2	663	25.5	2,593	25.2	1,067	26.7	3,633	25.4	354	25.8	3,264	25.9	305	23.9
3	508	19.5	2,131	20.7	801	20.1	2,944	20.6	269	19.6	2,566	20.4	264	20.7
4	460	17.7	1,613	15.7	629	15.8	2,243	15.7	219	16.0	1,911	15.2	250	19.6
5 – most deprived	300	11.5	1,293	12.6	453	11.4	1,768	12.4	209	15.3	1,544	12.3	207	16.2
χ2 and P value			χ2 =14.3; p<0.07				χ2 =20.7; p=0.008				χ2 =58.6; p<0.001			
Route to Diagnosis														
ER	146	5.6	348	3.4	122	3.1	460	3.2	62	4.5	409	3.2	66	5.2
GP	931	35.8	4,198	40.9	1,804	45.2	5,977	41.9	602	43.9	5,296	42.1	541	42.3
Screening	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0
Two-week referral	725	27.9	4,115	40.1	1,415	35.5	5,578	39.1	492	35.9	4,884	38.8	453	35.4
Elective Referral	288	11.1	970	9.4	364	9.1	1,355	9.5	115	8.4	1,184	9.4	109	8.5
Unknown	510	19.6	640	6.2	286	7.2	909	6.4	99	7.2	814	6.5	109	8.5
χ2 and P value			χ2 =608.9; p<0.001				χ2 =608.7; p<0.001				χ2 =566.6; p<0.001			
Stage														
I	310	11.9	1,554	15.1	581	14.6	2,152	15.1	196	14.3	1,848	14.7	155	12.1
II	239	9.2	1,635	15.9	682	17.1	2,326	16.3	197	14.4	2,076	16.5	195	15.3
III	154	5.9	1,273	12.4	495	12.4	1,777	12.4	151	11.0	1,579	12.5	143	11.2
IV	281	10.8	1,085	10.6	404	10.1	1,443	10.1	177	12.9	1,286	10.2	168	13.1
Unknown	1,616	62.2	4,724	46.0	1,829	45.8	6,581	46.1	649	47.4	5,798	46.1	617	48.3
χ2 and P value			χ2 =290.4; p<0.001				χ2 = 298.4; p<0.001				χ2 =297.7; p<0.001			

*Patients who were not give a CNS name were asked to not report their experience with the other three CNS questions (contacting CNS, speaking to CNS, and understanding CNS); **Abbreviations**: CNS = Clinical Nurse Specialist; for Column percentage; IMD = indices of multiple deprivation; GP = general practitioner; ER = emergency presentation. ** All χ2 tested for differences between three groups (Excellent, non-excellent, and not having CNS) across all variables in the table.

Table 7-6: Hazard ratio of death for all cancer patients according to their care experience with cancer clinical nurse specialists (CNS)

Experience Type		**Model 1**		**Model 2**		**Model 3**		**Sensitivity analysis****	
	Adjustments	**Age and sex**		**Age, sex, and stage**		**All covariates**		**All covariates**	
Colorectal cancer	**Experience Level**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**	**HR**	**95% CI**
CNS name	*Not given*	1.78	1.68-1.88	1.60	1.51-1.69	1.40	1.32-1.84	1.37	1.05-1.62
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.22	1.16-1.28	1.12	1.07-1.19	1.13	1.07-1.18	1.07	1.00-1.16
CNS Listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.31	1.21-1.41	1.24	1.15-1.34	1.21	1.14-1.31	1.19	1.06-1.33
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.30	1.21-1.41	1.24	1.15-1.33	1.22	1.12-1.30	1.18	1.05-1.32
Lung cancer									
CNS name	*Not given*	0.79	0.74-0.86	0.91	0.84-0.98	0.92	0.84-0.99	0.87	0.79-0.95
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.09	1.04-1.14	1.04	0.99-1.09	1.05	1.00-1.10	1.00	0.95-1.07
CNS Listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	0.98	0.91-1.06	1.03	0.96-1.11	1.04	0.97-1.12	1.01	0.92-1.10
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.04	0.98-1.12	1.04	0.98-1.12	1.04	0.97-1.12	0.98	0.89-1.06
Breast cancer									
CNS name	*Not given*	1.94	1.82-2.08	1.72	1.61-1.84	1.34	1.25-1.44	1.05	0.85-1.09
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.06	1.01-1.11	1.02	0.97-1.07	1.03	0.98-1.08	0.96	0.85-1.09
CNS Listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.19	1.11-1.28	1.12	1.10-1.27	1.15	1.07-1.23	1.15	0.97-1.37
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.36	1.26-1.46	1.25	1.16-1.34	1.23	1.14-1.31	1.06	0.87-1.28
Prostate Cancer									
CNS name	*Not given*	1.58	1.48-1.69	1.42	1.33 -1.51	1.09	0.99-1.13	1.09	0.88-1.24
Contact CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.01	0.94-1.07	1.02	0.95-1.09	1.05	0.95-1.07	0.99	0.87-1.28
CNS Listening	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.21	1.09-1.32	1.14	0.04-1.25	1.11	1.00-1.20	1.03	0.86-1.25
Understand CNS	Excellent	1.00		1.00		1.00		1.00	
	Non-excellent	1.35	1.23-1.49	1.30	1.13-1.42	1.26	1.15-1.39	1.23	1.01-1.49

Model 1: Excellent experience as a reference and adjusting sex (for lung and colorectal patients) and age ; **Model 2:** Excellent experience as a reference and adjusting sex, age, and stage; **Model 3 :** Excellent experience as a reference and adjusting sex, age, ethnicity, areas, deprivation, route to diagnosis (unknown as a category), stage at diagnosis (unknown as a category), and time since diagnosis in days;** **Sensitivity analysis:** Same as Model 3 but eliminating patients with the worst outcomes based on the least 25% quartile of survival time (in days).

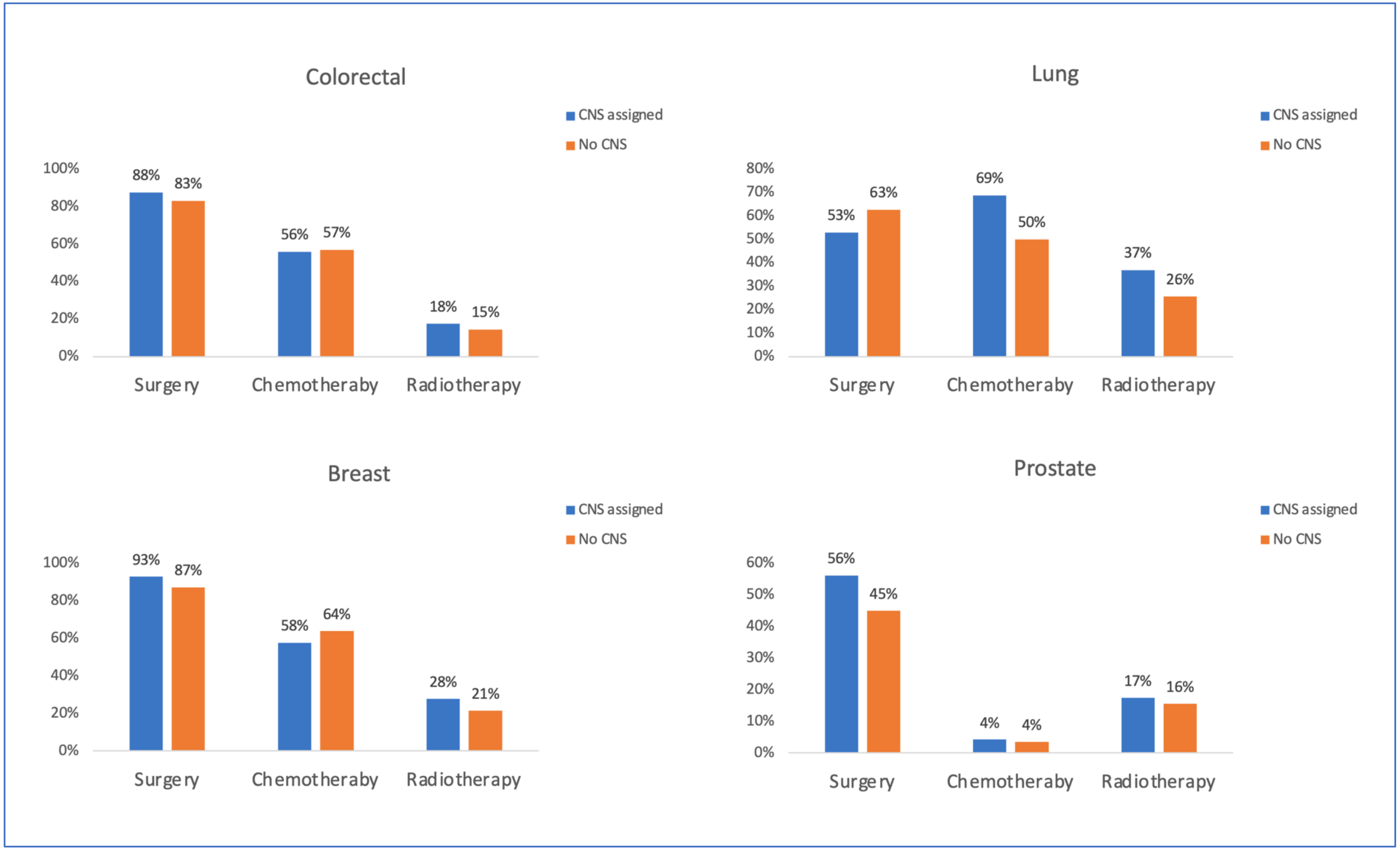


Figure 7-5: Proportion of colorectal, lung, breast, and prostate cancer patients receiving treatment according to their experience with being given a clinical nurse specialists (CNS) name or not as reported in the National Cancer Patient Experience Survey

7.4 Discussion:

7.4.1 Summary of main findings:

This study aimed to examine whether having a better care experience with CNS is associated with better cancer survival in England. Overall, cancer patients' survival varied in relation to their reported communication experiences with CNS between the three groups compared (excellent experience, non-excellent experience, and no CNS name given). Patients who reported not being given a CNS name had the lowest survival and those who reported excellent experience had the highest survival for colorectal, breast, and prostate cancers. However, this association was attenuated/explained among lung cancer patients when accounting for their demographic characteristics and cancer stage. In addition, patients' experiences with the degree to which explanations given by a CNS were understandable was the aspect of CNS care that appeared to be most associated with a decreasing risk of death for the patient, followed by the experience of feeling that a CNS had listened to them.

7.4.2 Comparison with previous studies:

I have shown in the fifth chapter the importance of the CNS role in improving cancer patients' experiences with other aspects of care experience. This chapter now demonstrates a variation in patients' survival in relation to their experiences with CNS. Few studies have investigated the role of CNS in cancer patients' outcomes. For example, Stewart and others investigated the role of lung cancer CNS working practices on patients' receipt of anticancer treatment (Stewart et al., 2018). The study found that patients who were assessed early by lung CNS were more likely to have an increased treatment uptake (Stewart et al., 2018). Another recent study by the same group investigated whether the working practices of lung CNS are associated with cancer care outcomes for patients with lung cancer in England (Stewart et al., 2020). A limited association was found between having a CNS assessment before or at diagnosis and a lower hazard of death (HR = 0.83, 95% CI: 0.73 –0.94), or hospital unplanned admissions (Stewart et al., 2020). My results align with these findings on the importance role of CNS on cancer patients' experiences and outcomes. While my findings do not prove causality, they suggest that the CNS role is having an influence on both cancer patients' experiences and their subsequent survival.

Moreover, as shown in the second chapter of this thesis, very few studies have investigated the association between cancer patients' experiences and their survival. The availability of these datasets, CPES-NCRAS in England and SEER-CAHPS in the USA containing information on both cancer patients' experiences and their survival status, have enabled researchers to explore such an association (Chawla et al., 2015; S. Alessy et al., 2019). Two recent studies from SEER-CAHPS assessed the association between patients' experiences with several care aspects and the survival of patients with the ten most common cancers in USA (DiMartino et al., 2021; Mohan et al., 2020). In the first study, patients who reported lower overall care experiences also had a higher risk of death, but the association was attenuated after adjusting for several possible confounders including patients' demographic factors and their healthcare utilization (DiMartino et al., 2021). The other study assessed the association between excellent care experiences and several clinical outcomes including patients' mortality, their emergency department visits, and their healthcare expenditures (Mohan et al., 2020). The study found no association between highly rated patients' experiences and improved clinical outcomes (Mohan et al., 2020).

While this pattern has been shown in my study, it also raises an important question about the complexity of factors affecting patients' survival throughout the care pathway. This in turn re-emphasises the importance of developing a conceptual framework before undertaking the analysis to ensure potential confounders of the relationship are considered.

Future research should focus on optimising the new linked CPES-registration dataset within NCRAS to determine whether other aspects of patients' experiences play a role in patients' survival. In addition, recent years of CPES rounds can be further linked with the NCRAS treatment datasets to determine whether patients' experiences with CNS play a role in their assessment for or allocation to treatment regimes. Future research should also focus on whether it is CNS availability, the size of the cancer centre or its ability to foster organisational cultures that empower both CNS and the whole cancer team that lead to the improved experiences of care and outcomes.

7.4.3 Study implications

To my knowledge, this study is the first to use linked cancer experience and cancer registration data to examine the association between patients' experiences and their survival in England. My study is particularly important as it has shown that better care experiences are associated with better patient outcomes (Doyle et al., 2013; S. A. Alessy, Lüchtenborg, et al., 2019). One way of interpreting my findings is that better experiences with CNS enables a trusted relationship to grow more quickly in the initial period after diagnosis which therefore promotes continuity of care. This could prevent or offset the effect of seeing different clinicians at subsequent appointments and re-explaining concerns, which patients often describe as a frustrating experience. The lack of a trusting relationship is therefore expected to lead to less adherence with CNS instructions, less seeking of CNS help or advice from the CNS, especially around treatment decision making.

Another interpretation of the finding that patients who have no CNS name had the lowest survival is that better experience with CNS, especially being given a name of a CNS, helps and supports the patient to navigate the cancer care pathway and be involved in an informed treatment decision. The Lung Cancer Nurse Specialist (LCNS) working practices survey showed that over 90% of LCNSs reported routinely providing holistic needs assessment, health promotion, psychological support, and social support, while 82% of LCNSs reported being confident in challenging all MDT members (Stewart et al., 2018). Such results on the importance of CNS in cancer care have been shown in chapter 5 of this thesis, when those who reported being given a CNS name had better experiences with care co-ordination, involvement in treatment decision, and the overall care experience across colorectal, lung, breast, and prostate cancers.

In addition, a CNS is also a direct access point for getting help and support from the whole cancer team when it is needed(National Cancer Action Team, 2010; Young et al., 2020). In particular, when patients have symptoms, they speak to the CNS who will speak to the oncology team or allied health professionals. In cases where CNSs are not able to manage the patient's symptoms, they arrange for them to see the oncology team. From a patient's perspective, that process is seamless and timely, and without a CNS, it is very hard to access the oncology team and a lot of time may potentially be wasted resulting in symptoms not being dealt with in a timely fashion.

Cancer care has come into focus during the coronavirus 2019 (Covid-19) pandemic. Several cancer supportive services, including CNS, have been relocated or modified alongside the cancer care pathway modifications (Hanna et al., 2020). Given that cancer patients are predicted to suffer delays in diagnosis and treatment due to the impact of the COVID-19 pandemic on NHS capacity, and some patients are reluctant to seek medical care both before and after diagnosis, the role of CNS in maintaining remote consultation and support will be even more vital (Maringe et al., 2020). Future studies need to assess the role of CNS care during the COVID-19 pandemic, measure patients' experiences with CNS telemedicine, and identify areas for improvements based on patients' perspectives.

Moreover, the variations in survival in relation to patients' experiences between the four main cancers might also be explained by the fact that CPES only samples a section of the wider cancer population and studies have shown that patients with the poorest prognoses are not always well represented (S. A. Alessy, Davies, et al., 2019). It is also possible that patients with better prognosis might be more likely to be referred to a CNS. For example, my analyses show that around 40% of colorectal cancer patients and 45% of lung cancer patients who reported not being given a CNS name were diagnosed at stage 3 or 4, although stage data have a large proportion of missingness. However, the actual proportion of patients being assigned a CNS cannot be verified as the data on CNS allocation contained within COSD data in the English cancer registry are not currently completed and cleaned for all cancers. The variation between cancers might also be explained by the variation in CNS allocation across cancer services. My results (as shown in Figure 7-5) indicate that higher proportions of patients were given a CNS name in surgical rather than cancer services in colorectal, breast, and prostate cancers, but not for lung cancer.

As discussed in chapter 5, improving patients' experiences of cancer care and care outcomes have been a high priority in the NHS cancer strategy. Although CNS play a vital role in cancer patients' care pathways, there are still concerns about the challenges facing CNS in cancer care because of restrictions on funding and an ageing workforce (Macmillan Cancer Support, 2014; Whittaker et al., 2017). Whilst the CNS workforce is continuing to grow, more are now employed on lower salary scales than in previous years, suggesting they are less experienced and skilled, which might impact on the quality of care and hence patients' experiences (Macmillan Cancer Support, 2017). Moreover, some variability still exists in the number of CNS vacancy posts across England by cancer type and oncology services locations (Macmillan Cancer Support, 2017). This variability will therefore require careful workforce planning to ensure recruitment and retention to the CNS workforce in order to maintain the level of patient experience reported in this study.

7.4.4 Strengths and limitations:

One strength of my study is the large sample size and the different cancer types studied. NCRAS is considered one of the most comprehensive cancer registrations in the world. This allowed for detailed case-mix adjustment of this association using a large sample and diverse cancer population. Another strength of this study is the development of a conceptual framework that was used to explore factors potentially underlying this association. Several previous studies have warned against investigating such an association without a detailed and large dataset and without a clear and well-developed conceptual framework from the literature (Anhang Price et al., 2014; Xu et al., 2015; Manary et al., 2013). This project, therefore, used a population-based dataset linked with a national patient experience dataset and started with developing a conceptual framework based on two systematic reviews to identify possible confounders and apply the appropriate adjustment. In addition, there is a gap in the literature on research assessing the possible influence of care experiences on outcomes. This study begins to fill this gap and adds new knowledge that can be used for designing studies in this area.

However, I recognize that my study has some limitations. First, for the purpose of this PhD project, I only looked at one aspect of cancer patients' experiences – their experience of CNS care. Future research might build on this work and focus on more than one aspect of experience and assess whether these results are consistent across other aspects of experience and across all different cancers. In addition, treatment episodes are important in cancer patients' experiences and survival, and a potential confounder when assessing the association between patients' experiences and their subsequent survival.

Treatment data, however, are not recorded in very great detail in the English cancer registry for the patient cohort in this thesis – patients who were diagnosed prior to 2013. I, therefore, did not account for treatment in the survival models. Future studies assessing this association should take into account curative treatment as a potential confounder once treatment episodes data are appropriately captured and quality assured. Finally, NCRAS data completeness for stage and ethnicity have improved since 2012, while route to diagnosis data became available in England after 2006 (Henson et al., 2019). However, a proportion of patients had missing information on disease stage, ethnicity, and route to diagnosis (Elliss-Brookes et al., 2012). Further details on the missingness proportion for stage, ethnicity, and route to diagnosis variables are provided in Table 2-5 in this chapter. For lung cancer stage, missing information was extracted with information available from the NLCA.

7.5 Summary

This chapter demonstrates evidence of an association between patients' experiences with CNS and their subsequent outcomes. These findings align with the findings in chapter 5 and suggest that removing CNS from cancer care might diminish cancer care quality and outcomes. My findings can be used by cancer policy makers, charities, cancer services, and patient representatives as evidence of the significant role CNS play in cancer care. Future research should focus on optimising the new registrations datasets within NCRAS to determine what aspects of patients' experience with CNS play the most vital role in patients' assessment, treatment, and their subsequent survival. This chapter is the last analysis chapter in this thesis. The next chapter will give an overview on thesis findings, their implications, and future research directions.

Chapter 8 : General discussion and conclusion

This last chapter provides a general discussion of the overall results presented in this thesis. It points out the strengths and limitations of this work with implications and future research directions being given towards the end.

8.1 Summary of main thesis findings:

This PhD thesis aimed to assess whether the variation in cancer patients' experiences is associated with their subsequent survival. It consisted of five different projects beginning with establishing the existing theoretical knowledge from the literature and following this up with analyses of the epidemiological data. Each project had one or more research questions, which were identified to address a specific area of this thesis, but also contribute to the overall aim of this project.

The first project, a systematic review, assessed how cancer patients' experiences have been linked to survival in the international literature. The review revealed a variety of different methods and perspectives on how cancer patients' experiences were linked in different kinds of studies to survival across different types of cancer. Patients' satisfaction, psychosocial support, satisfaction with quality of life were the most common aspects of patient experience found to be associated with survival in the literature. This review was important in order to identify the gap in the literature on this possible association, and to emphasise the role of the designing a theoretical framework prior to quantitative analyses. The second project within this thesis examined how representative CPES responders for the four main cancers (breast, colorectal, lung, and prostate) are compared with the English cancer registry population with respect to individual characteristics and tumour stage at diagnosis. Overall, across all cancer types survey responders had a higher median survival, were younger, more likely to have a White ethnic background, to be living in less deprived areas, and to be diagnosed with stage II and III disease. This project was also significant in showing the limited generability of CPES-NCRAS dataset, and therefore informed the interpretation of rest of the quantitative analysis findings in projects 3 and 5.

The third project examined whether being given the name of a CNS is associated with reporting more positive care experiences for patients with these same four cancers. A strong association emerged between being given the name of a CNS and reporting being more involved in treatment decisions, perceiving care as more coordinated, being treated with dignity and respect, and better overall experiences with NHS cancer care across all four cancer types. This project demonstrated evidence of the positive impact of a CNS on patients' experiences across several important aspects of the cancer care pathway.

The fourth project systematicaly assessed the international literature to identify all factors influencing cancer patients' experiences of care. Patients' demographic and disease characteristics, and their journies across the cancer care pathway seemed to influence their reported experiences in a postive or negative way. This project therefore demonstrated the importance of considering all these factors when designing patient experience programs or using the data gathered to inform improvement policies.

In the last project of this thesis, I examined whether having better care experiences with a CNS are associated with better cancer survival in England. I used the CPES-NCRAS linked dataset and focused again on the four most common cancers. I designed the analytical approach for this project after considering the findings from project 4 and developing my conceptual framework for the possible association.

Patients who reported not being given a CNS name had the worst survival compared to patients who reported excellent or non-excellent experience with the assigned CNS. This association seemed to disappear among lung cancer patients when accounting for the cofounders of demographic factors including areas and deprivation, and stage at diagnosis.

8.2 Thesis implications:

Several implications can be drawn from the work presented in this thesis that are relevant for the research community and for policy makers. First, the CPES-NCRAS data 2010-2014 was linked by a partnership team from Cancer Research UK, Macmillan Cancer Support, and NCRAS to enable further research exploring patient experience of cancer care (Carneiro et al., 2017). My PhD is the first research project to use this linked dataset and was based on a partnership between King's College London, Public Health England and patient representatives from the NCRI Consumer Liaison Forum. The different analyses from this dataset revealed its strengths in terms of size and data availability as well as its limitations in terms of representativeness. These findings can be used to formulate improvement initiatives for patient experience datasets and to develop additional hypotheses by the research community. Moreover, the thesis methodology can also inform future research projects using English cancer registry datasets. My work is particularly informative as it has identified several methodological challenges in using the cancer registration datasets, some data quality limitations, and has outlined the data cleaning process.

In addition, literature and research on cancer survivorship has grown globally in recent years (Nekhlyudov et al., 2019). The two systematic reviews in this thesis are particularly important for informing cancer survivorship research in many areas including patient experience assessment efforts, data analysis, and evidence driven policies. Furthermore, many cancer survivorship research topics such as patients' reported outcomes and quality of life research aspects are assessed using surveys similar to CPES. My findings about the CPES representativeness alongside the two systematic review findings can inform future work on cancer survivorship especially in the area of what factors influence patients' experiences and how to link aspects of their care to survivorship. This thesis may also be helpful in supporting cancer policy makers, cancer charities and user representatives using CPES findings, in arguing for further improvements nationally and locally in the importance of improving patients' experiences of care.

This thesis identified limitations in the representativeness of CPES responders among patients with lung and colorectal cancers. This issue can be addressed by using continuous sampling or a specific survey to capture the missing experiences for patients with the poorest prognoses. Furthermore, this thesis emphasised the role of CNS in improving patients' experiences and suggests that removing this care will diminish cancer service delivery and care outcomes in England. These findings are important for cancer policy makers and for cancer charities such as Macmillan Cancer Support, as they advocate for and support the role of CNS in cancer patients care across the UK (Macmillan Cancer Support, 2014).

Finally, the current healthcare strategy 'Achieving world-class outcomes: a strategy for England 2015 – 2020' emphasizes the importance of improving both cancer patients' experiences and their cancer outcomes (The Independent Cancer Taskforce, 2015b). This thesis has identified several potential areas for improving cancer patients' experiences in England such as capturing the experiences of those with the poorest cancer prognosis and considering demographic and clinical factors that have been shown to influence patients' experiences. These can be implemented in assessing the progress of the current strategy or planning future strategies.

8.3 Thesis strengths, limitations, and future research directions:

Strengths and limitations of each project in this thesis have been considered within the discussion section in each of chapter. In terms of strengths, overall, this thesis used a variety of methods to answer the important questions about the degree to which an association exists between cancer patients' experiences and their subsequent survival. The reason I used a variety of methods is that, to my knowledge, this is the first comprehensive project to tackle this association using population-based data. It was therefore important to use different methods to understand the updated research in this field, to examine the structure and limitations of the linked CPES-NCRAS datasets, and to inform the design of my methodology.

Another strength of this thesis was the use of population-based datasets that consist of the NCRAS data linked with the CPES dataset, which is specifically designed to assess cancer patients' experiances. Big data on cancer patients' experiences are being used in USA and Canada to influence clinical practice and improve cancer care subsequently. Published work from this thesis is therefore expected to inform future research using large cancer patient experience datasets in both national and international settings.

Additionally, a strength of this thesis is the involvement of two patient representatives: Janette Rawlinson and Matthew Baker in the intrepretation of the findings. They themselves had conducted work on the CPES and have worked with researchers and cancer charities in UK to improve patients' experiences and their participation in research. Throughout the PhD, they have provided me with constructive discussion and feedback on my findings and interpretations and suggestions of how this work can be used by the wider audience of policy makers and user representatives using CPES findings.

This thesis, however, has some limitations. I only looked at one aspect of patient experience. The novelty of this project required a foundation theoretical framework and methodology to be established from the literature prior to data analysis. Future research might focus on more than one aspect of experience and assess whether these results are consistent across other aspects of experience and across all different cancers. In addition, treatment episodes are important in cancer patients' experiences and survival. Treatment data, however, are not recorded in very great detail in the English cancer registry for the patient cohort in this thesis – patients who were diagnosed prior to 2013. Since then, treatment data have been linked from much more detailed national chemotherapy and radiotherapy datasets and a consistent approach to surgical coding has been established using linked Hospital Episodes Statistics data. Future research should link these datasets to CPES results to assess whether and which treatment episode has an impact on patients' experiences and whether these in turn may influence survival.

As this thesis identified limited representativeness of CPES responders to the wider patient community for the most common cancers in England, future research might examine the representativeness of CPES responders for all cancers. This is going to be of particular interest as CPES has introduced an online response option since 2015 (Pham, Abel, et al., 2019), which might further affect the survey representativeness. Future research might also assess whether an association exists between other aspects of patient experience measured in CPES and patients' subsequent survival.

CPES is one of the most comprehensive and largest cancer patient experience surveys in the world. The four-year iterations of CPES (2010 -2014) I used in this thesis might not reflect the most updated patients' experiences with care, especially, with the new rounds of recent CPES becoming available every year. Although these data might appear outdated now, this thesis work begun in 2017, only three years after the 2014 CPES iteration. In addition, linking the CPES required a careful and long process time in addition to that usually needed for the CPES and cancer registry data to be processed, quality assured, made available, extracted, and cleaned.

Finally, CPES aimed to monitor the national progress in cancer care in England and drive quality improvements at local hospital trust levels (Quality Health, 2019). Since the survey started in 2010, several rounds of its dataset have been used in national reports and journal publications, but the impact of CPES on cancer care policy in England has not yet been fully evaluated. Future research should do so with detailed analyses of what has been improved since the implementation of CPES both for a wider range of experiences and for patients with different cancers.

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Appendices

Publication 1

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How have Patients' Experiences of Cancer Care Been Linked to Survival? A Systematic Review

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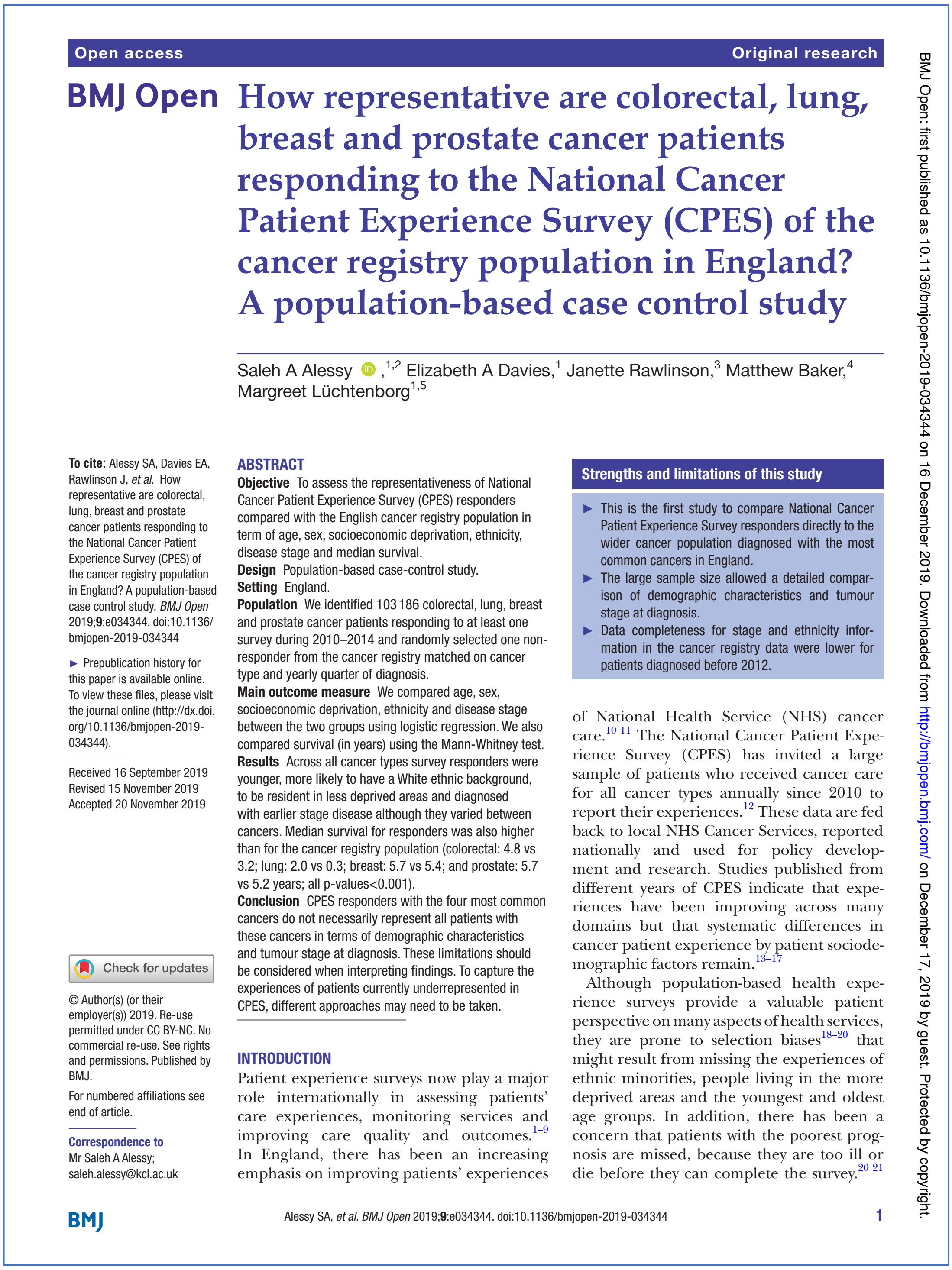
Publication 2



Open access Original research

BMJ Open

How representative are colorectal, lung, breast and prostate cancer patients responding to the National Cancer Patient Experience Survey (CPES) of the cancer registry population in England? A population-based case control study

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ABSTRACT

Objective To assess the representativeness of National Cancer Patient Experience Survey (CPES) responders compared with the English cancer registry population in term of age, sex, socioeconomic deprivation, ethnicity, disease stage and median survival.

Design Population-based case-control study.

Setting England.

Population We identified 103 186 colorectal, lung, breast and prostate cancer patients responding to at least one survey during 2010–2014 and randomly selected one non-responder from the cancer registry matched on cancer type and yearly quarter of diagnosis.

Main outcome measure We compared age, sex, socioeconomic deprivation, ethnicity and disease stage between the two groups using logistic regression. We also compared survival (in years) using the Mann-Whitney test.

Results Across all cancer types survey responders were younger, more likely to have a White ethnic background, to be resident in less deprived areas and diagnosed with earlier stage disease although they varied between cancers. Median survival for responders was also higher than for the cancer registry population (colorectal: 4.8 vs 3.2; lung: 2.0 vs 0.3; breast: 5.7 vs 5.4; and prostate: 5.7 vs 5.2 years; all p-values<0.001).

Conclusion CPES responders with the four most common cancers do not necessarily represent all patients with these cancers in terms of demographic characteristics and tumour stage at diagnosis. These limitations should be considered when interpreting findings. To capture the experiences of patients currently underrepresented in CPES, different approaches may need to be taken.

Strengths and limitations of this study

- This is the first study to compare National Cancer Patient Experience Survey responders directly to the wider cancer population diagnosed with the most common cancers in England.
- The large sample size allowed a detailed comparison of demographic characteristics and tumour stage at diagnosis.
- Data completeness for stage and ethnicity information in the cancer registry data were lower for patients diagnosed before 2012.

INTRODUCTION

Patient experience surveys now play a major role internationally in assessing patients' care experiences, monitoring services and improving care quality and outcomes.[1–9] In England, there has been an increasing emphasis on improving patients' experiences of National Health Service (NHS) cancer care.[10 11] The National Cancer Patient Experience Survey (CPES) has invited a large sample of patients who received cancer care for all cancer types annually since 2010 to report their experiences.[12] These data are fed back to local NHS Cancer Services, reported nationally and used for policy development and research. Studies published from different years of CPES indicate that experiences have been improving across many domains but that systematic differences in cancer patient experience by patient sociodemographic factors remain.[13–17]

Although population-based health experience surveys provide a valuable patient perspective on many aspects of health services, they are prone to selection biases[18–20] that might result from missing the experiences of ethnic minorities, people living in the more deprived areas and the youngest and oldest age groups. In addition, there has been a concern that patients with the poorest prognosis are missed, because they are too ill or die before they can complete the survey.[20 21]

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Publication 3

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Moving cancer prevention and care forward in Saudi Arabia

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ABSTRACT

Cancer is a major public health problem in The Kingdom of Saudi Arabia (KSA). The economic prosperity and urbanization alongside healthcare improvements have made significant improvements in healthcare over the past three decades, which resulted in a longer life expectancy. The kingdom implemented initiatives to improve the healthcare system including access to primary and secondary healthcare centres, healthcare workforce, and medical technology. The rapid economic and population growth have, however, happened alongside rapid demographic and socio-economic changes such as increased tobacco use and decreased physical activity, which are expected to influence the prevalence of some types of cancer in KSA. As a result, cancers and non-communicable diseases (NCDs) including diabetes, cardiovascular diseases (CVD), chronic respiratory diseases, are now the leading cause of death and responsible for 73 % of all deaths replacing infectious diseases as a leading cause of death in last 30 years. Cancer incidence and prevalence are projected to double by 2030 in the KSA, causing a surge in health care costs and placing an economic burden. This paper highlights the challenges facing primary cancer prevention measures in KSA that will be needed to reduce exposure to risk factors and the actions needed to monitor the outcomes of cancer care.

1. Cancer burden in the Kingdom of Saudi Arabia (KSA)

Saudi Arabia is a large country in the Middle East which extends over four-fifths of the Arabian Peninsula. The estimated population is around 34 million people, of whom, 21 million are Saudi nationals (51 % males, and 49 % females) and 13 million are non-Saudi nationals (69 % males and 31 % female [1]. In 2016, a total of 16,859 new cases of cancer were registered in KSA with the age-standardized incidence rates (ASR) being 74.7 per 100,000 in men and 91.3 in women [2]. The annual cancer incidence is projected to increase to around 40,000 by the year 2030 and result in around 19,000 cancer deaths (Fig. 1) [3]. In common with many countries worldwide, KSA faces the challenges of a growing cancer incidence, inadequate cancer surveillance, lifestyle changes that increase cancer risk, as well as insufficient cancer control research and preventive measures.

2. Cancer registration in KSA

The Saudi Cancer Registry (SCR) is a population-based registry that was established in 1992 [2]. While there have been many efforts since then to improve national cancer registration processes, there is still a lack of regular and complete linkage between the cancer registry and other data such as mortality statistics, primary care, and hospital episodes data. SCR data lacks information on cancer specific deaths and data available to project the future cancer burden is inadequate. For example, the latest national cancer control programmes for 2014–2025 were developed based upon cancer data for 2006 rather than data for more recent years [4]. Given the recent increase in cancer incidence and current changes to the healthcare system, older data might not accurately reflect the burden of cancer, thus hindering proper planning and the effective implementation of national cancer control plans. In this era of increasing cancer data linkage, SCR should extend the scope of their data to include extensive cancer morphology, routes to diagnosis, specific treatments received, patient survival, and population cancer mortality [5].

Moreover, each resident in KSA has a unique id number, which can be used to extend SCR data linkage with socioeconomic and demographic data that being collected across other government agencies. In addition, a continual data quality control and improvement program is needed to ensure that high-quality data can be provided to the general research community and the general public such as incidence, survival, and mortality. Using real-world cancer data will help facilitate region-specific research to investigate possible reasons behind a number of important questions. These include ascertaining the cancer incidence in

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Publication 4

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Cancer care during the COVID-19 pandemic: a perspective from Saudi Arabia

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Abstract

The coronavirus disease 2019 (COVID-19) pandemic continues to disrupt many healthcare settings worldwide including cancer care. COVID-19 has been associated with worse outcomes amongst cancer patients. Saudi Arabia has experienced several Middle East respiratory syndrome coronavirus (MERS-CoV) outbreaks that affected the continuity of cancer care. In this paper, we describe how Saudi Arabia responded to COVID-19, how cancer care was re-restructured during this pandemic and how the recent MERS-CoV experience may have improved the Saudi response to COVID-19.

Keywords: *cancer, care, COVID-19, Saudi Arabia*

Short Communication

Introduction

The COVID-19 pandemic continues to escalate, posing a worldwide public health threat across many healthcare systems [1]. COVID-19 has caused significant disruption to many secondary healthcare services, including cancer care [2]. Interruptions to cancer care can be expected to have a long-term impact on cancer patients' diagnoses, their care management and subsequent outcomes [3, 4]. In addition, cancer patients are usually susceptible to infectious diseases, which can be life-threatening for this population. Vulnerability is due to the severity of disease, together with underlying co-morbidities and cancer treatment side effects [5]. Healthcare systems around the world have taken different approaches to control COVID-19 [6] and to ensure the continuity of other urgent health care such as cancer care [2]. Plans have varied based on several factors, including the capacity of each healthcare system, experiences with the outbreaks of previous infectious diseases and specific economic, political and social factors [6].

Background

Saudi Arabia is a large Middle Eastern country, which extends over four-fifths of the Arabian Peninsula. It has a relatively young population with only around 5% aged over 65 [7]. The last estimated population size for Saudi Arabia was around 34 million in 2020 [7]. This number includes 21 million Saudi nationals (51% males and 49% females) and

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Results A total of 319 DRPs were identified in 235 patients, in which 280 (87.8%) of 319 DRPs were deemed to be preventable. The majority of preventable DRPs were related to dose selection (219 [78%] of 280). None of the preventable DRPs were life-threatening or fatal. The majority were assessed as moderate in severity (264 [94.3%] of 280). There was no significant difference between DRP incidence with age (mean 3.5, $p=0.389$), sex ($p=0.436$), and weight (mean 13.47, $p=0.323$). Younger children (aged 2 years or younger) admitted to the PICU were more likely to have a DRP (odds ratio 4.44, $p=0.000$). Scheduled admissions were 2.89 times more likely to be exposed to DRP compared with transferred admissions ($p=0.005$). Additionally, DRP incidence increased proportionally to the number of medications.

Conclusion Our results show a high incidence of preventable DRPs, which were found to be related to dosing and drug choice problems. These results may be used for designing the epidemiology study in the pediatric population aiming to establish appropriate prevention strategies towards improvement and safe medicine use in this vulnerable patient population.

55 COMPARISON OF THE LINKED CANCER REGISTRY AND CANCER PATIENT EXPERIENCE SURVEY DATASETS IN ENGLAND AND THE UNITED STATES

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Background Patient care experience surveys are now used internationally to assess, monitor, and improve healthcare quality. The National Cancer Patient Experience Survey (CPES) is an annual English survey that invites patients to report their experiences of National Health Service (NHS) cancer care. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey is widely used in the USA to assess patients' experiences of healthcare plans. Several years of collated data for each survey have recently been linked to population-based cancer registry data. We aimed to compare strengths and weaknesses of the datasets in order to consider the questions they may best answer.

Methods We obtained published information about both datasets, and compared data sources, time period, patient age, cancer types, survey method and response rate, linkage method, and question themes.

Results The English dataset of 233,445 patients was created by linking 2010–2014 national CPES with cancer registry data by matching individual identifiers, whereas the US dataset of 150,750 was created by first merging national Medicare data with regional Surveillance Epidemiology with End Results (SEER) data and then with all 1998–2010 CAHPS survey data. The major differences were that the US dataset was largely limited to patients over the age of 65 years and included a large non-cancer comparison group of 571,318 patients as well as data on health costs. Both linkages included all cancer types, with breast, prostate, colorectal, and lung cancer representing 50% of English and 61% of US patients. Both were postal surveys, with non-respondents being followed up by mail in England and by telephone in the USA. Response rates were similar in England (67%) and the USA (71%). The questions themes were similar, with CPES focussing on more cancer-specific experiences.

Conclusion The English dataset is likely to provide more detailed and representative data answering questions about cancer experiences in the English population. However, it may be possible to use both datasets to compare the experiences of older patients receiving government-funded cancer care in each country. The addition of economic data to English survey data as in the US data is an intriguing avenue for future research. A translated version of CAPHS is being used in Saudi Arabia, meaning that further data linkage and international comparisons may be possible in due course.

56 ELECTRONIC OCCURRENCE VARIANCE REPORTS (EOVR) MANAGEMENT SYSTEM

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Background The Royal Commission Health Services Program (RCHSP) has been consuming thousands of occurrence variance report (OVR) forms (paper-based) to report all hospital incidents, with 200–300 OVRs per month. This has resulted in substantial challenges for the risk management unit regarding regular tracking, trending, and analysis of all OVRs while complying to the determined timeframes. The Quality Management and Planning Department (QMPD) and information Technology (IT) Department have started collaboration on an initiative to make the incident reporting system electronic to capture incident data, do incident follow-up, and communicate incident learning across all departments through an efficient, effective, and user-friendly system with good follow-up capability. The aim of this study was to improve the timeliness, efficiency, easy accessibility, and effectiveness of the OVR system.

Methods The new system is web-based and staff can access it using their usernames and passwords. Filling an OVR is easier as data entry occurs by ticking from displayed options with the availability of entering free text for more details if needed. Automatic notifications will be sent to the relevant staff throughout the organization. A comprehensive action assignment and follow-up system has been developed. Easy access to data across the organization and updated real-time view of the OVR dashboard are also available any time. Forwarding submitted OVR(s) to appropriate entities and tracking them has become more accurate and efficient. Pilot testing has been conducted for 2 months before full implementation.

Results The electronic system has significant benefits making it more convenient to all stakeholders. The number of reported adverse events, near misses, and sentinel events further increased. The ease of access to the web-based module to fill OVRs, the real-time incident log, the ability to attach any type of files to log entries, and the automatic time-stamped audit log/referencing are all features that make the new system more convenient. The action assignment and easy tracking system, the integrated emergency notification, and the electronic forms management enabled the risk management unit to manage the system more effectively and efficiently. Processing an OVR by quality staff decreased markedly from more than 120 minutes in the old system to 20 minutes in the new electronic system. The new system secured access and ability to create

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ARTICLE

Developing a roadmap for cancer patient experience initiatives in Saudi Arabia: lessons from healthcare settings in the United States and England, UK

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Abstract

Patient experience is now widely used as a measure of healthcare quality. In Saudi Arabia, the public healthcare system is being transformed at a national level to improve the healthcare services provided. Patient experience assessment initiatives have commenced across many care settings including cancer care. Gathering data on cancer patients' experiences of care has been introduced nationally in the United States (US) and England, UK and has continued to be used for over two decades. This has resulted in a considerable amount of literature on what patient experience is, how to measure it, and how it can be applied within cancer care settings. In this paper we aim to set out lessons learned from the US and England, UK in assessing and using cancer patient experience data in order to inform current patient experience initiatives in Saudi Arabia. These lessons include how to define patient experience, explain its different aspects and their measurement, and maximize both the value and use of the data gathered. Several methodological and implementation challenges have been identified within the global literature that need to be taken into account in order to meet patient experience goals in Saudi Arabia. These include developing a specific patient experience definition and its different aspects, using the appropriate data collection methods, gathering representative patient perspectives, and overcoming resistance to data utilization and policy changes among health professionals.

Keywords

Cancer, data collection, healthcare quality, patient experience, patient satisfaction, person-centered healthcare, Saudi Arabia, service reconfiguration, UK, USA

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Introduction

Patient experience has emerged over many years as an important research area and is now widely considered as an important aspect of care quality alongside patient safety and clinical effectiveness [1-3]. It is conceptualized as the full range of patients' interactions with the health workforce and healthcare system [4] and as part of a process of moving towards patient- and person-centered care. A considerable international literature on patient experience has grown in response to the increasing emphasis on, and measurement of, patients' perspectives on healthcare systems [1,5,6]. Recent research has now linked better patient experience to improved clinical effectiveness, patient safety and disease outcome in many care sittings including cancer [7,8]. Presently, patient experience measures are being widely used in cancer care within many international healthcare systems [6,9-12].

Cancer is a major public health concern in Saudi Arabia. The healthcare system in Saudi Arabia has been given a high priority by the government in the last three decades. This has been demonstrated through infrastructure