Inequalities in cancer care for people with physical disabilities: A mixed methods study

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By

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Summary

Background

Limited evidence suggests that people with disabilities are more likely to be diagnosed with cancer at an advanced stage compared to people without disabilities. This has been linked to a reduced use of screening services and increased barriers to accessing care.

Methods

Using a mixed methods design the aim to generate understanding of the disparities in care experiences of people with disabilities on both the macro (organisational, and service delivery) and micro (personal) levels.

Data linkage of routinely collected data and national survey data to explore disparities in cancer outcomes, comparing populations self-identifying as having a disability and a population not considered to have a disability. The outcomes explored included uptake of cancer screening services, later stage of cancer at diagnosis and risk cancer related mortality. Experiences of cancer service as someone with a pre-existing physical disability were explored using in-depth interviews and analysed using narrative analysis.

Results

Results showed that individuals with a disability were less likely to attend screening services, with reduced odds of having a mammogram (OR=0.66, 95% CI=0.58 to 0.74), cervical screen (OR=0.79, 95% CI= 0.70 to 0.87) and bowel screen 0.80 (95% CI=0.74 to 0.87). Results also

showed people with disabilities were diagnosed with cancer at a later stage (OR=1.19, 95% CI= 0.88 to 1.61, p=0.27) and had a higher risk of cancer related mortality (1.67 (95% CI=1.34 to 2.08)). Qualitative findings found that people with pre-existing physical disabilities going through cancer care face additional barriers to receiving safe and timely care such as lack of suitable equipment, lack of staff knowledge and not feeling listened to.

Conclusion

The key thesis being put forward is that inequalities in cancer care do exist for people with disabilities on the wider level, shown through the quantitative analysis and on a personal level, shown through in-depth interviews.

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Abbreviations

IGRP   INFORMATION GOVERNANCE REVIEW PANEL

SAIL   SECURE ANONYMISED INFORMATION LINKAGE

NHS   NATIONAL HEALTH SERVICE

CSW   CERVICAL SCREENING WALES

BTW   BREAST TEST WALES

BSW   BOWEL SCREENING WALES

WCISU   WELSH CANCER INTELLIGENCE SURVEILLANCE UNIT

ADDE   ANNUAL DISTRICT DEATH EXTRACT

WHO   WORLD HEALTH ORGANISATION

SAP   STATISTICAL ANALYSIS PLAN

DFLE   DISABILITY FREE LIFE EXPECTANCY

ICF   INTERNATIONAL CLASSIFICAITON OF FUNCTIONING, DISABILITY

       AND HEALTH

NSW   NATIONAL SURVEY FOR WALES

ONS   OFFICE FOR NATIONAL STATISTICS

PHW   PUBLIC HEALTH WALES

DAG   DIRECTED ACYCLIC GRAPH

CPRD   CONVENTION ON HUMAN RIGHTS OF PERSONS WITH DISABILITIES

PAF   POSTCODE ADDRESS FILE

ALF   ANONYMISED LINKING FIELD

GP   GENERAL PRACTITIONERS

WIMD   WELSH INDEX OF MULTIPLE DEPRIVATION

PCC   PARTICIPANTS CONCEPT CONTEXT

ADL   ACTIVITIES OF DAILY LIVING

CDS   CRITICAL DISABILITY STUDIES

ICIDH   INTERNATIONAL CLASSIFICATION OF IMPAIRMENTS, DISABILITIES AND HANDICAPS

UPIAS UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION

DPI   DISABLED PEOPLES INTERNATIONAL

Chapter 1: Background

Introduction

This thesis investigates whether health disparities exist for people with physical disabilities in Wales and England, specifically in cancer care. To explore this, this thesis adopts a mixed methods design to gather information on disparities in cancer outcomes for a population with physical disabilities in Wales and captures experiences of cancer care for people with disabilities across England and Wales. The conceptual basis for identifying a population with physical disabilities is explored and operationalised for use in both the quantitative and qualitative parts of the thesis. The implication of the approach to definition is explored in depth, with lessons learned identified and discussed for future research in this area.

This chapter introduces the thesis and key concepts such as cancer in the U.K., health inequalities for people with disabilities and limitations in the existing evidence base. This Chapter also introduces the conceptual framework used to underpin this research and outlines the researcher's background. The final section of the chapter outlines the structure of the thesis chapters.

Outlining disability

The World Report on Disability estimates that there are 1 billion people with severe or moderate disabilities around the world (WHO, 2011). In the U.K estimates are around 14.6 million people with disabilities (Scope, 2022). Within the U.K. several Welsh local authorities have the highest proportion of households with one or more people with a long-term limiting illness or disability (DWP, 2013). Numbers of people with functional limitation or physical impairment are likely to

increase as the population ages. Disability free life expectancy (DFLE) from the Office for National Statistics puts the DFLE for men at 62 years and 61 for females in the U.K (ONS, 2021). Further to this, the U.K. disability statistics show that the prevalence of disability rises with age with 9% of children having a disability, 22% of working age adults and 42% of adults over state pension age (House of Commons research briefing, 2022). The most common impairment type in the U.K. is mobility (46%), followed by stamina, breathing or fatigue at 33% and mental health at 29% (House of Commons research briefing, 2022).

Disability is defined in a variety of ways in a variety of contexts. The world report on disability for example uses the international classification of functioning, disability and health (ICF) as their approach to disability definition. The ICF classifies disability as an umbrella term that incorporates a person's level of activity participation, physical limitations and environmental barriers and posits we are all somewhere on the spectrum of disability severity (WHO, 2002). Under the ICF classification, we can understand the term 'disability' to refer to a range of mental, intellectual and physical factors which may be disabling in interaction with the social and environmental factors at play at any given time.

The ongoing debate around disability definition is important to consider to explain who we are talking about when we say people with disabilities. The U.K. government defines disability under the Equality Act (2010) as "a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities". In this definition and in the existing literature on inequities for people with disabilities, physical, mental health and intellectual disabilities are often discussed under the umbrella term of disability.

Disability is discussed in general terms, encompassing mental, physical and intellectual disabilities at times in this thesis, for example when discussing debates around definition and

legislation. However, the focus of this research is on people who consider themselves to have a physical impairment, functional limitation or physical disability.

While people with disabilities can have a wide range of mental, physical and intellectual health needs that may intersect, those experiencing physical impairments or functional limitations may experience a unique set of barriers to accessing cancer care, for example physical accessibility, disability stigma and lack of suitable equipment. Those with predominantly mental health or intellectual impairments may experience their own unique set of barriers when accessing healthcare. The research landscape reflects this, with research tending to focus on intellectual, mental health or physical disabilities respectively. There is a lack of research looking directly at cancer care experiences or access to cancer services for people with physical impairments, despite mobility impairment and stamina/breathing impairments being the two most common impairment types reported in the U.K (House of Commons research briefing, 2022). Whilst it is acknowledged that people with a physical disability may have other conditions (e.g. cognitive or visual) that may compound barriers to cancer services, this thesis is aimed at exploring inequities in cancer care for a population experiencing any form of physical impairment, who self-identify as having a disability.

Objective versus subjective disability

In common discourse about defining disability and in disability focused research, there is a distinct lack of focus on self-perception of disability status. In research on populations with a disability based on survey data, commonly used qualifiers for disability are responses to questions such as 'Do you have an illness, disability or infirmity, likely to last 12 months or longer?'. Whilst arguably this is a self-rated qualifier of disability status, it focuses purely on the objective, more medicalised definition of disability. Questions of this nature often amalgamate

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the concepts of illness, disability, frailty and infirmity. This approach does not allow for personal meanings of disability to shine through. Limited research on objective verses subjective disability status has shown that there is a need to pay attention to the differences in self-reported versus clinician reported physical disability and functioning status as these have been shown to differ in certain healthcare contexts (Feuering et al, 2014 and Buckley et al, 2012). This is an important point to reflect on when preparing to undertake research on populations considered to have a disability as it illuminates the possible gap between researcher groupings of populations with a disability and the perception of disability status among the individuals with said disabilities, highlighting the need to adopt cooperative research methods.

Although relatively little attention has been paid to self-perception of disability, there has been some focus on the subject of disability and health perception. It is not always correct to assume that the presence of a disability means one would consider themselves to be unhealthy. As Shakespeare, Bright and Kuper (2018) make clear in their report on the health status of persons with disabilities for the UN general assembly, subjective and objective health are not the same. The World Health Organisation defines health as "a state of physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). To be in a health state, therefore, can result from the actions taken in everyday life that can improve wellbeing such as eating the right foods, socialising, monitoring of emotional wellbeing and undertaking other health promoting behaviours relative to the individual. This can be achieved alongside and regardless of the presence of an objective health condition or biological impairment.

The Office for National Statistics report on the subject of disability and health (2011, Office for National Statistics) looked at analysis of the 2011 census data from England and Wales. Participants were asked where they rated their health on a five-point Likert scale and whether

their health problem or disability limited their day-to-day activities. The results showed that 4.3% of the population reported having a disability but also reported being in good health. Furthermore, the overall population of respondents with self-reported good health were in the older demographic (over 85 years). This highlights the need to break the assumption between disability status and health status as one can have a disability yet not be limited by their condition or one can be limited by their condition and still consider themselves to be healthy. That is not to say that people with disabilities do not often require more contact with healthcare providers than those without disabilities, and may still experience barriers to healthcare despite perceiving themselves to be in good health.

Cancer in the United Kingdom and Wales

There are around 375,000 new cancer cases each year in the UK (Cancer Research UK, 2018). Numbers will increase to three million by 2030 as a consequence of the increasing age of the population, improvements in diagnostic procedures, more bespoke and effective treatments, and post-treatment survival increases (Maddams et al, 2009). Despite the fact that 69% of people diagnosed with cancer in the United Kingdom have at least one long-term condition (Macmillan, 2015), limited attention has been paid to the dual impact of going through cancer and having a disability. In 2021 the Welsh government set out the Quality statement for cancer (Welsh government, 2021). Several of the priorities laid out in the quality statement could benefit people with disabilities, however there is no explicit mention of this population. The first relevant quality principle is in regard to equity, promoting equal access and consistent care for all. The second refers to person centred cancer care, stating that person centred care should be culturally embedded in services and services should have a common approach to assessing and accommodating for people's individual needs. National cancer experience surveys such as the

Wales cancer patient experience survey and the cancer patient experience survey in England provide cancer patients in the U.K. and Wales with an opportunity to provide feedback on a range of pre-set questions regarding their cancer care. The cancer patient experience survey in England does disaggregate results based on gender and deprivation status, however, neither survey presents results disaggregated by disability status or long-term health condition status. The Wales cancer patient experience survey results from 2016 show that less than half (45%) of people who completed the survey felt that the impact of their treatment on day-to-day activities was properly discussed with them (Macmillan, 2017). Results like this could point to increased difficulties in cancer care for people with disabilities who may already struggle with their day-to-day activities or require prior information on how they might be affected so they can properly prepare.

Health inequities for people with disabilities

People with disabilities have the same rights and needs in healthcare as people without disabilities, including access to sexual and reproductive health, screening and other preventative services. Yet, research on access to healthcare for people with disabilities has found that people with disabilities are less likely to receive certain types of immunization services and routine screening services, with likelihood decreasing with disability severity (Gibson and O'Connor, 2010). Inequitable access to healthcare services is important to consider for people with disabilities as lack of access to vital health services arguably constitutes a violation of human rights for this group. Due to factors such as increased likelihood of poverty, increased unemployment, higher levels of deprivation (Disability rights UK, 2020) and increased likelihood of secondary health conditions (Duda, 2021), people with disabilities can be more vulnerable to poor health. Despite potentially requiring more contact with healthcare services

than people without disabilities, health inequalities persist for this group (Shakespeare et al, 2018). People with disabilities may require a range of specialised healthcare services specific to their health condition or physical impairment. However, research from Bright et al (2018) argues that people with disabilities experience low access to specialised healthcare, such as rehabilitation services. Previous research has shown that persons with disabilities face additional stigma, and environmental and organizational barriers to accessing healthcare (Scheer et al, 2003). The world report on disability argues organisational barriers, including waiting lists and complex referral systems, can disproportionately affect people with disabilities. This can result in unintentional discrimination by failing to meet the needs of people with disabilities and excluding them from services (WHO, 2011).

To understand barriers to inequities in healthcare services we must first understand what we mean by healthcare access and quality in healthcare. Gulliford et al (2002) argue that healthcare access does not merely refer to the availability of services and points to the utilisation of services as a guide to understanding equality in healthcare access. It is argued that the possibility for all to gain access to services can depend on the financial, organisational and social/cultural barriers that may exist for certain groups (Gulliford et al, 2002). Further to the issues of access, quality of care and acceptability for service users is an important concept to consider as services with high uptake can also provide low quality care. Therefore, access is not the only indicator of equity in healthcare. Different dimensions of quality of healthcare have been identified in the literature; technical quality, interpersonal quality and amenities (Donabedian, 1980). Technical quality refers to the outcome of health care in achieving positive health outcomes, interpersonal quality refers to meeting patient needs and amenities refers to the physical surroundings and resources of the organisation (Donabedian, 1980). In their research on understanding quality in healthcare

Mosadeghrad (2013) found that client perceptions of healthcare quality focused on caring treatment and fast, effective and timely diagnoses. More comprehensive views on healthcare access conceptualisation incorporate factors of access and quality. Arguably, structural features of the healthcare system, features of individuals (including enabling or disabling factors) and process (i.e. how access is realised) should all be considered when discussing access (Levesque et al, 2013). In their discussion on meaningful access for people with disabilities, Francis and Silvers (2020) argue that accessibility must incorporate issues of accommodation and modification in order to achieve meaningful access for people with disabilities. By accommodation they are referring to adjustment e.g., physical aids to allow people with disabilities to function successfully in healthcare settings and by modification they refer to changing policy, law and organisational structures to eliminate the barriers faced by people with disabilities.

Cancer services for people with disabilities

Cancer services can include diagnostic services such as screening services, clinical investigations, patient diagnosis, treatment (chemotherapy, radiotherapy, etc.), rehabilitation services and palliative care. This thesis focuses on the services within the cancer pathway, that is the services that fall under the patient's journey from the initial suspicion of cancer through to clinical investigations, patient diagnosis, and treatment (NHS.uk).

Limited evidence suggests there are disparities in access to cancer services for particular groups (Bone et al, 2014). Specifically, there is some evidence that people with disabilities are more likely to be diagnosed with cancer later when it is at an advanced stage compared to people without disabilities (Sarfati et al, 2016). This has been linked, among other factors, to a reduced

use of screening services and increased barriers to accessing care (Angus et al, 2012; Merten et al, 2015). Some qualitative research evidence to date has looked at possible barriers to accessing cancer screening services, the majority of which look at women's screening services such as mammograms. Barriers identified have included unsuitability of screening technology, lack of understanding about needs of persons with disability by healthcare professionals and poor accessibility of screening services (Peters and Cotton, 2015).

Socio-economic status and demographic factors

There is undoubtedly a complex interplay between socio-economic status, demographic variables such as gender and ethnicity and the healthcare system. Research has demonstrated that individuals from a more deprived socio-economic background have lower rates of cancer survival than those from a more affluent background in the UK (Coleman et al, 2001). A study by Rutherford et al (2013) found that for women with breast cancer in the East of England, lower socio-economic status and higher levels of deprivation were associated with poorer chances of survival and later stage at diagnosis. When combining the effects of socio-economic factors with disability, research has shown that people with ill health and lower incomes are less likely to have access to all necessary healthcare services (Beatty et al, 2003) and that women with disability are more likely than men with disability to have unmet health needs (Sakellariou and Rotaru, 2017). Socio-economic disparities in healthcare access are a particular concern for people with disabilities as they are more likely to face unemployment and experience poverty than the general population (Braithwaite and Mont, 2009). Considering this, more research is needed that addresses the intersection of socio-economic status/demographic variables and disability in relation to healthcare access, and cancer care access in particular.

Conceptual framework- framing access to health care

This thesis utilises the conceptual framework of patient-centred access to health care as outlined by Levesque et al (2013). This framework underpins the approach to analysis and informs the discussion and interpretation of results. This research aims to identify potential inequalities in cancer care for people with disabilities, therefore an understanding of what we are aiming to unpick when speaking of inequalities is necessary. Levesque et al define healthcare access as the opportunity to identify healthcare services, to obtain services and to have healthcare needs fulfilled. To expand on this further, Levesque's conceptual framework incorporates five different dimensions of accessibility of services which interact with corresponding individual abilities, resulting in healthcare access. The five dimensions include accessibility, acceptability, availability and accommodation, affordability, and appropriateness. Accessibility refers to whether people know of a services existence, can reach it and the service has impact on their health. Acceptability refers to the social factors impacting a service which can result in a service being inequitable for certain subsections of society. Availability and accommodation is defined as whether services can be reached physically and in a timely manner. Affordability denotes the economic capacity for people to be able to use appropriate services. Appropriateness under this framework means the fit between services and patients need, including timeliness and the technical and interpersonal quality of services.

The individual characteristics proposed by Levesque et al include the ability to perceive (health literacy, health beliefs and trust), the ability to seek (personal and social values, culture and gender), the ability to reach (living environment, transport and mobility), the ability to pay (income, social capital) and the ability to engage (empowerment, information and caregiver support).

This framework provides a comprehensive overview of the complex process of healthcare access and is used in this thesis as a guide to explore, assess and measure access to cancer care services for people with disabilities. Levesque's framework will be referred to throughout the thesis and is explored in depth in the discussion chapter.

Limitations of evidence base

There is a significant lack of information regarding access to and experiences of other aspects of cancer care such as treatment and diagnosis for persons with disabilities. While some research evidence on the various cancer outcomes exists in relation to persons with disabilities, relatively few studies incorporate multiple outcomes such as screening uptake, cancer staging data and treatment options given. Doing so would improve understanding of the complete picture of cancer care for people with physical disabilities. Furthermore, this research will illuminate the experience of cancer care for people with physical disabilities from a qualitative perspective which will add to our understanding of the needs and barriers to quality cancer care for this group, adding to the existing literature that focuses on barriers to screening services. This research will also add to our understanding of the impact of socio-economic and demographic variables combined with the presence of a pre-existing physical disability on cancer care outcomes, which is a previously underdeveloped research area.

Despite the great importance of the issues of cancer care and health inequities for people with disabilities, there has been little to no attention in this regard in terms of NHS improvement plans or tracking data for this group. This thesis will address the gap in the monitoring of data and cancer outcomes for people with disabilities and in collecting the experience of cancer care beyond screening services.

Researcher background and project funding

This project was a Knowledge Economy and Skills Scholarship (KESS) funded PhD. KESS funded projects are part funded by the Welsh Government, the European social fund and a relevant industry partner, which varies by project. For this project the industry partner was Tenovus cancer care. Part of the requirement of KESS studentships is that industry partners provide advice and guidance as experts in the field and students are expected to work in the partner organisation for 30 days per academic year. Tenovus were excellent partners for this project and provided support and guidance in the advisory group for this project and assisted with advertising the project when recruiting for interviews. Unfortunately, due to the COVID-19 pandemic I was not able to complete the 30-day working requirement.

This project was conceptualised by the supervisory team at Cardiff University school of Healthcare Sciences and advertised on the school website. I came to the project with a background in Occupational Therapy. As an Occupational Therapist I am interested in facilitators and barriers to completing activities of daily living and instrumental activities of daily living such as medication management and accessing healthcare services. As this project focused on access to healthcare for people with disabilities it felt like a perfect fit for me to utilise my professional background and further my knowledge of healthcare access barriers.

Structure of thesis

Chapter 2 will review the existing literature to establish where a gap in the literature and collective understanding might exist. This chapter presents the reasoning behind the use of a scoping review to investigate the understanding of this broad topic area in the existing literature. The scoping review methodology will be presented, followed by the methods employed for data

collection and analysis. The findings of the initial scoping review are presented, followed by a

synthesis of the findings. Finally, a follow up literature review conducted in the final year of this

research project is presented to ensure all relevant literature is included in this thesis.

Chapter 3 introduces the mixed methods research design of this research. Methodological

considerations such as intersectionality and critical disability theory will be discussed in relation

to the research aims. The chapter then goes on to discuss the quantitative and qualitative study

design considerations respectively. Lastly, research design processes undertaken such as ethical

approval are presented.

Chapter 4 explores the reasons for taking a carefully considered approach to defining disability,

the multitude of approaches to defining disability and the contexts in which this is important.

With the approaches to defining disability discussed, this chapter concludes with a brief

application of these findings to this research project, both the qualitative and quantitative aspects.

The definition as applied to the quantitative section of this research will be explored in further

detail in chapter 5.

Chapter 5 introduces the National Survey for Wales, its background, collection methods, linkage

and access via the SAIL databank. The questions chosen from the survey to identify the

population with a physical disability will be identified and discussed, with their strengths and

limitations. The result of the application of said questions to the survey respondents for all the

survey years will be explored, the population with a disability and population without will be

characterised, including demographic information and exploration of access to services. Further

information about the population will be presented, such as consistency of self-reported

disability across survey years (where respondents were included in more than one survey year).

The representativeness of the population to the population of Wales will be explored also. The

results from the survey year 2016/17 will then be looked at in further detail as this survey year included more lifestyle related questions and disability related questions. The findings of the application of disability definition across all the survey years and the findings from survey year 2016/17 will be discussed in terms of what they tell us about the population.

Chapter 6 introduces the quantitative part of the exploration of disparities in cancer care for people with disabilities in Wales. Explanation is provided on how the National Survey for Wales population is linked with routinely collected cancer registry data for analysis. This chapter presents the first cancer outcome under focus; uptake of screening services. The datasets used, specifically the Cervical Screening Wales (CSW), Breast Test Wales (BTW) and Bowel Screening Wales (BSW), which, when linked with the NSW population allowed analysis of uptake of screening services for each screening service respectively between physically disabled and non-physically disabled populations. Analysis of having a delayed (6 months or more) cancer screening was also undertaken. This chapter will also explore two more important outcomes in the cancer journey, stage of cancer at diagnosis and survival time after cancer diagnosis between people with and without physical disabilities. To do this the National Survey for Wales population will be linked with routinely collected data from the Welsh Cancer Intelligence and Surveillance Unit (WCISU) and the Office for National Statistics (ONS) data on deaths with cancer as the underlying cause. These datasets will be introduced along with the methods for linkage, statistical analyses, and data management.

Chapter 7 presents the results of the quantitative analysis with a discussion on its relevance to existing literature.

Chapter 8 presents the methodology and methods carried out for the qualitative part of this mixed methods research project. The methodological considerations will be presented along with

the qualitative research objective. Sampling and recruitment of participants, the data collection process, data management, analysis and ethical considerations will be discussed.

Chapter 9 presents the narratives created to present the experiences of the five participants who self-identified as having a disability and had gone through cancer care.

Chapter 10 provides reflections on the impact of the COVID-19 pandemic on this research and the use of routinely collected data.

Chapter 11 is a general discussion and interpretation of the findings with an aim to triangulate and contextualise the findings from both the quantitative and qualitative parts of the research. Strengths and limitations of both methodologies are also explored along with implications and reflections arising from this research.

Summary of chapter

This chapter introduced the thesis and key concepts relevant to the thesis such as cancer in the U.K., health inequalities for people with disabilities and limitations in the existing evidence base. The concept of disability was outlined briefly, this will be explored further in chapter 4 of this thesis. The final section of the chapter outlined the structure of the thesis chapters. The next chapter presents the scoping review conducted to establish a thorough understanding of the existing research evidence on the topic of cancer care for people with physical disabilities.

Chapter 2: Literature review- Exploring the inequalities and experiences of cancer care for people with pre-existing physical disabilities

Introduction to chapter 2

To explore possible inequalities in cancer care for people with physical disabilities in Wales and England, it is necessary to review the existing literature to establish where a gap in the literature and collective understanding might exist. This chapter presents the reasoning behind the use of a scoping review to investigate the understanding of this broad topic area in the existing literature.

The scoping review methodology will be presented, followed by the methods employed for data collection and analysis. The findings of the initial scoping review are presented, followed by a synthesis of the findings. Finally, a follow up literature review conducted in the final year of this research project is presented to ensure all relevant literature is included in this thesis.

Methodology

A scoping review was undertaken with an aim to provide an overview of the existing literature on this topic. Scoping reviews are useful when conducting research on a complex topic as they aim to map and synthesise the existing literature. A scoping review was chosen for this thesis as scoping reviews aim to summarise the overall state of literature on a broad topic which is useful in identifying a gap in the existing literature (Arksey and O'Malley, 2005). Scoping reviews are also useful for topic areas where there may be few pieces of research on topic (Arksey and

O'Malley, 2005). It was therefore felt that with two broad topics such as cancer and disability, topics which, when combined narrow the field of available research, it would be useful to choose a literature review method that outlines the current landscape. The framework developed by Arksey and O'Malley (2005) and refined by Levac (2010) was employed. The steps of the framework are: 1) identifying the research question; 2) identifying relevant studies; 3) study selection 4) charting the data; 5) collating, summarising, and reporting the results. This framework provided a process by which to collate and present a range of research on this broad topic.

To explore the quality of the included studies the Critical Appraisal Skills Programme (CASP) checklist was used, the type of checklist used was dependent upon the methods utilised for each piece of research. The quality of the papers in general was good and scores ranged from 6 to 9.

Research question

What is known from the existing literature about the experience and inequalities of cancer care for people with pre-existing physical disabilities?

Inclusion criteria

Population of study: Adults (over 18 at time of study) with physical disabilities that have experienced cancer care (cancer care here refers to pre-diagnosis services such as screening, diagnostic services and cancer treatment services).

The approach to defining disability for this literature review followed the ICF model of disability. The ICF classifies disability as an umbrella term that incorporates a person's level of activity participation, physical limitations and environmental barriers and posits we are all somewhere on the spectrum of disability severity (WHO, 2002). Under the ICF classification, we

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can understand the term 'disability' to refer to a range of mental, intellectual and physical factors which may be disabling in interaction with the social and environmental factors at play at any given time. As this project is focusing on disabilities related to physical factors studies were included if the disability was related to any kind of physical factor, including research related to specific physical illnesses or impairments. For the purposes of this review the term "disability" is used to include anyone with a physical illness, mobility limitation or functional impairment.

Type of studies: Qualitative and quantitative, mixed methods and systematic review research designs. This scoping review included both qualitative and quantitative research due to the dual focus of qualitative experience of cancer care for people with physical disabilities and inequalities in cancer care outcomes for people with pre-existing physical disabilities.

Type of publication: Published research studies only.

Publication date: Studies published in the last 10 years. This timeframe was chosen as a sufficiently long period of time to gather enough information on the topic whilst also retrieving information that would be relevant to the current healthcare landscape.

Language: Studies published in English.

Exclusion criteria
Research with adults with disability related to mental health and research with adults with learning disabilities.

Grey literature

Identifying relevant studies

Studies were initially identified using searches of MEDLINE, CINAHL, AMED, PSYCHinfo, and also searching by hand through studies chosen to be included in the review. Search terms such as "disability", "functional limitation", "mobility difficulty", "cancer" and "neoplasms" were used to search in each database. A list of search terms can be found in table 1. The reference lists on the retrieved papers were searched to identify any relevant studies that were not found in the initial searches.

Table 1 showing search terms for scoping review

Search terms used for scoping review
disab* AND cancer OR neoplasm
impairment AND cancer OR neoplasm
mobility limitation AND cancer OR neoplasm
mobility difficulty AND cancer OR neoplasm
functional impairment AND cancer OR neoplasm
impairment AND cancer OR neoplasm

Study selection

The mnemonic "PCC" (participants, concept, context), as recommended by the Joanna Briggs Institute (JBI, 2014), was adopted to define the inclusion criteria of the studies.

> *Population*- Adults with pre-existing physical disabilities (prior to receiving a cancer diagnosis). Due to the nature of this scoping review, it is acknowledged that the definition of disability will be wide ranging depending on the context each piece of research. For the purposes of this review the term "disability" is used to include anyone with a physical illness, mobility limitation or functional impairment.

> *Concept*- Experience of illness/healthcare, inequalities in health and illness outcomes/access

> *Context*- Cancer care experienced in any healthcare setting. The context of the review is not limited to a setting or country. Due to limited existing literature on the topic of cancer care for people with physical disabilities, this review has not been limited to any type of disability or any specific stage of the cancer journey.

Charting the data

Relevant data identified from each study was collected in a spreadsheet to identify any emerging themes or gaps in the literature. Data collection categories included name, year, origin, aims, study population and sample size, methodology, outcomes/measurement criteria, key findings relevant to the research question and key themes. The full data collection spreadsheet can be found in appendix 1. To chart the data in a clear and meaningful way, information was also collected on the stage of the cancer journey the paper was in reference to (e.g., screening,

diagnosis, treatment) and the type of physical disability or definition of disability (e.g., mobility difficulty, persons with Cerebral Palsy).

Collating, summarising, and reporting results

A total of 34 research papers were deemed to fit the inclusion criteria outlined above. A summary of the papers included can be found in table 2. A summary of searches can be found in the PRISMA diagram below (figure 1).

Table 2 summarising articles included in scoping review

Author	Year	Country	Sample	Main results	CASP score
Goutard et al	2009	Fran	F, Neuromuscular patients (ages 20-74), n=49	Rates of screening uptake. 68% had screening for cervical cancer	6
Armour et al	2009	U.S.	2008 Behavioral Risk Factor Surveillance System used to estimate disability prevalence	Women with disabilities less likely to attend B & C screening.	7
Clark et al	2009	U.S.	Matched cohort study of 93 WWD and 93 WND	Positive exp of mammograms women with disabilities more likely to return, lower screening rates.	6
Iezzoni et al	2010	U.S.	F, n=20 w/ Mobility impairments	Inaccessible equipment incl. mammography machines, examining tables and weight scales.	6
Rivera Drew and Short	2019	U.S.	F n= 20, 907, aged 21-64	Disability negatively associated w/ pap smear test	7

Banks et al	2010	Aus	M& F, n= 89574, aged over 45	Risk of psychological distress in individual w/ cancer relates to level of disability	8
Iezzoni et al	2011	U.S.	F, n=20 w/ Mobility impairments	Treatment decisions related to how various therapies would affect their arms, anesthesia concerns related to underlying condition, clinicians not considering post-op needs.	9
Llewellyn et al	2011	Aus	F, n= 75, WWD ages 50-69	Expectations= be kept informed, actively involved in mammography procedure and to be treated with respect. Barriers to this= lack of info and consistency, difficulty expressing needs	8
Courtney-Long	2011	U.S.	F, ages 40-74	Women with disability lower odds of mamography use for both age cohorts compared to WND	7
Weir et al	2011	U.S.	F, n= 35 171 ages of 42-69	Those on medicaid managed care plans had negative association with screening mammography after adjusting for confounders	6
Park et al	2012	S Korea	n= 93758 cancer ages, 20 +	Short term mortality- no significance with disabled pop. Preexisting disability higher long-term mortality than nondisabled group.	6
Angus et al	2012	Can	F, n=24, mobility difficulties	Areas 'of complex work' identified, e.g., arranging and attending screening appointments	6
Kung et al	2012	Taiwan	F, ages 50 to 69	Severe and multiple disability related to lower use of other services	7

Lin et al	2012	Taiwan	F, n= 502, age 15+ state registered disability	Treatment options. Women age 50 + more likely to accept hysterectomy than younger counterparts	8
Jarman et al	2012	U.S.	F, n= 739	Needed accommodations: accessible changing area, oral description of procedure, accessible parking	
Volker et al	2013	U.S.	F, n=19	Care providers unable to accommodate additional needs. Wish for Oncologists to recommend cancer treatment that took underlying disability in to account	6
Martin et al	2013	U.S.	F, N= 350, age 20-80	Likelihood of attending screening decreased by 20% if ADL limitation present	7
Horner-Johnson	2013	U.S.	F, N= 120,147, ages 18-64	Women with Disability less likely to be up to date with breast and cervical screening, disparities greater for women with complex limitations	7
Guilcher et al	2014	Can	N= 10, 363 (4,660 reported disability)	Women with moderate disability more likely to screen than women without, women with severe disability less likely than both	6
Peters and Cotton	2014	Aus	12 Women with disability, ages 50 to 75	Feeling out of control, not being listened to, feeling helpless, alone and afraid and experiencing pain, and humiliation	8
Bussiere et al	2015	Fran	F, n= 1052	higher severity of functional limitation, the lower the likelihood of cancer screening	9
Horner-Johnson et al	2015	U.S.	F, n= 65 506, ages 18-64	Women with disability less likely to be up to date with breast and cervical screening and women in rural areas less likely.	8

Iezzoni et al	2016	U.S.	F, age 21-65	Statistically significantly lower rates of pap testing for women with disability compared to women without	8
Welch Saleeby et al	2016	U.S.	F, n= 10, self-identified as disabled	Cost, equipment, better info, unwelcoming facilities (staff), lack of policies and procedures around disability, equipment availability,	7
Iezzoni	2016	U.S.	U.S. residents aged 50-75	Few statistically significant differences in colorectal cancer screening uptake over time for people with disability	8
Steele et al	2017	U.S.	N= 15 079, ages 21 to 75	Women with disability less likely to receive pap and mammogram	8
Deroche et al	2017	U.S.	N= 37, 974. Linked data, ages 50-75	People with spinal cord injury less likely to be up to date with Colorectal screening	7
Sakellariou and Rotarou	2017	Chile	linked data, national survey, n=Pap test (66,281) and the mammogram (35,294)	Disabled women less likely to receive screening than non-disabled women.	7
Wook Shin et al	2018	S Korea	Linked admin data	Disability associated with a lower screening rate.	6
Nandam et al	2018	U.S.	N= 118, women with CP, age 40+	65.3% had mammograms within last 2 years, severity of fine motor deficits associated with lower screening	8
Puts et al	2010	Can	M&F, n=112, age over 65	Participants who refused treatment often lived alone, not married and had ADL disability	7

Puts et al	2017	Can	N=32, ages 70+	Factors that influence treatment decision making process: relationship with oncologist, benefits vs harm, comorbidity and functional status did not play a role in treatment decision	7
Floud et al	2017	U.K.	F, n= 473 185	Women with Disability less likely to participate in breast and bowel screening, varies by type of disability	9

Figure 1. Scoping review paper selection process
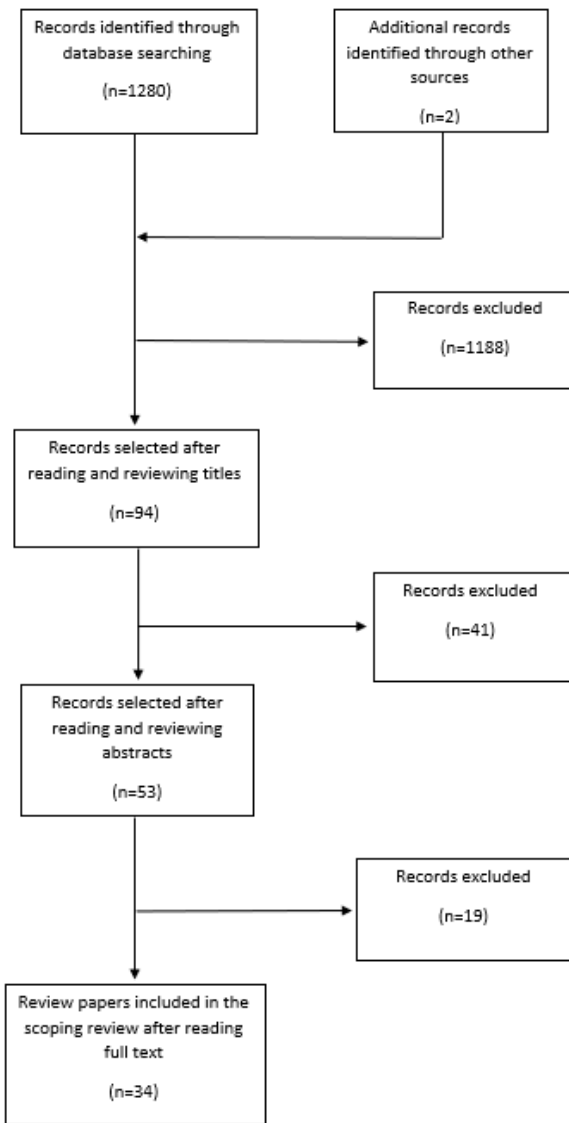
A summary of data collected for the first literature search, including characteristics of the research identified can be found in appendix 1.

Initial analysis of the charted data involved becoming familiar with each research paper, the research was then separated into different categories related to the stage of the cancer journey it focused on (screening, treatment, or outcomes). The screening data was further separated into research pertaining to disparities in accessing screening services and research involving experiences of screening services. The approach to analysis of the data was adapted depending upon the methods used in the research papers. As all the research looking at disparities in accessing screening services were quantitative, a narrative synthesis of results was undertaken. Thematic analysis was employed to analyse the data on experiences of screening services as this was solely qualitative in design. A narrative synthesis was also undertaken for the treatment and outcomes related research as the methods used were both quantitative and qualitative.

Results are reported under the headings related to the stage of the cancer journey (Screening, treatment, and outcomes). Results from all stages are integrated in the summary.

Literature review update

The initial scoping review was conducted in early 2019. It was necessary to complete a new literature review covering the elapsed years between the first literature review and the thesis write up to ensure the researcher was up to date on the research conducted in the area. The same databases were searched as in the first literature review; MEDLINE, CINAHL, AMED and Psychinfo. A total of 1830 results were retrieved using the same key words as the previous searches. A total of seven articles were found to fit with the inclusion criteria stated in the scoping review methods. The findings from these studies are synthesised below.

Results

Presented below is a narrative summary of the results of the scoping review. The results are presented under headings related to the stage of the cancer journey the research is in reference to.

Screening

The literature on cancer screening services for people with physical disabilities falls broadly in to two areas: disparities in accessing cancer screening services and experiences of screening services. In total, 28 research studies referenced screening services of people with physical disabilities, 8 research papers focused on experiences of screening services and 20 studied inequalities in accessing screening services.

Disparities in accessing screening services

20 research studies looked at disparities in accessing screening services for people with physical disabilities. All research on this topic took a quantitative approach, either using secondary use of national survey data or routinely collected healthcare data. 17 research studies looked at breast and cervical cancer screening services and 3 looked at bowel screening services.

Disparities in accessing breast and cervical cancer screening services

Across all 17 research studies, the presence of a physical disability was negatively associated with accessing breast and cervical cancer screening services. Research from Armour et al (2009) found that significantly less women with disabilities (72.8%) attended mammography services compared with women without disabilities (77.8%), similarly with pap smear tests (78.9% vs 83.4%). Even when having a disability was positively associated with receiving invitations for cervical cancer screening, rates of accessing screening services remained lower than women without disabilities (Rivera-Drew and Short, 2010).

Several of the identified research studies included the analysis of the impact of sociodemographic factors on disparities in receipt of breast or cervical cancer screening services. Geographic location was found to be a contributing factor to lower likelihood of receiving these screening services for women with physical disabilities especially women in rural locations who were less likely to receive recommend breast and cervical cancer screening within the recommended timeframe (Horner-Johnson et al, 2015). Higher levels of education and income have both been associated with increased likelihood of receiving breast and cervical cancer screening services (Kung et al, 2012). Similarly, women with physical disabilities were less likely to receive breast and cervical cancer screening services if they were single or unemployed (Sakellariou and Rotarou, 2017). Age as a contributing factor was explored in Courtney-Long et al's (2011) research that explored the association between mammography use and disability. Data from women with and without disabilities were analysed in two age cohorts; women over 40 and women aged between 50 and 74. Results showed lower use of mammography services for both age cohorts compared to women without disabilities.

Type and severity of physical disability and their impact on screening rates was considered in the literature. As is often the case with research regarding disability, the definition of physical disability used varied. Types of disability included in the literature on disparities in screening access included: Activities of daily living disability (Martin et al, (2013); fine motor difficulties related to cerebral palsy (Nandam et al, (2018); functional limitation (Bussiere et al, 2015); and mobility difficulties (Floud et al, 2017). In each piece of research, regardless of the approach to defining physical disability, presence of a type of physical disability was associated with lower screening rates compared with people without physical disabilities for both breast and cervical cancer screening services. Goutard et al (2009) research was the exception to this rule. This

research explored breast and cervical cancer screening adherence for women with neuromuscular disease and found similar rates of screening uptake as compared to the general population. This study had a relatively small sample of 45 women with neuromuscular disease specifically, so results may not be generalisable to the wider population of women with physical disabilities.

Severity of physical disability was found to be an indicator of decreased likelihood of accessing screening services for women (Guilcher et al, 2014., Bussiere et al, 2015., Wook-Shin et al, 2018., Horner-Johnson et al, 2013). Disparities in access were higher for women with complex limitations (Horner-Johnson et al, 2013) and 'Severe' disabilities (Guilcher et al, 2014., Bussiere et al, 2015., Wook-shin et al, 2018). The definition of what constitutes a severe disability varied across the literature. Weir et al (2011) posited severity of disability as degree of illness burden and found that higher illness burden was associated with lower mammography rates for women on Medicaid managed care plans in the U.S. Further to this, research from Iezzoni et al (2016) showed that women with severe movement disabilities had the highest percentage differences in receipt of cervical cancer screening services as compared to the non-disabled population. In contrast, research from Clark et al (2009) found that severity and type of disability were not associated with repeat screening, women with two or more limitations had a higher percentage of repeat mammography (56.4%) than women with one identified limitation (53.7%).

Disparities in accessing bowel/colorectal cancer screening services

The literature regarding bowel cancer screening receipt for people with physical disabilities paints a mixed picture. In comparison to literature investigating receipt of breast and cervical cancer screening services, numbers of studies looking at bowel screening services is low, with only 3 out of 20 studies found referencing this service.

Research from Steele et al (2017) reports seemingly positive results, showing people with physical disabilities being more likely to have been in receipt of colorectal screening services compared with people without physical disabilities (Steele et al. 2017). The aim of Iezzoni et al (2016) research was to compare use of colorectal cancer screening services between people with and without chronic disabilities over time. Using data from the National health interview survey (Non-institutionalised U.S residents), the research team used multivariable logistic regression analysis to assess the association between self-reported colorectal cancer screening services, sociodemographic factors and disability type. Results showed an increase in colorectal cancer screening services receipt over time for both men and women and all disability types. Furthermore, there were few statistically significant differences between the population with and without disabilities. Where statistically significant differences did appear, this was in favour of the population with disabilities as they reported higher colorectal cancer screening services use than people without disabilities. To the credit of this research the data included a comprehensive definition of chronic disability with emotional, cognitive, and functional disabilities included. However, a breakdown of the results related to each type of disability was not presented. Similarly, Steele et al (2017) used data from the U.S National Health Interview Survey and found that people with disabilities were more likely to report receipt of colorectal cancer screening services than those without disabilities.

In contrast, findings from Deroche et al (2017) demonstrated that people with spinal cord injury were less likely than those without disability to adhere to recommended bowel screening services. This research utilised hospital discharge, Medicaid and Medicare data to investigate the likelihood of receipt of bowel cancer screening services for people with three types of disability (blind or low vision, intellectual disability or spinal cord injury). As spinal cord injury is the only

physical disability represented in this sample, findings may be limited in their application to the wider population of people with physical disability. Research from the U.K. on this subject comes from Floud et al (2017). This study used data from the National Health Service routine screening programme and linked this with data from the 'Million Women Study', to investigate participation in breast and bowel cancer screening for women with disabilities. Results from analyses showed that women with disabilities were 25% less likely to take part in bowel screening than those without and that self-care difficulties were linked with decreased likelihood of receipt of these services.

Screening barriers and experiences

A total of 8 research papers looked at barriers to accessing screening or experiences of screening services for people with physical disabilities, all used qualitative research methods. The majority of these were focused on women's experiences of cancer screening services. Following thematic analysis of the papers, three overarching themes were identified: Physical accessibility, Healthcare staff and Self. These overarching themes were split into subthemes including equipment, facilities and the built environment, knowledge of healthcare staff, attitudes of healthcare staff, advocating for self and not feeling adequately informed.

Physical accessibility

Equipment

A recurring barrier to accessing screening for women with physical disabilities in the literature was mammography equipment. Women across the 7 studies reported issues with mammography equipment, issues covered related to the fact that mammography screening equipment seems to be designed with the assumption that all women's bodies are able to stand for sustained periods

of time, balance, lift their arms above their head and keep their bodies still (Iezzoni et al, 2010.,
Welch-Saleeby, 2016). With these normative assumptions about women's bodies in mind, many
women felt that their bodies were expected to fit with the requirements of the mammography
equipment rather than the equipment being able to adapt to their individual needs (Iezzoni et al,
2011., Iezzoni et al 2010., Sakellariou et al, 2019). Angus et al's (2011) research in to access to
cancer screening for women with disabilities involved focus groups with 24 women with
mobility disabilities. The results demonstrated that for women with mobility disabilities,
screening procedures could result in embarrassing situations and situations where women did not
feel safe due to inappropriate equipment. Women with physical disabilities consistently reported
that their bodies were 'man handled', 'pushed' and 'pulled' (Angus et al, 2011) to fit the
requirements of screening equipment.

Mammography equipment was not the only type of screening equipment identified in the
literature as often being inaccessible for women with physical disabilities. Iezzoni et al (2010)
and Welch-Saleeby (2016) found that examining tables and weighing scales were also an issue.
For example, participants in the Welch-Saleeby's (2016) study reported that during screening
procedures that required the use of an examining table, transfers to and from the table were
difficult and healthcare staff were often unprepared for this, resulting in spontaneous and often
unsafe transfers. Therefore, the need for tables that are adjustable and preparation from
healthcare staff were identified as ways to bridge this gap in service provision (Iezzoni et al,
2010). Secure and safe seating, specifically for women who experience spasms or tremors was
identified as one way to remedy the lack of adaptive equipment in Angus et al's (2011) research.
Further to this, Llewellyn et al (2011) study found that where rooms with adaptive equipment
were available at a facility, this room was often unavailable to them at the time of booking.

As mammography and other screening equipment was identified as a significant barrier to accessing screening services for women with physical disabilities, it follows that the necessity for adaptations to such equipment was imperative for many women for them to gain access to screening services. Examples of adaptations identified in the literature included handle bars (Iezzoni et al, 2010); physical assistance from healthcare staff or others to assist with balance and standing for prolonged periods, (Peters and Cotton, 2014) and adapted seating (Iezzoni et al, 2010). Women with physical disabilities in Iezzoni et al's study (2010) reported that healthcare professionals often relied upon them to use their own assistive equipment to successfully carry out the screening procedure. Similarly, participants in Iezzoni et al's (2011) study demonstrated that they were often physically examined in their own mobility aids (e.g., wheelchairs) for examinations that would usually occur lying down, which resulted in worry that they were not getting a quality and thorough examination. It is evident from the literature that inaccessible equipment, as an integral part of screening procedures for women, must be improved and made to adapt to individual needs to ensure positive screening experiences for women with physical disabilities.

Facilities and built environment (Including transport)

Barriers to accessing screening services within and around healthcare facilities were identified in three out of the seven research studies. The physical, built environment of healthcare facilities was identified as a common barrier to accessing screening services in Sakellariou et al (2019) and Angus et al (2011). Within healthcare facilities, barriers identified included difficulties with getting around inside hospitals (Sakellariou et al, 2019); inaccessible changing rooms (Welch-Saleeby, 2016) and check in counters at inappropriate heights (Welch-Saleeby, 2016). Participants in Sakellariou et al's (2019) study, looking at barriers to accessing cancer services

for people with a pre-existing disability, reported that even when services to aid with getting around healthcare institutions were available, these were often not sensitive enough to the individual needs of people with physical disability and therefore feelings of dependence on family and friends were exacerbated. Further to this, Welch-Saleeby (2016) looked at barriers and facilitators to breast health services for women with disabilities and through their focus group sessions found that participants often found primary care facilities were less accessible that larger healthcare institutions and many reported travelling further for more accessible community locations for breast health services.

In the literature, transport to and from screening services was found to be a barrier for people with physical disabilities. Lack of accessible transportation services, lack of disabled parking spaces and requiring help with transportation were difficulties experienced by participants (Sakellariou et al, 2019., Welch-Saleeby, 2016., Angus et al, 2011).

Healthcare staff

Healthcare staff attitudes towards people with physical disabilities

A recurring theme across the literature on screening experiences for women with physical disabilities was that of staff attitudes. Staff attitudes was identified as a theme in 6 out of the 8 research papers and highlighted as more important than accessibility in Welch-Saleeby's (2016) research, participants in this study explained that they would go to less accessible locations to get screened if experiences with healthcare staff there were positive. Some participants relayed positive experiences with healthcare staff (Llewellyn et al, 2011., Iezzoni et al, 2010), which were largely to do with staff taking creative approaches to gaining images from scans and treating them with respect. However, most experiences with healthcare staff attitudes across the 6 studies were negative.

Whilst women with physical disabilities have reported holding expectations that they will be treated with respect during receipt of screening services (Llewellyn et al, 2011), negative experiences with healthcare staff in this setting were reported widely in the literature. These experiences can be summarised as dehumanising and disrespectful. It was evident that the healthcare staff discussed held deep seated stigma and assumptions about disabled people, for example in Angus et al's research (2011) participants relayed the experience of not being treated like an expert on their own body and their companion being spoken to instead of directly to them. Related to the mammography equipment discussed in the previous section, women discussed the dehumanising effect of being 'pushed and pulled' (Iezzoni et al, 2010) by healthcare staff to fit with the needs of the machinery. With this alone being unacceptable, other women discussed a distinct lack of communication during this process (Peters and Cotton, 2014) and reported feeling like a 'voiceless body' (Peters and Cotton, 2014) as a result.

In their research, Llewellyn et al (2011) investigated non-physical barriers to accessing screening services for women with disabilities. With a relatively large sample size of 75 women with disabilities, this research involved individual interviews focused on experiences of screening services, specifically key expectations and barriers to receiving the expected level of care. Results showed that women with disabilities had expectations to be appropriately informed, involved and to be treated with respect. Barriers to this included not feeling listened to by healthcare staff and feeling out of control due to lack of communication from healthcare staff. Being listened to by healthcare staff was reported as playing a key role in minimising pain during the procedure for some women, which highlights the importance of healthcare staff attitudes towards people with disabilities in the outcome of screening services for women with physical disabilities. The findings of this research are presented here with caution as the characteristics of

the disabilities of the participants in this research are not explained, therefore it is unclear what percentage of the participants had physical difficulties related to their disabilities. The findings presented in this paper however do discuss physical constraints to accessing screening, so it is deemed appropriate to be included in this scoping review.

Lack of knowledge by healthcare staff

Lack of knowledge by healthcare staff was identified as a theme emergent in three out of the seven studies on screening services. Lack of knowledge can be understood by the way of two distinctly different but intertwining stands of knowledge; knowledge around how best to work with people with physical disabilities and knowledge about the specific needs of the individual with physical disabilities prior to their appointments. Lack of knowledge around the needs of the individual prior to the appointment was identified by participants through the perceived reliance of healthcare staff on self-reporting of disability. (Sakellariou et al, 2019). An example of this lack of knowledge comes from Iezzoni et al (2010) research into physical access barriers to diagnosis and treatment of breast cancer, which involved interviews with 20 women with mobility impairments. One participant in this research explained how they were asked if they could stand for the screening procedure despite being in a wheelchair, demonstrating the lack of prior knowledge of that practitioner of the needs of this individual.

Lack of knowledge around how best to work with people with physical disabilities was reflected in assumptions made by healthcare staff around the function and form of bodies of people with physical disabilities (Sakellariou et al, 2019), the physical inaccessibility and layout of examining rooms (Angus et al, 2011) and type of equipment used (Peters and Cotton, 2014., Angus et al, 2011). These separately important types of knowledge are key to positive and successful outcomes of a screening procedure for people with physical disabilities. Knowledge

of the types of needs and adaptations that people with physical disabilities may require is important in making decisions that can result in the best care for this population, knowledge of individual needs builds on this and is a necessity to provide person centred care that is responsive to the unique needs of each person.

Self

Advocating for self

Related to theme of lack of healthcare staff knowledge is the theme of advocating for self. It was commonly reported across the seven studies that participants often felt they had to advocate for themselves to gain access to screening services and to receive quality and safe care (Sakellariou et al, 2019., Angus et al, 2011., Peters and Cotton, 2014). One way in which participants in two of the seven studies reported advocating for themselves was during appointments. Participants in Angus et al's (2011) study reported that as healthcare professionals did not demonstrate knowledge of their individual needs, they had to speak up for themselves to keep themselves safe and to ensure their needs were met. Participants reported feeling that even when they did advocate for themselves, the information they imparted often went unheard (Angus et al, 2011). This was echoed in Sakellariou et al research (2019). Alongside having to advocate for themselves during the screening appointment, results from Angus et al (2011) research showed that women with physical disabilities felt that they were having to advocate for themselves from booking the screening appointment, through to navigating transport and managing schedules.

Not feeling adequately informed

The theme of not feeling adequately informed was identified as interacting with screening services for women with physical disabilities. One way in which not feeling adequately informed manifested itself was through lack of general information around screening services. Information

that was lacking included, why it is important to have screening services (Llewellyn et al, 2011); awareness of where accessible screening locations were (Welch-Saleeby, 2016); what will happen during the procedure (Peters and Cotton, 2014); what is required of them (Peters and Cotton, 2014) and who will undertake the procedure (Peters and Cotton, 2014).

Updated literature review findings on screening services

In the updated literature review search no research looking directly at screening uptake or experience was found. One study looked at disparities in stage at diagnosis for men with disabilities. Research from Wook Shin et al (2021) found that distribution of stage at diagnosis was similar between men with and without disabilities. However, having a diagnosis of cancer without staging information was more common in men with severe disabilities compared to those without disabilities. This research study used disability registration data from the Korean government to identify the population with disabilities and included physical as well as other types of disabilities (cognitive impairment, communication impairment etc.). Therefore, the population under study may be a more medicalised subset of the population with disabilities in Korea and not completely reflective of the population with physical disabilities. Research from Agaronnik et al (2020) also looked at cancer diagnosis but from a qualitative angle. This research explored attitudes about having a cancer diagnosis for people with pre-existing mobility difficulties. Findings from their interviews showed that for some of their participants, cancer presented more difficulties emotionally than the difficulties experienced with their disability. This research provides valuable insight into the emotional and practical support systems people with disabilities employ when faced with a cancer diagnosis which could inform tailored healthcare provision.

Post diagnosis: treatment and experiences of living with cancer

In total, 5 research papers explored the issue of treatment and experiences of living with cancer. The findings have been split in to three themes including treatment decisions, treatment experiences and experiences of living with cancer.

Treatment decisions

Treatment decisions around cancer care are a vital and pivotal stage of the cancer journey. Despite this, there is a distinct lack of research surrounding this topic in relation to people with physical disabilities. Existing research that has explored this area, similarly to the screening literature discussed above, has focused on treatment decisions for women with physical disabilities and a diagnosis of breast cancer, leaving a large gap for research into other people with a physical disabilities and other gender identities.

The literature suggests that the impact of treatments on pre-existing functional or mobility limitations play a large role in considerations around the type of treatment to accept by persons with physical disabilities. In their research, Iezzoni et al (2010) looked at barriers to treatment of breast cancer for women with mobility difficulties. From their analysis of 20 interviews, they found that 7 of the participants made their treatment decisions with the impact the treatment would have on their arm mobility in mind. Whilst 5 out of the 20 women reported they wouldn't consider a treatment with major surgery involved (such as mastectomy) due to the potential complications, for example lymphedema. The impact of surgery on current functional and mobility status was also identified as a theme in Volker et al's (2013) research. Their study used focus group interviews to explore the experience of living with a pre-existing functional disability and cancer. When discussing living with a cancer diagnosis, respondents reported difficulties with post-surgical care which limited their previous level of independence. Findings

from Volker et al (2013) study also showed that the impact of post-treatment related fatigue was a consideration as many of the participants in this study already experienced varying levels of fatigue related to their pre-existing functional limitations. Participants from this study were a relatively homogenous sample and therefore application of findings to other identities within the physical disabilities' community may be limited.

Refusal of cancer treatment for people with physical disabilities is a topic broached in Puts et al's (2009) research focusing on the characteristics of older newly diagnosed cancer patients who refused treatment. This research study was included in this review with caution as the focus of the research is on age rather than physical disability status. However, a measure for instrumental activities of daily living (IADL) disability and activities of daily living (ADL) disability were included in the research with most participants shown to have a disability under these criteria. The criteria for disability in this study is considered to fit with the definition of disability chosen for this scoping review. Findings from statistical analyses looking at the characteristics of patients and the treatment proposed and received showed that most people who refused cancer treatments were women with breast cancer and that participants who refused were more likely to have an ADL disability.

There is a paucity of research on cancer treatment decisions for people with physical disabilities. Choice of treatment related to cancer is a complex decision, one which should be made in collaboration between healthcare professional and the individual with cancer. Considering which type of treatment to choose for someone with a physical disability may form a more complex picture when considering the interplay between their pre-existing physical health needs and the effects of treatments. We have seen from the few pieces of existing literature on the topic that people with physical disabilities are more likely to decline treatment in some situations and may

require further support and time to make their treatment decisions in collaboration with their healthcare provider. Therefore, further research is needed to explore the experience of decision making around cancer treatment and factors that interact with this decision.

In their research on disparities in surgical treatment for breast cancer patients with pre-existing disabilities, Ansmann et al (2019) found that patients with a physical disability had a higher chance of undergoing a mastectomy than women without disability. Clinical data was collected and complemented with a post-operative survey completed by patients. This research provides an insight into cancer treatment disparities that might exist for people with physical disabilities, to the researcher's knowledge, this is the only study found that focuses on the topic of treatment disparities. Research previously mentioned by Wook Shin et al (2021) on disparities in prostate cancer care for men with disabilities also looked at rate of surgery for cancer treatment between people with and without disabilities. They found that men with disabilities were less likely to undergo surgery than men without disabilities.

Treatment experiences

Further to the discussion around treatment decision making experiences, the experience of cancer treatment itself is an area that is explored in the literature. Environmental barriers, unsuitable equipment and a lack of knowledge and adaptability from healthcare staff were identified in relation to treatment experiences across the literature (Volker et al, 2013., Iezzoni et al, 2010., Iezzoni et al, 2011). As with the literature covering treatment decisions however, very few pieces of research were found that looked at this aspect of cancer care for people with physical disabilities.

Environmental barriers and unsuitable equipment formed part of the experience of treatment for people with physical disabilities. Examples of unsuitable equipment echoed the findings from the

previous chapter on screening in that equipment used, such as examining tables, weight scales and radiotherapy equipment were not adaptable to the individual needs of people with physical disabilities (Iezzoni et al, 2010). This resulted in unpleasant experiences, such as one participant in Iezzoni et al's (2011) research that recalled an experience of their arms being held down to the table with masking tape during treatment. Environmental barriers within the hospital environment were identified as a difficulty also, particularly a lack of resources that would facilitate independence in self-care activities for people with physical disabilities (Volker et al, 2013).

Across the 3 studies that explored the experience of treatment, lack of knowledge and preparedness of healthcare staff occurred as a theme. Healthcare staff's lack of knowledge around the needs of people with physical disabilities became apparent and this resulted in a lack of anticipation of potential interactions of surgery or treatment with pre-existing physical difficulties (Volker, 2013., Iezzoni et al, 2011). This was illustrated in Volker et al 's (2013) study, where participants recalled experiences of staff that did not consider the appropriate pain medication for an individual with a physical disability that was already on pain medication for their disability related pain. There was a general sense in the few studies that considered treatment experiences of cancer care for people with physical disabilities that healthcare staff and facilities were unable to understand or accommodate their individual needs (Volker et al, 2013., Iezzoni et al, 2011., Iezzoni et al, 2010).

In summary, research into experiences of cancer treatment provides us with a brief glimpse of the possible barriers and areas for improvement needed in this area of cancer care for people with physical disabilities. However, more research is needed to explore further barriers to quality cancer care for this group and to identify potential facilitators to positive experiences.

Research from Sakellariou et al (2020) and Agaronnik et al (2021) looked at experiences of cancer care and treatment for people with physical disabilities. Findings from Sakellariou et al (2020) focused on understanding experiences of cancer care for people with physical disabilities through the lens of disability-based discrimination. Findings from their in-depth case studies showed that disability-based discrimination can take the form of healthcare staff's lack of knowledge of disability related needs, care that is inconsistently aligned with disability related needs and institutional leanings towards care that is made with 'normative' bodies in mind. Agaronnik et al (2021) explored cancer treatment experiences for people with pre-existing mobility disabilities. Data was collected via in-depth interviews with twenty participants. Findings from this study aligned with findings from Sakellariou et al (2021) as healthcare provider awareness of disabilities and bias towards people with disabilities were found to negatively affect the experience of cancer treatment for their participants.

Experiences of living with cancer

Research that looks specifically at the experience of living with cancer and a physical disability is lacking. Searches revealed few results that looked at the experience of living with cancer, with only one study covering this topic.

Research from Banks et al (2010) looked at levels of psychological distress in people diagnosed with cancer related to type of cancer and various demographic factors. Using logistic regression, it was found that levels of psychological distress were 6 to 8 times higher in people with a disability than those without. The definition of disability in this study is related to needing help with daily tasks, it is not detailed whether this is due to a physical, mental, or cognitive disability. Therefore, findings from this research are applied here with caution. This research is

included here due to the lack of research attention paid to the experience of living with cancer for people with physical disabilities.

With the limited amount of research available on this subject, it is difficult to come to any conclusions about the experience of living with cancer for people with physical disabilities. Considering the research on treatment experiences alongside Banks et al (2010) research, there is a suggestion that there are further emotional and practical challenges that come with the unique experience of living with a physical disability and having cancer, which can result in high levels of psychological distress. However, further research is needed in this area before wider conclusions can be drawn.

Outcomes: Long-term survivor quality of life and mortality rates

One research paper was found that explored outcomes for people with physical disabilities. Research from Park et al (2012) analysed mortality data between cancer patients with pre-existing disabilities and those without disabilities. They found no significant difference between mortality rates for those with and without pre-existing disabilities when observing short term survival (<5 years). When comparing long-term survival rates (over 5 years) however, they found that people with pre-existing disabilities had higher long-term all-cause mortality than the non-disabled group. Their analysis of effects of disability on all-cause mortality was broken down into types of disability including impaired mobility disability and internal organ disability. Analysis of these subgroups revealed that for both male and female participants, presence of a pre-existing impaired mobility disability was significantly associated with higher long-term mortality. This research did not include information regarding clinical stage at diagnosis or type of treatment received, which could have had a confounding effect on outcomes.

Becker et al (2012) provided research focusing on post-treatment survivorship quality of life for people with a pre-existing disability. Using survey methods and the Functional Assessment of Cancer Therapy-General (FACT-G) scale to assess quality of life, results showed that quality of life scores were similar to the population without a pre-existing disability in all areas except physical well-being. However, the overall quality of life scores were lower for people with pre-existing disabling conditions. Analysis also revealed that cancer related variables, for example, type of cancer, were not predictors of quality of life score. Participants reported via comments on the survey that their pre-existing disabling condition impacted their ability to partake in health promoting behaviours rather than their experience of having cancer. The findings from this research may not be applicable to the wider population of people with physical disabilities as it included a sample that consisted largely of women who had breast cancer and had a neuromuscular disease prior to their diagnosis.

Research from Wook Shin et al (2019) looking at disparities in prostate cancer for men with disabilities found that people with disabilities had a higher all-cause mortality risk than those without disabilities. They also found men with physical disabilities had a slightly higher risk of death with prostate cancer as the underlying cause than the population without disabilities. Strengths of this study include the large sample size and breakdown of disability by type and severity. Research from Marrie et al (2021) looked at mortality rates for people with colorectal cancer who have Multiple Sclerosis. Findings from their Cox proportional hazards regression analysis showed that after adjusting for relevant confounders, having multiple sclerosis was associated with an increased risk of colorectal cancer specific death. These findings provide valuable information of inequalities in cancer survival for people with a specific cancer and a

specific illness. However, this could mean that the findings are not generalisable to the wider population with physical disabilities and other cancer diagnoses.

Summary of findings

The findings showed that there are issues with access to screening services for people with physical disabilities and barriers to quality care in other areas of cancer care e.g., treatment options, post treatment care, medication etc. Also, staff attitudes and knowledge of working with people with disabilities created discontent in the level of care received for people with physical disabilities. The quantitative and qualitative literature on screening services give us different but both very useful insights in to access to these services for people with physical disabilities. The quantitative literature suggests that, on the whole, uptake of screening services is lower in physically disabled populations as compared to non-physical disabled populations. The qualitative literature may shed some light as to why uptake of services may be lower, such as lack of accessible equipment, poor staff attitudes, transportation barriers and lack of knowledge around how to best serve physical disabled patients from healthcare staff.

The literature on the experiences of cancer care (post diagnosis) for people with physical disabilities, although sparse in volume, reflects that of the screening services literature. People with physical disabilities faced barriers in the form of inaccessible equipment, stigma from staff and lack of knowledge or preparation in working with people with physical disabilities. The literature on disparities in cancer care for physically disabled people demonstrated the possibility of poorer quality of life and wellbeing for people with physical disabilities as compared to the non-physically disabled population. When considering these two disparate areas of knowledge in unison, the possibility that well-being and quality of life for people with a cancer diagnosis and a

pre-existing physical disability could be improved if quality of care were brought up to the same standard as the non-disabled population should be considered. However, there are too few pieces of research available to come to any firm conclusions on this topic at this time. More research is needed on the effect of poor experiences of cancer care for physically disabled people on cancer outcomes.

Findings from this literature review on screening services, mortality rates and treatment options indicate that sociodemographic factors can play a role in outcomes for people with cancer and a physical disability. Common sociodemographic factors included in analysis in the literature reviewed includes gender, household income, ethnicity, geographical location and age. Findings from this review suggest these factors may further impact upon care disparities for people with a pre-existing disability. Further research would benefit from exploring the impact of intersectional identities on the experience of cancer care for people with physical disabilities.

The definition of disability used in each piece of research must be considered in any form of synthesis of the findings, as the approach to defining disability and physical disability specifically can vary widely. This has implications for interpretation as it could mean that synthesis is misguided or even incorrect if the populations being discussed differ inherently from each other. Approaches to definition of disability vary significantly in the literature. In the quantitative literature (screening, outcomes etc) approaches range from referring to specific physical illness diagnosis definitions such as Multiple Sclerosis to self-reported disability from national surveys. The majority of literature on screening services employs national survey information to inform the researchers of disability status and sociodemographic factors. Survey questions utilised to define physical disabilities varies, however. There is no correct or

ubiquitous approach to defining disability within national surveys, as with the wider discussion around definition of disability within disability studies research.

Current research findings suggest there are disparities in cancer care for people with physical disabilities. However, people with disabilities are not one homogenous group. This may justify future research that drills down further and looks at specific cancers and specific disabilities. The vast majority of literature on this broad topic relate to access to screening services for women with physical disabilities. It follows that with limited access to screening services, this group may experience a ripple effect and see impacts upon their stage of diagnosis, treatment options and survival rate. Further research is required to investigate these latter stages of the cancer journey and the possible impact of lack of access to screening services might have on outcomes. Finally, there is a focus on the experience of screening services for people with physical disabilities, gaining information on the experience of care throughout the cancer pathway would be key to improving cancer care for this population.

Limitations of the literature reviews

It is important to explore the limitations of the scoping review and literature review update. The main limitation of these reviews was that they were undertaken by only one researcher. Although findings, study inclusion and strategy were discussed with the supervisory team, one researcher conducted the literature reviews. This could introduce bias to the selection of studies and the interpretation of the studies.

These reviews were limited to English language only papers, this limits the findings somewhat in its scope and generalizability. This is because the findings generally will be grounded in the

Western cultural viewpoint. A few studies from Korea were included as they were available in English language, however, viewpoints from elsewhere in the world are limited in these reviews.

Another limitation of these literature reviews is the lack of consensus on and detail of disability definition across the studies included. The lack of clarity on the approach to disability definition and therefore the population that was included in some of the studies makes it difficult to ascertain who we are capturing when we speak of 'mobility difficulties' or 'physical disabilities'. Without clarity on the types of difficulties or disability definition, generalizability and applications of finding is difficult. Further to this, some populations in the research identified has multiple morbidities and others had a single diagnosis. This could result in varying barriers and experiences of cancer services.

Literature review gap

- The literature review identified a lack of literature looking at disparities beyond screening services data. This thesis adds data analysis on further aspects of the cancer journey for people with disabilities (stage at diagnosis and mortality outcomes).
- In the existing literature there is a general lack of clarification of researcher's approach to defining the population with disabilities. Therefore, this thesis aims to be transparent in the approach to disability definition and creation of a disability population variable for analysis.
- This thesis aims to provide evidence from multiple sources in the same population (England and Wales) which strengthens the evidence base of this research area and bridges the gap between qualitative and quantitative findings that are evident in the existing literature base on this topic.

Chapter summary

This chapter has presented the methods and findings from an initial scoping review conducted in March 2019. Presented also are the results of a follow up review conducted in January 2022. Findings showed a lack of research exploring experiences of the cancer journey post cancer screening services. Also, a lack of research exploring cancer related outcomes for people with physical disabilities such as stage at diagnosis and mortality was identified. The research appraised also established a need for consensus and further investigation into the use of different approaches to definition of disability across research studies. These gaps are reflected in the aims of this thesis.

Chapter 3 introduces the research design and methodology for this mixed methods study.

Chapter 3: Research Design and Methodological considerations

Introduction to chapter 3

The previous chapter presented the results of the literature review investigating the existing literature on cancer care for people with pre-existing disabilities. This chapter introduces the mixed methods research design of this research. Methodological considerations such as intersectionality and critical disability theory will be discussed in relation to the research aims. The chapter then goes on to discuss the quantitative and qualitative study design considerations respectively. Lastly, research design processes undertaken such as ethical approval are presented.

Research paradigm

Transformative paradigm

Considering the focus on health inequalities, the research was guided by a transformative paradigm. A transformative paradigm provides a framework for conducting research that pays attention to power, privilege and voice of underserved communities and prioritises human rights within research (Shannon-Baker, 2016). The transformative paradigm is heavily guided by its axiological principles of social justice and considers whose reality is privileged in the research context, by following this paradigm, the researcher is empowered to reflect upon their relationships with the people in the study and the power dynamics at play (Mertens, 2010). The methodology of this study, as informed by the transformative paradigm followed a cyclical pattern in that input from the community being researched was sought throughout the process and the voices of the community of people with physical disabilities will be fed back to the

healthcare providers in the form of guidance on providing cancer care for this community. As a non-disabled researcher conducting research concerning people with physical disabilities, it felt imperative that this research was conducted 'with' and not 'on' the population group in question. The transformative paradigm provided a framework for this research that emphasised reflective and inclusionary practice at all stages of the research process.

Methodological considerations

Critical disability studies

As this is an exploratory study looking at inequalities experienced by people with disabilities, this research draws on thinking and tools employed by critical disability study (CDS) scholars. In line with other critical theories such as critical race theory, critical disability uses a variety of tools and approaches to dissect the interaction of power, society and disability. The overriding aim of critical disability studies is to uncover the ways in which people deemed as having a disability are oppressed in society and to highlight issues of dis/ableism. Although the concepts of disablism and ableism interconnect, there is some argument that disablism and ableism are two different forms of oppression. Kumari Campbell (2008) posits that disablism refers to the social construction and production of disability. Whereas ableism refers to the cultural beliefs, processes and practices that confounds a view that there is a 'perfect' or 'normal' human body (Kumari Campbell, 2019). Disability under this view then is seen as a 'falling away' from ableness (Kumari Campbell, 2008). Both understandings of disability related discrimination arguably result in or are a result of the systematic exclusion of people with disabilities (Garland-Thompson, 1996). In approaching this research with critical disability theory in mind it is hoped

that this research can go some way in illuminating the embedded structures and processes that exclude people with disabilities from cancer care services.

Some of the tools of critical disability studies will be employed in this research, in particular intersectionality, scrutinization of language around disability and understanding disability as a socially constructed phenomenon. Critical disability studies look at the power structures that oppress people with disabilities but also how these interact with other power structure issues such as gender discrimination. Guided by CDS and the transformative paradigm's principles of social justice and paying attention to power and privilege in research, it is necessary to consider the other identities a person with disability may hold, such as also being a woman or being from an ethnic minority group. Intersectionality as a theoretical perspective will be used to guide this research, it is increasingly being applied to research on health determinants and inequities as a tool to explore the impact of multiple, intersecting axes of identity that affect an individual's position of power or oppression and potentially any discrimination (Hankivsky and Christoffersen, 2008). Intersectionality highlights the need to explore multiple categories of social identity that are inextricably linked and therefore does not place importance of one category of identity over another. In this research context, studying cancer care outcomes for a person with a physical disability without exploring the complex systems of identity that could also impact on their equity of health experience would be an inadequate piece of research (Hankivsky and Christoffersen, 2008). Therefore, this research study will assess the impact of physical disability alongside socio-economic variables and demographic factors such as race, gender, household income and rural vs urban location, among others.

A further way in which critical disability studies impacts this work is in the understanding of disability as a socially constructed phenomenon. Wendell (1996) argues that the production of

disability in any situation is created through the refusal of people individually and collectively to adapt to the needs of people considered to have a disability. Similarly, Garland-Thompson (2002) argues that disability is produced through a dichotomous disability/ability system. These understandings will guide this work mainly in the interpretation/discussion phase when considering how the findings might uncover certain power dynamics or cultural practices which result in the exclusion of people with disabilities.

Lastly, the examination of terminology around disability will be a feature of this research. The importance of terminology and the social construction of disability understanding has led to careful consideration around the choice of definition of disability in this research. An examination of the theory behind disability definition will be presented in chapter 4 along with consideration of how this applies to this research project.

Research aim and objectives

The identified gap in the existing research identified in the literature review was research that explores and contextualises the cancer care inequalities for people with disabilities beyond access to screening services.

Therefore, the aim of this research was:

To generate understanding of the disparities in care experiences of this population group on both the macro (structural, organisational, and service delivery) and micro levels.

To achieve this aim, this research was designed as a mixed methods study. The quantitative part of the project was designed to utilise a large amount of routinely collected health data to illuminate any potential disparities in cancer outcomes between people with disabilities and

people without disabilities in Wales at the macro level. The impact of socio-economic and demographic variables was also analysed to gain an understanding of the outcomes for people with a pre-existing disability from different backgrounds as evidence suggests that socio-economic factors can also have an impact on cancer outcomes (Coleman et al, 2001).

The purpose of the qualitative element was to identify potential barriers and facilitators to quality cancer care, screening services and outcomes for this group. This will be achieved by gathering evidence of the lived experience of cancer care as someone with a pre-existing physical disability.

The objectives of the study were to:

1. To investigate disparities in cancer care between people with and without physical disabilities in Wales. Including access to cancer screening, cancer stage at diagnosis, and survival, between people with and without physical disabilities.
2. To explore the combined influence of disability and other demographic and socio-economic variables on cancer care outcomes.
3. To explore the experiences of cancer services for people with disabilities.

Research Questions

Research question 1:

What are the characteristics of the population with a disability identified in the National Survey for Wales?

Research question 2:

Are there disparities in cancer care for people with physical disabilities in Wales?

Research question 3:

What is the experience of cancer care in Wales for people with physical disabilities?

Mixed methods study design

To address the research questions and achieve the objectives, this study follows a concurrent triangulation mixed methods strategy, taking place in two parts:

1) quantitative element: linking and analysis of cross-sectional anonymised data, identification of a physically disabled population.

2) qualitative element: interviews with people with physical disabilities regarding their experiences of cancer care.

Data was collected concurrently and analysed concurrently, findings from one section of the project did not influence the collection or analysis of the other portion of the project. Findings were intercalated at the interpretation phase where the results from the qualitative analysis were used to contextualise and explore on a deeper level the quantitative component (Andrew and Halcomb, 2009). Both the quantitative and qualitative data has equal weight and status in this project.

Quantitative study design

This is a brief summary of the quantitative research design, more detail will be covered in the quantitative methods (chapter 6).

Big data healthcare research

To answer research question 1 and 2, the use of a large volume of population health data is necessary. Therefore, the quantitative element of this mixed methods study draws on linked and anonymised routinely collected healthcare data and national survey response data. This portion of the project can be considered to be a 'Big data' healthcare study and will follow the principles of epidemiology and population health research.

The quantitative element of this project is considered a 'big data' study under the widely accepted '3 V's (Mooney, Westreich and El-Sayed, 2016) definition of 'big data'. The term 'Big data' generally refers to the collection and analysis of large volumes of information (Mooney, Westreich and El-Sayed, 2016). The 3 V's definition refers to: variety, volume and velocity of big data datasets. Variety here suggests that portions of the wider dataset in question were originally collected for differing reasons and brought together into a single dataset for analysis (Mooney, Westreich and El-Sayed, 2016). Volume simply refers to the high number of observations characteristic of big datasets as compared to historical datasets within a certain research area (Mooney, Westreich and El-Sayed, 2016). The definition of velocity in this context refers to the speed at which information is processed and analysed in real time or close to real time (Mooney, Westreich and El-Sayed, 2016). This research project can be considered a big data healthcare research study under the 3 V's definition.

- Variety: The dataset compiled for analysis via SAIL consists of data from various sources including electronic health records and national survey data.
- Volume: The national survey used gathers roughly 12,000 of respondents each year and electronic and national survey data cover the entire Wales geographical area.
- Velocity: The data collected for analysis covers the period of 2012-2019.

Epidemiological underpinnings

Epidemiology is a discipline concerned with the distribution, determinants and outcomes of health-related events in a specified population (Last, 2001).

This study is considered epidemiological as it is looking at health determinants (cancer screening access, mortality, stage of cancer at diagnosis) in a specified population (people with physical disabilities). In designing this epidemiological study choice of datasets and study design were key considerations. To answer the research questions, it was necessary to collect retrospective data on health outcomes and a cross sectional study design was chosen as both exposure and outcome needed to be measured simultaneously in the same individual. The datasets were chosen based on the hypotheses formulated, the components and variables needed to test the hypotheses were identified in advance of requesting the datasets.

Statistical analysis plan

The statistical analysis plan (SAP) was completed in April 2020 (appendix 2) and reviewed by the project supervisors. The statistical analysis plan outlines the data requested, variables of interest, the approach to analysis and considerations of bias prior to accessing the data.

Applying the definition of disability to the Quantitative data

Operationalising and applying the choice of disability definition to the population respondents of the National Survey for Wales (NSW) (2012-2017) meant examining questions asked in the survey to identify which aligned with a more bio-psycho-social approach to disability definition such as the ICF. The challenge was choosing a question or set of questions that were present in all of the survey years. Some survey years included more questions related to health and disability than others. The 2016/17 survey year for example included a section directed

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specifically at people with disabilities and included questions on environmental access issues. This impact of differing questions over years will be explored further in the next chapter. The questions chosen to identify the population with a disability in the NSW were "Do you have an illness, disability or infirmity lasting or expected to last 12 months or more?" and "Does your illness, disability or infirmity impact your day-to-day activities?". Those who answered yes to both questions were considered to have a disability. Although the first question mentions disability explicitly, it was decided that the first question alone did not fulfil the approach to definition chosen. By combining these questions, the definition of disability reflected a more bio-psycho-social approach to disability as it encompassed the physical and functional aspects of disability. Unfortunately, there weren't any questions related to environmental or social issues that were present in all the survey years. The results, strengths, and limitations of this application of disability definition to the NSW will be presented in more detail in the next chapter.

Qualitative research design

Narrative research

The qualitative portion of this project followed a narrative inquiry research design. This approach was chosen with an aim to elicit rich interview data that could capture many facets of the experience of someone with a pre-existing physical disability who has gone through cancer. In recording and analysing the data the interviewee and I were making a collaborative story based on both of our understandings of the shared social world we live in. Narrative interviewing was chosen as the method of data collection and each participant's resulting interview data was formed into their own narrative and presented as a story unique to their experience. This is a

brief summary of the qualitative research design, more detail will be covered in the qualitative methods chapter, chapter 8.

Applying definition of disability to the Qualitative research

As the recruitment of participants allowed for self-identification of physical disability the wording on the recruitment poster was intended to encompass a wide range of physical impairments and daily functional difficulties without detailing any specific health conditions. The wording on the recruitment poster to advertise the study on social media was the following: "Do you have difficulties with any of the following: Moving around, breathing, chronic pain, looking after yourself day to day e.g., washing, dressing, getting out and about. If so, we would like to hear from you about your experiences for a research study looking at cancer care for people with physical disabilities". See recruitment poster in appendix 3.

It was hoped that wording the recruitment poster in this way would allow participants to decide whether their physical impairments or functional needs constituted a physical disability, leaning towards a more subjective view of disability definition. Moving around, breathing, and chronic pain were intended to encompass the biological component of disability. Whereas the inclusion of looking after yourself day to day was intended to touch on the functional aspect of disability. By including "getting out and about" in the examples of difficulties with looking after yourself day to day, an element of the environmental impact on disability was included. Furthermore, by having the more physical components listed separately to the functional components it was intended to reflect the belief that the physical aspect of disability was not a pre-requisite to having functional difficulties and vice-versa. In this way, the approach to defining physical

disability reflected the ICF with a sliding scale approach to defining physical disability that encompasses the physical, societal and environmental aspects of disability.

Research ethics

Initial ethical approval was gained from Cardiff University's School of Healthcare Science's research ethics committee on the 19[th of] July 2019 (see appendix 4).

Minor amendment approval was sought to include the advertisement of the project on social media platforms. Approval for the revised proposal was gained on the 14th of January 2020 from the Chair of the School of Healthcare Science's Research Committee and ratified by the rest of the committee. Please see appendix 5.

A further amendment approval was sought following the decision to include proxy interviewing in the project. Approval for the revised proposal was gained on the 7th of May 2020 from the Chair of the School of Healthcare Science's Research Committee and ratified by the rest of the committee. Please see appendix 6.

Good Clinical Practice training was completed initially in November 2019 and kept up to date by the primary researcher throughout the project timeline.

Project Steering Group input

The Steering Group for this project involved experts from the fields of cancer care, the project supervisors, and one advisor with lived experience of having had cancer and a pre-existing physical disability. The steering group provided invaluable advice and direction in the early stages of the project on key issues such as interview recruitment strategy, approach to defining disability and interview questions.

Information governance approval

As this project requires access to a large amount of population health data, the SAIL databank was identified as the source of big health data. The Secure Anonymised Information linkage (SAIL) databank provides linked and anonymised population health and social care data for research projects. The application process for access to SAIL data is completed in two stages. The first is a scoping project form produced in discussion with a SAIL analyst. The second requires completion of SAIL's Information Governance Approval Panel (IGRP) form which is assessed by an independent panel. Completing the IGRP form involved outlining the objectives of the project, the datasets and variables within them that were needed for analysis and a statistical analysis plan.

IGRP permission was granted in November 2020 which grants access to the core SAIL datasets. As this project requires access to several SAIL restricted datasets (such as those from screening providers and Welsh government), permissions were sought via SAIL from the external data providers. Permission from Welsh Cancer Intelligence and Surveillance Unit (WCISU) was granted in November 2019, Screening data providers in January 2020 and the Welsh Government for use of National Survey for Wales data was granted in February 2020. Please see appendix 7 for the IGRP application form and supporting documents.

Impact of COVID-19 pandemic on study design

The initial design of this study was a sequential mixed methods design. The plan was to collect and analyse the quantitative data first to explore the issue on a macro level then explore the findings on a qualitative level through interviews tailored to the quantitative findings. However, due to the delays in accessing the data from SAIL due to the COVID-19 pandemic I had to adapt

the research plan to a concurrent mixed methods design as the analysis of the quantitative data coincided with the analysis of the qualitative interview data. The plan to triangulate the findings in the discussion chapter and to contextualise the qualitative findings with the quantitative findings remained the same.

Summary of chapter

This chapter has introduced the methodological, paradigmatic and research design considerations of this mixed methods research project. The methodological considerations of both the qualitative and quantitative portions of the project were introduced and will be discussed in more detail in the following chapters (chapter 6 and 8), along with the methods for each. The next chapter will present an investigation into the existing theory around defining disability in research.

Chapter 4: Defining disability

Introduction to chapter 4

This chapter attempts to explore the reasons for taking a carefully considered approach to defining disability, the multitude of approaches to defining disability, and the contexts in which this is important. With the approaches to defining disability discussed, this chapter concludes with a brief application of these findings to this research project, both the qualitative and quantitative aspects. The definition as applied to the quantitative section of this research will be explored in further detail in the following chapter.

This chapter will explore the different disability definitions that are used in a variety of contexts including public health and administrative settings. It is important to acknowledge that the rights of people with disabilities are affected by the way they are categorised in all arenas. Consequently, the way they are categorised in one context e.g., institutionally, can affect the choice of definition in another, e.g., research. This chapter will also provide a brief overview of what is understood by the terminology around definitions, including models, classification schemes and the operationalisation of both with regards to academic research. An examination of the literature and debates around models of disability from the viewpoint of disability studies will be considered with consideration of the application to this project. Finally, objective versus subjective definitions will be looked at as this is a generally neglected area of consideration within this topic. The chapter will conclude with a summary and application to this research project.

Background

Research in the area of disability studies has attempted to address and highlight some of the inequalities experienced by people with disabilities in the UK and globally (Groce, 2009). It is becoming increasingly acknowledged that the way disability is defined can and does have an impact on the way people with disabilities are stigmatised and excluded from various aspects of society (Oliver and Barnes, 2012., Abberley, 2007), the opportunities available to them and fundamentally the fulfilment of their human rights (Groce, 2009).

To conduct research on a population with disabilities, it is necessary to define what one means by the concept of 'disability'. This is a highly contested topic (Oliver and Barnes, 2012) and how disability is defined is a complex question to answer. Whilst all efforts should be made to considerately apply a definition of disability, the outcome will inevitably homogenise a very diverse population. For instance, research from Pongiglione et al (2017) demonstrated that the approach to classifying disability in quantitative research can erase valuable information on severity and burden of disability on populations by comparing binary and ordinal classifications of disability. Limited research also suggests that choice of disability definition can lead to great variation in the populations captured. Grovnick (2009) looked at the effects of definition of disability choice on research outcomes. The research looked at functional definitions, administrative definitions, and subjective definitions on outcomes of studies of socio-economic factors in the lives of people with disabilities. They found significant differences in the characteristics of the population when analysed along with commonly used variables such as gender, age, and employment status. For example, when administrative definitions were used, males were overrepresented in the population. Whilst this research usefully highlights the importance of methodological considerations in disability related research, the methods of

analysis used in this study are not clearly stated, making it difficult to replicate. Limited research also suggests that some commonly occurring issues with disability choice in research are that researchers are often not clear on the definition they are using and don't explicitly adhere to the same definition throughout the study (Grovnick, 2007).

It is therefore important for researchers in this area to consider the conceptual basis of their definition of disability, for any personal bias to be confronted in their choice of definition, and implications of the choice of definition thought through. It will be necessary to consider the choice of definition of disability in this study; there will be a need to identify a population of people with disabilities to compare with a population not considered to have a disability in the quantitative element of the research and in the recruitment of participants for the qualitative element. There is also a need for the populations of people with disabilities to have a similar conceptual basis to allow for conclusions made from each analysis to be compared and contrasted.

The term disability is often used as an umbrella term encompassing physical, sensory, mental health, developmental and cognitive disabilities. The focus of this research is on inequalities in the population of people with a physical disability meaning people with a functional or mobility impairment or difficulty. For the purposes of this chapter and throughout the thesis the term disability will be used to refer specifically to physical disabilities, although it is acknowledged that the disability types can and often do intersect.

Distinction between models, classification schemes and definitions of disability

Before discussing the spectrum of models related to disability definitions, it is important to clarify what is meant by models, classification schemes and definitions of disability. Altman (2001) attempted to clarify the distinction between definitions of disabilities, models, and classifications schemes. She argued that answering the question 'what is disability?' is a complex scholarly and political pursuit that is rooted in the deeper philosophical considerations of the conceptualisation of disability rather than purely linguistics or semantics. A model can be understood as a recommended structure for understanding complex phenomena that can be used to organise thinking (Bickenbach, 2012). A definition of disability then, according to Altman is something that is grounded in a model but is shaped by the user of the definition to be fit for purpose. In an academic or research context the choice of definition of disability will likely reflect their discipline and methodological assumptions (Bickenbach, 2012). Altman also explores the concept of a classification scheme, which she argues is the outcome of translating a model into an empirical instrument which happens through a process of linking concepts with observable phenomena in the world, which she calls 'operationalization'. In discussing how to define disability it is necessary then to explore the range of models in current discourse with an aim to operationalize the model into a useable format for this research study.

Models of disability

Each theory and model considered under disability studies has its own guiding principles behind it. What Garland-Thompson refers to as the disability studies matrix is vast and ever expanding but includes the medical model, the social model of disability, cultural models (disability as a

mark of culture) and minority models (disability as a civil rights concern), amongst others. For

the purposes of this discussion, I will consider those that appear to be on the opposing ends of

the spectrum, the medical model and the social model, alongside arguably a more relational

model in the form of the International Classification of Functioning, Disability and Health (ICF).

Academics generally agree that it is not possible for a single definition to encompass the entirety

of the disability experience and whichever model is used as the guide in research will inevitably

be deemed to be lacking. Iezzoni and Freedman (2008) recommend using a model that

encompasses both medical and social perspectives in research. The pros and cons of which will

be explored further on in this chapter.

Medical model

The medical model of disability is characterised by a focus on disability as a medical diagnosis, a

biological (physical, sensory, or cognitive) 'flaw' or defect in an individual that can be labelled

and attempted to be 'cured' by the medical professions. The medical model of disability, Oliver

(2007) argues, reinforces the prevailing view of society towards disability, that of personal

tragedy theory. Personal tragedy theory, led by a medically focused view of disability, labels the

individual with a disability as a victim of their circumstance and places them in a powerless

position (Oliver, 2007). Whilst disability scholars acknowledge that there are many positives to a

medical diagnosis of a condition; including the medical interventions that can and have improved

the lives of people with disabilities (Goodley, 2017). An overt leaning towards a medical

definition of disability can lead to policies and attitudes towards disability that focus on person

fixing over context changing solutions to improve the lives of people with disabilities (Oliver

and Barnes, 2012). To further this point, Abberley (2007) argues that to frame the disadvantage

of people with disabilities in society in the context of biological abnormalities detracts from the impact of an unequal society that values able bodied people over disabled bodies.

In a medical context the interpretation of disability as a purely medical phenomenon can result in care that is generic and not catered to individual needs, de-humanisation of the disabled person and stigma from healthcare professionals. In a welfare context, as Oliver (1996) puts it, individual or medical models of disability place disability as a personal issue that burdens social systems. Furthermore, in a shifting political landscape, placing the onus of disability on individual impairments and ignoring the social and environmental context can result in governments restricting the definition more and more in times of austerity (Soldatic and Grover, 2012), leaving some people with disabilities potentially further excluded from society.

The medical model has come to be associated with an archaic notion of disability (Shakespeare, 2014). Moreover, it can be considered as a proxy or a 'symbol' that represents negative or exclusionary attitudes towards people with disabilities and paternalizing attitudes by medical institutions (Shakespeare, 2014). That is not to say that research and policies do not sometimes still use the medical model as their reference point, as an analytical category. The medical model perhaps represents the insidious set of institutional characteristics that systematically marginalise people with disabilities that can be easily overlooked if not explicitly acknowledged. Shakespeare (2014) delineates the medical model as a stance towards disability that is individualised and overly medicalised (Shakespeare, 2014), rather than a model itself. For the purposes of this discussion and ease of debate, I will refer to this collection of symbolic ideas as the medical model as this is what it is commonly referred to in the literature. It is seemingly impossible to define disability without a reference to the biological characteristics that may be involved in the experience of disability; therefore, it is not useful to untangle oneself from this

aspect of the definition completely. This said, to acknowledge the dangers of over medicalising the definition of disability in research is also important.

The International Classification of Impairments, Disabilities and Handicaps (WHO,1976) was the precursor to the International Classification of Functioning, Disability and Health (ICF) and has been regarded as 'The official, international underpinning of the medical model of disability' (Hurst, 2000). Developed by the World Health Organisation with similar aims to the ICF, to create a global system for classifying disease and disability. The ICIDH, conceptualised in 1980 and reissued in 1993, was based on the biopsychosocial disease model, it was intended to be a challenge to the medical model, with an aim to draw attention towards the social exclusion of people with disabilities (Bury, 2000). The ICIDH conceived disease consequences across three domains: The structural and functional bodily impairments, disabilities, or restrictions in activities of daily living and handicaps or participation limitations in social integration (Badley, 1987). The ICIDH's conceptual meaning of disability was 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (Bickenbach, 2012). The understanding of disability in this way places the focus on a medicalised view of the 'functioning' human body as the prevailing notion of normal. The WHO was widely criticised for the ICIDH (Hurst, 2003). Critics argued that it followed a linear model of disability, with the roots of disability being in bodily impairment and the outcomes of disability being in 'handicap', therefore reflecting the medical model of disability and the traditional view of disability at the time (Hurst, 2003).

The Social Model

In contrast to the medical model of disability, more socially and politically oriented models emerged from disability rights movements in the 1960's and 1970's, such as the Union of the

Physically impaired Against Segregation (UPIAS) group. More socially oriented definitions of disability focus on the historical, cultural, social, political, and environmental barriers that disable people rather than focusing on individual impairment as the sole disabling factor (Goodley, 2017). Shakespeare (2014) argued that the biological component was left out of earlier iterations of the social model. In later conceptualisations the biological, bodily component is separated from the notion of disability. The Disabled People's International (DPI) definition for example includes "the functional limitation within the individual caused by physical, mental or sensory impairment" and refers to 'Disability' as "The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (dpi.org).

What is commonly referred to as the social model goes beyond the UPIAS separation of impairment and disability by arguing that there is not a causal link between impairment and disability (Oliver and Barnes, 2012). The social model of disability places a clear focus on the environmental, economic, and cultural barriers which are the disabling factors in the lives of people who are viewed to have a form of impairment (Oliver, 2004). The social model of disability has been widely praised for offering an alternative way of conceptualising disability and has provided a foundation for political action of people with disabilities (Owens, 2015). The social model has also been the conceptual foundation for emancipatory research, including research undertaken by the British Government (Sykes and Groom, 2009).

There have also been many critiques mounted against the social model. The main critique of the social model of disability is that it ignores the social-relational aspect of disability and that it doesn't place enough emphasis on the bodily impact on disability (Shakespeare, 2014). Thomas (2012) argues that impairment can become disability through structurally oppressive forces that

interact with impairment and restrict disabled persons opportunities, for example, cultural stereotypes of disability. Disabled feminist theorists have criticised the social model of disability for not incorporating the many ways disability can be experienced, including the intersection between the discrimination already faced by being female in society and simultaneously being labelled as having a disability (Lloyd, 2007).

The International Classification of Functioning, Disability and Health (ICF)

Following criticism from people with disabilities, disability scholars and other allies alike, the World Health Organisation reformulated their classification of disability, the ICIDH, to what has become known as the ICF (The international Classification of Functioning, Disability and Health). The ICF was created as an attempt to bridge the gap between the social and medical models of disability to form a 'universal', bio-psycho-social approach to classifying disability (WHO). Within the ICF, the concept of disability is framed as an umbrella term encompassing three levels: impairment, activity limitations and participation restriction. Disability then, is classified as dysfunction at one or more of these levels. The ICF framework posits disability as resulting from the interaction between health conditions and contextual factors, including the environmental (including social) and personal.

One of the main criticisms of the ICF is imparted from its primary aim, to become an international classification system. Critics of the model claim that the ICF is grounded in Western notions of disability and functioning and therefore does not allow for application or variation within cultures (Goodley, 2017). The ICF has also been criticised for a lack of definition of concepts such as impairment and activity limitations and has generally been criticised for being too vague (Shakespeare, 2014).

The ICF has been received positively in some respects. Shakespeare (2014) posits that the interactional nature of the ICF model allows for a wide range of experiences of disability to be accounted for. Another positive of the ICF can be found in the way it approaches 'defining' disability. With its 'universal' approach, in that the 'sliding scale' of disability can be applied to all human beings, meaning that under the ICF we are all somewhere on the spectrum of disability. According to Bornman (2004) this means that the 'label' of disability no longer creates a minority group as it is an interaction between the individual and environment, resulting in a continuous rather than dichotomous classification system (Bickenbach, 2012). Finally, a benefit of using the ICF in research comes from another of its aims, the aim to standardize health and disability data internationally. The more the ICF is adopted and applied to various types of research methodologies, the more data and insights that can be drawn and compared internationally. Currently, it appears to be the best attempt at classifying disability in a holistic way but requires further adoption of the model to explore its benefits and drawbacks in application to research.

Definitions of disability

This section will focus on why defining disability is important and the implications of the varying approaches and uses.

Approaches to definition of disability vary with context, purpose, and scope. The application of a definition of disability has an impact on public health statistics, recipients of financial benefits, clinical care decisions and the outcomes of scholarly research. Oliver and Barnes (2012, pp. 14-16) outline their argument for why defining disability is important to consider in four points:

1. The choice of definition can have an impact on policy/treatment towards disabled people.

2. It can affect access to financial aid, via the creation of a legitimate social category.

3. Politics of minority groups- the opportunity for minority groups to take back power over terminology.

4. The potential impact on disability statistics- economic implications e.g., allocation of funds.

The following section will consider definitions of disability within legal and administrative, public health statistics, and clinical settings.

Legal and administrative definitions

Official definitions of disability, including those used for identifying who should be in receipt of state benefits and support, are used to define the population to meet societal or organisational need. Stone (1984) argues that legal and administrative definitions used in this way create a 'disability category', which has the ultimate goal of keeping the majority of the population in the workforce except for the most in need. The framework for applying the disability category depends upon the political, social, and economic concerns of the current administrative government of the time (Soldatic and Meekosha, 2012). In the United Kingdom, under the Disability Discrimination Act (1995) and latterly the Equality Act (2010), a person has a disability 'if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'. A definition worded in this way combines the concepts of impairment and disability (Goodley, 2014). An individual must demonstrate 'substantial and long-term adverse physical or mental *impairment*...' and their *disability* must have an 'adverse effect of his ability to carry out normal day-to-day activities'. This approach arguably excludes the environmental or societal restrictions that can render a person disabled, therefore aligning it more closely with a medical model of disability. Various

permutations of policy relating to disability benefits in the UK have focused on the individual 'proving' they fit this criterion. The application of this definition in this way individualises and problematises disability.

Legal and administrative definitions used for the purposes of allocation of state benefits often place an emphasis on the individual fitting in to a category of disability, often with administrative 'checking' of disability or functional status in order to discover who can and cannot be legitimately placed in this category (Altman, 2001). The definition used for disability is important here as it can affect access to financial aid. For those who are in need but do not fit the eligibility criteria, this can mean limited access to all areas of life such as healthcare, education and employment which can ultimately lead to further disablement, social isolation, and stigmatisation (Dorn and Keirns, 2009). As Soldatic and Grover (2013) demonstrate, trends in defining disability for legal and administrative purposes have tended to head towards stricter and stricter eligibility criteria (Soldatic and Grover, 2013). In their analysis of Australian and UK policy shifts in disability criteria in both countries, the researchers point to a co-occurrence of high unemployment rates and shrinking of disability criteria (Soldatic and Grover, 2013). A similar phenomenon of restricting of criteria has also been noted in the United States (Altman, 2001). This is an important point as it demonstrates how fluid the concept of disability status can be depending on the needs of the legal or administrative system setting the boundaries of definition.

Globally, the understanding of disability definition and disability rights received wider attention in 2006 due to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006). The CPRD developed a treaty which aimed to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons

with disabilities, and to promote respect for their inherent dignity" (WHO, 2008), the countries

entering into the treaty committed to develop laws, policies, and administrative efforts to secure

the rights of persons with disabilities. Article 25 of the treaty stated that "States Parties recognize

that persons with disabilities have the right to the enjoyment of the highest attainable standard of

health without discrimination on the basis of disability" (United Nations, 2006). In terms of

definition, the convention steered clear of explicitly defining disability. The CRPD

acknowledges that disability is an evolving concept and occurs in interaction with various types

of environmental and social barriers. This shift in approach to the definition of disability

mirrored the undulating landscape of disability rights movements and academic approaches,

more closely aligning itself with social models such as the social model of disability. The

convention was followed by the World Health Organisation and World Bank's World Report on

Disability (2011) which aimed to support implementation of the CRPD, this report drew together

the latest evidence surrounding the rights of persons with disabilities and provided

recommendations from the findings. The World Report on Disability utilised the International

Classification of Functioning, Disability and Health (ICF) as the conceptual framework for

defining disability. Again, this demonstrated an incorporation of disability rights movements and

disability scholars' arguments against medicalised models of disability.

The United Nations Sustainable Development Goals (SDG) (2018) included aims set out by

United Nations members to work towards a more inclusive, sustainable way of living across the

globe. A United Nations report on the inclusion of disability in the SDGs (United Nations, 2018)

laid out the goals to which disability rights is tied. These included the importance of disability

related data collection that is internationally standardised and comparable globally. The need for

accessible living spaces was also a key goal where the rights of people with disabilities is

concerned. The SDG report on disability inclusion (2018) followed the CRPD approach to defining disability.

Public Health

Population health data is generally used to describe the contours of a nation's health and wellbeing and to inform related policy (Fujiura and Rutkowski, 2001). Data on numbers of people with disabilities in a population are usually garnered from surveys and censuses on wider population health issues and numbers gathered will depend on the conceptual basis of the definition chosen. Defining disability in the public health arena can have policy related uses and also to inform public health initiatives to understand and target the process of disablement (Altman, 2001).

Following The International Seminar on the Measurement of Disability in 2001, the Washington Group on disability statistics was formed to address a perceived need for an internationally applicable approach to identifying disability in national surveys, censuses, and research (Washington group, 2020). The Washington group consists of representatives from national statistics offices in over 140 countries worldwide, non-governmental organisations and disability organisations. The aim of this group was to create a set of tools that could be incorporated easily into existing national surveys and censuses to create disability data that was internationally comparable and to tackle the difficulty of collecting quality disability data in low- and middle-income countries (Washington group, 2020). The group created a set of questions which included a short set of six, an enhanced short set and an extended set of questions. The approach to defining disability in the question sets focuses on the interaction of functional limitations and environmental restrictions resulting in participation limitations, therefore fitting with the ICF model of disability.

The Washington group and the resulting survey questions indicate an increasingly acknowledged importance on incorporating self-reported disability into national disability statistics. In their paper introducing the question sets, The Washington group put forth the argument that gathering accurate public health statistics on disability is important in order to estimate the prevalence of disability in a population and to measure the extent of exclusion of disabled people from society (Washington group, 2020). They suggest that by approaching disability definition from the perspective of disability and health being on a continuum of functioning and activity participation, surveys and censuses can reach a more accurate understanding of the types of disability experienced by a population. Then, by disaggregating the data collected on disability (by age, gender etc) and monitoring participation in society (e.g., education and healthcare), nations can begin to understand the type and extent of exclusion people with disabilities might face.

Clinical definitions

Clinical definitions of disability will vary depending upon the healthcare context and generally relate to access of treatment or rehabilitation services. Used in this way, definition of disability in a healthcare context will generally follow the medical model of disability as it relates to specific health conditions for individuals to access specialist care. However, as this research hopes to explore, there may be a need for identification of disability to enable individuals with additional needs to be identified when requiring healthcare that is not related to their disability related needs. Altman (2001) points out, the clinical definition of disability used will have a basis in the governing body or authority regulating the healthcare setting. Furthermore, there is evidently a relationship between clinical and administrative definitions of disability in the UK as general practitioners and their assessment of healthcare need are often the deciding factor in receipt of

certain benefits. Similarly, clinical healthcare workers such as nurses and allied health professionals are often placed in roles to assess an individual's disability status to ascertain whether they can legitimately claim disability benefits. Clinical definition and perception of disability is an area that requires more research attention.

Approaches to definition

In summary, the approach to choosing a definition of disability is far from a straightforward endeavour. One must take in to account the political, social, economic, and legislative landscape when considering the implications of their choice of definition as well as the impact it could have on their research outcomes. The conceptual models considered in this chapter demonstrate a spectrum of ideas on the answer to the question 'how do you define disability?', but this is only the foundational step in the quest to find a workable definition and apply it to research. As Altman (2001) demonstrates, it is necessary to take the model or conceptual foundation to the next level and develop a classification scheme by operationalising the concepts. The medical model provides a necessary but problematic approach to the definition of disability. Whereas the social model perhaps goes too far the other way in stating the environment is the only cause of disability to be able apply it as a sole model of disability definition in research. The ICF provides a useful middle ground in the form of a biopsychosocial model, which is not without its drawbacks, however. Finally, the dearth of literature on objective versus subjective perceptions of disability demonstrates a need to consider the viewpoint of those experiencing disability during the development of a research methodology and throughout the research process.

Application to this study

In relation to this research project, this exploration into the literature surrounding definitions of disability has reinforced the importance of developing a sound understanding of the conceptual base on which the choice of definition rests. In consideration of the pros and cons of the models discussed, the ICF model seems to be the most applicable to this study. The ICF forms a more holistic model as it considers both the medical and environmental/social context of a person's life. It also fits with the researcher's belief that disability and health are on a sliding scale, with each individual having elements of health and disability in their lives at various stages. To base the definition within a medical or social model solely would narrow the population down too much, therefore a broader, more holistic approach such as the ICF seems appropriate. The operationalisation of the ICF will be the required next step, considering the data set being used along with the model's parameters will be necessary. This will be explored in the next chapter.

Summary of chapter

This chapter has explored the importance of choosing a disability definition, specifically considering its application to research. The various models of disability definition have been laid out and discussed in relation to this research project. The final section outlined the approach to definition as applied to the qualitative and quantitative elements of this research study. The following chapter will further explore the choice of definition in its application to the respondents of the National Survey for Wales (2012-2017).

Chapter 5: Defining disability in the National Survey for Wales population-methods

Introduction to chapter 5

The previous chapter presented background theory on approach to defining disability. The quantitative portion of this research project incorporates linked population level survey data from the National Survey for Wales (NSW) (years 2012-2017) with cancer registry data from screening services and the Welsh Cancer Surveillance and Intelligence Unit (WCISU).

The chapter will begin with an introduction to the National Survey for Wales, its background, collection methods, linkage and access via the SAIL databank.

Introducing the National Survey for Wales

Background information

The National Survey for Wales (NSW) is a cross-sectional survey of the adult population in Wales run annually by the Welsh government. A sample of addresses is selected at random from the Royal Mail's Postcode Address File (PAF), stratified by local authority. Survey data is collected via face-to-face interviews with one randomly selected adult in each selected household. Following a review on cost effectiveness in 2014, a move to decrease the amount of face-to-face interviews was made including more phone, postal and web-based options for households (Welsh Government, 2014). Each year, the survey is completed by around 12,000

people aged 16 and over (StatsWales). Survey collection periods run from April to March the following year, with the exception of 2012 where an additional survey was undertaken in a shorter time period from January to March 2012. From 2016/17 The Welsh Health Survey, Active Adults Survey, Arts in Wales Survey, and Welsh Outdoor Recreation Survey were ceased and incorporated into the National Survey.

Bias

There is opportunity for potential bias as the survey is based on face-to face interviews; samples for face-to-face surveys are often geographically clustered to keep travel costs to a minimum, this can lead to a less varied sample (Nicolaas, 2012). Data collected using face-to-face interviews may also be subject to interviewer effects such as social desirability bias and interviewer error. There is a risk of coverage bias if portions of the population are not included or they do not have access to the mode of data collection, for example, the survey does not cover people living in communal establishments (e.g., care homes, residential youth offender homes, hostels, and student halls). The survey is weighted to adjust for non-response, which helps make the results as representative as possible to the Welsh population (StatsWales).

As previously mentioned, in 2014, survey collection was moved to phone, postal and web-based interviewing techniques. This could introduce potential bias in the later survey years as access to certain demographics using these techniques could be more difficult than the previous face-to-face methods. Data quality could also be affected by these interviewing techniques. With phone, postal and web methods there is an increased risk of non-response bias, self-selection bias (when contacting households via post) and increased risk of measurement differences (Welsh Government, 2014).

The Secure Anonymised Information Linkage Databank

The NSW datasets were made available for use via the Secure Anonymised Information Linkage (SAIL) databank. The SAIL databank provides a safe platform for researchers to access health and administrative data that can be linked to answer research questions. SAIL creates an anonymised linking field (ALF) for each individual in the dataset, making their information linkable across multiple health, social care, and education datasets whilst retaining the anonymity of individuals. As the NSW datasets are restricted datasets in the SAIL databank, external permission is required from the Welsh Government in addition to being granted Information Governance Review Panel (IGRP) permission from the SAIL data governance team.

Datasets requested

The NSW datasets requested from SAIL included survey years completed annually between January 2012 to April 2017.

Survey data were provided in separate datasets by year, so linkage was required to combine all the survey years into one dataset for analysis of the entire population. This was completed by merging the datasets using the ALF as the key variable in the merging process.

Population characteristics

The National Survey for Wales data provided variables on population characteristics such as age at survey interview, gender, ethnicity, urban or rural status, deprivation index and whether respondents had visited their GP in the last 12 months. Details on how variables were re-coded is given below.

Age at survey interview

Individuals' self-reported age was captured in the NSW and taken at the time of their survey interview. For the CSW descriptive analysis age was recoded into categories of 5 to 10-year age groups (24-29 years, 30-39, 40-49, 50-59, 60-65). The descriptive analysis for the BSW dataset was recoded into age categories comprising ages 60-64, 65-69, 70-74. Similarly, for the BTW descriptive analysis on age the age categories used were as follows; 50-54, 55-59, 60-64, 65-70. The different age brackets for descriptive data for screening services was based on the size of the age range for the recommended screening e.g., ten-year periods were used when the age range for recommended screenings were larger, for example for breast screening. The continuous variable for age (years) was used in all of the regression models to maximise the amount of data in the model.

As the stage at cancer diagnosis and mortality analyses were restricted to only those who had a cancer diagnosis, the age variable for the stage at diagnosis and cancer mortality respective studies was taken from the WCISU dataset containing age at cancer diagnosis. This was used in lieu of the age recorded at the time of the NSW interview as it was deemed to be more relevant to the issue under examination, stage at diagnosis and mortality. The age variable was provided as a continuous form and recoded into age categories of 18-29, 30-39, 40-49, 50-59, 60-69, 70-79, 80,89, 90+.

Gender

The gender variable is from the NSW and coded as 1= male and 2= female. Some later NSW survey years include the option of 'other' in the gender question, however none who selected the 'other' category were present in the combined NSW datasets.

Ethnicity

The ethnicity variable included the categories listed in table 3 below. Due to the fact that some categories in the ethnicity variable were too small to report and the data would be deemed as potentially identifiable, categories were collapsed into White (0) and Other ethnic groups (1). While this was a reluctant choice as it diminished the information available for ethnic minorities and the intersection of disability and ethnicity on the outcomes it was necessary in order to include this variable in the analysis. Table 3 below demonstrates the re-coding for the ethnicity variable.

Table 3 showing re-coding of ethnicity variable

White- British (English, Welsh, Northern Irish)	White (coded 0)
White- Irish	
White- Gypsy or Irish traveler	
White- other	
Mixed- White and Black Caribbean	Other ethnic groups (coded 1)
Mixed- White and Black African	
Mixed- White and Asian	
Mixed- Other	
Asian- Indian	
Asian- Pakistani	
Asian- Bangladeshi	
Asian- Chinese	

Asian- Other	
Black- African	
Black- Caribbean	

Urban or rural status

The variable for urban /rural status has seven categories ranging from Urban > 10k less sparse to Hamlet and isolated dwellings- sparse (Table 4). The variable was recoded into urban= 1 and rural categories recoded into rural=0. The datapoints including the words urban and town went into the urban category and those with the words village and hamlet went into the rural category. Table 4 below demonstrates the re-coding for this variable.

Table 4 showing re-coding of urban/rural status variable

Urban >10k less sparse	Urban (coded 0)
Urban>10k-sparse	
Town and Fringe-less sparse	
Town and fringe- sparse	
Hamlet and isolated dwellings- less sparse	Rural (coded 1)
Hamlet and isolated dwellings- sparse	
Village- less sparse	
Village- sparse	

Welsh index of multiple deprivation

The Welsh index of multiple deprivation (WIMD) score is the official measure of relative deprivation for small areas in Wales. It is calculated based on eight types of domains of deprivation including access to services, housing and physical environment (see Figure 6). Small areas of Wales (Lower super output areas) are ranked from 1 for the most deprived area to 1909 for the least deprived and grouped into quintiles (where 1 = most deprived and 5= least deprived). For these analyses, deprivation quintiles was used. Using the WIMD as an indicator for individual deprivation has its limitations as it assumes that all people living in a deprived area are deprived (also known as the 'ecological fallacy' (Ess and Sudweeks, 2001), where in fact this may not be the case.

Figure 2 showing Welsh Index of Multiple Deprivation measure
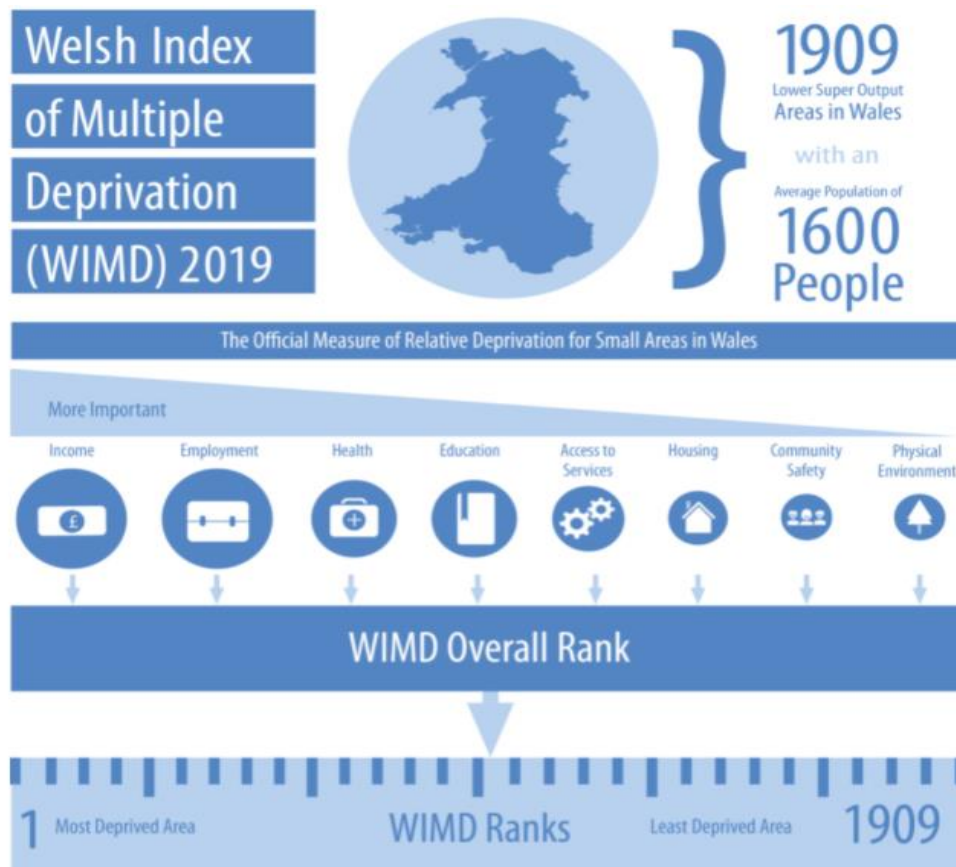
Reference: Welsh Government, 2021

Healthcare usage: GP visit

The survey question 'Have you visited your GP within the last 12 months' informs the variable GP visit. The answers included 'yes', 'no-wanted to but couldn't' and 'no- didn't need to'. The 'no' categories were combined as numbers were small.

Summary of chapter

This chapter introduced the NSW, the SAIL databank and the survey data linkage process using Anonymised Linking Fields. The next chapter presents the application of the chosen disability definition to the NSW population (2012-2017). Characteristics of the populations with and

without a self-reported disability are explored along with the consistency and variation of disability status. The implications of the choice of disability definition is discussed along with the strengths and limitations of this approach.

Chapter 6: Defining disability in the National Survey for Wales population-results

Introduction to chapter 6

The previous chapter introduced the National Survey for Wales, its background, collection methods, linkage and access via the SAIL databank. In this chapter, the linked survey and cancer outcomes data will be utilised to estimate the prevalence of disability within the population and to explore and record possible exclusion from services and parts of society that disable people whilst answering questions regarding inequalities in cancer outcomes for people with disabilities. It is therefore necessary to identify the relevant population with a physical disability in the NSW. This chapter will present and explore the results of the application of the chosen definition of disability to the National Survey for Wales population (2012-2017).

The questions chosen from the survey to identify the population with a physical disability will be identified and discussed, with their strengths and limitations. The result of the application of said questions to the survey respondents for all the survey years will be explored, the population with a disability and population without will be characterised, including demographic information and exploration of access to services. Further information about the population will be presented, such as consistency of self-reported disability across survey years (where respondents were included in more than one survey year). The representativeness of the population to the population of Wales will be explored also. The results from the survey year 2016/17 will then be looked at in further detail as this survey year included more lifestyle related questions and

disability related questions. The findings of the application of disability definition across all the survey years and the findings from survey year 2016/17 will be discussed in terms of what they tell us about the population. Further discussion of the findings in relation to existing literature and policy will be included in the discussion section of this chapter.

Defining disability in the NSW

NSW survey data were provided in separate datasets by year, so linkage was required to combine all the survey years into one dataset for analysis of the entire population. This was completed by merging the datasets using the Anonymised Linking Field (ALF) as the key variable in the merging process.

The number of survey respondents with a corresponding ALF varied by survey year, with survey years 2013/14 and 2014/15 having significantly more respondents with missing ALFs. Table 5 below shows the ALF breakdown for each survey year. As there was high linkage for 2012, 2013 and 2016, descriptive statistics were carried out on the missing ALF respondents in 2013/14 and 2014/15 survey years to check for bias.

Table 5 Showing the NSW population with and without ALF

	Survey year				
	Jan-Mar 2012	2012/13	2013/14	2014/15	2016/17
NSW interviews achieved	unknown	14,552	14,771	14,285	10,493
Survey respondents in dataset	2,255	9,303	14,771	14,285	8,932
Survey respondents in dataset with ALF's	2,155 (95.6%)	8,923 (96.0%)	9,413 (63.7%)	8,929 (62.5%)	8,532 (95.5%)
Survey respondents in dataset with no ALF	100 (4.4%)	380(4.0%)	5,358 (36.3%)	5,356 (37.5%)	400 (4.5%)

Overall NSW population characteristics

Table 6 below shows selected population characteristics of the NSW respondents disaggregated by survey year. Results show consistency across survey years for all characteristics looked at. There is a similar mean age across survey years ranging from 51 to 55 years. Across all survey years we see consistently a higher percentage of female respondents and a higher percentage of respondents from urban areas vs rural areas. Across all survey years there is a consistent spread of respondents across the five deprivation quintiles.

The Welsh 2011 census results show similarities with the captured population in the NSW. No bias was found in comparison between the 2011 census and the NSW population characteristics across survey years (Office for National Statistics, 2011). For example, the 2011 census results report the median age of the population of Wales to be 41 years. The proportion of males to females in the census population was also similar to the NSW population, showing a slightly higher proportion of females.

Table 6 showing NSW population characteristics by survey year

Variable	Survey year				
	Jan-Mar 2012	2012/13	2013/14	2014/15	2016/17
Number of responders	2,255	9,303	14,771	14,285	8,932
Age mean (sd) (years)	51 (18)	53 (19)	54 (19)	54 (19)	55 (18)
Gender n (%)					
Males	1,065 (47.2%)	4,267 (45.9%)	6,433 (43.6%)	6,261 (43.8%)	3,956 (44.3%)
Females	1,190 (52.8%)	5,036 (54%)	8,338 (56.4%)	8,024 (56.2%)	4,973 (55.7%)
Urban/rural classification n (%)					
Urban	1,337 (59.3%)	5,645 (60.7%)	8,713 (59%)	8,423 (59%)	5,258 (58.9%)
Rural	918 (40.7%)	3,658 (39.3%)	6,058 (41.0%)	5,862 (41%)	3,674 (41.1%)
Deprivation quintile n (%)					
1- most deprived	Not in survey	1,730 (18.6%)	2,805 (19.0%)	2,535 (17.7%)	1,394 (15.6%)
2-	Not in survey	1,903 (20.5%)	3,009 (20.4%)	2,957 (20.7%)	1,672 (18.7%)
3-	Not in survey	2,100 (22.6%)	3,251 (22.0%)	3,223 (22.6%)	2,056 (23%)
4-	Not in survey	1,849 (19.9%)	3,075 (20.8%)	3,026 (21.2%)	2,151 (24.1%)
5- least deprived	Not in survey	1,721 (18.5%)	2,631 (18%)	2,544 (17.8%)	1,659 (18.6%)

Questions selected and re-coding

The questions chosen to identify the population with a disability across all NSW survey years were "Do you have an illness, disability or infirmity lasting or expected to last 12 months or more?" and "Does your illness, disability or infirmity impact your day-to-day activities?".

It was necessary to combine the answers into one variable for analysis. The responses to the first question "Do you have an illness, disability or infirmity lasting or expected to last 12 months or more?" were coded 1- "yes", 2- "no". The follow up question was only answered if respondents answered yes to the first question. Possible responses to "Does your illness, disability or infirmity impact your day-to-day activities?" were coded 1- "yes, a lot", 2- "yes, a little" and 3- "not at all". A new variable was created where yes, a little or yes, a lot were combined and coded as 1- "Person with physical disability", and those who answered no to the follow up or to the original question "Do you have an illness, disability or infirmity lasting or expected to last 12 months or more?" were classed as 0- "No physical disability".

It is acknowledged that in coding the disability related question in this way we do not know the nature or type of disability. Physical disability is assumed here to be the majority of disability that is being captured as mobility related disability is the most prevalent in the UK (Disability Unit, gov.uk). Also, there are specific learning disability related questions in the National Survey for Wales which would capture this population. Additional disability related questions were included in the survey year 2016/17; these will be explored further in relation to type of disability we may be capturing with these questions. Although type of disability is not known across all survey years, for the purposes of this research the population self-reporting as having a disability are referred to as 'people with a physical disability' or 'people with a disability', but physical disability is assumed.

Multiple survey responses

Of the total survey interviews, 501 individuals had multiple survey responses (had been interviewed in multiple, separate survey years). The first survey interview was kept, and the second interview response removed to allow for the longest possible period in the study for all NSW participants. The total number of responders between 2012 and 2017 was 49,546, of which 12,095 (24%) were removed. 11,594 (23%) had no ALF to enable linkage, and 501 (1%) were multiple survey responses. 37,451 individual responses remaining.

Multiple survey responses and disability status over time

The presence of some respondents in the combined NSW dataset that had responded to two surveys (multiple surveys in different survey years) gave us an opportunity to investigate disability status consistency over time. After removal of the NSW respondents who did not have an ALF and were therefore un-linkable with the outcome datasets, there were a total of 37,451 (98.7%) respondents who had had one survey across the survey years and 501 (1.3%) respondents who had undertaken two. The total number of respondents who had one survey response and their disability status was known was 36,861. Disability status was consistent across the multiple survey responses with only 6 respondents changing from no physical disability status to physical disability in their second survey response. Although we cannot be sure about each individual's disability status over the five-year period that the NSW data spans (2012-2017), there is some confidence in the long-term nature of disabling conditions present in the population due to the results presented here. The "long-term limiting" aspect of the question chosen and the specification in the question that the disability illness or infirmity has been present for 12 months or more also increases researcher confidence in self-reported disability status consistency over the five-year study period.

Results of application of disability questions to NSW

Table 7 shows that the proportion of responders self-reporting long-term illness are consistent across survey years (around 43% in survey years 2012 to 2014/15), although this rose to 53% in 2016/17. It is unclear why this rise may have occurred, although this will be discussed in further detail in this chapter. The same trend can be seen in the limiting long term illness question also as those that identified that their long-term illness was limiting by a lot was 20% in survey year 2016/17 as compared to 15% in the previous survey years.

Results of combining the limiting long term illness responses shows that across the survey years the population identified as having a disability made up 30% to 37% of the survey populations as compared to non-disabled population (including those who had a long-term illness that was not limiting), which made up 12% to 15% of the population. Prevalence of disability in the 2016/17 survey year are again higher at 39% in 2016/17. The percentage of the population across the surveys that either did not identify as having a long-term illness or that did not deem their long-term illness as limiting made up 48% to 57% of the population.

Table 7 N (%) of the NSW population broken down by survey year and response to the disability related questions chosen

Survey year	Jan-Mar 2012	2012/13	2013/14	2014/15	2016/17
Do you have an illness, disability or infirmity lasting or expected to last 12 months or more?					
Yes, long term illness	969 (43.0%)	4,145 (44.6%)	6,326 (42.8%)	6,136 (43%)	4,754 (53.2%)
No long-term illness	1,284 (56.9%)	5,141 (55.3%)	8,421 (57%)	8,078 (56.5%)	4,145 (46.4%)
Missing (don't know or refused)	2 (0.1%)	17 (0.2%)	24 (0.2%)	71 (0.5%)	33 (0.4%)
Does your illness, disability or infirmity impact your day-to-day activities?					
A little	350 (15.5%)	1,506 (16.2%)	2,161(14.6%)	2,023 (14.2%)	1,596 (17.9%)
A lot	343 (15.2%)	1,455 (15.6%)	2,252 (15.2%)	2,198 (15.4%)	1,775 (19.9%)
Not at all	276 (12.2%)	1,183 (12.7%)	1,908 (12.9%)	1,910 (13.4%)	1,378 (15.4%)
Missing (not applicable= no long-term illness, don't know or refused)	1,286 (57%)	5,159 (55.5%)	8,451 (57.2%)	8,156 (57.1%)	4,183 (46.8%)
Physical Disability					
Physical disability (Limited by long standing illness)	693 (30.7%)	2,961 (31.8%)	4,413 (29.9%)	4,221 (29.5%)	3,371 (37.7%)
Not disabled (Not limited by long term illness or no illness)	1,562 (69.2%)	6,342 (68.2%)	10,358 (70.1%)	10,064 (70.5%)	5,561 (64.2%)

Population with self-reported disability characteristics

Table 8 below presents some characteristics of the total (all survey years) NSW respondent

population displayed by disability status. Data is presented in total number and percentage.

Further characteristics and demographics were explored but weren't presented here as there was no significant difference found between the disabled and non-disabled populations. The characteristics and demographics shown here include age, gender, deprivation score, urban or rural location, employment status and whether they had seen their GP about their own health in the last 12 months. Results show that the mean age of the population with a physical disability is higher than those without at 62 years compared to 50. The population with a physical disability have a higher percentage of people aged over 80+ at the time of survey response (14.5%) compared to 4.8% of the no physical disability population. People with a physical disability have a slightly higher percentage of people living in urban areas at 61% compared to those without disabilities (58%). There is a slightly higher percentage of females in the physical disability population (57.5%) compared those without at 54.8% female. Deprivation results show that the population with a physical disability have a higher percentage in the highest deprivation quintile (21.1%) compared to those without a disability (15.2%).

Table 8 showing characteristics of the population with a self-reported disability and those without

	No Physical disability (PD) N=33,724(68%)	Physical disability (PD) N=15,659(32%)
Age mean (SD) (Years)	50 (18)	62 (17)
Age category		
≤25 years	2,940 (8.7%)	381 (2.5%)
25-29	2,437 (7.2%)	408 (2.6%)
30-34	2,739 (8.1%)	539 (3.4%)
35-39	2,659 (7.9%)	593 (3.8%)
40-44	2,972 (8.8%)	832 (5.3%)
45-49	3,015 (8.9%)	952 (6.1%)
50-54	2,977 (8.8%)	1,159 (7.4%)
55-59	2,692 (8%)	1,357 (8.7%)
60-64	2,773 (8.2%)	1,734 (11.1%)

65-69	3,130 (9.3%)	1,979 (12.6%)
70-74	2,252 (6.7%)	1,807 (11.5%)
75-79	1,516 (4.5%)	1,639 (10.5%)
80+	1,618 (4.8%)	2,279 (14.5%)
Gender n (%)		
Males	15,248 (45.2%)	6,660 (42.5%)
Females	1,8474 (54.8%)	8,998 (57.5%)
Urban/rural classification n (%)		
Urban	19,616 (58.2%)	9,658 (61.7%)
Rural	14,108 (41.8%)	6,001 (38.3%)
Deprivation quintile		
most deprived	5,138 (15.2%)	3,301 (21.1%)
	6,218 (18.4%)	3,291 (21.0%)
	7,238 (21.5%)	3,361 (21.5%)
	7,195 (21.3%)	2,870 (18.3%)
least deprived	6,375 (18.9%)	2,143 (13.7%)
Employment status		
In employment	20,135 (59.7%)	3,502 (22.4%)
Not in employment	13,572 (40.2%)	12,143 (77.5%)
Missing	17 (0.1%)	14 (0.1%)
Seen a GP in the last 12 months		
Yes	18,414 (72.8%)	10,837 (93.7%)
No, didn't need to	6,763 (26.8%)	682 (5.9%)
No, wanted to but couldn't	100 (0.4%)	51 (0.4%)

Table 8 also shows a significantly higher percentage of people with a physical disability who had seen their GP about their own health in the last 12 months (prior to survey interview date). Signalling that the population of people with a disability had more contact with primary care practitioners. The percentage of the population for both disability status' that wanted to see their GP but couldn't is the same percentage for both the population with disabilities and the non-disabled population which was an unexpected result based on previous literature that suggests

that people with disabilities may experience issues with access to primary care services (Welch-Saleeby, 2016., Iezzoni et al, 2006).

There were stark differences in employment status between people with and without a self-identified physical disability. The percentage of people who were not in employment at the time of survey interview was higher in those with a physical disability (77.5%) compared to those without a physical disability (40.2%). However, comparison of these populations was not age adjusted which limits the comparability of the populations. Looking at the characteristics of those that have a self-reported disability vs those without a disability, we are seeing patterns in individuals with disabilities that we would expect regarding characteristics such as age, GP visits, education etc. which improves researcher confidence in the questions chosen to identify the population with a physical disability.

Further characteristics

The National Survey for Wales undertaken in 2016/17 was the first survey after the amalgamation of the Welsh health survey, Active Adults Survey, Arts in Wales Survey, and Welsh Outdoor Recreation Survey. The NSW 2016/17 therefore included more questions related to access and environmental aspects of life for the population of Wales. This provided an opportunity to explore the application of the chosen disability definition in more detail in regard to the type of limiting illness/disability people identified as having and the breakdown of these by demographic characteristics. In addition, there were disability related questions included in this survey year that were worded differently to the other survey years. The number of limiting illnesses/disabilities people self-identified as having was also captured in this survey year, which was not captured in the previous years.

Findings from survey year 2016/17

Type of limiting illness

In the 2016/17 survey respondents who answered yes; a lot or yes; a little to the question *"Does your long-term illness, disability or infirmity limit your day-to-day activities"* were also asked which type of long-term limiting illness their disability fell under. Categories include physical disability, mental health disability, limiting ear or eye disability or other/unclassifiable. The results (table 9) show that the majority of respondents who classified themselves as having a long-term limiting illness or disability classified their disability as a physical disability (74.5%).

Table 9 showing type of disability of respondents to the question *"Does your long-term illness, disability or infirmity limit your day-to-day activities"*

Type of long-term limiting illness/disability	Frequency	Percent
Long-term limiting physical disability	2,451	74.7
Mental health limiting illness/disability	508	15.5
Limiting Ear or Eye illness/disability	266	8.1
Other/Unclassifiable	57	1.7
Total	3,282	100.0

Number of long-term limiting illnesses

Respondents who self-identified as having a long-term limiting disability were asked how many long-term limiting illnesses or disabilities they had; one or two or more. The results in table 10 below show that of those with a physical disability, 44.1% had two or more illnesses or disabilities. The percentage goes up for those with a primary mental health limiting disability, with 51.8% of the population having two or more. For those with a limiting ear or eye illness/disability, 74.8% identified themselves as having two or more illnesses/disabilities. The population whose disabilities were unclassifiable also had a high percentage of having two or more comorbidities at 68.4%.

Table 10 Showing number of limiting illness in respondents of the question *"Does your long-term illness, disability or infirmity limit your day-to-day activities"*

		Frequency	Percent
Long-term limiting physical disability	One	1,369	55.9
	2 or more	1,082	44.1
	Total	2,451	100.0
Long-term limiting mental health disability	One	245	48.2
	2 or more	263	51.8
	Total	508	100.0
Long-term limiting sensory disability	One	67	25.2
	2 or more	199	74.8
	Total	266	100.0
Other/Unclassifiable long-term limiting disability	One	18	31.6
	2 or more	39	68.4
	Total	57	100.0

Characteristics of population by type of long-term limiting disability

By taking a look at the demographics of the population of NSW survey respondents in the year 2016/17 we are able to characterise the population by type of long-term limiting disability. Results shown in table 10 show a significantly lower mean age for the population who have a mental health disability (46) compared to those with a physical disability (63), unclassifiable (60) and sensory (68). Gender across the disability types was fairly consistent, although there was a slightly higher percentage of females in the mental health disability category at 61%. The percentage of the population living in urban areas was higher across all disability categories, however it was highest in the category of those living with a mental health disability (67.9%). Higher percentage of those in the highest deprivation grouping were also seen in the population with a mental health disability (52.9%).

Table 11 showing characteristics of population considered to have a disability by disability type

	Long-term limiting physical disability	Long-term limiting mental health disability	Long-term limiting sensory disability	Other/Unclassifiable long-term limiting disability
Age mean (SD) (Years)	63 (16)	46 (15)	68 (14)	60 (20)
Gender				
Males	1,049 (42.8%)	198 (39%)	114 (42.9%)	25 (43.9%)
Females	1,401 (57.2%)	310 (61%)	152 (57.1%)	32 (56.1%)
Urban/rural classification				
Urban	1,448 (59.1%)	345 (67.9%)	150 (56.4%)	36 (63.2%)
Rural	1,003 (40.9%)	163 (32.1%)	116 (43.6%)	21 (36.8%)
Deprivation				
1- most deprived	890 (36.3%)	269 (52.9%)	104 (39.1%)	11 (19.3%)
2	598 (24.4%)	109 (21.5%)	49 (18.4%)	16 (28.1%)
3	554 (22.6%)	83 (16.3%)	66 (24.8%)	16 (28.1%)
4- least deprived	409 (16.7%)	47 (9.3%)	47 (17.7%)	14 (24.6%)

Alternative disability related question

The 2016/17 survey year included an additional disability related question which, when compared to the long-term limiting illness questions chosen across all of the survey years provides an interesting insight into survey question wording around health and disability. Under the section 'Health' in the survey, the additional question (not in other survey years) was: "Do you have a health problem or disability?" If respondents answered yes to this question the follow up question was as follows: does your condition limit activities in any way? Answers to the follow up question were the same as the long-term limiting illness question: Yes; a lot, yes; a little and not at all. The differences appear subtle between the two questions; however, the health

problem or disability question does not specify the 'long-term' aspect of the condition which is present in the long-term limiting question. This may affect people's response to the question. The phrases illness and infirmity are also removed from the 2016/17 specific question and replaced with 'health-problem'; the word disability is present in both questions. The follow up question is also worded slightly differently for the 2016/17 question; respondents are asked whether their condition limits activities in any way. Here, the day-to-day aspect which is found in the long-term limiting question is removed and 'condition' is used to describe the persons 'health-problem or disability'. Table 12 Shows the number and percentage breakdown of the answers to the follow up questions for both long-term limiting illness and health problem or disability wordings. Results show a higher percentage of respondents who answered yes; a lot to the health problem or disability question at 51.8% compared to 37.4% of those who answered Yes; a lot to the long-term limiting illness or disability question. Those who felt their long-term limiting illness or disability was not limiting was 29% compared to 4.1% of people who identified as having a health problem or disability but did not feel it limited activities in any way. The result here strengthens the argument that wording of survey questions around disability can significantly alter the population that is captured.

Results of cross tabulating the questions 'Does your health problem or disability limit your activities in anyway' and 'Does your long-term limiting illness, disability or infirmity limit your day-to-day activities?' are shown in table 13. Results show that most people who defined themselves as having a limiting health problem or disability also identified as having a long-term limiting illness, disability or infirmity. With only 3 respondents not corresponding across the two questions. The results show the two disability related responses are also similar in terms of severity of disability. The results of table 12 and 13 when considered together suggest that while

the population identifying as having a health problem, disability, or long term limiting illness may be capturing the same population, there appears to be a large percentage difference in severity of condition chosen depending on the question wording.

Table 12 showing self-perceived disability severity for two disability related questions

Disability related question	Answer	Frequency	Percentage
Health problem or disability	Yes; a lot	1,745	51.8%
	Yes; a little	1,486	44.1%
	Not at all	137	4.1%
Long-term limiting illness	Yes; a lot	1,775	37.4%
	Yes; a little	1,596	33.6%
	Not at all	1,378	29%

Table 13 showing a cross-tabulation of populations answering two disability related questions

	Limiting health problem or disability	Limiting health problem or disability	Total
Long-term limiting illness	Yes; a lot	Yes; a little	
Yes; a lot	1,618	131	1,773
Yes; a little	127	1,355	1,595
Total	1,745	1,486	

Discussion

The exploration of the population self-reporting as having a disability in the NSW as presented in this chapter aimed to increase researcher transparency on the approach to defining disability and to add to the literature on disability definition in national surveys.

The application of the long-term limiting illness/disability/infirmity questions in NSW years 2012 to 2017 was explored in terms of creating a self-reported disability variable for analysis. The characteristics of the population of people who self-identified as having a disability, compared with the population considered not to have a disability were also explored. Findings showed that the characteristics of the population self-reporting as having a disability were consistent with characteristics of populations of people with disabilities as presented in the literature (WHO, 2015., United Nations, 2016). For example, in this chapter, the population self-reporting as having a disability had a higher percentage of the population who were older compared to those who did not report having a disability. Also consistent with the wider literature was the finding that the NSW population with self-reported disability were more likely to be classed as experiencing higher levels of deprivation (Shandra, 2018). Some descriptive data on access to services was presented in relation to contact with primary care and employment status. These findings were also consistent with the wider literature (Shandra, 2018). The concurrence with the characteristics of populations of people considered to have a disability as presented in previous literature increases researcher confidence of the validity of the population of people with disabilities captured in this research.

A limitation of the approach to identifying a population with disabilities in this study is that disability status was only captured at the time of survey interview. As there were five separate

surveys included in the five-year study period with unique participants in each year, disability

status and demographic factors were taken at different time points. It is relatively uncertain as to

the long-standing nature of each participant's disability status. For example, if a participant in the

NSW survey year 2012/13 self-reported as having a long-term limiting disability, they would be

included in the study for the following five years, with disability status unknown past 2012/13.

In this chapter, the confidence in the assumption that disability status, although taken at time of

survey interview for each person, would be consistent over the study period was examined using

data on those who had multiple survey responses. Although only a small sample of participants

were recruited in multiple survey years, the results showed consistency in self-reported disability

status for most of the participants.

Results from this chapter showed that in the 2016/17 survey year where we were able to

disaggregate by disability type, most respondents who self-reported as having a disability

reported a physical disability. Further to this, many respondents also reported having two or

more types of disability, suggesting that most of the participants would have some type of

physical impairment or disability alongside their mental health or sensory disability. The

findings from this survey year give some confidence in the type of disability we are capturing

across the survey years as there was general consistency found in other characteristics across the

survey years. However, as information on type of disability is missing from the first four survey

years, we cannot be certain, limiting the direct application of these results to those with a

physical disability. The unique contribution of this chapter' exploration of disability definition

comes from the additional disability related question in the 2016/17 survey, which allowed for an

examination of the impact of survey question wording on the population captured. These

findings add to the literature on the populations self-reporting disability definition in national surveys, which Grovnik (2009) argues is lacking from the wider literature on defining disability.

A further limitation of this approach to identifying a population with disabilities is the choice to make the classification binary. Research from Pongiglione (2017) looked at the implications of different classifications of disability status on research outcomes, their findings showed that binary classifications do not capture the effect of severe disability on outcomes. By capturing a binary classification of disability in this study, arguably we are losing important information on severity of disability and duration of disability related functional limitations.

The approach to disability definition in this study is compliant with current thinking on defining populations with disability but limitations of self-reported disability status remain. In the literature, limitations reported of self-reported disability approaches include the subjective nature of defining disability using self-report measures (Bosworth et al, 2021). In using self-reported disability status, we lack an understanding of how each individual classifies the term 'disability' and how they apply this to their own context. An alternative method of identifying a population with disabilities for this study could have been via clinical records. Clinical definitions may give further insight into the type of impairments the population might have but may not have given us an idea of functional limitation in everyday life. Furthermore, people who have clinical diagnoses may not consider themselves to have a disability. We would be at risk of over medicalising our approach to disability definition if this route had been chosen. Further research into the impact of self-reported disability status on research outcomes would be of benefit.

Summary of chapter

This chapter introduced the NSW, the SAIL databank and the survey data linkage process using Anonymised Linking Fields. This chapter also presented the application of the chosen disability definition to the NSW population (2012-2017). Characteristics of the populations with and without a self-reported disability were explored along with the consistency and variation of disability status. The implications of the choice of disability definition were discussed along with the strengths and limitations of this approach.

The following chapters will present the linkage of the NSW population with cancer outcome data from the Welsh Cancer Intelligence and Surveillance unit, screening services datasets and mortality data. The methods used to undertake regression analyses to explore outcomes between the population with a disability and the non-disabled population identified in this chapter will be presented followed by the results of analyses.

Chapter 7: Methods- Cancer outcomes

Introduction to chapter 7

The previous chapter outlined the approach to identifying physical disability within the National Survey for Wales (NSW) population. To explore disparities in cancer outcomes for people with physical disabilities in Wales it is necessary to link the NSW population with routinely collected cancer registry data. This chapter presents the methods used to explore the first cancer outcome under focus; uptake of screening services. The datasets used, specifically the Cervical Screening Wales (CSW), Breast Test Wales (BTW) and Bowel Screening Wales (BSW), which, when linked with the NSW population allowed analysis of uptake of screening services for each screening service respectively between physically disabled and non-physically disabled populations. Analysis of having a delayed (6 months or more) cancer screening was also undertaken.

This chapter will also explore the methods used to explore two more important outcomes in the cancer journey, stage of cancer at diagnosis and survival time after cancer diagnosis between people with and without physical disabilities. To do this the National Survey for Wales population will be linked with routinely collected data from the Welsh Cancer Intelligence and Surveillance Unit (WCISU) and the Office for National Statistics (ONS) data on deaths. These datasets will be introduced along with the methods for linkage, statistical analyses, and data management.

Methods

Study design

This study is a cross sectional retrospective routine data linkage study. A cohort of responders to the National Survey for Wales (NSW) was combined with electronic health records outcome data within the SAIL Databank including uptake and delay of cervical, bowel and breast screening, and cancer stage and mortality between 2012 and 2017.

Hypotheses for outcomes

The outcomes of the study are:

- Screening uptake and delay (Cervical, Breast and Bowel screening services).

    The null hypothesis for screening services being tested is that there are no differences between uptake of screening services or likelihood of delayed screening between the physically disabled and non-physically disabled population in Wales. The research questions being asked for screening services are: Do people with a physical disability experience lower screening uptake than those with no disability, do people with a physical disability experience more delays in screening than those with no disability and what socio-demographic factors contribute to lower screening rates and screening delay?

- Cancer stage at diagnosis

The null hypotheses being tested for the stage of cancer at diagnosis analysis is that there is no difference between stage at diagnosis between people with and without physical disabilities. The research question for the staging outcome is: Do people with physical disabilities experience later cancer stage at diagnosis than people without physical disabilities?

- Mortality

The null hypothesis for the mortality outcome being tested here is that there is no difference in likelihood of mortality between people with and without physical disabilities in Wales. The research question for the mortality outcome is: Do people with physical disabilities experience a greater likelihood of death by cancer than people without disabilities?

Data sources

SAIL Databank

The SAIL Databank is a privacy protecting Trusted Research Environment and the national data safe haven for Wales holding de-identified data sources made available to researchers in an anonymised format. Data are principally for individuals living in Wales and using Welsh services (e.g. health and other public services). Data sources include health, education, housing, and employment. The data sources requested for this study are:

National Survey for Wales (NSW)

Further information on the NSW including background information, the linking process and data management of the NSW datasets can be found in the previous chapter 6.

Cervical Screening Wales (CSW)

Cervical Screening Wales (CSW) is the body responsible for the cervical screening programme in Wales. The CSW dataset is provided by Public Health Wales NHS trust and made available via SAIL. Datasets hold administrative and clinical, individual level data regarding invitations to screening, screening procedures and assessments (SAIL, 2022). The time period for data coverage differs by event type; invitation and screening procedure data is available from 1990 to 2018 and assessment data is available from 2011. The approximate size of datasets per year for invitations is 335,000 records, for screening procedures 225,000 and assessment data (for those who require tests after screening) approximately 25,000 cases per year (SAIL, 2022).

The CSW datasets requested for this project included data from 2012 to 2017 and included information on invitations, screening type and date, screening results and treatments. The datasets of interest were invitations dataset and the screening dataset.

Breast Test Wales (BTW)

Breast Test Wales (BTW) are the organisation responsible for providing breast screening services in Wales, and the data is held by Public Health Wales with access made available via the SAIL databank. Breast Test Wales provide administrative and clinical services including mammograms to screen for the early detection of breast cancer. Women resident in Wales are routinely invited for breast screening between the ages of 50 and 70. The SAIL Databank holds information on approximately 5,500 assessments and 110,000 screening test records per year.

The BTW datasets requested for this project included data from 2012 to 2017 on invitations, screens and results of mammography tests (SAIL, 2022). The datasets of interest were invitations dataset and the screening dataset.

Bowel Screening Wales (BSW)

Bowel Screening Wales (BSW) data is provided by Public Health Wales and provides clinical and administrative data on bowel screening services in Wales. Bowel screening is currently offered to men and women aged 60 to 74. Bowel screening kits are designed to identify minute amounts of blood in faeces, test kits are sent to patients homes and require patients to complete the test themselves and send it back. There are two types of faecal testing kits used by Bowel Screening Wales; the feacal immunochemical testing (FIT) test kit and the guaiac faecal occult blood test (gFOBt) test kit. The gFOBt was replaced by the more accurate FIT kit by the UK national screening committee in 2018 (PHW, 2021). However, as this data spans the years 2012 to 2017 the first kit sent out to the public for routine screening was the gFOBt kit and the FIT was generally used as a follow up in a case where the gFOBt results were inconclusive. The eligible age for bowel screening services have also been widened to include 58 and 59 year olds.

The data requested from Bowel Screening Wales for this project spans the years 2012 to 2017 and contains all individuals who are eligible and were invited for a bowel screening test. The datasets for Bowel Screening Wales include information on invitations, screening tests and results. Approximately 280,000 invitations and 140,000 screening test records per year.

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

The Welsh Cancer Intelligence and Surveillance Unit (WCISU) provides individual level data on incidences of cancer for the resident population of Wales. Data is collected via direct or indirect

admissions to Welsh hospitals related to occurrences of cancer. As the national cancer registry

for Wales WCISU is responsible for the recording, storage and reporting on incidences, survival

and mortality of diagnosed cancers in Wales. WCISU began staging of all cancers in 2010, the

database storage began in 1997 and now holds approximately 686,000 records. The data was

made available via the SAIL database and the providing organisation is Public Health Wales.

Annual District Death Extract (ADDE)

The Annual District Death Extract (ADDE) data is provided by Digital Health and Care Wales

(formerly NHS Wales Informatics Service (NWIS). Data is collected by The Office for National

Statistics (ONS) and provides information on death registrations relating to Welsh residents,

including those that died outside of Wales. This information is available via SAIL from 2003

onwards and contains approximately 32,000 deaths per year.

Linkage

Records within SAIL are anonymised and linkable with an anonymous linking field (ALF),

which allows individuals to be tracked over time and across datasets. Each individual in the

NSW can therefore be linked to screening datasets (CSW, BTW, BSW), WCISU and the ADDE,

while ensuring researchers have no access to any personal identifiable data

Study Population

The study population consisted of individuals who had completed the National Survey between

2012 to 2017. These datasets were linked and where multiple survey responses existed for the

same individual (identified via the same ALF), data from the earliest survey completion was

used and duplicates removed. This was decided in order to maximize the time in study for each

survey participant. The final NSW dataset was then linked with the screening data WCISU and

ADDE datasets. For all NSW responders we looked at screening outcomes but for stage and death from cancer, it is only looked in those with a cancer diagnosis.

Creation of the study populations

Cervical screening Wales linkage

The CSW invitation, ALF and screening datasets were linked using the patient ID numbers for each patient. Figure 3 shows the datasets in relation to one another. Figure 2 represents the separate linkage of the NSW datasets (NSW dataset with the corresponding ALF for each respondent) and the linkage of the CSW datasets (invitations, screenings and ALFs). The resulting NSW and CSW datasets were then linked together using the ALF to form the CSW analytic dataset.

The presence of a patient in the linked CSW dataset (either invited or screened) served as the indicator for eligibility for cervical screening in the study period. After linkage of the CSW datasets, the CSW analytic dataset was linked with the NSW dataset (using participants ALFs) which was narrowed by age and gender following PHW guidelines on eligibility for cervical screening. The recommended age range for routine cervical screening is 25 to 64 years. The time frame for screening for 25 to 64 years olds is every 3 years and for 50- to 64-year-olds every 5 years.

As the NSW data was collected at different time points over the study period it is worth noting that for all screening datasets invites and screening information could have preceded the completion of the NSW interview. However, it is assumed that physical disability status as a long-term limiting condition is likely to have affected the individual for a significant period, so disability status is considered to be consistent for all participants across the study period.

Figure 3 showing CSW and NSW dataset linkage
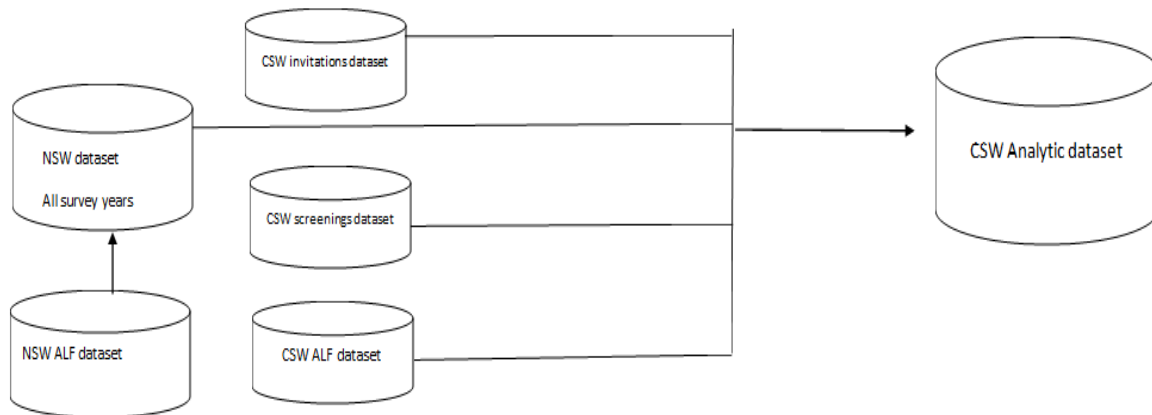
Breast Test Wales linkage

The BTW invitation, ALF and screening datasets were linked using the patient ID numbers for each patient. Figure 4 shows the datasets in relation to one another. Figure 4 represents the separate linkage of the NSW datasets (NSW dataset with the corresponding ALF for each respondent) and the linkage of the BTW datasets (invitations, screenings and ALFs). The resulting NSW and BTW datasets were then linked together using the ALF to form the BTW analytic dataset.

The NSW population was refined to include female survey responders aged 50 to 70 years inclusive, reflecting PHW's guidelines on eligibility for cervical screens. Using the ALF, each individual in the CSW analytic dataset was linked with their data in the National Survey for Wales dataset (NSW).

Figure 4 showing BTW and NSW datasets linkage.
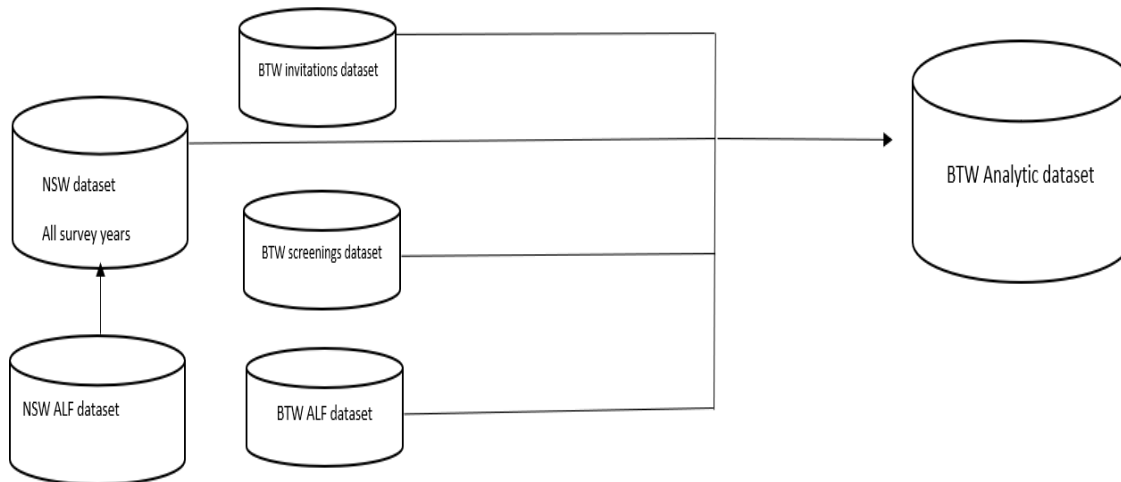
Bowel Screening Wales linkage

The BSW invitations and screening datasets did not require linkage prior to analysis as both invitations and information on return of test were both included in the tests dataset. The tests dataset was linked with the BSW dataset containing the ALF using the patient ID number field to enable linkage with the NSW. As with the other screening datasets, the BSW dataset was then linked with the refined NSW dataset using the ALF. For bowel screening the NSW dataset only needed to be refined by age (60-74 years) as both genders are invited for bowel screening. Figure 5 Below shows the BSW and NSW datasets in relation to each other.

Figure 5 showing the BSW and NSW datasets linkage.
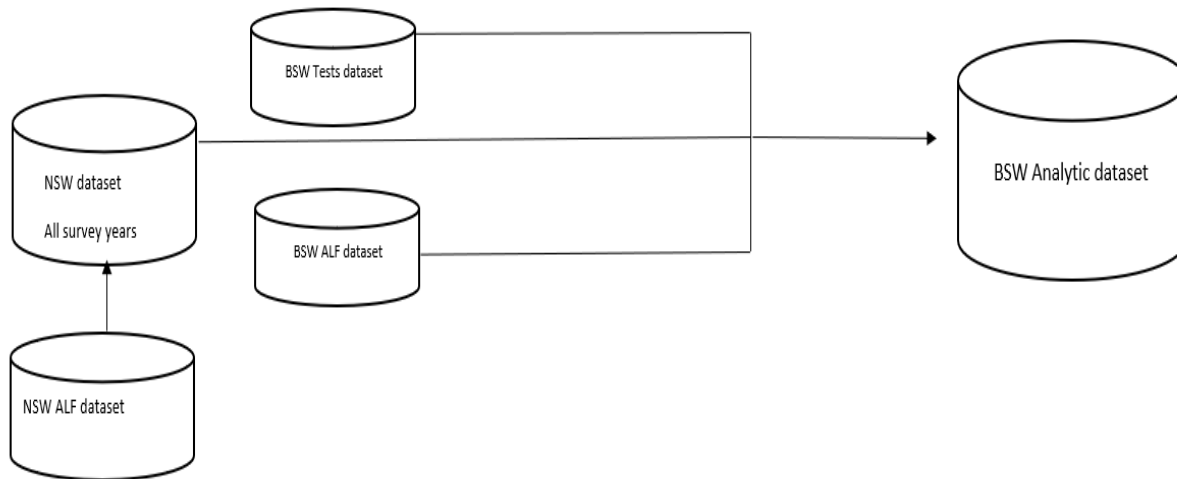
Staging and Mortality datasets

Individual data in the ADDE and WCISU datasets were connected with their Anonymised

Linking Field (ALF) with the individual patient ID numbers provided in the datasets. The

linkage with their corresponding ALF enabled linkage with the NSW datasets. Only those with a

cancer diagnosis were included in the staging and mortality analysis. Complete case analysis was

completed, analyses included everyone with a cancer diagnosis and stage in the WCISU dataset.

Patients were excluded if staging data was missing. Figure 6 below represents the data linkage

process for the stage at diagnosis and mortality datasets.

Figure 6 showing staging/mortality analytic dataset linkage
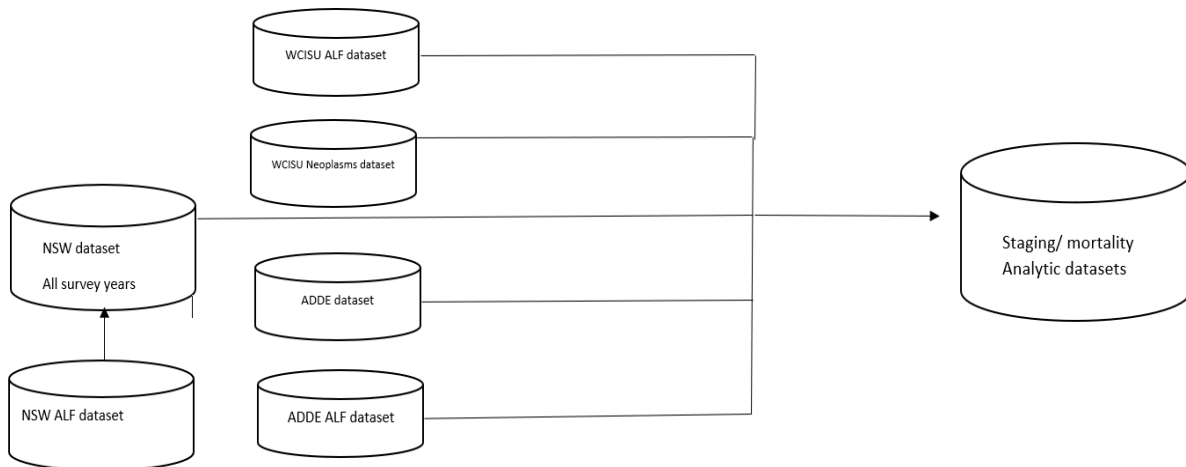
Observation period

NSW participants were recorded at the time point that they completed the survey (between the years 2012 to 2017). The observation period for all screening services data (CSW, BTW and BSW) and for stage of cancer at diagnosis, spans January 2012 to December 2017.

The mortality study period covers January 2012 to December 2018.

Exposure: Physical disability status

The previous chapter offers more detail on the approach to capturing physical disability status. Self-reported physical disability status was identified using the NSW variable 'Limited at all by long term illness'. This variable is derived from two NSW questions; people who answered yes to the questions 'Do you have any physical or mental illnesses lasting or expected to last for 12 months or more' and 'Does your condition or illness reduce your ability to carry-out day-to-day activities?'. The final physical disability variable was coded as 1= Limited at all by illness/disability, 0= Not limited by illness disability. The population coded as 'limited at all by illness/disability' was considered to have a physical disability.

Outcomes

Cervical screening

The CSW Invitations dataset included a variable indicating the sequential order that invites were sent, where one patient had multiple invitations over the five-year time period. This allowed for linkage with the corresponding screening date (where a screen was undertaken). However, even though invitations to screen were dated and invitations numbered sequentially within the Invitations dataset, it was difficult to confidently link each cycle of screening test to the correct invitation as screens were not numbered sequentially. It was hoped that the analysis would focus on uptake of routine cervical screening, however, data on the type of screening recall the patient was on (e.g. routine, repeat advised, inadequate firs test, etc.) when the invite was sent was deemed to be too incomplete to be of use in analysis. As it was difficult to determine which type of recall the invite was sent for, the decision was made to include all types of recall (routine or otherwise) and to use any screening date as a proxy for screening uptake in the study period.

Any interaction with screening in the study period was used as a proxy indicator for screening uptake. Where multiple linked invites and screens existed for one patient (identified using their ALF), duplicate invites and screens were flagged to indicate where a screen existed and priority was given to the existence of a screen (where someone had multiple invites and one screen) as the choice was made to focus on interaction with screening services in the study period.

Cervical screening uptake

Individuals in the CSW dataset that had at least one screening invitation but no screening date between 2012-2017 were coded as 0 and deemed to not have had a screen within the study period. Those who had at least one screening date were coded as 1 indicating they were screened within the time period (2012-2017).

Delay in cervical screening uptake

Those with more than 6 months between invitation and screen were deemed to be delayed in their screening uptake. A time calculation between corresponding invitations and screens was made and those with 6 months or more delay were coded as 1, those with under 6 months between invitation and screen were coded as 0 and deemed to not delayed in screening uptake.

Eligibility for Bowel Screening

The presence of a patient in the BSW Tests dataset served as the indicator for eligibility for bowel screening in the study period. Linkage of the bowel screening datasets (Invitations and tests) was attempted however there was no sequential ordering variable in either dataset, therefore the datasets could not be confidently linked with the corresponding test or invite. The information lost due to this included information on the type of recall (routine- first invite, routine recall or FIT recall) the patient was on. As it was not possible to determine which type of recall the invite and corresponding test was sent on, the decision was made to use any screening kit returned date in the tests dataset as a proxy for screening uptake in the study period. The tests dataset included both invitation date and return kit date so no linkage was required.

Any interaction with screening in the study period was used as a proxy indicator for screening uptake. Where multiple linked invites and screens existed for one patient (identified using their ALF), duplicate invites and screens were flagged to indicate where a screen existed and priority was given to the existence of a screen (where someone had multiple invites and one screen) as the choice was made to focus on interaction with screening services in the study period.

Bowel Screening uptake

Individuals in the BSW dataset that had at least one screening invitation but no screening date between 2012-2017 were coded as 0 and deemed to not have had a screen within the study period. Those who had at least one screening date were coded as 1 indicating they were screened within the time period (2012-2017).

Delay in Bowel screening uptake

Those with more than 6 months between invitation and screen were deemed to be delayed in their screening uptake. A time calculation between corresponding invitations and screens was made and those with 6 months or more delay were coded as 1, those with under 6 months between invitation and screen were coded as 0 and deemed to not delayed in screening uptake.

Eligibility for Breast screening

The presence of a patient in the linked BTW dataset (either invited or screened) served as the indicator for eligibility for breast screening in the study period.

The BTW invitations dataset did not include a variable indicating the sequential order that invites or screens were sent or undertaken. This meant allowed for linkage with the corresponding screening date was less clear than in the other screening datasets. To best link the invitation with the corresponding screens the datasets were linked in ascending date order. Due to the same issue, data on the type of screening recall the patient was on (e.g., routine, GP referral, self-referral, etc.) at the time of screening test could not be confidently determined. The decision was made to include all types of recall (routine or otherwise) and to use any screening date as a proxy for screening uptake in the study period. Any interaction with screening in the study period served as a proxy for screening uptake, duplicate invites and screens were flagged to indicate

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where a screen existed, and priority was given to the existence of a screen (where someone had multiple invites and one screen) as the choice was made to focus on interaction with screening services in the study period.

Breast Screening uptake

Individuals in the BTW dataset that had at least one screening invitation but no screening date between 2012-2017 were coded as 0 and deemed to not have had a screen within the study period. Those who had at least one screening date were coded as 1 indicating they were screened within the time period (2012-2017).

As the breast screening datasets did not include a variable indicating sequential order of invitation we were unable to run the delay analysis for the breast screening data.

Stage at diagnosis

The stage at diagnosis variable in the WCISU neoplasm dataset contained information regarding the clinical stage of diagnosed neoplasms in Wales between 2012 to 2017. The initial coding of the variable included 17 stages including 0, 0A, 1, 1A, 1B, 2, 2A, 2B, 3, 3A, 3B, 3C, 4, 4A, 4B, 4C, and X (not enough information to stage). For the purposes of descriptive analysis, the categories were collapsed into 5 categories which were In Situ 0, 0A (coded 0), Stage 1 and 1A-Local involvement only (coded 1), Stage 2, 2A and 2B-Extension to adjacent tissue (coded 2), Stage 3, 3A, 3B and 3C- Lymph node involvement (coded 3), Stage 4, 4A, 4B and 4C-Metastases (coded 4) and not enough information to stage X (coded 5). The In Situ stage represents a mass of cells that are caught at a pre-cancerous stage and a category X represents cancerous cells without enough information to stage. Only the stages diagnosed as cancer 1-4 were included in the analysis.

Mortality

For the cancer specific mortality analyses, a flag was created in the ADDE dataset to highlight anyone who had died with cancer as the underlying cause. This was identified using the ICD-10 (ICD, 2010) codes, with an ICD code starting with 'C' flagged as died from cancer. The event variable for the cancer specific mortality analysis then was derived from the cancer flag variable, those who died from cancer were flagged as 1 (died of cancer in the study period), those who were either alive or died of another cause in the study period were coded as 0. For the descriptive analysis this information was separated into a categorical variable which included the datapoints 1- died from cancer in the study period, 2- died of other cause in the study period and 0- alive at the end of the study period. To create the cancer specific time-to-event variable a new variable was created which replaced the study end date with their death date if the person died of cancer before the end of the study period. The time-to-event variable was then created which calculated the time in days between the date of diagnosis and the cancer death date or end of study period.

Selection of socio-demographic variables

Directed Acyclic graphs

Directed acyclic graphs (DAGs) provide a simple and transparent way to identify and show knowledge, theories, and assumptions about the causal relationships between variables in observational data (Tennant et al, 2021). DAGs also have been argued to aid model interpretability (Tennant et al, 2021).

Cervical and Breast Screening

Sociodemographic variables that were identified as confounders (associated with exposure and outcome) were selected based on existing literature. These include age, Welsh index of multiple

deprivation- overall score, whether individual had visited their GP in the previous year and urban/rural status.

The assumed relationships between the variables, exposure and outcomes are depicted in the Directed Acyclic Graph (DAG) (Figure 7A: Cervical and Breast screening; Figure 7B: Bowel screening). The same variables were though to affect both cervical and breast screening services, therefore the DAG in Figure 7A. reflects the relationships between uptake of screening and the relevant variables for both cervical screening and breast screening. The DAG represents an assumption that increasing age leads to increased likelihood of having a physical disability, that lower socio-economic status leads to disability and increased contact with primary care services. It is thought that primary care contact is associated with increased likelihood of attending screening services and lower socio-economic status contributes to a decreased likelihood of utilising screening services. Following the social model of disability, environmental access has been included in the DAG as reduced environmental access is thought to be a factor in disabling individuals and contributes to lack of access to health and social care services (Stillman et al, 2017). The literature also suggests that that there will be more difficulty with environmental access in rural settings for people with physical disabilities. Meaning that inaccessible spaces create disability, which is in line with the thinking on the social model of disability, as discussed in the previous chapter. In the NSW dataset, socio-economic status is represented using the WIMD score. As a proxy for environmental access and healthcare access urban/rural status was used in the model.

Bowel Screening

Participation in bowel screening is available to both men and women. However, screening uptake is thought to be influenced by gender directly (Wernli et al, 2014). Gender is classed as a

competing exposure as it is associated with outcome only and not exposure. Including competing

exposures in a regression model does not affect bias but should improve precision. The below

DAG (figure 7B) reflects this and the relationships between other socio-demographic variables

and bowel screening uptake.

Figure 7 Directed Acyclic Graph depicting the hypothesised causal pathways to (A) cervical and breast screening and (B) bowel screening

A. Cervical and Breast screening
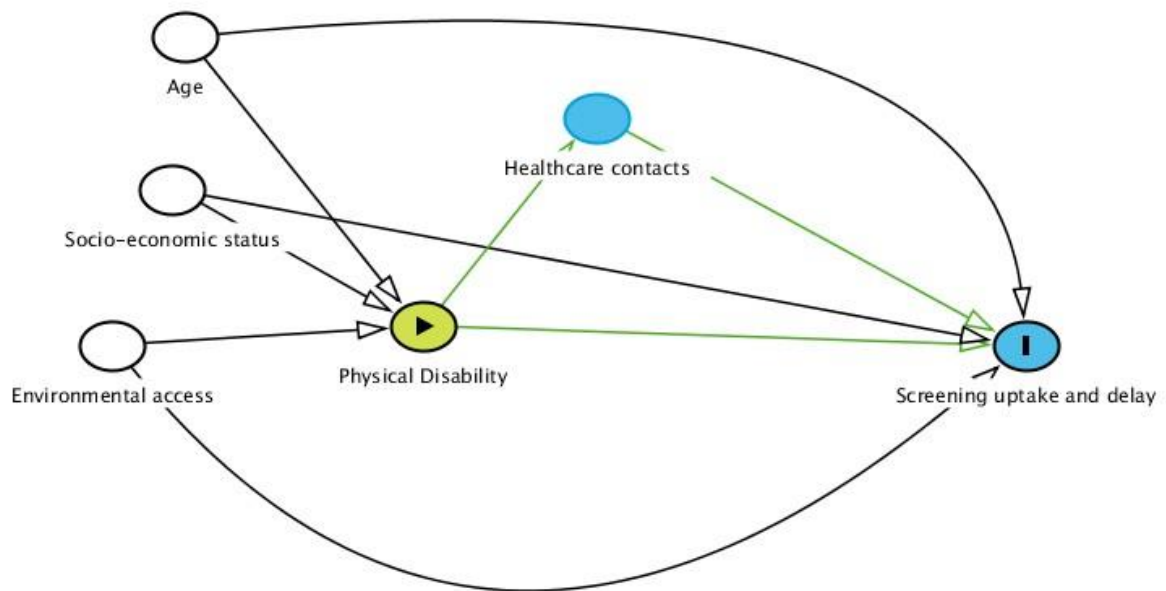
B. Bowel screening
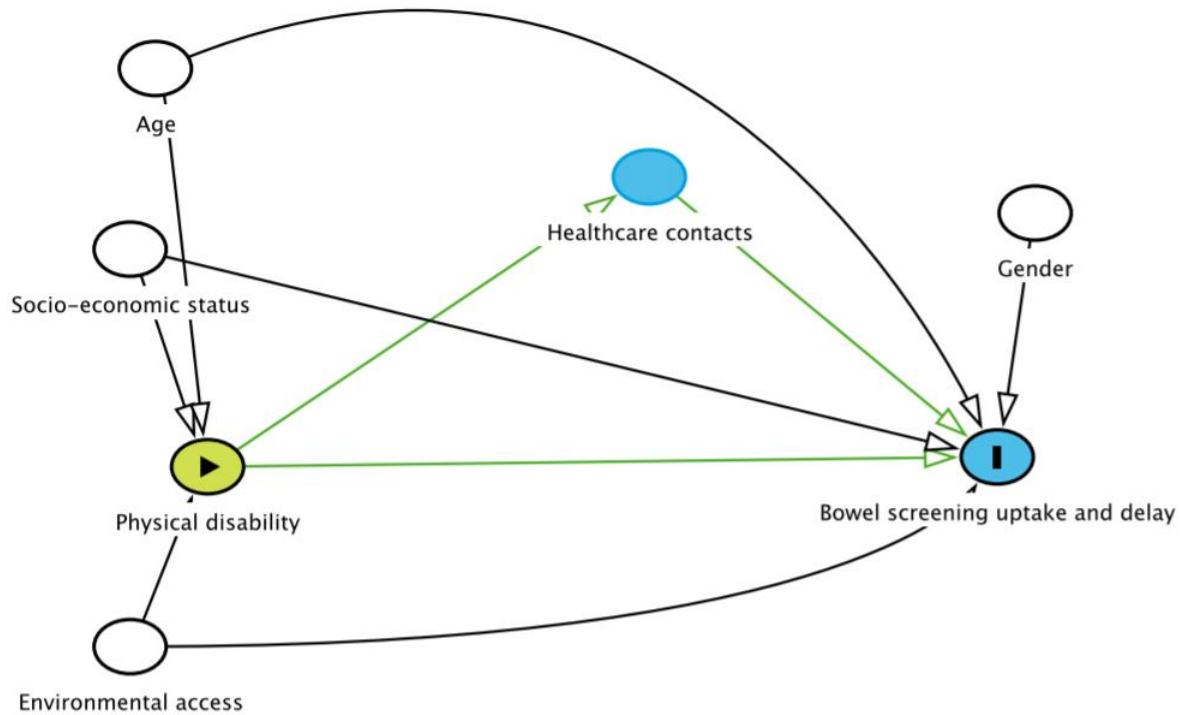
Stage at diagnosis and mortality

Sociodemographic variables that were chosen as predictive variables in the adjusted models for both stage at diagnosis and mortality were selected based on existing literature and include age, Welsh index of multiple deprivation- overall score, Gender, Ethnicity, Marital status, and urban/rural status. The assumed relationships between the variables are depicted in the Directed Acyclic Graph (DAG) below (figure 8C). The DAG represents an assumption that increasing age leads to increased likelihood of having a physical disability and that physical disability contributes to a lower socio-economic status, decreased likelihood of being married (Clark et al, 2009) and increased contact with primary care services.

It is thought that primary care contact is associated with increased likelihood of being diagnosed with cancer at an earlier stage and lower socio-economic status. This DAG follows research findings that not being in a marriage or civil partnership contributes to a decreased likelihood of

being diagnosed at an earlier stage (Buja et al, 2018). Following the social model of disability, environmental access has been included in the DAG as reduced environmental access is thought to be a factor in disabling individuals and contributes to lack of access to health and social care services (Stillman et al, 2017). In the NSW dataset socio-economic status is represented using the WIMD score.

As a proxy for environmental access and to consider healthcare care access the urban/rural status was used. There is an assumption here that there will be more difficulty with environmental access in rural settings for people with physical disabilities, including lack of access to public transport. Previous research (Park et al, 2017) shows that men are more likely to be diagnosed with cancer at a later stage and ethnicity also has a bearing on stage at diagnosis (Lantz et al, 2006). These variables are believed to have a direct influence on stage at diagnosis. Gender and ethnicity in these models are classed as competing exposures as they are associated with outcome only and not exposure. Including competing exposures in a regression model does not affect bias but should improve precision.

Type of cancer and lifestyle factors are thought to be a strong predictor of stage at diagnosis and cancer related mortality. We did not have access to these datapoints; however, they are included in the DAG as unobserved variables as they are thought to be key influences on both outcomes (figure 8D).

C. Cancer Stage

D. Mortality- cancer related
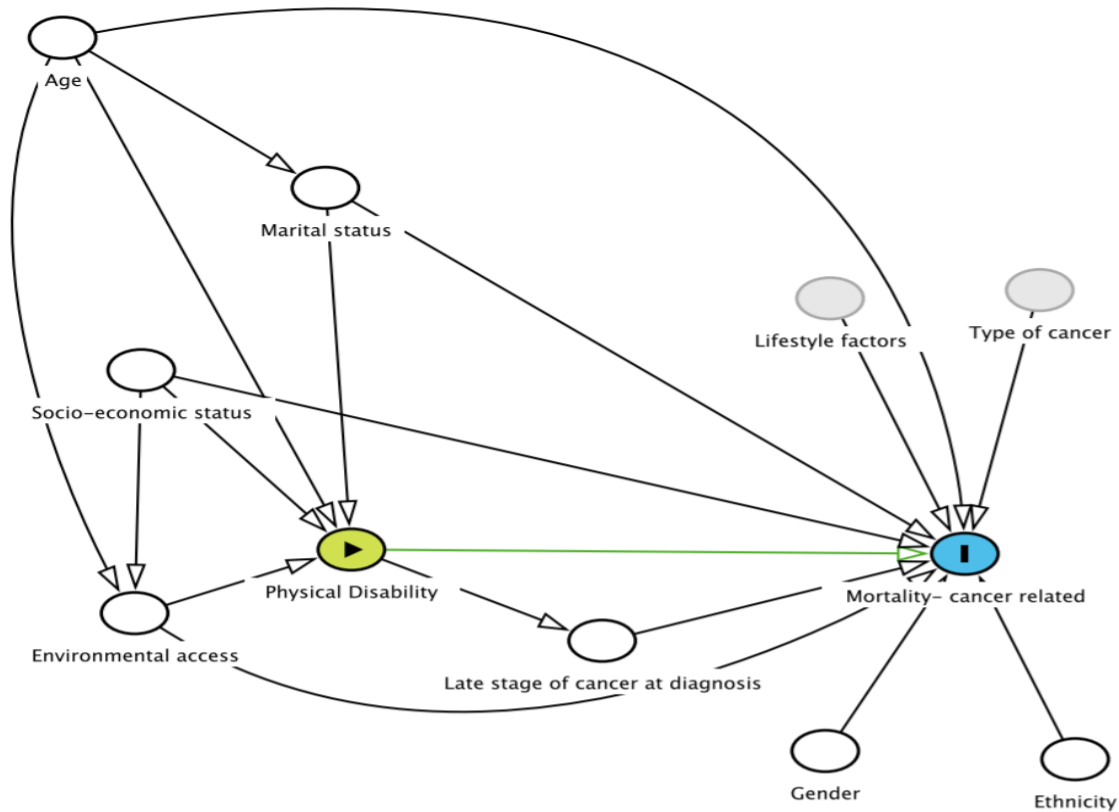
Statistical analyses

Screening services

Descriptive analysis for screening services

The process of linking the survey respondents with the screening data is presented in a population flow chart for each screening service. The linked NSW and screening services data was analysed descriptively for population of each screening dataset, by disability status and by screening group (screened or not screened). Means and standard deviations are presented for continuous data, and number and percentage presented for categorical data.

Descriptive analyses were also run to determine if there was any bias between the non-physically disabled and physically disabled population when considering time in study (time between national survey for Wales interview date and date of death or end of study period).

Logistic regression models for screening services

For each screening service, univariable logistic regression models were run to examine the effect of physical disability on uptake and delay of screening services. This is presented as the unadjusted model, meaning that only disability status was included as a predictor in the model.

Guided by the DAG, an adjusted logistic regression model was run. This adjusted model included covariates thought to be associated with exposure and outcome (confounders). The adjusted model examined the effect of physical disability and uptake of screening services and delay in uptake of screening services whilst considering relevant socio-demographic factors. Covariates were selected on the basis of existing literature, further detail on the covariates included in the model can be found in the previous section on socio-demographic variable selection.

Odds ratios (ORs) for between-group differences were calculated with 95% confidence intervals (CIs) and p-values. Odds ratios represents the effect of the covariate on the likelihood of having taken up screening services in the study period or having over a 6-month delay in uptake of screening services, respectively.

Stage at diagnosis and mortality

Descriptive analysis

A population flow chart is presented for both outcomes to demonstrate the linking and exclusion process for the stage at diagnosis and cancer mortality outcomes. The NSW and linked WCISU

population data were analysed descriptively by disability status, mortality status and by stage at diagnosis. Means and standard deviations are presented for continuous data and number and percentage presented for categorical data.

Regression models

Stage at diagnosis

Since stage was an ordered categorical variable (Stage 1 to 4), ordinal regression models were run to examine the effect of physical disability on stage of cancer at diagnosis. The proportional odds assumption was tested using the 'omodel' logit command in STATA to test the assumption that the relationship between the outcome groups is consistent or proportional. Two models were run; the first examined using unadjusted (physical disability alone in the model) and adjusted (all variables thought to be of associated with physical disability and outcomes).

Unadjusted and adjusted logistic regression models were also run to examine the effect of physical disability on the binary outcome later vs earlier stage at diagnosis. The binary logistic regression model coding involved collapsing the four cancer stages into a binary variable, including early stage (stages 1-2), coded as 0 and later stage diagnosis (stages 3-4), coded as 1. ORs alongside 95% CIs and p values are presented in the results.

Mortality with underlying cause of cancer

For the mortality outcome, hazard ratios (HRs) with 95% CIs were estimated for the relative risk of cancer specific mortality in individuals with physical disability compared to those without a physical disability using Cox proportional hazard models. Individuals were followed up to time of death (by cancer), or end of study period. Violation of the proportional hazards assumption was ascertained and testing using chi-square test and by inspecting the log (−log(survival)) plot

and Schoenfeld residuals. The relationship between physical disability status and mortality was firstly examined (unadjusted analysis) and then known confounders (including cancer stage) were additionally adjusted for.

Software

Analysis was conducted in SPSS version 25 and STATA version 16. Syntax and output files were saved as an ongoing record of changes and data cleaning process.

Chapter summary

This chapter outlined the methods undertaken in the data management, linkage, and preparation for analyses for the cancer outcome datasets including screening services, stage of cancer at diagnosis and cancer related mortality. The next chapter presents the results of the analyses for all cancer outcomes.

Chapter 8: Results- Cancer outcomes

Introduction to chapter 8

The previous chapter outlined the methods undertaken in the data management, linkage, and preparation for analyses for the quantitative analysis. This chapter presents the results of the analyses for all cancer outcomes including screening services, stage of cancer at diagnosis and cancer related mortality.

This chapter addressed the second objective of this research project: to explore the combined influence of disability and other demographic and socio-economic variables on cancer care outcomes. And provides an answer to the second research question: are there disparities in cancer care for people with physical disabilities in Wales?

The cancer care outcomes under investigation are:

- access and uptake of screening services including breast cancer, cervical cancer and bowel cancer screening services

- Stage of cancer at diagnosis

- Mortality with underlying cause of cancer

Screening services

The following section will present the results of the analysis on the screening services datasets, Cervical Screening Wales (CSW), Breast Test Wales BTW), and Bowel Screening Wales (BSW).

Cervical Screening

Observation period

The duration in study for each participant was calculated from the date of interview (survey years 2012 to 2017) to the end of the CSW observation period or to date of death (when this occurred before end of CSW observation period). CSW observation period ran from 2012 to 2017. No bias was identified when examining the length in study for those with or without physical disabilities.

Descriptive results - CSW cohort

The National Survey for Wales (NSW) general population (N=49,546) was refined by gender and age to reflect the recommended population group eligible for cervical screening according to Public Health Wales (PHW) guidelines (Public Health Wales). This includes women and people with a cervix aged between 25 to 64 years. Of those present in the NSW between the years 2012-2017 and eligible based on the PHW guidelines n=13,940 remained after the dataset was refined. A summary of the refined, CSW eligible NSW population by disability status is seen in table 13. Table 13 shows the refined population to be slightly younger than the general NSW population with mean ages of 49 (people with disabilities) and 44 (people without disabilities). Other demographic factors such as deprivation quintile and urban/rural location were considered to be similar to the wider NSW population.

Figure 9 Population flow chart for NSW and CSW linkage
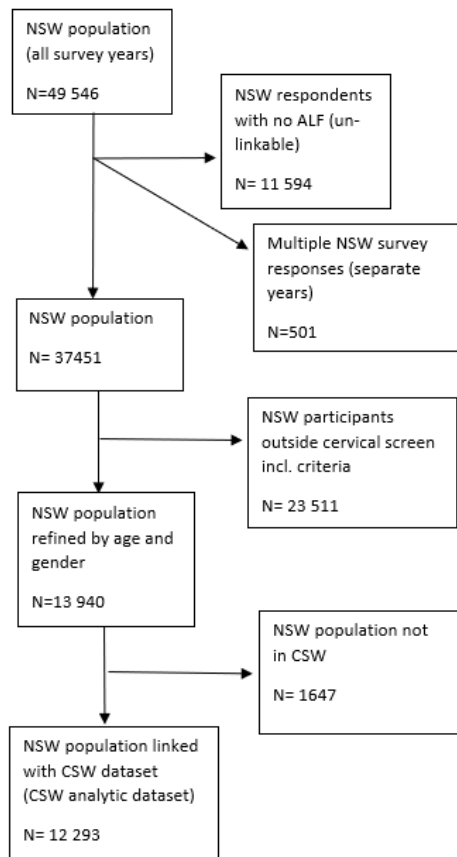
The refined NSW population eligible (based on demographic criteria) was merged with the

linked Cervical Screening Wales (CSW) dataset. The CSW dataset included n=12,293 patients

who had either been screened or invited for screening in the time period 2012-2017 after the

removal of duplicate invites or screens. A total of n=1,647 NSW participants were present in the

NSW eligible population but not present in the CSW dataset (indicating they had not been

invited or had not been screened). Figure 9 demonstrates the linkage and population refinement

process for the linked CSW and NSW datasets.

When linking the NSW and CSW there were 1,647 NSW respondents who were not present in

the CSW dataset. These respondents were below the clinical cervical screening age range at the

time of interview which could explain their absence from the CSW. Considering the age profile

and survey years of those not included in the CSW population (those who did not have a record

of being either screened or invited in the time period), it was assumed that our NSW eligible

population was capturing participants that may not have been eligible for routine screening in the

time period. Therefore, a decision was made to use presence in the linked CSW dataset as a

proxy for eligibility during the study period.

Table 13 Characteristics from the eligible CSW/NSW population by disability status

Variable	Physically disabled population n=3,838 (44 missing disability status)	Not-physically disabled population n=10,058
Age (years) mean (SD)	49 (11)	44 (12)
Age category		
20-24	29 (1%)	200 (2%)
25-29	238 (6%)	1,165 (12%)
30-34	288 (8%)	1,338 (13%)
35-39	316 (8%)	1,194 (12%)
40-44	423 (11%)	1,325 (13%)
45-49	445 (12%)	1,268 (13%)
50-54	555 (15%)	1,161 (12%)
55-59	623 (16%)	1,038 (10%)
60-64	732 (19%)	1,083 (11%)
65-69	189 (5%)	286 (3%)
Missing	0 (0%)	0 (0%)
Urban/rural classification		
Urban	2,494 (65%)	6,023 (60%)
Rural	1,344 (35%)	4,035 (40%)
Missing	0 (0%)	0 (0%)
Seen a GP in last 12 months		
Yes	2,770 (72%)	5,919 (59%)
No	107 (3%)	1,832 (18%)
Missing	963 (25%)	2,316 (23%)
Welsh index of multiple deprivation (WIMD) quintiles		
1- most deprived	957 (25%)	1,710 (17%)
2	825 (22%)	1,883 (19%)
3	787 (21%)	2,140 (21%)
4	615 (16%)	1,960 (20%)
5- least deprived	444 (12%)	1,781 (18%)
Missing	210 (6%)	584 (6%)

SD=standard deviation

Cervical screening – Uptake of screening services

There was a total of 12,293 patients in the CSW dataset and included for analysis. Demographic information on the CSW population can be found in table 14. Of the total CSW population 12,046 (98%) had been invited for a cervical screen in the study period. Of those invited 10,032 (82%) were screened. Of those with a physical disability 2,403 (77%) had been screened, compared with 7629 (83%) of the non-physically disabled population. The mean age of those who had not been screened (46) was higher than those who had been screened (43). Deprivation quintile appeared to effect screening uptake as of those from the most deprived quintile 77% had been screened compared to 87% of people in the least deprived quintile. Of those who had seen their GP in the last year 84% had been screened compared to 74% of those who had not seen their GP in the last year. A summary of information on cervical screening by population demographic can be found in table 14.

Table 14 shows the results of the adjusted and unadjusted logistic regression models examining the association between having a physical disability and attending a cervical cancer screening. The unadjusted model indicates that there is a statistically significant ($p=<0.001$) association between the presence of a physical disability and returning a cervical screen test. The unadjusted odds ratio (OR) was 0.67 (95% confidence interval (CI)=0.60 to 0.73), showing that those with a physical disability were 33% less likely to have returned a cervical screen test.

The adjusted model indicates that there are statistically significant ($p=<0.001$) associations between presence of a physical disability and likelihood to take up screening services within a 5-year period. After adjusting for the confounders, results show that those with a physical disability were 21% less likely to have attended a cervical screen (OR= 0.79, 95% CI= 0.70 to 0.87).

Therefore, it is possible to reject the null hypothesis and conclude that, within the population studied, there are associations between presence of a physical disability and uptake of screening services within a 5-year period.

Cervical screening results- Screening delay

The same procedure described in the previous section was followed to determine the covariates included in the model for screening delay. Table 14 shows the demographic information for the CSW population by delay/no delay status. Twenty seven percent of the physically disabled population had 6 months or more delay to their screen compared to 24% of the non-physically disabled population. 27% of those in the highest deprivation quintile had a delay to their screen compared to 21% of those from the least deprived quintile. A higher percentage of patients had a delay to their cervical screen if they had reported not seeing their GP in the last 12 months (26%) compared to those who had seen their GP (24%). Those in the highest age bracket (60-65) had a lower percentage of cervical screening delay at 18% compared to the youngest age bracket (24-29), 26% of the 24–29-year-old population had a delay to their cervical screen.

Table 15 shows the results of the adjusted and unadjusted logistic regression models examining the association between having a physical disability and having a delay (6 months or more) in attending screening. The unadjusted model indicates that there is a statistically significant (p=<0.001) association between the presence of a physical disability and having over a 6-month delay in attending a cervical screen with an unadjusted odds ratio of 0.87 (95% CI=0.78 to 0.97), showing that those with a physical disability were 13% less likely to have been screened within 6 months of invite.

The adjusted model (adjusted for the confounders age, deprivation, and rurality) indicates that there are statistically significant (p=<0.001) associations between presence of a physical disability and likelihood to take up screening services within 6 months of invitation with an odds ratio of 0.87 (95% CI= 0.78 to 0.97). This means that people with a physical disability were 13% less likely to have been screened within 6 months of invitation than those without a physical disability. Therefore, it is possible to reject the null hypothesis and conclude that, within the population studied, there are associations between presence of a physical disability and uptake of screening services within 6 months of invitation.

Table 14 Factors associated with attending a cervical screen- adjusted and unadjusted model results

Factors	No. of patients (%)			Unadjusted	Adjusted
	All	Uptake of cervical screening N= 10,032 (82%)	Not screened N=2,261(18%)	OR (95% CI), p-value	OR (95% CI), p-value
Physical Disability status					
No physical disability	9,163 (74)	7,629 (83)	1,534 (17)	Reference	Reference
Physical disability	3,130(26)	2,403 (77)	727 (23)	0.67 (0.60 to 0.73), p<0.001	0.79 (0.70 to 0.87), p<0.001
Age (cont. in model) mean (sd)	44 (11)	43 (11)	46 (12)	-	-
24-29	1,602 (14)	1,352 (84)	250 (16)	-	-
30-39	3,064 (25)	2,625 (86)	439 (14)	-	-
40-49	3,242 (26)	2,734 (84)	508 (16)	-	-
50-59	2,878 (23)	2,268 (79)	610 (21)	-	-
60-65	1,507 (12)	1,053 (70)	454 (30)	-	-
Urban/rural					
Urban	7,572 (62)	6,172 (82)	1,400 (18)	-	-
Rural	4,721 (38)	3,860 (82)	861 (18)	-	-
Deprivation quintile					
1 most deprived	2,345 (19)	1,813 (77)	532 (23)	-	-
2	2,418 (20)	1,905 (79)	513 (21)	-	-
3	2,591 (21)	2,122 (82)	469 (18)	-	-
4	2,284 (19)	1,924 (84)	360 (16)	-	
5 least deprived	1,974 (16)	1,707 (87)	267 (14)	-	
Missing	681 (6)				

Table 15 Factors associated with having a delay (6 months or more) in attending cervical screening- adjusted and unadjusted model

Factors	No. of patients (%)			Unadjusted model	Adjusted model
	All	No delay	Delay	OR (95% CI), p value	OR (95% CI), p value
Physical disability status					
No physical Disability	9,163 (74)	5,588 (76)	1,797 (24)	Reference	Reference
Physical Disability	3,130 (26)	1,667 (73)	618 (27)	0.87 (0.78 to 0.97), p<0.001	0.87 (0.78 to 0.97), p<0.001
Age (cont. in model) mean (SD)	44 (11)	47 (13)	45 (12)	-	-
24-29	1,602 (13)	979 (74)	347 (26)	-	-
30-39	3,064 (25)	1,911 (74)	660 (26)	-	-
40-49	3,242 (26)	2,007 (75)	682 (25)	-	-
50-59	2,878 (23)	1,656 (74)	572 (26)	-	-
60-65	1,507 (12)	702 (82)	154 (18)	-	-
Urban/rural					
Urban	7,572 (62)	4,507 (75)	1,471 (25)	-	-
Rural	4,721 (38)	2,748 (74)	944 (26)	-	-
Deprivation quintile					
1 most deprived	2,345 (19)	1,275 (73)	477 (27)	-	-
2	2,418 (20)	1,350 (73)	459 (21)	-	-
3	2,591 (21)	1,528 (75)	513 (25)	-	-
4	2,284 (19)	1,407 (76)	453 (24)	-	-
5 least deprived	1,974 (16)	1,295 (79)	348 (21)	-	-
Missing	681 (6)				

Bowel cancer Screening

Observation period

The duration in study for each participant was calculated from the date of interview to the end of the BSW observation period or to date of death (when this occurred before end of BSW observation period). No bias was identified when examining the length in study for those with or without physical disabilities.

Descriptive results- BSW cohort

The National Survey for Wales (NSW) general population (N=49,546) was refined by age to reflect the recommended population group eligible for bowel screening according to Public Health Wales (PHW) guidelines (Public Health Wales). This includes male and females aged between 60 to 74.

The refined NSW population eligible (based on demographic criteria) was then merged with the linked Bowel Screening Wales (BSW) dataset. The BSW dataset included n=31,754 patients who had either been screened or invited for screening in the time period 2012-2017. A total of n=23,990 NSW participants were present in the NSW eligible population but not present in the BSW dataset (indicating they had not been invited or had not been screened). Figure 10 shows the refinement process for the BSW dataset.

Figure 10 showing the refinement process for the BSW dataset.
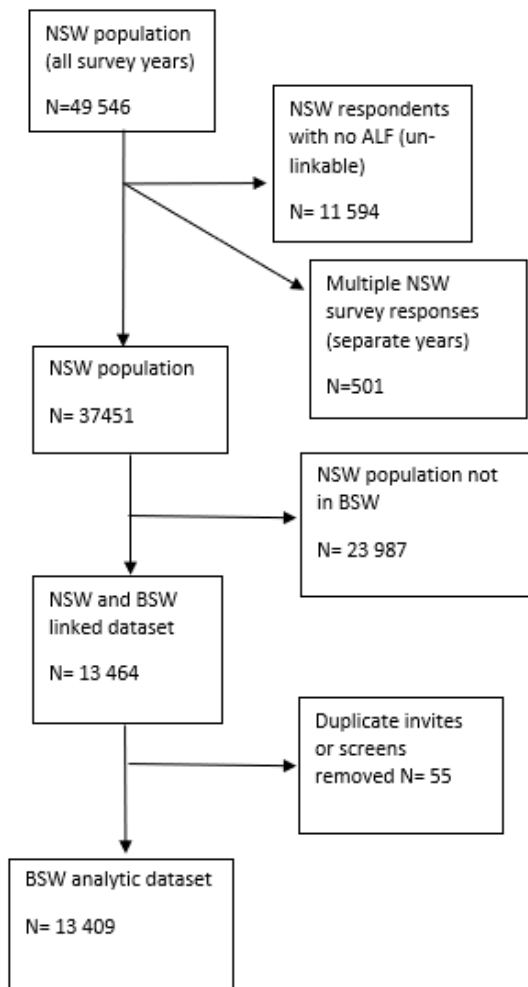
When linking the NSW and BSW there were 23,987 NSW respondents who were not present in the CSW dataset. These respondents were generally below or over the clinical bowel screening age range at the time of interview which could explain their absence from the BSW datasets. Considering the age profile and survey years of those not included in the BSW population (those who did not have a record of being either screened or invited in the time period), it was assumed that our NSW eligible population was capturing participants that may not have been eligible for

routine screening in the time period. Therefore, a decision was made to use presence in the linked BSW dataset as a proxy for eligibility during the study period.

There was a total of 13,409 patients in the linked and refined BSW dataset. Demographic information on the BSW population can be found in table 16. Table 16 shows in comparison to the NSW general population, the BSW population has a higher mean age at 68 for the physically disabled population and 67 for the non-physically disabled population. There is a slightly higher percentage of men in the BSW dataset in comparison to the general NSW population. Other demographics are considered in line with the NSW general population.

Table 16 BSW population descriptive characteristics

Variable	Physically disabled population N= 5,461 (37 status missing)	Not physically disabled population N= 7,911
Age mean (SD) (Years)	68 (5)	67 (5)
Age category		
60-64	1,631 (30%)	2,758 (35%)
65-69	1,470 (27%)	2,219 (28%)
70-74	2,360 (43%)	2,934 (37%)
Missing	0 (0%)	0 (0%)
Gender		
Female	2,574 (47%)	3,959 (50%)
Male	2,887 (53%)	3,952 (50%)
Missing	0 (0%)	0 (0%)
Urban/rural classification		
Urban	3,286 (60%)	4,183 (53%)
Rural	2,175 (40%)	3,728 (47%)
Missing	0 (0%)	0 (0%)
Seen a GP in last 12 months		
Yes	3,877 (71%)	4,566 (58%)
No	221 (4%)	1,382 (17%)
Missing	4,098 (75%)	1,963 (25%)
Welsh index of multiple deprivation overall score		
1 most deprived	1,052 (19%)	918 (11%)
2	1,112 (20%)	1,292 (16%)
3	1,236 (23%)	1,709 (22%)
4	1,007 (18%)	1,825 (23%)
5 least deprived	740 (14%)	1,724 (22%)
Missing	314 (6%)	443 (6%)

Bowel screening - screening uptake

Of the total BSW population 13,409 (100%) had been invited for a bowel screen in the study period. Of those invited 8500 (82%) were screened (returned a test kit). Of those with a physical disability 3,250 (60%) had been screened, compared with 5,224 (66%) of the non-physically disabled population. The mean age of those screened and not screened was the same at 66 years. There was a stark difference in the percentage of those screened in the least deprived quintile (72%) compared to the highest (55%). Those who had seen their GP in the last year had a higher percentage of screening uptake (65%) compared to those who had not (55%). There was a slightly higher percentage of those who were screened in the rural category (65%) compared to those in the urban category (62%). Females had a higher percentage of screening uptake (65%) compared to males (62%). A summary of information on bowel screening by population characteristics can be found in table 16.

Table 17 shows the results of the adjusted and unadjusted logistic regression models examining the association between having a physical disability and returning a bowel screening test. The unadjusted model indicates that there is a statistically significant ($p = <0.001$) association between the presence of a physical disability and returning a bowel screen test. The unadjusted odds ratio was 0.76 (95% CI=0.70 to 0.81), showing that those with a physical disability were 24% less likely to have returned a bowel screen test.

The adjusted model with all covariates added shows a statistically significant ($p = <0.001$) association between having a physical disability and returning a bowel screen test. The adjusted odds ratio for physical disability was 0.80 (95% CI=0.74 to 0.87), indicating that those with a physical disability were 20% less likely to have returned a bowel screen test. Therefore, it is

possible to reject the null hypothesis and conclude that, within the population studied, there are associations between the presence of a physical disability and uptake of bowel screening services within a 5-year period.

Bowel screening results- delay

Table 18 shows the patient characteristics of the BSW population by screening delay/no delay. There was a small amount of delay in screening uptake for those who had been screened in the study period. For all patient characteristics the population who had a delay in returning their bowel screening test was 1%.

Table 18 shows the results of the adjusted and unadjusted logistic regression results examining the association between having a physical disability and having over a 6-month delay in returning a bowel screening test. The results of the unadjusted model show there is not a significant association (p=0.13) between having a delay in returning bowel screening test and the presence of a physical disability (p-value= 0.18). The odds ratio was 1.40 (95% CI= 0.85 to 2.39), indicating people with a physical disability may have 40% increased odds of having a delay to bowel screening, but the confidence interval is wide indicating the results may not provide a precise representation of the odds, so results should be interpreted with caution.

In the adjusted model, the presence of a physical disability was not significant (p=0.18). All confounders added were also not significant. The odds ratio was 1.70 (95% CI= 0.89 to 3.42), indicating people with a physical disability may have 70% increased odds of having a delay to bowel screening. Again, the confidence interval is wide indicating the results may not provide a precise representation of the odds, results should be interpreted with caution.

Table 17 Factors associated with returning a bowel screen- adjusted and unadjusted model results

Factors	No. of patients (%)			Unadjusted model	Adjusted model
	All	Screened N=	Not screened N=	OR (95% CI), p value	OR (95% CI), p value
Physical Disability status					
No physical disability	7,911 (59%)	5,224 (66%)	2,687 (34%)	Reference	Reference
Physical disability	5,461 (40%)	3,250 (60%)	2,211 (40%)	0.76 (0.70 to .081), p<0.001	0.80 (0.74 to0.87), p<0.001
Missing	37 (0.3%)	-	-		
Age (cont. in model)					
mean age (SD) (Years)	66 (6)	66 (6)	66 (66)	-	-
60-64	4,401 (33%)	2,763 (63%)	1,638 (37%)	-	-
65-69	3,704 (27%)	2,480 (67%)	1,224 (33%)	-	-
70-74	5,304 (40%)	3,257 (61%)	2,047 (39%)	-	-
Deprivation quintile					
5 least deprived	2,472 (18%)	1,775 (72%)	697 (28%)	-	-
4	2,838 (21%)	1,899 (67%)	939 (33%)	-	-
3	2,952 (22%)	1,880 (64%)	1,072 (36%)	-	-
2	2,413 (18%)	1,418 (59%)	995 (41%)	-	-
1 Most deprived	1,975 (15%)	1,084 (55%)	891 (45%)	-	-
Missing	759 (6%)	-	-	-	-
Gender					-
Female	6,863 (51%)	4,436 (65%)	2,427 (35%)	-	-
Male	6,544 (49%)	4,063 (62%)	2,481 (38%)	-	-
Urban/rural					
Urban	7,488 (56%)	4,677 (62%)	2,811 (38%)	-	-
Rural	5,919 (44%)	3,822 (65%)	2,097 (35%)	-	

Table 18 Factors associated with having a delay (6 months or more) in returning bowel screen- adjusted and unadjusted model results

Factors	No. of patients (%)			Unadjusted model	Adjusted model
	All	No delay	Delay	OR (95% CI), p value	OR (95% CI), p value
Physical Disability status					
No physical disability	7,911 (59%)	5,176 (99%)	48 (1%)	Reference	Reference
Physical disability	5,461 (40%)	3,229 (99%)	21(1%)	1.4 (0.85 to 2.39), p0.13	1.7 (0.89 to 3.42), p0.18
Missing	37 (0.3%)	-	-		
Age (cont. in model)					
mean age (SD) (Years)	66 (6)	66 (6)	66 (5)	-	-
60-64	4,401 (33%)	2,731 (99%)	32 (1%)	-	-
65-69	3,704 (27%)	2,466 (99%)	14 (1%)	-	-
70-74	5,304 (40%)	3,234 (99%)	23 (1%)	-	-
Missing	-	-	-	-	-
Deprivation quintile					
5 least deprived	2,472 (18%)	(no. too small)	(no. too small)	-	-
4	2,838 (21%)	1,403 (99%)	15 (1%)	-	-
3	2,952 (22%)	1,864 (99%)	16 (1%)	-	-
2	2,413 (18%)	1,882 (99%)	17 (1%)	-	-
1 most deprived	1,975 (15%)	1,759 (99%)	16 (1%)	-	-
Missing	759 (6%)	-	-	-	-
Gender					-
Female	6,863 (51%)	4,407 (99%)	29 (1%)	-	-
Male	6,544 (49%)	4,023 (99%)	40 (1%)	-	-
Missing	-	-	-	-	
Urban/Rural					-
Urban	7,488 (56%)	4,645 (99%)	32 (1%)	-	-
Rural	5,919 (44%)	3,785 (99%)	37 (1%)	-	-
Missing	-	-	-	-	

Breast cancer screening

Observation period

The duration in study for each participant was calculated from the date of interview to the end of the BTW observation period or to date of death (when this occurred before end of BTW observation period). No bias was identified when examining the length in study for those with or without physical disabilities.

Descriptive results- BTW cohort

The National Survey for Wales (NSW) general population (N=49,546) was refined by age to reflect the recommended population group eligible for breast screening according to Public Health Wales (PHW) guidelines (Public Health Wales). This includes females aged between 50 to 70.

The refined NSW population eligible (based on demographic criteria) was then merged with the linked Breast Test Wales (BTW) dataset. The BTW dataset included n=15,709 patients who had either been screened or invited for screening in the time period 2012-2017, 6719 multiple screens were removed from the BTW dataset. These were identified using patients ALF. A total of n=28,462 NSW participants were present in the NSW eligible population but not present in the BTW dataset (indicating they had not been invited or had not been screened). Figure 11 shows the refinement process for the BTW dataset.

Figure 11 Refinement process for BTW dataset

NSW population (all survey years)
N=49 546

NSW respondents with no ALF (un-linkable)
N= 11 594

Multiple NSW survey responses (separate years)
N=501

NSW population
N= 37451

NSW population not in BTW
N= 28 462

NSW and BTW linked dataset
N= 8990

BTW refined by age range
N= 1705

BTW analytic dataset
N= 7285
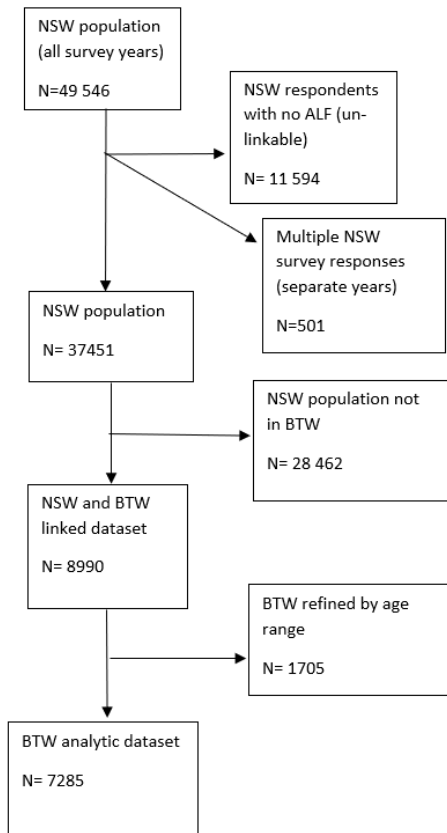
When linking the NSW and BTW there were 28,462 NSW respondents who were not present in the CSW dataset. These respondents were generally below or over the clinical breast screening age range at the time of interview which could explain their absence from the BTW datasets. Considering the age profile and survey years of those not included in the BTW population (those who did not have a record of being either screened or invited in the time period), it was assumed that our NSW eligible population was capturing participants that may not have been eligible for routine screening in the time period. Therefore, a decision was made to use presence in the linked BTW dataset as a proxy for eligibility during the study period.

There was a total of 7,285 patients in the linked and refined BTW dataset. The mean age of the

BTW population was the same between those with and without a physical disability (60). The

population without a physical disability living in rural areas was slightly higher (46%) than those

in the same category in the general NSW population (41.8%). Other characteristics were thought

to be comparable to the general NSW population. Characteristics of the BTW population can be

found in table 19.

Table 19 Characteristics of BTW population by disability status

Variable	Physically disabled population n=2,769 (missing disab stat=21)	Not physically disabled population n=4,495
Age mean (SD) (Years)	60 (6)	60 (6)
Age category		
50-54	535 (19%)	1,117 (25%)
55-59	615 (22%)	1,020 (23%)
60-64	722 (26%)	1,067 (24%)
65-70	897 (33%)	1,291 (28%)
Missing	0 (0%)	0 (0%)
Urban/rural classification		
Urban	1,675 (60%)	2,426 (54%)
Rural	1,094 (40%)	2,069 (46%)
Missing	0 (0%)	0 (0%)
Seen a GP in last 12 months		
Yes	1,939 (70%)	2,534 (56%)
No	91 (3%)	847 (19%)
Missing	739 (27%)	1,114 (25%)
Welsh index of multiple deprivation overall score		
1 most deprived	586 (21%)	577 (13%)
2	578 (21%)	762 (17%)

3	618 (22%)	1,031 (23%)
4	496 (18%)	982 (22%)
5 least deprived	349 (13%)	927 (20%)
Missing	142 (5%)	216 (5%)

Breast screening - uptake of screening services

Of the total BTW population 7,276 (99.9%) had been invited for a breast screen in the study period. Of those invited 5,924 (81%) were screened. Of those with a physical disability 2,112 (76%) had been screened, compared with 3794 (84%) of the non-physically disabled population. The mean age of those screened and not screened was the same (60). 10% of the least deprived quintile were not screened compared to 26% of the most deprived quintile. 17% of those that had seen their GP in the last 12 months were not screened compared to 22% of those who had not seen their GP in the last 12 months. A summary of information on breast screening by population demographic can be found in table 19.

Table 20 shows the results of the adjusted and unadjusted logistic regression models examining the association between having a physical disability and attending a breast screening service. The unadjusted model indicates that there is a statistically significant (p-value <0.001) association between the presence of a physical disability and attending a breast screening service. The unadjusted odds ratio was 0.59 (95% CI=0.53 to 0.67), showing that those with a physical disability were 41% less likely to have attended a breast screen in the study period.

The adjusted model with all covariates added shows a statistically significant (p-value <0.001) association between having a physical disability and attending a breast screening service. The adjusted odds ratio for physical disability was 0.66 (95% CI=0.58 to 0.74), indicating that those with a physical disability were 40% less likely to have attending a breast screening service.

Therefore, it is possible to reject the null hypothesis and conclude that, within the population studied, there are associations between the presence of a physical disability and uptake of breast screening services within a 5-year period.

Table 20 Factors associated with attending breast screening- adjusted and unadjusted model results

Factors	No. of patients (%)			Unadjusted model	Adjusted model
	All	Screened N=5924	Not screened N=1361	OR (95% CI), p value	OR (95% CI), p value
Physical Disability status					
No physical disability	4,495 (62%)	3,794 (84%)	701 (16%)	Reference	Reference
Physical disability	2,769 (38%)	2,112 (76%)	657 (24%)	0.59 (0.53 to 0.70), p0.001	0.66 (0.58 to 0.74), p0.001
Missing	21 (0.3%)	-	-		
Age (cont. in model)					
mean age (SD) (Years)	60 (6)	60 (6)	60 (6)	-	-
50-54	1,655 (23%)	1,348 (82%)	307 (18%)	-	-
55-59	1,642 (23%)	1,343 (82%)	299 (18%)	-	-
60-64	1,795 (24%)	1,454 (81%)	341 (19%)	-	-
65-70	2,193 (30%)	1,779 (82%)	914 (18%)	-	-
Missing	-	-	-		
Deprivation quintile					
5 least deprived	1,281 (18%)	1,148 (90%)	133 (10%)	-	-
4	1,480 (20%)	1,224 (83%)	256 (17%)	-	-
3	1,654 (23%)	1,359 (82%)	295 (18%)	-	-
2	1,347 (18%)	1,049 (78%)	298 (22%)	-	-
1 most deprived	1,165 (16%)	865 (74%)	301 (26%)	-	-
Missing	358 (5%)	-	-		
Urban/rural					
Urban	4,114 (57%)	3,706 (83%)	766 (19%)	-	-
Rural	3,171 (43%)	730 (78%)	595 (19%)	-	
Missing	-				

Stage at diagnosis and Mortality outcomes

Study cohort

A total of 49,546 responders were included in the National Survey for Wales (NSW) general population between 2012 and 2017. (N=49,546 was refined by removing those without an ALF (n=11,594) and removing multiple survey responses (n=501).

1,745 NSW responders were identified in the WCISU datasets with a cancer diagnosis between the years 2012 to 2017. Multiple diagnoses of cancer were identified by searching for duplicates in the WCISU dataset using patients ALF. After removal of multiple diagnoses (n=116) this number reduced to 1,629. The choice was made to focus on an individual's primary cancer diagnosis to maximise the amount of people in the study and as we had no information on whether the second incidence of cancer was a primary diagnosis in itself or a secondary cancer diagnosis from the first instance of cancer. In some instances, cancer diagnosis may have come before survey completion, however it is assumed that disability status would have been consistent across the study period. After linkage with the NSW and Annual District Death Extract (ADDE) population the number in the stage at diagnosis and the mortality dataset was 1,629. Figure 12 below demonstrates the linkage and refinement of the population.

Figure 12 linkage and refinement of the WCISU population
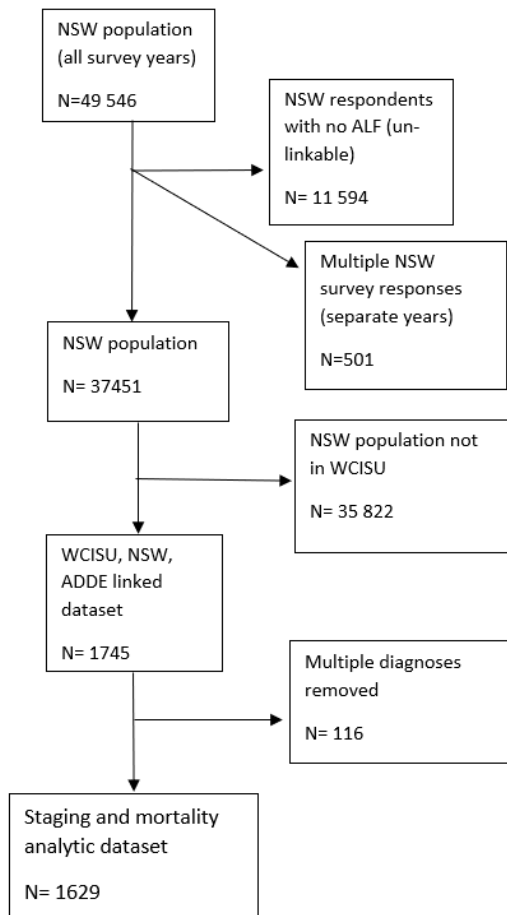
A summary of the population with a cancer diagnosis by disability status can be seen in table 21 People self-identifying as having a physical disability (PD) make up 47.5% (n=773) of the population; this percentage is higher than the population in the NSW population which ranged from 30.7% (Survey year 2012) to 37.7% (survey year 2016/17). Seven individual's PD status could not be determined. This suggests some bias towards having a self-identified disability in this smaller population with a cancer diagnosis. Further to this, the population age is higher than the wider NSW population, those with a disability in the wider population had a mean age of 62 and those without a disability had a mean age of 50. In the population with a cancer diagnosis, we see those with a disability have a mean age of 68 and those without a disability have a mean age of 62. The population with a cancer diagnosis has a

similar proportion of males than females in comparison to the wider NSW population. We could not report on ethnicity in the descriptive results because the populations were too small and would have compromised anonymity.

In comparing the physically disabled population with the non-disabled population in this dataset we see that the mean age is higher for the physically disabled population (68), there is a slightly higher percentage of females than males in both the physically disabled and non-disabled populations. People with a physical disability had a higher percentage of people living in urban areas (62.7%) compared to people without disabilities, as is seen in the wider NSW population. People without disabilities had a higher percentage of people whose marital status was single at the time of survey (15.9%) compared to 9.3% of people with a disability. People with a disability had a higher percentage of the population in the highest deprivation quintile (18.8%) compared to the non-disabled population (16.5%).

Table 21 Descriptive results of staging and mortality analytic dataset by disability status

Variable	Physically disabled pop. N=773	Not physically disabled pop. N= 849
Age mean (SD) (Years)	68 (13)	62 (16)
Age category		
20-29	13 (1.6%)	57 (6.7%)
30-39	26 (3.4%)	50 (5.9%)
40-49	28 (3.6%)	66 (5.9%)
50-59	89 (11.5%)	119 (14%)
60-69	207 (26.8%)	237 (27.9%)
70-79	262 (33.9%)	203 (23.9%)
80-89	131 (17%)	110 (12.9%)
90+	17 (2.2%)	7 (0.8%)
Gender		
Female	390 (50.5%)	489 (57.6%)
Male	383 (49.5%)	360 (42.4%)
Urban/rural classification		
Urban	485 (62.7%)	491 (57.8%)
Rural	288 (37.3%)	358 (42.2%)
Seen a GP in last 12 months		
Yes	583 (75.4%)	544 (64.1%)
No	23 (3%)	104 (12.2%)
Missing	606 (21.6%)	201 (23.7%)
Welsh index of multiple deprivation overall score		
1 most deprived	145 (18.8%)	140 (16.5%)
2	147 (19%)	139 (16.4%)
3	167 (21.6%)	168 (19.8%)
4	132 (17.1%)	181 (21.3%)
5 least deprived	139 (18%)	176 (20.7%)
Missing	43 (5.6%)	45 (5.3%)
Marital status		
Single	72 (9.3%)	135 (15.9%)
Married	367 (47.4%)	422 (49.7%)
Divorced	123 (15.9%)	115 (13.5%)
Widowed	197 (25.5%)	158 (18.6%)
Separated	13 (1.7%)	19 (2.2%)
Missing	Removed (no. too small)	0(0%)

Table 22 Descriptive results for WCISU population by stage at diagnosis.

Variable	Cancer diagnosis N=1,622	In situ N=371	Stage 1 N=346	Stage 2 N=305	Stage 3 N=191	Stage 4 N=205	No stage N=204
Disability status							
PD	773 (47.5%)	160 (20.7%)	150 (19.4%)	150 (19.4%)	108 (14%)	110 (14.2%)	95 (12.3%)
No PD	849 (52.1%)	211 (24.9%)	196 (23.1%)	155 (18.3%)	83 (9.8%)	95 (11.2%)	109 (12.8%)
Missing status	7 (0.4%)	-	-	-	-	-	-
Age group							
Age mean (SD) (years)	65 (15)	54 (20)	66 (12)	67 (12)	69 (11)	68 (10)	72 (11)
Gender							
Female	883 (54.2%)	268 (30.4%)	227 (25.7%)	132 (14.9%)	80 (9.1%)	87 (9.9%)	89 (10.1%)
Male	746 (45.8%)	105 (14.1%)	121 (16.2%)	175 (23.5%)	112 (15%)	118 (15.8%)	115 (15.4%)
Urban/rural							
Urban	980 (60.2%)	243 (24.8%)	195 (19.9%)	178 (18.2%)	110 (11.2%)	129 (13.2%)	125 (12.8%)
Rural	649 (39.8%)	130 (20%)	153 (23.6%)	129 (19.9%)	82 (12.6%)	76 (11.7%)	79 (12.2%)
WIMD-overall score							
1 Most deprived	265 (17.5%)	77 (27%)	51 (17.9%)	47 (16.5%)	37 (13%)	38 (13.3%)	35 (12.3%)
2	288 (17.7)	79 (27.4%)	49 (17%)	51 (17.7%)	27 (9.4%)	41 (14.2%)	41 (14.2%)
3	337 (20.7%)	64 (19%)	89 (26.4%)	76 (22.6%)	42 (12.5%)	29 (8.6%)	37 (11%)
4	315 (19.3%)	59 (18.7%)	72 (22.9%)	68 (21.6%)	41 (13%)	43 (13.7%)	32 (10.2%)
5 Least deprived	316 (19.4%)	68 (21.5%)	66 (20.9%)	53 (16.8%)	42 (13.3%)	37 (11.7%)	50 (15.8%)
Missing	88 (5.4%)	-	-	-	-	-	-
Seen a GP in last 12 months							
Yes	1,132 (69.5%)	260 (23%)	238 (21%)	213 (18.8%)	146 (12.9%)	140 (12.4%)	135 (11.9%)
No	127 (7.8%)	32 (25.2%)	25 (19.7%)	17 (13.4%)	15 (11.8%)	25 (19.7%)	13 (10.2%)
Missing	370 (22.7%)	81 (21.9%)	85 (23%)	77 (20.8%)	31 (8.4%)	40 (10.8%)	56 (15.1%)

Marital status							
Single	207 (12.7%)	111 (53.6%)	30 (14.5%)	18 (8.7%)	10 (4.8%)	25 (12.1%)	13 (6.3%)
Married	794 (48.7%)	152 (19.1%)	173 (21.8%)	161 (20.3%)	108 (13.6%)	100 (12.6%)	100 (12.5%)
Divorced	239 (14.7%)	48 (20.1%)	54 (22.6%)	53 (22.2%)	26 (10.9%)	29 (12.1%)	29 (12.1%)
Widowed	356 (21.9%)	53 (14.9%)	81 (22.8%)	67 (18.8%)	48 (13.5%)	48 (13.5%)	48 (13.5%)

Cancer stage at diagnosis

A summary of information on stage at diagnosis by population demographic can be found in table 22 above. Of the total population 14.2% of people with disability were diagnosed at stage 4, compared to 11.2% of the non-disabled population. Overall, there was a slightly lower percentage of those with a physical disability and a cancer diagnosis (47.5%) compared to those without a physical disability (52.1%). The mean age was highest in the stage 4 group (68 years) and lowest in the in-situ group (54 years). There was a higher percentage of females with a cancer diagnosis (52.2%), but a lower percentage of females with a stage 4 diagnosis (9.9%) compared to males (15.8%). There was a slightly higher percentage of people living in urban areas with a stage 4 diagnosis (13.2%) compared to rural areas (11.7%). Those in the highest deprivation quintile had a slightly higher percentage of stage 4 diagnosis (13.3%) than those in the lowest deprivation quintile (11.7%). Those who had not seen their GP in the last 12 months had a higher percentage of stage 4 (19.7%) than those who had seen their GP in the last 12 months (12.4%).

Results of the unadjusted ordinal regression model shows a coefficient of 0.33 (95% CI= 0.12 to 0.55, p value=0.003) indicating that for a one unit increase in stage (1 to 5) we expect a 0.33 increase in the log odds of having a later stage of cancer at diagnosis. The proportional odds assumption was tested using the 'omodel' logit command in STATA to test the assumption that the relationship between the outcome groups is consistent or proportional. Results of the proportional odds assumption test showed that the model was valid. Results showed that the probability of stage 1 and 2 cancer is lower for those with no physical disabilities and the probability of stage 3, and 4 cancer is higher for those with a physical disability (table 23).

Table 23 Likelihood of Cancer Stage by disability status

Likelihood of Cancer Stage	1	2	3	4
No PD	0.37	0.29	0.17	0.17
PD	0.29	0.29	0.20	0.22

When adjusting for covariates (age, gender, etc) the odds ratio reduced to 1.33 (95% CI=1.00 to 1.77, p=0.049), indicating that people self-reporting physical disability have 1.33 times the odds of having a higher stage (2, 3 or 4) cancer compared to individuals self-reporting not having a physical disability.

Cancer stage at diagnosis - early vs later stage

Results of the unadjusted logistic regression model looking at the odds of having a later stage cancer at diagnosis (stages 3 or 4) are shown in table 24. Results show that the unadjusted model odds ratio with 95% confidence interval is 1.43 (1.12 to 1.84, p=0.005), indicating that people with a self-reported physical disability were 43% more likely to have a later stage at diagnosis than those not reporting a physical disability.

When adjusting for covariates (age, gender, ethnicity, deprivation, rurality, marital status) people with a self-reported physical disability were 19% more likely to have a later stage at diagnosis than those without a physical disability (OR=1.19, 95% CI= 0.88 to 1.61, p=0.27).

Table 24 showing results of adjusted and unadjusted logistic regression results for stage at diagnosis

Factors	No. of patients (%)			Unadjusted model	Adjusted model
	All	Late stage N= 397	Early stage N= 655	OR (95% CI), p-value	OR (95% CI), p-value
Physical Disability status					
No physical disability	849 (51.1%)	178 (44.8%)	351 (53.6%)	Reference	Reference
Physical disability	773 (47.5%)	218 (54.9%)	300 (45.8%)	1.43 (1.12 to 1.84), p0.005	1.19 (0.88 to 1.61), p0.27
Missing	7 (0.4%)	-	-	-	-
Age (cont. in model)					
mean age (SD) (Years)	65 (16)	70 (11)	67 (12)	-	-
20-29	70 (4.3%)	No. too small	No. too small	-	-
30-39	77 (4.7%)	No. too small	18 (2.7%)	-	-
40-49	92 (5.6%)	14 (3.5%)	44 (6.7%)	-	-
50-59	209 (12.8%)	49 (12.3%)	94 (14.4%)	-	-
60-69	437 (28.8%)	124 (31.2%)	200 (30.5%)	-	-
70-79	465 (28.5%)	125 (31.5%)	202 (30.8%)	-	-
80-89	246 (15.1%)	70 (17.6%)	86 (13.1%)	-	-
90+	33 (2%)	13 (3.3%)	10 (1.5%)	-	-
Deprivation quintile					
5 least deprived	265 (17.5%)	79 (19.9%)	119 (18.2%)	-	-
4	288 (17.7%)	84 (21.2%)	140 (21.4%)	-	-
3	337 (20.7%)	71 (17.9%)	165 (25.2%)	-	-
2	315 (19.3%)	68 (17.1%)	100 (15.3%)	-	-
1 most deprived	316 (19.4%)	75 (18.9%)	98 (15%)	-	-
Missing	88 (5.4%)	20 (5%)	33 (5%)		
Gender					
Male	746 (45.8%)	230 (57.9%)	296 (57.9%)	-	-
Female	883 (54.2%)	167 (41.1%)	359 (54.8%)	-	-
Marital status					
Single	207 (12.7%)	35 (8.8%)	48 (7.3%)	-	-
Married	794 (48.7%)	208 (52.4%)	334 (51%)	-	-
Divorced	239 (14.7%)	55 (13.9%)	107 (16.3%)	-	-
Widowed	356 (21.9%)	96 (24.2%)	148 (22.6%)	-	-

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Separated	13 (1.7%)	No. too small	17 (2.6%)	-	-
White	No. too small	No. too small	No. too small	-	-
Other	No. too small	No. too small	No. too small	-	-

Mortality with underlying cause of cancer

The population with a cancer diagnosis (those present in the WCISU dataset) were used to identify individuals to be included in the death with cancer as underlying cause cox regression models. The same population, as described in the descriptive results section of the staging outcome was used for the mortality results. Of the self-reported physical disability population 64.6% were alive at the end of the study period, compared to 78.9% of the non-disabled population. 24.6% of the physically disabled population died of cancer in the study period and 11% died of another cause in the study period. In the non-disabled population, 15.5% died of cancer in the study period and 5.5% died of another cause in the study period. There were no patients that died of cancer in the study period in the youngest age bracket (20-29), there were 105 people in the 70-79 age bracket that died of cancer in the study period. 78.5% of females were alive at the end of the study period compared to 64.7% of males. 67% of those from the most deprived quintile were alive at the end of the study period compared to 76.6% of the population who were in the least deprived quintile. In terms of ethnicity, 73.2% of the white population were alive at the end of the study period compared to 63.6% of those who were in the 'other' category. The marital status category with the highest percentage of those alive at the end of the study period was those who were single (84.1%) compared to those who were widowed (59.3%). The stage at diagnosis variable shows us that the percentage of those who were alive at the end of the study period was lowest in the stage 4 category (23.9%) compared to the In-situ category (89%).

Time to death with cancer as underlying cause- unadjusted model

The unadjusted cancer death specific cox regression model (table 25) shows a significant difference in time of cancer diagnosis to death between people self-reporting physical disability

and non-physical disability groups (hazard ratio (HR)= 1.67 95% CI=1.34 to 2.08, p=0.00). This demonstrates an increased risk of death with cancer as the underlying cause for people with a physical disability. There was no violation of the proportional hazards assumption in this model (chi-squared test = 0.7258).

Time to death with cancer as underlying cause- adjusted model

After adjusting for the relevant covariates, results show that there is a difference between time to cancer death between groups (physically disabled and not physically disabled) (HR= 1.14 (0.76 to 1.69), p=0.063), however results are not significant. Having stage 4 cancer at diagnosis was a significant predictor in the model and demonstrated increased risk of death with cancer as the underlying cause (HR= 36.4 (11.02 to 120.45, p=0.00). Age was the only other significant predictor in the model, results show that with each one-year increase in age, risk of death with cancer as the underlying cause increased by 3% (HR= 1.03 (1.01 to 1.05), p=0.003).

Results of the proportional hazards assumption test show a non-significant result of 0.7447, so we can conclude that the proportional hazards assumption has not been violated in this model.

Table 25 Factors associated with cancer related mortality- adjusted and unadjusted model results

Variable	Died within study period (non-cancer) N=132	Died with cancer as underlying cause in study period N=321	Alive at the end of study period N=1,169	Unadjusted HR (95% CI), p value	Adjusted HR (95% CI), p value
Disability status					
Physical Disability	85 (11.0%)	189 (24.5%)	499 (64.6%)	1.67 (1.34 to 2.08), p0.00	1.14 (0.76 to 1.69), p0.063
No Physical Disability	47 (5.5%)	132 (15.5%)	670 (78.9%)	Reference	Reference
Age group					
Age mean (SD) (years)	77 (10)	72 (10)	62 (16)	-	-
20-29	0 (0%)	0 (0%)	70 (100%)	-	-
30-39	0 (0%)	0 (0%)	77 (100%)	-	-
40-49	0 (0%)	9 (9.8%)	83 (90.2%)	-	-
50-59	9 (4.3%)	33 (15.8%)	167 (79.9%)	-	-
60-69	22 (5%)	81 (18.5%)	334 (76.4%)	-	-
70-79	39 (8.4%)	105 (22.6%)	321 (69%)	-	-
80-89	50 (20.3%)	84 (34.1%)	112 (45.5%)	-	-
90-99	12 (36.4%)	9 (27.3%)	12 (36.4%)	-	-
Gender					
Female	43 (4.9%)	147 (16.6%)	693 (78.5%)	-	-
Male	89 (11.9%)	174 (23.3%)	483 (64.7%)	-	-
Urban/rural					
Urban	82 (8.4%)	193 (19.7%)	705 (71.9%)	-	-
Rural	50 (7.7%)	128 (19.7%)	471 (72.6%)	-	-
WIMD-overall score					
1 most deprived	23 (8.1%)	71 (24.9%)	191 (67%)	-	-
2	18 (6.3%)	57 (19.8%)	213 (74%)	-	-
3	31 (9.2%)	50 (14.8%)	256 (76%)	-	-
4	22 (7%)	65 (20.6%)	228 (72.4%)	-	-
5 least deprived	22 (7%)	52 (16.5%)	242 (76.6%)	-	-
Ethnicity					
White	85 (7.3%)	225 (19.4%)	848 (73.2%)	-	-
Other	(no.s under 5)	(no.s under 5)	7 (63.6%)	-	-

Marital status				
Single	6 (2.9%)	27 (13%)	174 (84.1%)	-	-
Married	53 (6.7%)	152 (19.2%)	587 (74.1%)	-	-
Divorced	14 (5.9%)	52 (21.8%)	173 (72.4%)	-	-
Widowed	58 (16.3%)	87 (24.4%)	211 (59.3%)	-	-
Stage at diagnosis				
In situ (stage 0)	33 (8.8%)	8 (2.1%)	332 (89%)	-	-
Local Involvement only (stage 1)	22 (6.3%)	18 (5.2%)	308 (88.5%)	-	-
Extension to adjacent tissue (stage 2)	24 (7.8%)	37 (12.1%)	246 (80.1%)	-	-
Lymph node involvement (stage 3)	13 (6.8%)	84 (43.8%)	95 (49.5%)	-	-
Metastases (stage 4)	12 (5.9%)	144 (70.2%)	49 (23.9%)	-	-
Not enough information to stage	28 (13.7%)	30 (4.7%)	146 (71.6%)	-	-

Chapter summary

This chapter sought to explore whether people with a physical disability experience lower screening up- take screening delay, later cancer stage at diagnosis and higher mortality rates compared to those without a disability. The contribution of relevant socio-demographic factors was also explored. The approach used was a retrospective cohort study approach utilizing linked National Survey for Wales datasets with Cervical Screening Wales, Bowel Screening Wales, Breast Test Wales, Welsh Cancer Intelligence Surveillance Unit and Annual District Death Extract datasets respectively for each separate set of analyses between the years of 2012 to 2017.

For all screening services descriptive results suggest that rates of uptake of screening was highest for those without a physical disability. The logistic regression models suggest that there is an association between having a physical disability and lower screening uptake and delay compared with those without a physical disability for all screening services. Results also suggests that there is an association between having a physical disability and delayed uptake of cervical screening services, a significant association was not found between having a physical disability and delayed uptake of bowel screening services. Stage at diagnosis results suggest that people with physical disability have higher odds of having a late-stage cancer diagnosis and have higher risk of mortality with an underlying cause of cancer.

Discussion of the main findings and interpretation of the findings in the context of the qualitative results from this thesis, published research, implications for policy and practice and strengths and limitations of the study are discussed in chapter 11

Chapter 9: Qualitative methods

Introduction to chapter 9

The previous chapter presented the results of the quantitative part of this thesis. This chapter presents the methodology and methods carried out for the qualitative part of this mixed methods research project. The methodological considerations will be presented along with the qualitative research objective. Sampling and recruitment of participants, the data collection process, data management, analysis and ethical considerations will be discussed. The objective of the qualitative part of this research was to understand the experiences of people with a pre-existing disability going through cancer care in England or Wales. This focuses on how specific people with physical disabilities experienced cancer care rather than trying to generalise the experiences captured to explain the wider experience of living with a pre-existing disability and having a cancer diagnosis and treatment. The literature review presented in chapter 2. showed that there was a gap in literature looking at the experience of cancer diagnosis and treatment for people with physical disabilities. Therefore, the decision was made to not have a specific focus on one part of the cancer journey. Rather, the idea was to elicit stories that covered the entire cancer journey and experience, from screening to treatment, whilst allowing for the participants to guide the interview to focus on whatever felt important to them by using a semi-structured interview format. The contribution of this part of the thesis to the mixed-methods project was to understand cancer care for people with physical disabilities from a personal, lived experience level. This can illuminate some of the possible reasons behind the inequities found in the quantitative element.

Qualitative methodology

The qualitative part of this project followed a narrative inquiry research design. This approach was chosen with an aim to elicit rich interview data that could capture many facets of the experience of someone with a pre-existing physical disability who has gone through cancer. The approach to narrative inquiry was guided by Polkinghorne's understanding of narratives in research. Polkinghorne (1995) posited that narratives are a way to draw together events and activities into a coherent, temporally organised whole that conveys a certain meaning and allows us to understand the effect of certain happenings on a specified outcome. Polkinghorne use the phrase 'narrative configuration' (Polkinghorne, 1995, p. 5) to describe the creation of narratives in research from qualitative data with an aim to detail human action, with events tied together by a' thematic thread', namely a plot (Polkinghorne, 1995, p.5). This research has utilised the narrative-type of narrative inquiry as outlined by Bruner (1985), where a story is created using qualitative data around a specific event or experience. Similarly, Ricoeur (1984) argued that narrative making can serve as a vehicle for one to understand links between events as they can help us to understand an individual's understanding of themselves, their experience and their future possibilities. For Ricoeur, narrative making is a way humans form a sense of self-identity. Ricoeur argues, humans consistently use emplotment by linking past events in a way that is meaningful for them (1984).

Narratives have been used in healthcare research as a way to embrace the enmeshed experiences of health, illness, healing, and survivorship (Reed, Josephsson and Alsaker, 2020., Stamm et al, 2008, Smith-Chandler and Swart, 2014). Studies from Alsaker et al (2009) and Stamm et al (2008) looked at the experiences of people living with rheumatic conditions. Both studies looked at similar phenomena but utilised narrative inquiry in methodologically different ways. Alsaker et al (2009) for example used ethnographic

methods to study meaning making in everyday activities for women living with rheumatic conditions. Their main focus of inquiry was how a 'good' everyday life was created, and how meaning of their illness went beyond diagnosis and was created in everyday action. Stamm et al (2008) combined biographical and narrative interview data to construct the life stories of people living with rheumatoid arthritis. Both studies provide good examples of how narrative inquiry can be used to foreground patient experiences in health and illness. In her seminal work on the moral challenges experienced by African-American families caring for children with chronic health conditions, Mattingly (2014) constructs narratives that explore the complex interactions between health, illness, health systems and navigating personal construction of an enjoyable life. Mattingly's work displays the usefulness of narratives in encapsulating human experience of health and illness on a personal, societal and cultural level. Smith-Chandler and Swart (2014) argue in their work on using narratives in disability research, that narratives can be used as a tool to centralise the voices of people with disabilities where other research may unintentionally oppress. The researchers here suggest using an integrated theoretical approach with analysis on the descriptive, personal level and moves towards an interpretive analysis with wider application to the disability experience. However, the authors caution against attempting to amalgamate participant experiences to form a generalised disability identity.

Narrative inquiry appeared to be the most appropriate way to gain an understanding of the phenomenon under investigation in this research as the experience of cancer care as someone with a pre-existing physical disability is a complex set of circumstances, illness experiences, and personal history intertwined. In understanding humans as natural storytellers both individually and socially, I approached data collection as gaining an understanding of each individual's lived experience by hearing their interpretation of events in telling their own

story. In recording and analysing the data the interviewee and I were making a collaborative story based on both of our understandings of the shared social world we live in.

Theory around narratives in research informed the methods chosen for data collection and analysis. The approach to data analysis was influenced by the work of Mattingly (1998) and Alsaker's work on narratives of recovery and living with chronic conditions (Alsaker et al, 2009., Reed, Josephsson and Alsaker, 2020). In Alsaker's work on recovery from illness, recovery is viewed as a process of narrative meaning making that involves the exploration of how an individual makes sense of their everyday lives, experiences, hopes for the future and contexts in relation to each other (Reed, Josephsson and Alsaker, 2020). Mattingly's work (1998, 2014) guided the style and approach to story writing. Mattingly often attends to singular events as the focus of the narratives created on people's experiences of caring for a loved one. This, Mattingly argues, allows for consideration of how the experiences someone has had as revealed in the telling of their own stories, can tell us not only about what happened but also holds life's possibilities for the future and portends to what else could have happened in the story. In this study, I too focused on singular events in each person's story to attempt to illuminate the complexities of each person's context, highlighting the individual action around each event to allow the reader to consider the implications the action had on the overall story.

Sampling and recruitment

Due to the very specific combination of lived experiences I was looking for in this research study, criterion sampling was chosen to recruit participants. The inclusion criteria for interviews was those over 18, have had a diagnosis of cancer and cancer treatment in England or Wales, and self-identified as having a physical disability that pre-existed their diagnosis of cancer. See recruitment poster in appendix 3.

Recruitment began in March 2020, at the start of the COVID-19 pandemic and the first lockdown in the U.K. and was completed by September 2020. All recruitment was completed online via charity organisation distribution groups and websites and social media sites (Facebook, Instagram, twitter and reddit). Prior to the pandemic the plan had been to also advertise in physical social spaces such as community centres, but this was not possible due to the pandemic lockdowns The online recruitment strategy was based around utilising the social media followers of cancer charity and disability organisations to advertise the recruitment poster. I created social media accounts using my university email address and details so that I could contact these organisations and also so they could link in my profile when posting the advertisement so that participants could get in touch with me directly via social media. My university email address was also on the recruitment poster for those who would rather get in touch via email. I contacted various cancer charities and disability organisations via email and/or through their social media accounts to ask them to schedule posts from their accounts featuring the recruitment poster and research study details. Some organisations that only had websites posted information on their website or sent out an email to their distribution group of members. It generally took longer than anticipated for organisations and individuals to get back to me regarding whether or not they would advertise as their priority was disseminating information regarding the ongoing situation with the pandemic.

I was aiming to get as diverse a participant group as possible to account for intersecting identities and the experience of cancer care, such as race and gender. With this aim in mind, I contacted social media groups for people from minority groups going through cancer and organisations with an affiliation to minority groups such as LGBTQ+ organisations and news outlets. I made regular tweets via the twitter account set up for the project with hashtags known to be relevant to people affected by cancer and the online disability community.

Another avenue for social media recruitment was to contact disability bloggers and Instagram influencers with a large following to advertise the research on their Instagram and Instagram stories.

When potential participants got in touch either via social media channels or via email, they were sent an information pack about the research to inform them of the criteria and what would be involved. If the participants got in touch via social media this information was sent to them in a message as I was not able to attach documents via social media. When participants had read the information (I made sure to leave at least 24 hours before responding to allow participants time to absorb the information) and decided they wanted to be involved I sent them a consent form to sign. I asked those who got in touch via social media for their emails and permission to send them a consent form via email. I sent the consent forms via my university email so that I could send and receive attachments from participants. Sending and receiving consent forms electronically and e-signatures proved to be a slight stumbling block in the recruitment process. Some participants were not familiar with the technological process required to download, sign, and return the consent form electronically. Therefore, a decision was made to allow for gaining of verbal consent prior to interview in lieu of an electronic signature. This change to gaining consent was approved the School of Healthcare Sciences research ethics committee. Two of the participants that were not familiar with the electronic signatures gave their consent verbally prior to interview. I read the consent form to them and gave them time to decide whether they would like to give consent to be interviewed. The consent form can be found in appendix 8.

Data collection went on for 7 months to allow for disruption caused by the COVID-19 pandemic and was relatively labour intensive as getting information noticed on an ever-changing social media feed during a global pandemic was a difficult task. This meant contacting and re-contacting organisations to encourage them to post frequently on my

behalf. Responses to the recruitment advertisements slowed down towards the end of the recruitment period when I was mostly posting from my own accounts. I wanted to keep recruitment open however until I felt I had enough data to say something about the experience of going through cancer care as someone with a physical disability.

A total of 5 participants were recruited and took part in the interviews. There were others who got in touch but either decided they did not want to take part or did not fit the inclusion criteria. This was mostly related to people getting touch who had a disability as a result of their cancer diagnosis or treatment, so did not have a pre-existing disability. The people who got in touch told me where they had seen the recruitment poster. Two had seen the report of the research poster via the ME Society's Facebook page and contacted me via Facebook. Three had been contacted via their keyworker at the Spina Bifida charity 'Shine' and got in touch with me via email.

Data collection

Data collection spanned from March to September 2020. Ten interviews were conducted in total. Two interviews were conducted with each participant, with the second interview taking place about a month after the first or as soon as was convenient for the participant. The decision to conduct two interviews per participant was made to enable each participant to reflect on the first interview and to allow time to process the heightened emotions that may have been brought up. Two interviews allowed myself the time to transcribe the first interview and identify any initial themes I thought may be of benefit to explore further or to clarify certain points.

 Interviews were either conducted over the phone or via Zoom, and whether the interview took place on a phone call or via video call was left up to the participant. Each initial interview lasted roughly one hour, and each subsequent interview lasted between 30 minutes

and an hour depending on the amount of information gathered in the first interview or the necessity of clarifying some details. Interviews were recorded via a dictaphone and either using my computer's recording app (when interviews were held over the phone) or Zoom's record feature, to ensure there was a backup of each interview recording in the event that one method failed.

Interviews were semi-structured to allow for the focus of the participant narrative to focus on what was important to them. I had a five-to-ten-minute chat with each participant before asking the first question in the initial interview. This was aimed at building rapport and to help them understand further the research. It felt important to have this time to build rapport as they were sharing personal aspects of their lives so them feeling comfortable was the top priority. Also, I was aware that the narratives that would be created would be a co-production between myself and the participant so me getting to know their context and details about their lives around the cancer diagnosis would help to make for a richer narrative. Each initial interview started with the question "Can you tell me the story of your cancer journey?". Follow up questions were intended to either clarify meaning, encourage the participant to continue or to enquire about a part of the cancer journey that had not been covered yet. The aim of the initial interview was to get an overall understanding of each person's cancer journey, their diagnosis, treatment, and outcomes, but also to allow them to focus on whichever aspect was important for them to re-tell.

The month left between first and second interview allowed me to transcribe and read through the first interview and give the participant time to reflect on the first interview. I got in touch with each person about three weeks after the first interview to arrange the second and they were undertaken at a time convenient to each person. When listening and transcribing the first interview I also noted my field notes down. Field notes included observations I made during the first interview such as tone of voice, laughter, or facial expressions. I made initial,

brief notes during each transcription to highlight areas that might need further clarification or other areas to expand upon in the second interview. As no new information was forthcoming in the second interviews as the interview process went along it became clear that two interviews were sufficient to gather enough data for each of the participants. As the sampling method chosen was criterion sampling and the focus being on lived experience there was no strict sample size I was hoping to reach. The intention was to gain an overview of people's experiences of cancer care to help to interpret the quantitative findings which cover the cancer journey from screening services to diagnosis and risk of mortality. Therefore, data collection was concluded when a range of experiences on the cancer journey were covered.

Key considerations for interviewing

Proxy interviewing

The third participant to get in touch contacted me via email. She informed me she had recently been going through a deterioration in her speech and therefore did not feel comfortable undertaking the interview herself but wanted to still take part. She suggested that her mother do the interview on her behalf and gave me her mother's contact details. After reflecting on whether this fit with my research design and considering how I would construct her narrative based on someone else's account, I sought an amendment to the ethical review to allow for proxy interviewing in my research.

I then got in touch with the participant's mother, and we discussed the research over the phone to allow her to decide if she wanted to take part. As time went on, I was able to see how valuable this insight would be into the experience of cancer care from someone with a physical disability who also had speech difficulties. Going into the first interview it was my intention to fully focus on her daughter's perspective through the perspective of her mother. With an intention to include the daughter's perspective as much as possible I reached out to

her via email after the first interview to ask her perspective on some of the points raised by her mother. I later learnt from her mother that she was experiencing ill health and could not respond to my emails at the time. As the interviews progressed, it became clear that what I was hearing was the mother's perspective on her daughter's cancer journey. When analysing the data and writing up the narrative I was sure to be clear about whose perspective I was hearing and that the construction of the narrative on the daughter's story was a collaboration between myself and her main carer, her mother.

Dealing with fatigue

A consideration during the interview process referred to accommodations needed for each participant. With an awareness that each participant might have needs around their disability which might impact their ability to complete the interview I asked in the interview set up stage about any needs they might have that I could accommodate for. This was particularly relevant for the participants who had a diagnosis of ME (Myalgic encephalomyelitis), for which one of the main symptoms is fatigue. One participant with ME and I discussed the possibility of breaking the hour interview down into twenty-minute chunks as she was concerned that she wouldn't be able to get through the whole hour. Although she decided she would rather try the whole hour interview, I made it clear that should she need to stop at any time that we could reconvene at a time suited to her. I also left the interview time and date as flexible so that participants could see how they were feeling on the day and reschedule if they felt the need.

Dealing with emotional distress

Going through an illness such as cancer can cause feelings of stress, sadness, and anxiety. I went into each interview with an awareness that re-telling these stories to me might have an emotionally taxing element to the participants and myself. To ensure I was taking care of the participants' mental wellbeing as much as possible, I made sure to say at the beginning of

each interview that should they find anything too distressing to talk about they could stop the interview at any time, or we could move on to another topic. During the interviews there were a few moments where participants did get upset and while I was conscious not to interrupt their flow, I also asked whether they wanted to carry on at the next appropriate opportunity. To look after my own mental wellbeing when hearing emotional distressing stories, I ensured I wrote a reflective piece after each interview to process the information.

Data management

The interviews produced audio data. All interviews were recorded on two devices for each interview. The recording devices used depended on the medium by which the interview was being conducted. The interviews that were held over the phone were recorded using my laptops built in audio recording app and a Dictaphone, the interviews that were held over Zoom were recorded using Zoom's built-in recording feature and a Dictaphone. Dictaphone recordings, laptop recordings and Zoom recordings were downloaded onto my password protected laptop and stored in a password protected file and deleted from their original locations. A backup of each recording was also stored on a USB drive which was kept in a locked filing cabinet. Participant details such as name and where they were recruited from was kept in a password protected and encrypted excel file.

I transcribed all the interviews verbatim. I chose to do this myself rather than pay for a service to do it as I thought it would allow me to get immersed in the data myself. The transcribed textual data, field notes and reflections were also kept on a password protected laptop and password protected file with all identifiable information, such as hospital names and names of people removed. The transcription process involved playing each interview down at a slower speed and typing verbatim, the transcribed documents included other information such as pauses, laughter and sighs. Transcribed files were uploaded into NVIVO

for initial reading and identification of themes. Nvivo was used to read the transcripts through and code with initial themes and concepts.

Data analysis

In the data analysis stage, the two interviews for each participant were treated as one body of data and one narrative was created from the content of both interviews. Each narrative was focused around a specific event from the interviews and the events surrounding it organised into a coherent whole to form a story. The process of data analysis took place in three stages and is discussed below. The approach to data analysis was inspired by Lindseth and Norberg's (2004) approach to narrative method for researching lived experience. Their approach was developed to analyse ethnographic data, however, their recursive approach felt relevant to this research also. Lindseth and Norberg's (2004) approach involves reading the text to develop a naïve impression, breaking the text down into meaning units using thematic analysis, developing the coherent whole then moving back through to the naïve interpretation to check understanding. The process of analysis was also guided by Polkinghorne's ideas of emplotment and narrative configuration as analytic tools (1995). The analysis was guided by questions such as, "how did this event happen?" and "why did this event come about" as suggested in Polkinghorne's work (1995, page 15), I then looked for pieces of information that could contribute to a story to answer these questions. As Polkinghorne suggests, analysis was completed in a recursive fashion (1995) and involved re-visiting the data and the emerging plot multiple times.

The first stage of data analysis was an initial reading of the transcribed text. This was intended to get an initial impression of the content of the data. I noted my thoughts and feelings about the text, main events, or incidents. After the first read through I wrote a paragraph intended to capture my initial interpretation of the text.

The second stage involved re-reading the text and noting any emerging storylines. This stage was completed using NVIVO to facilitate the collection of significant events in each story and to begin noting any similarities across the texts. Events or themes in each story that were thought to be significant or potentially meaningful were highlighted and coded in NVIVO. The use of NVIVO also allowed me to keep a record of my thoughts on emerging storylines.

Following the assembly of emerging storylines I wrote the first draft of each narrative. The choice of event to centre around was made based on the impact on each person's story. From my reading into the feeling of the text I tried to focus on the event that seemed to me the most important and impactful event to the interviewee.

The data collection process was ongoing in that I was beginning data analysis on earlier interviews while still continuing to recruit and interview new participants. Therefore, the process of data analysis can be considered as cyclical as data collection from new interviews informed the next re-engagement with each text. As I wanted each narrative to say something unique about the experience of going through cancer care as someone with a disability, it was necessary to re-engage with the texts and the initial narrative created with an increased understanding and knowledge of the phenomenon under investigation. Figure 13 below demonstrates the data analysis process.

Figure 13 showing qualitative data analysis process
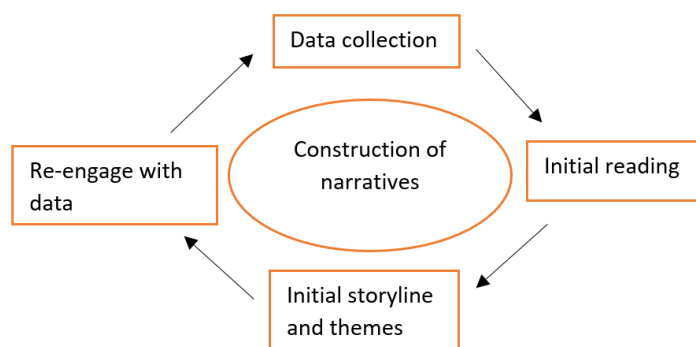
Narrative synthesis

After each narrative was finalised, I began to look over the common threads noted during my initial readings and noted the commonalities coming through from the finalised narratives. The aim with creating a synthesis of the themes across the narratives was not to amalgamate the experiences, rather it was to broaden the understanding of the commonalities and therefore the distinctive qualities of the experience of going through cancer care as someone with a physical disability.

Ethical considerations

This project was approved in the first instance by the Research Ethics Committee of the School of Healthcare Sciences at Cardiff University in July 2019. Alterations to the ethical approval were submitted and approved in January, April and May 2020 to reflect the changing approach to data collection due to the pandemic restrictions. Ethical considerations throughout the research design, data gathering, and data analysis stage are detailed below and include informed consent, confidentiality and accommodating emotional distress.

Informed consent

Informed consent was gained from each participant following their appraisal of the information pack (appendix 9) and knowledge that the participants could withdraw from the study at any time was imparted.

Confidentiality

Participants names and details were kept in an encrypted excel file and pseudonyms were created for use in the narratives. All identifiable information such as hospital names and names of people were removed from interview transcripts. Participant interview data was kept on a password protected personal computer.

Accommodating needs/emotional distress

It is acknowledged that the telling of experiences around cancer could be emotionally distressing for interview participants, participants were informed that they could withdraw from the study or stop an interview if they were feeling under too much emotional strain. As the narrative interviewing technique allows for the interviewee to guide the interview as much as they wish, with little to no input from the interviewer, it was hoped that participants would discuss issues they felt comfortable with. It was also acknowledged in the consent form that there was no necessary benefit to participants in taking part. However, it is hoped that the results and dissemination of the findings will result in improved cancer care for people with physical disabilities in Wales.

Chapter summary

This chapter has outlined the methodology and methods for conducting the data collection and analysis of the qualitative portion of this research. Narrative inquiry methodology was introduced and explored. The methods for data collection, including steps taken for recruitment and narrative interviewing techniques, were discussed along with the approach to data analysis and ethical considerations. The next chapter will present the results of the narrative inquiry in the form of individual narratives from the five participants.

Chapter 10: Narratives of cancer experience

Introduction to chapter 10

The previous chapter outlined the methods adopted for the qualitative part of this thesis. This chapter presents the narratives created to present the experiences of the five participants who self-identified as having a disability and had gone through cancer care. The preceding chapters presented the results of the quantitative analysis of this thesis. The results demonstrated some disparities in cancer outcomes for people with pre-existing disabilities in Wales. The narratives presented here aim to illuminate the very unique experiences of each person, each with their own disability related needs, types of cancer, treatments, and stage at diagnosis. Each narrative will be presented separately to allow for focus on the individual experience of each participant. A synthesis highlighting some of common themes across the narratives is presented at the end of this chapter.

Lisa's story

Introduction

...If I just sat and just thought, well, someone will pick me up at some point

and do something with me, I'd be dead now.

Lisa is in her forties; she works as a counsellor and lives at home with her two children and her husband. Lisa was born with spina-bifida, a visible disability as she is paralysed from the waist down and uses a wheelchair. I spoke to Lisa in her home via Zoom on two occasions both in May 2020, a few months into the first lockdown in the U.K. During our interviews,

Lisa explained that her job as a counsellor takes place at a GP surgery, and it was in fact her colleagues there that examined her when she thought she had a cellulitis infection. This suspected cellulitis infection turned out to be a sign of bladder cancer. After the suspected infection did not go away with antibiotics, Lisa's colleagues suggested she go to A&E. From there, she was admitted to hospital under the urology department.

Lisa's experiences of cancer care will be explored, starting with a pivotal action Lisa took prior to her cancer surgery. The events that led to Lisa making this decision will be discussed to illuminate the tensions, barriers and possible discriminatory attitudes Lisa experienced which led her to take action.

Waiting for surgery

After her admission to A&E, Lisa told me that she had spent a few weeks in hospital under the urology department undergoing investigations which had led to a diagnosis of bladder cancer. Following this, Lisa was at home with a surgery date in place when she started to feel that she was nearing end stage as she was feeling increasingly weak, and her skin had begun to break down. Lisa expressed that she felt at the time that if she had waited the 6 or so weeks until her surgery, she wouldn't survive. In Lisa's words:

> *I had been scheduled for surgery on July 11th so we're talking, actually*
>
> *we're talking, they found it on the 15th of April, we're now looking at*
>
> *11th July, me having to go in, and I just thought I'd be dead by then.*

Propelled by this feeling, Lisa felt compelled to take action. Lisa says she searched online for the email of the surgeon that was due to perform her surgery. Lisa then emailed telling them her story and asking if her surgery date could be moved forward. Lisa told me the surgeon replied on the same day and informed her that there was an audit happening later that month, which meant the surgery rooms were not in use on that day so her operation could take place

earlier in June. In her discussions with me Lisa expressed her relief and surprise that the surgeon put in a request for the surgery to take place on that day and it was accepted. Lisa feels her intervention and the surgeon acting on this promptly are part of the reason she is still alive today as her surgery was performed two weeks earlier than originally scheduled. Lisa expressed her feeling towards the surgeon:

> *I was a bit cheeky sending him that email, I don't suppose he gets many*
> *emails like that, but he didn't say how dare she, he listened, and he did*
> *something about it.*

Delays to Lisa's diagnosis

Lisa's experiences prior to this might go some way in explaining why she felt she had to take action herself, rather than let the system run its course. Prior to sending the email to the surgeon Lisa told me she had experienced delays to her cancer diagnosis and investigations while in hospital. Firstly, the delays to Lisa's diagnosis of bladder cancer were related to the lack of suitable equipment at her GP surgery. Lisa said she first suspected something was wrong when she was experiencing repeated urine infections, months before her admission to hospital. She told me she was not examined at this time due to the fact the GP did not have the suitable equipment to transfer her from her wheelchair to the examination bed. This resulted in Lisa being admitted to the urology department for investigations months later, via A&E, when the suspected cellulitis infection did not go away.

Further to this, Lisa told me that when in hospital undergoing investigations, her diagnosis and treatment were delayed further due to a staff error. Lisa said she was sent home prematurely by her urology consultant which meant she was transferred to a different clinical pathway; Lisa believes this delayed her having an MRI scan and subsequently her treatment. Lisa retold the moment she was told to return home:

I'll never forget how he came into my room and said I think you should go

home for two weeks. And then just put me, he knew he was putting me in

a different system, I didn't know that. He knew he was slowing down what

was going to be happening to me by doing that.

Feelings of discrimination

As well as the administrative and equipment related delays, Lisa relayed events in her cancer

journey that led her to a belief that she was discriminated against as a woman with a physical

disability. The results of these events possibly also led to delays in treatment and left Lisa

feeling as though the staff did not think her life was worth saving. As an inpatient on the

urology ward Lisa told me that she felt she was repeatedly ignored by the staff there and for a

while what was going on wasn't communicated to her. In addition to this, Lisa said she saw

an oncologist towards the end of her two weeks stay in hospital, which formed part of the

evidence for Lisa that the staff did not act quickly enough on her behalf. Lisa expressed the

feeling in this way:

And they walked past the end of my bed everyday they just kind of came

in, looked at me, said my name, looked at my chart, put it back and walked

on. And it happened every day, nothing was said to me and I was pulling

my hair out! It's like, do something I'm dying here, and I've got children at

home! And yeah, it was a long time, well it felt like a long time until I got to

see the oncologist um but I'm really glad that they did let me see her in the

end.

As mentioned, Lisa said she did eventually have a conversation with the oncology consultant, during which Lisa told me she brought up the fact that she had had two caesarean sections. Lisa thought the consultant appeared shocked and it was revealed that the consultant had not been aware of this information, even though she had been in every one of Lisa's multi-disciplinary team meetings. Lisa felt the consultant not being aware of basic information about her embodied the feeling that the majority of the staff she had encountered had not given her diagnosis, investigations and therefore her life adequate attention. Lisa questioned in our interview why the fact she had had two children had not been communicated and whether the staff's attitudes and presumptions about her as a disabled woman led them to assume that she did not have children. Because of this experience and the delay in actually seeing an oncologist, Lisa felt that the urology team had not pushed for her to see a consultant and that their attitudes towards her as a woman with a visible physical disability had led to delays in her diagnosis and treatment. Lisa put it this way:

> *It was her saying to me 'no one's told me that you had children up to this*
> *point' that made me wonder whether in some way, and this is my*
> *overriding feeling that has really stayed with me, is that I feel that I as a*
> *disabled person, I was treated differently, that…the urology team in*
> *[hospital] had decided that in some way I wasn't worth saving. They hadn't*
> *really pushed to get me to an oncologist, they hadn't told her the full story.*

Compounding Lisa's feeling of being dismissed by the urology team, Lisa told me she found out later down the line that the urology consultant had presented her as a case for surgery to remove the cancer, but she had been turned down. Lisa then explained that at a later date the oncology consultant presented her case again to the surgeon and Lisa was accepted. Lisa explained:

> *I found out later from that oncologist that they [urology team] had*
>
> *presented me already to the surgeon…who in such a way that he had*
>
> *turned me down to surgery. She then presented me… in a different way*
>
> *and he accepted my case. And, um, so anyway…and that's one part of it,*
>
> *and this again follows my belief about the attitude to me as a disabled*
>
> *person.*

Post-surgery

After her surgery Lisa told me she spent a period of convalescence in hospital, followed by some time recovering at home with the support of her husband and district nurses for the first few weeks. Lisa tells me she is now cancer free, and she shared with me some of the physical changes she has had to adapt to since surgery, such as the use of a colostomy bag and remaining areas where her skin is yet to heal. Following her experiences of cancer care, Lisa's focus appears to be a will to prevent others with physical disabilities going through similar experiences. For example, Lisa told me she had created a petition for hoists and adjustable equipment to be available at all GP surgeries in Wales which she was enthusiastic about taking further.

Summary of Lisa's story

Lisa's story demonstrates her will to survive when faced with a healthcare system that does not appear to value her life. Lisa's story is fraught with disability discrimination; Lisa encounters individual staff's potentially discriminatory and dismissive attitudes towards her, such as the staff on the urology ward and the initial urology consultant who possibly caused delays by putting her on another pathway. Lisa's story is indicative of an arguably more insidious discrimination also, that of institutional discrimination. With the hindsight of her diagnosis, the beginning of Lisa's cancer journey was the missed opportunity for her GP to

catch her cancer earlier by examining her there and then. However, due to the lack of equipment Lisa's cancer went un-diagnosed for longer than it necessarily would have. Lisa is helped along in her fight to survive by a few members of healthcare staff that listen and act on her behalf such as the oncology consultant and the surgeon. But the clear hero in Lisa's story is herself, she fights for her right to survive and for her life to matter to the healthcare staff and to the wider system.

Claire's story

Introduction

We're…definitely on a conveyor belt going along, if there is not a conveyor

belt there's nothing for you.

Claire and I spoke over zoom in May and June 2020. Claire chose not to have her video on for the first interview but turned it on for the second, allowing me to gauge more of her facial expressions and feeling of the story she told me. Claire was diagnosed with breast cancer after finding a lump in 2016. Initially, Claire told me she was reluctant to see the GP to get it checked as she had had a previous negative experience with a mammogram. Claire relayed to me that she had tried to get a home visit from her GP as she is in bed most of the time due to her illness, but this did not materialise, therefore Claire had to find a time when she had enough energy to make a trip to the GP surgery. Eventually, she did get the lump checked and it was confirmed to be cancerous. Claire has Myalgic encephalomyelitis (ME) and Postural tachycardia syndrome (POTS) which leave her with extreme fatigue, muscle pain and an increased heart rate upon sitting or standing, among other symptoms.

The dual burden experience of Claire as someone with a debilitating, hidden disability going through cancer is explored here through an event that occurred 18 months into Claire's cancer

journey. The event is seen as a culmination of challenging care interactions during Claire's chemotherapy, demonstrating the personal fight against ME/hidden disabilities stigma and for recognition of her disability related needs that Claire went through. Claire's story also shows a wider fight for resources within the NHS context Claire received her cancer care in.

Uncomfortable comments

Claire told me she was nearing the end of her chemotherapy treatment for breast cancer when she contacted a MacMillan counsellor to support her to confront her oncologist over attitudes and behaviour towards Claire that she had found upsetting. Claire explained that a meeting was set up with the Oncologist, Claire, and the MacMillan counsellor. In the meeting, Claire told me she was able to express how the Oncologist had made her feel since the beginning of her chemotherapy. In our interviews, Claire said that the oncologist had repeatedly made comments related to Claire's use of a wheelchair which had made Claire feel uncomfortable. Claire told me the meeting did not go well, that she had left crying and that the experience overall was horrible. To begin to understand why Claire called for this meeting and Claire's response to the difficult relationship she experienced with her Oncologist, I will explore the events leading up to this moment as told by Claire.

Claire's chemotherapy

Claire's chemotherapy treatment had been administered, Claire told me, over an 18-month period. During this time Claire experienced, in her words "horrendous" side effects which left her in bed more often than she had been before chemotherapy and unable to bathe or feed herself. Claire described it like this:

> *I was just getting weaker and weaker and sicker and sicker as it went on,*
>
> *the work that I had to do was making my ME much worse, my POTS was*
>
> *much worse and I had just overwhelming symptoms and side effects from*

the drugs, and allergic reactions to virtually everything, rashes,

swelling, inflammation as well that I had to cope with. And my body was

swelling up, I was putting on weight, I was getting more and more

swollen.

Over this period, Claire told me she had some interaction with her Oncologist which Claire described as being repeatedly strange and uncomfortable. Initially, Claire expressed feeling lulled into a false sense of security as on their first meeting the Oncologist said she did not know what ME was. This signalled to Claire that the Oncologist may not hold some of the stigmatizing attitudes towards the diagnosis of ME that other healthcare professionals had demonstrated towards her in the past. Claire went on to say that the Oncologist's initial naivete around ME did not spare her from trivializing and belittling comments. These comments were directed particularly towards Claire's use of equipment such as walking aides and wheelchairs when coming in for her cancer treatment. From Claire's point of view, the Oncologist seemed to demonstrate a distinct lack of understanding around the physically disabling nature of ME, significantly damaging their interactions. Claire said of these interactions:

It was fairly constant. Each appointment it would be something strange, it

was either going to be ME or it was going to be weight, or it was going to

be something really strange, such as coming to the end of treatment with

her and saying well the thing you've got to do now is go out running. 'Well,

how do you expect me to do that?' 'Well, you'll just have to, you'll just

have to stand up and go out running'. 'Well, you do realise that will make

my ME much worse? I'm going to be more bedbound'. And she just simply

didn't believe it, she couldn't understand, so I said 'well, what else can I

do? What can I do within the limits of my disability?' And she was

stumped.

Claire's reported interactions with the Oncologist throughout her chemotherapy demonstrate the lack of awareness and understanding the Oncologist had about ME and the result for Claire was a distinct lack of help with her disability related needs which were exacerbated by going through chemotherapy. Claire reflected in this way:

... there were times, for instance, when my oncologists said, "I didn't think

you were going to make it through chemo", but there was no help to make

it so that I could make it through chemo.

Claire said the chemotherapy unit itself was a space in which she had to push to get her disability needs recognised. Claire described the chemotherapy unit environment in vivid detail. Claire painted a picture of a loud, busy and stiflingly hot room where, in Claire's words, it was "survival of the fittest". Finding herself in this somewhat overwhelming environment whilst having her chemotherapy administered, Claire felt her needs were not being catered for. For example, she found that the reclinable chemotherapy chairs were impossible for her to recline because she was physically too weak to pull the lever. During one of her chemotherapy sessions, Claire said she noticed that there was one hospital bed in the chemotherapy unit that was being used on and off by elderly frail patients. When the bed became free Claire said she spoke up and insisted that she be given use of the bed so she could get through the chemotherapy with less impact on her ME symptoms. Claire explained that she was met with resistance:

I had to insist quite forcibly with the team there to ensure I got that bed

now (laughter). That was my bed, and I could pull the curtains round and

have privacy and I could...actually lay down as well and it was by the door

as well so there was a bit of staff, but I had to fight for that. But they tried

everything, they tried guilt tripping and you know the whole lot...to try and

get me to be a bit more quiet and stay in my place but I couldn't, it was

just horrible.

NHS resources

For Claire, receiving chemotherapy in this busy environment also showed a lack of resources in the NHS hospital she received her care in. In reflecting on her fight to be recognised as someone with a disability in previous healthcare interactions (pre-cancer), Claire noted that with cancer care there was an additional struggle:

With breast cancer it was just a different fight. I was fighting for resources

that weren't there.

The lack of acknowledgment and catering towards Claire's needs during her chemotherapy by the healthcare professionals and the wider healthcare system left the onus of getting through and arranging services in a way that helped on Claire. When Claire mentioned getting around the hospital in a wheelchair at one point, I asked her if the hospital provided it. Claire's response shows the extra work she had to do to get through her cancer treatment and the emotional toll this took:

No, it was my own, the hospital was not prepared to provide me with any

equipment. Yeah, there was nothing from them... I was having to ring PALs

[patient advise and liaison service] and the head of cancer services and the

head of this and whatever and I just couldn't do it, I couldn't have the

treatment plus fight them all the time. It was just undoable; I couldn't do

it.

Along with the stress of fighting for space and general resources in the NHS chemotherapy clinic, Claire found there was no service for her to help with getting to and from the clinic for appointments. Claire expressed the consequences of this in a humorous way but with serious undertones:

> *There was just nothing for bedbound and housebound people, there was*
>
> *no service, it was like…if you can't go to the hospital, you can't get your*
>
> *chemo and if you can't get your chemo you're going to die (laughter).*

Furthermore, despite having asked for the hospital to arrange care staff to come in to help her with her self-care needs after chemotherapy, Claire said she was left to recover and cater to her self-care needs alone after the chemotherapy and did not feel supported by the healthcare staff in this regard either.

The outcome of the meeting

In our interviews, Claire expressed that the emotional toll of receiving dismissive comments around her disability and having to push to get her disability needs acknowledged during her chemotherapy was unsustainable, and therefore she felt compelled to call the meeting with the oncologist to try draw this to her attention. In our interviews Claire did not go into detail about the experience of the meeting but told me the outcome of the meeting for her was unsatisfactory and demoralizing. Claire expressed that not only was the meeting itself emotionally difficult, but there was also no follow-up from either the Oncologist or the Macmillan counsellor.

Summary of Claire's story

Claire's experiences provide a unique insight into the experience of a severely disabled person with a hidden and stigmatized disability going through cancer. Claire tells her story from the perspective of someone who has historically had multiple struggles with the

healthcare system due to her diagnosis of ME. Claire relayed previous instances where her disability had been dismissed and trivialized and she had this in mind when approaching the healthcare system with her diagnosis of cancer. Claire described the fight to get her ME recognized prior to her cancer and her cancer story is centered around a fight for recognition also, with the additional fight for NHS resources. Claire came across as a bold and confident personality and with her prior experience seemed to feel equipped to fight for her needs to be met. However, even with Claire's spirit and sense of humor she describes the uphill battle as exhausting and extremely difficult as someone who is dealing with extreme fatigue when also going through a life-threatening illness such as cancer.

Susan's story

Introduction

I feel I've had to push and kick, excuse me, kick ass all the way through to

get what is needed.

Susan is 66 and her daughter, Jane, is 36. Jane has spina bifida and has limited use of her lower body, her disability is visible as Jane gets around on her arms when in the house and uses a wheelchair when out and about. Susan is Jane's main carer and usually has the support of Jane's brother, her daughter in law and her sister. However, the interviews I undertook with Susan were completed in September 2020 when many clinically vulnerable people were asked to shield themselves due to COVID-19, so Susan had very little practical support during the time of the interviews. Susan took part in the interviews with me on behalf of Jane as, Susan told me, Jane had recently experienced a change in her speech which meant she felt embarrassed to talk to people on the phone. Jane was informed about the research via Shine, the spina bifida charity. I communicated with Jane via email to set up the interviews and Jane

suggested her mother do the interviews on her behalf. The story presented here is about Susan's perspective of caring for Jane during her cancer journey.

In our interviews, Susan demonstrated to me through multiple examples of healthcare challenges Jane had faced prior to having cancer, that she has borne the brunt of administrative duties and has advocated for Jane throughout her life when she has felt care has been inadequate, and Jane's cancer journey seems to be no exception to that.

From the diagnosis stage onwards, Susan appeared to have had to chase healthcare staff for appointments, results, and safe care for her daughter. Susan started telling me the story of Jane's cancer journey at the point that Jane discovered that her nipple had inverted one day and reported this to her mother. Susan told me that initially doctors dismissed the idea that Jane might have breast cancer because of her young age. As a result, Susan said she made urgent calls and chased doctors to get Jane an earlier appointment than was originally given. Jane was diagnosed with breast cancer weeks later. Jane decided to have a mastectomy as she said she would "…rather be alive with one boob than dead with two" to her mother. Jane had the operation and spent one night in hospital.

By exploring Susan's perspective on Jane's care during her overnight stay in hospital after her mastectomy, we can begin to understand the experience of caring for a family member with a physical disability going through cancer. Touching on some of the concerns, battles, administrative work, and stresses that this can entail. Susan's view of three incidents that occurred during Jane's overnight stay will be discussed.

Jane's overnight stay in hospital- the fluid drain

During our first interview, after detailing Jane's journey to a diagnosis of breast cancer, Susan told me about Jane's overnight stay in hospital after having her mastectomy, which she described as a "shambles". Susan expressed multiple times throughout our interviews that she

felt relieved that Jane was only in hospital for one night because she did not feel Jane was safe on the ward. One of the examples Susan used to illustrate this feeling of Jane being unsafe was centred around the drain used to remove fluid from the surgery site. On the ward with Jane, before leaving to go home for the night, Susan said she kept checking the tubes and thought it was odd that there was nothing coming out. Susan relayed to me a conversation she was present for between Jane and the surgeon the next morning:

> Then when the surgeon came round in the morning, he said, "how are you?" and she said, "I'm in pain" and he said, "well you shouldn't be in pain because they've put a block in" and then he checked the drain and he said, "Oh my God, no wonder you're in pain they haven't turned the drain on". So, all the fluid was building up in the cavity where they had removed the breast and once he opened up that all the fluid came out and the pain went.

Jane's overnight stay in hospital- inappropriate equipment

Susan told me that on her return to the hospital in the morning, when speaking with Jane about her experiences the night before she said Jane told her that she had waited over 20 minutes for staff to bring her a commode. Susan added to this that when she was there, she saw the staff using a cardboard commode for Jane's toileting which was inappropriate for Jane and as Susan put it, it "got squished", which resulted in urine seeping into the bed. Susan said when she informed nursing staff about this, she was met with assurances that the healthcare assistants would come and attend to it soon. However, Susan made it clear to me that she didn't feel assured about this as she could see four healthcare assistants standing around looking at their phones. Susan's feeling about the situation can be seen in the following excerpt:

You know, I had to go and ask, I had to go and ask for the cardboard

inserts and even the outer one that the cardboard went in. Things like that,

they should have been aware of. But, like I said, I was just grateful she was

only in there one night, I would have been pulling my hair out thinking

about her there, cos they said, "oh we thought you were staying, we've put

the mattress on the floor", I said "no, I have to go home" … it's less work

for them isn't it then?

Jane's overnight stay in hospital- asking for a care package.

Connected to these events, Susan also told me that on the advice of Jane's keyworker from

the spina bifida charity Shine, she had insisted on Jane having a care package put in place for

her return home after her surgery. Susan was aware however that after surgery on her upper

body, Jane might find crawling difficult. Susan said that she was met with surprise:

When I said about having a care package in place they said "Oh, why

would you need that? We've never had anybody before, er, that's had a

mastectomy that needs a care package" and I said, "well, Jane can't walk".

And they said "Oh", you know, they obviously don't read the notes.

These three incidents connected to Jane's overnight stay in hospital, told from the perspective

of Susan give us an insight into the experience of caring for someone with a physical

disability going through cancer. With an understanding of Jane's overnight stay in hospital as

told by Susan, further aspects of Jane's cancer care will be explored on two fronts. Firstly, the

incident involving the use of the inappropriate commode is seen as an example of Susan

'doing the work' and advocating on Jane's behalf to get appropriate care. Other examples of

Susan 'doing the work' were demonstrated in my interviews with Susan and will be explored

further. Secondly, the discussion Susan had with staff around getting a care plan put in place

after the surgery highlights advice and support from Jane's spina bifida key worker that seemed to help Susan and Jane throughout Jane's cancer care.

Susan 'doing the work'.

The incident in the hospital where Susan had to ask the staff for appropriate equipment for Jane's toileting demonstrates the work Susan had to do to get Jane's needs catered for during her cancer care. Susan felt that the staff showed a lack of awareness of Jane's disability related needs which meant Susan had to inform them repeatedly. Other examples Susan told me of this type of work included when carers came in after Jane's mastectomy, Susan felt they were not informed about Jane's needs prior to coming to see Jane:

> *So, it's information really was the main problem, and I don't feel it should*
>
> *have been down to me every time to explain what was happening, what*
>
> *she'd had done, why she can't wash herself, why she can't wash her hair.*

Other examples of Susan doing the work to get Jane's needs catered for involve Susan having to chase appointments, results, and search for information regarding Jane's care. Susan put it this way:

> *I feel I've had to push and kick, excuse me, kick ass all the way through to*
>
> *get what is needed.*

Susan cited many examples in both of our interviews about calling different healthcare professionals to gain information about Jane's care, when Jane might receive a particular piece of adaptive equipment for example or to expedite urgent appointments, which seemed to take an emotional toll on Susan:

> *it's stressful… it's really stressful without everything that's going on, you*
>
> *know, looking after Jane and then you've got to ring this one and that one,*

and doctors, and the OT, and the wheelchair people and I've got bits of

paper you know, they don't remember. Ring this one, ring that one and

then you can't get through, then they probably don't get back to you.

Yeah… (sigh) it is stressful and that is all, the mental pressure is …what

um, is crippling, really.

Further to this, when discussing positive aspects of Jane's cancer experiences Susan mentioned that Jane knew what was going on during her cancer treatment. I asked whether Jane felt informed throughout the whole cancer journey. Susan's response suggests that, had Susan not been there to chase the information on behalf of Jane, she wouldn't have been so informed:

Alice: So, do you feel that Jane was kept informed throughout the whole

process?

Susan: Yeah, well mainly because you know, I just kept ringing.

As well as administrative and advocating work, Susan also shared examples of physical care work she undertook during Jane's cancer care. When discussing Jane's experiences of cancer screening services and breast clinics Susan shared this:

As I say, as far as the clinics went, they've all been great, but then I've

always gone with her and I've done any helping her on and off beds and

toileting and stuff like that. You can't expect them to have someone to

help with that.

Support from Jane's keyworker

Despite the stress and emotional toll on both Susan and Jane that came across in our interviews, there seemed to be a clear source of support for Susan throughout Jane's cancer

experience- Jane's key worker from the charity Shine. In the example from Jane's hospital stay she provides Susan with an important piece of advice which was to ask for a care plan for Jane for after her surgery. Susan also cited her support in a range of other areas, such as administrative support:

> *And that's where (Jane's key worker) is good because if I have a problem*
>
> *she will write, she will write to the doctors on my behalf you know?*
>
> *Because she's got more experience, she knows what to say and I'm*
>
> *terrible. I'd rather pick up a phone than write messages or write a letter, so*
>
> *I have got support there and she said to me the other day, "I'm Jane's*
>
> *outreach worker but I'm here for you too". So, she's the only one really in*
>
> *authority that I can turn to.*

Susan clearly showed that as well as practical support, Jane's keyworker provided an element of emotional support to both Susan and Jane:

> *Alice: (talking about positive interactions and support from Jane's*
>
> *keyworker) Do you think that made a difference to Jane's experience?*
>
> *Susan: Oh yes, yeah. That somebody's listening you know, because you do*
>
> *get to a point where you think that nobody cares (pause).*

As a key point of contact for Susan and Jane, Susan's keyworker is seemingly pivotal to Jane's cancer story. She appears knowledgeable about navigating cancer services, Jane's disability related needs and provides emotional and practical support.

After the overnight stay

Despite pointing out to the staff that Jane would need a care package put in place for when she went home, Susan told me that the support for Jane's personal care didn't arrive until a

week after Jane came home after her mastectomy, leaving the personal care tasks to Susan. When carers did arrive, as previously mentioned, Susan felt they were not fully informed of Jane's needs, meaning Susan had to continue to push for appropriate care for her daughter.

At the time of my interviews with Susan, Jane's cancer treatments were still ongoing. There had been delays in Jane receiving her chemotherapy and radiotherapy because of the impact of COVID-19. Jane was also experiencing ongoing healthcare challenges related to her spina bifida which meant she was experiencing a lot of physical pain at the time. Susan revealed there were ongoing stresses related to getting the right type of care for Jane, but Susan was optimistic about the future for her daughter and as COVID-19 restrictions were slightly eased at this time Susan was looking forward to regaining emotional and social support from friends and family to help both her and her daughter through.

Summary of Susan's story

In this narrative, Susan plays many roles. She is a parent watching her daughter go through cancer, sometimes she is Jane's carer, Jane's main advocate, a witness to poor care Jane receives and Jane's voice at times. Susan is experiencing an emotionally challenging time and her emotions are central to this narrative, even though the story is focused on her daughter, Jane. Susan's story highlights the personal work that a loved one of someone going through cancer or someone going through cancer themselves might have to go through, for example Susan is seen chasing appointments and results. Susan's story also shows the additional work she had to do as someone caring for a family member with a disability, she witnesses unsafe care, is expected to do care work for Jane when Jane is in hospital and pushes for Jane to have a care package on return from the hospital. Susan is 'doing the work' at all points of this narrative, emotional work, administrative and physical. Susan rightfully expects that healthcare staff will be aware of Jane's needs as Jane's disability is visible and she has had it

since birth. However, Susan finds Jane's very visible disability is rendered invisible by the healthcare staff's lack of knowledge and preparedness to cater for Jane's needs.

Ann's story

Introduction

it was all very frightening anyway but to be given advice by people who

obviously don't know what it's like to have ME...

Ann and I spoke over zoom on two occasions in September 2020. For the first interview Ann did not have her video on but had it on for the second interview. Ann lives with her husband and has two adult children. Ann suffers from Myalgic encephalomyelitis (ME) which she believes she developed during her first incidence of breast cancer in 2003. Her ME was diagnosed four years after this after experiencing several years of extreme fatigue, low blood pressure and poor circulation. Ann told me that in 2018 she received a second diagnosis of breast cancer. Due to the cancer being in the same breast Ann was unable to have radiotherapy, therefore Ann had a mastectomy and chemotherapy to treat her second episode of breast cancer. Ann spoke in our interviews of her experiences of both cancers, citing them as very different experiences, due in part to her ME symptoms that were present during the second occurrence. Ann expressed difficulties related to the NHS context she received her care in in both instances of breast cancer, however the second diagnosis, brought forth further challenges for Ann due to her ME symptoms and possible stigmatizing attitudes of healthcare staff towards this invisible disability, which will be explored further. Ann's journey demonstrates the different levels of knowledge of ME that the various healthcare professionals she interacted with held and we will explore the differential impacts these had on Ann.

Ann's mastectomy concerns

The first line of treatment for Ann's second diagnosis of breast cancer was a mastectomy. Ann told me that prior to going into hospital to have the surgery she had read information online related to the negative impacts that anaesthetics can have on the immune system of people who suffer from ME. Equipped with this information, Ann said she wanted to discuss the options with the anaesthetist. Ann recalled in our interviews that she had felt more scared about receiving the anaesthetic prior to surgery than of the surgery itself. Ann told me that when the opportunity did arise for her to speak to the anaesthetist, she found him to be very dismissive despite claiming to be aware of ME as a condition. Ann said of this interaction:

> *...he didn't want to acknowledge that ME was a problem and I asked him if*
>
> *he knew about ME and he said, "oh, I've operated on loads of people with*
>
> *ME, they're fine" and he wasn't gonna consider any changes or anything*
>
> *different. So that, that made me angry and concerned.*

Ann remembered feeling a sense that the anaesthetist was only interested in her signing the form to consent for surgery and did not want to spend the time allaying her fears or discussing options. Ann told me that she was aware that she did not have any other option than to sign the form as she had to have the surgery to save her life, however she was left with her fears unresolved and a sense of frustration. In Ann's words:

> *...for him not to accept that, it was very frustrating and... I didn't have any*
>
> *confidence in him. I wasn't going to not sign it and not have the operation,*
>
> *but I didn't have any confidence.*

Following this, Ann went on to tell me that she was also able to speak with her surgeon prior to her mastectomy. Ann had been concerned that she might take longer to come around after

the anaesthetic due to her ME. Like the anaesthetist, the surgeon also said he knew what ME was. Ann expressed that she doubted whether this was really the case because the surgeon was a retired consultant that had been brought back due to understaffing. Ann said she held this belief because, in her previous healthcare experiences older doctors had demonstrated that they did not have much knowledge or belief in the condition. However, Ann was surprised by the surgeon's actions as he moved her surgery so that she was first in the schedule for that day. The result of this was that Ann had more time in the recovery room after her operation and as Ann had predicted she was the first to go in for surgery but the last to wake up on the day in the recovery room.

Ann's chemotherapy

Ann told me that her approach to dealing with healthcare professionals she had encountered since having her diagnosis of ME was to assume that she probably knew more about the condition than they did. Therefore, prior to receiving chemotherapy Ann told me she also did her research on the effects of chemotherapy drugs on people who have ME and wanted to discuss this with the oncology consultant. Ann expressed her relief that the consultant was open to talking about the interactions of ME and chemotherapy. Ann told me, the consultant explained that recently he had treated six people with ME and three had survived. Ann said, although the information he presented was slightly unsettling she appreciated that he had been open and acknowledging of her condition. Ann said she also appreciated the fact that the option was completely left up to her. Ann chose to go forward with the chemotherapy despite her concerns.

Ann then went on to detail her experiences of receiving chemotherapy which, in her words, showed "the usual NHS gripes". By this it became clear that Ann was referring to long waiting times, administrative errors and understaffing. Although Ann presented these issues as very normal in the NHS, through our conversations Ann expressed that the impacts of

these usual gripes were especially taxing on her as someone with ME. Ann explained to me that in her day-to-day life pacing is very important to deal with the fatigue she experiences, therefore an event such as going to the hospital can be very disruptive and means a large expenditure of energy. For example, Ann explained that on one occasion her entire trip to the hospital to get her peripherally inserted central catheter (PICC) line fitted prior to her chemotherapy was wasted. Ann put this down to the staff being overworked. Ann described a busy environment in the unit where the PICC line was to be fitted. Ann told me that the nurse that attempted to fit the line could not find a vein and after a few attempts threw the equipment down and stormed off. This meant that Ann had to return another time to get her line fitted and her chemotherapy that had already been delayed due to administrative delays was pushed back even further.

When Ann did receive her chemotherapy, she described an environment that was loud, hot and overcrowded. Ann said she had long waiting times to been seen for her appointment in this environment, Ann described the impacts:

> *I just had to sit there but that in itself is very fatiguing. And even without*
> *ME, I know from the first time just sitting in a waiting room waiting for*
> *results or something is really quite stressful, so we were surrounded by*
> *people that were equally as stressed and sometimes there wasn't even*
> *enough chairs to sit on in this place... So, it was all a bit irritating and...*
> *there were times where I know I came home far more exhausted than I*
> *needed to have done because of that experience.*

Due to these experiences, Ann explained the overall mindset she had when approaching the hospital environment and staff during this time:

> *The feeling I got from the hospital was that it was just chaos, and you were*
>
> *lucky if you survived it really. Then you've got to keep on your toes to you*
>
> *know, keep them with you sort of thing.*

Post chemotherapy

After receiving chemotherapy, Ann told me she had growing concerns around a type of medication she was using which was related to her treatment. Ann decided to speak to the Macmillan nurse about this as she was feeling that the medication was further depleting her energy levels. To Ann's disappointment, she received advice from the Macmillan nurse that she needed to do more exercise to feel more energetic. As Ann explained in our interviews, she felt this was inappropriate advice for someone with ME as exercise can make symptoms worse, instead, further rest is often more helpful. Knowing that she had more knowledge about how to manage her ME than the Macmillan nurse, Ann explained that she ignored the advice and continued to manage her fatigue in a way she felt was best for her. Ann said about this advice:

> *But when you're told that, I know a lot of people now with ME, we have a*
>
> *big support group, it's good. Um, and if you're told that you just agree and*
>
> *go away and do something different because there's no point in arguing.*

Despite the challenges and extra stresses, Ann's treatment was effective, and she now describes herself as cancer free. Towards the end of our second interview, I asked Ann what she felt the NHS trust and the healthcare staff she encountered could have done to make the experience easier for her. In reply Ann said that much of the stress that came with her cancer experiences was due to administrative issues within the NHS and understaffing which all had

an impact on her levels of fatigue throughout her cancer journey. Ann summed up in this way when talking about going through cancer as someone with a long-term condition within the NHS:

> *...they haven't got anywhere near close to dealing with that [ME] because they're not dealing with just 'normal' people.*

Summary of Ann's story

Ann's story is told from the perspective of someone who has experienced two unrelated episodes of breast cancer. As Ann's ME symptoms started after her first episode of breast cancer, Ann was able to reflect on the differences between the two experiences, one being as a non-disabled person and the second as someone with a hidden disability. Ann reflects that there were additional burdens and difficulties going through cancer with ME and that she had to find ways to navigate the system to get the best results for herself. Ann shared examples of using her own knowledge of her ME related needs, where staff's knowledge may have been lacking, to get through the cancer whilst minimizing the negative impacts on her health. Ann's story highlights the importance of knowledge and understanding from staff when it comes to disability related needs and cancer care. Ann's experiences with staff ranged from highly dismissive to understanding and accommodating, allowing us to see the benefits of a healthcare system that is open to listening to the needs of disabled people and trusts them as experts of their own bodies. As Ann said herself, she found it hard to get her disability related needs met in a healthcare system that was struggling to cover the basics, with over-stretched staff and limited resources. Overall, it can be noted that it was Ann's self-management of her condition and knowledge of the cancer pathway that helped her get through this difficult time and to feel confident in speaking up for herself in voicing her concerns.

Sarah's story

Introduction

…they're geared up maybe for a disabled person, but you know once you

turn up two disabled people "where's your carer?'" Well, I don't have a

Carer!

Sarah is in her mid-50s, has spina bifida and uses a wheelchair full-time, so presents as a visibly disabled person. Sarah lives with her husband who is also a full-time wheelchair user. Sarah and I spoke over the phone on two occasions in September and October 2020. Sarah received a diagnosis of breast cancer in December 2017 after she found a lump which was checked out by her GP. Sarah was then urgently referred and decided to have a mastectomy as the first line of treatment. Sarah went on to have chemotherapy, radiotherapy, then targeted therapy for her particularly aggressive form of breast cancer. Sarah expressed difficulties and barriers related to her physical disability when accessing care for every type of treatment for her cancer.

Sarah's story shows assumptions that the healthcare system demonstrated towards her as a physically disabled person. Sarah's story also highlights issues with spaces that are seemingly made accessible as Sarah experienced services which are apparently made accessible but only for those who have an able-bodied carer. Sarah's journey will be explored starting with Sarah and her husband's experience of attending to Sarah's self-care after her mastectomy. The events prior to Sarah's discharge from hospital will be elaborated on and the subsequent difficulties with accessibility of both chemotherapy and radiotherapy from Sarah's point of view are detailed.

Sarah's journey is demonstrative of a complex, seemingly chaotic, and stressful cancer journey with many components and lines of treatment. Rather than have a specific event as the focus in Sarah's story, to attempt to do justice to Sarah's journey and the challenges she faced at almost every turn, I have attempted to outline the whole of her journey as told by Sarah. With the focus then being on the complex, disconnected and uncoordinated nature of Sarah's cancer care. Sarah's story will touch briefly on all of the types of treatments she had, including the challenges and barriers she relayed to me to highlight the complexity of traversing the cancer care landscape as someone with a visible physical disability.

"Just coping" after surgery.

Sarah's story begins with the weeks after Sarah had a mastectomy. Sarah told me she had been discharged without a package of care in place and as she put it her and her husband, who is also a wheelchair user, "just coped". As Sarah is paralysed from the waist down, she usually uses her upper body strength to transfer herself in and out of her chair. However, after her mastectomy she was unable to use her upper body as she normally would. As a result, Sarah detailed to me in our first interview how her and her husband adapted to attend to Sarah's needs post-surgery without the help of healthcare staff.

Knowing that she would not be safe to transfer herself from her wheelchair to the toilet for the first week post-surgery, Sarah said she avoided the use of the toilet entirely. She did so by using a catheter and making herself constipated so she did not need to empty her bowels. Sarah also told me that when it came to washing, she didn't feel safe in using the bath or shower, so for the first 10 days she was unable to wash. After 10 days, feeling slightly stronger Sarah explained how her and her husband negotiated Sarah's safe transfer to the shower:

> *And it sort of involved getting into bed, my husband would sort of get out*
>
> *of his wheelchair on to the floor um so he was sat in front of me so I*
>
> *couldn't fall and then I could sort of get onto the bed and then he would*
>
> *move my chair and then he would lift my legs onto the bed and turn me*
>
> *over, and that's how we sort of managed.*

"Panic mode"

In our interviews Sarah explained the events that led to this situation. Sarah explained that she was aware of the difficulties she would experience post-mastectomy with limited use of her upper body. So, two and a half weeks before her mastectomy was due to take place Sarah told me she had contacted the hospital to try to arrange an occupational therapy assessment. Sarah's intention was to be provided with adaptive equipment and training to use them so she could safely transfer and attend to her self-care after the surgery. Sarah was informed by staff that she would not be under the care of the community occupational therapy team until after her surgery and that she couldn't be seen in advance by the hospital occupational therapist either as they did not cover care in the community. Sarah describes her feeling at the time:

> *so, in the end I saw nobody... you know I had no choice, it was cancer, I had*
>
> *to have the operation. I thought, I'm just gonna have to have it done, and*
>
> *somehow... we're going to have to manage.*

As mastectomies are usually performed as a day case surgery, Sarah explained that she had to urge the staff to let her stay in hospital for at least one night as she knew she would not be able to return home straight after surgery with nothing in place to assist her. Sarah said she was not seen by an Occupational Therapist until the morning after her surgery when they were preparing for her discharge. The following morning then, Sarah described what she felt was the staff going into "panic mode". She said the Occupational Therapist and

Physiotherapist who came to assess her for discharge saw that she could not transfer, as Sarah had tried to warn them, then wanted to "throw everything at it" as Sarah put it. Sarah described how they then wanted to keep her in hospital for a few weeks while they arranged to have a hospital bed and a hoist fitted in Sarah's home and to arrange for carers to come in four times a day. Sarah said:

> I was like "no, no, no, no, no, no, not going down that road, there's no room for me to have a hospital bed".

> I didn't want any of that, I just wanted somebody's help basically to tell me how to transfer basically using the slide boards (laughter).

Sarah told me that, at this point, the staff were attempting to keep her in hospital for longer to arrange extra care that Sarah had expressed she did not want. Sarah then explained how she had to convince the staff that she had an appropriate bed at home that she could transfer from and that her and her husband could manage as she wanted to get out of hospital as soon as possible. Sarah described conditions in the hospital that did not feel safe. For example:

> I was in hospital, on a ward where I had no access to a toilet, where I couldn't get in and out of bed, where I wasn't being turned, where I was at risk of, I was at risk of pressure sores. You know, I knew I was at high risk being left in hospital because the care, with the greatest respect to the NHS wasn't good... I really needed to get home because I knew I would be safer at home.

As previously mentioned, Sarah was then discharged home where her and her husband managed her self-care without the adaptive equipment and training that Sarah had wanted.

Parking and inaccessibility

Following her mastectomy Sarah received chemotherapy, radiotherapy, and targeted therapy. Sarah described difficulties with inaccessible equipment and barriers to parking services when receiving both radiotherapy and chemotherapy. For example, Sarah said the chairs on the unit were inaccessible to her meaning she had to receive her chemotherapy in her wheelchair which meant she had nowhere to rest her arm during the treatment. Also, Sarah said that often the unit was so busy there was no space for her and her husband's wheelchairs to fit in the waiting room, leading to them having to wait for hours in the hospital corridor. Sarah explains the toll this took:

> *It just made the whole thing even more unpleasant and more difficult than it would otherwise have been. You know it's bad enough anybody, for anyone at any time, but you know, when you can't even sit down properly, you're sat out in the corridor for hours on end, when it's difficult to get a drink you know, it just makes it much, much more difficult.*

Further to this, parking was an issue for Sarah and her husband throughout her cancer journey. Sarah explained that often there was nowhere for them to park permanently, only 'disabled drop off' zones. Sarah said these were not useful for her and her husband as her husband was unable to stop, quickly drop her off and then drive on as was intended with the drop off zones. This became a regular burden when Sarah started to receive chemotherapy and subsequently radiotherapy which both required frequent trips to the hospital. Sarah explains:

> *I think when the hospital thinks about disabled people providing access, they always assume the disabled person is going to be with a carer and the carer will drop them off ... they don't think in terms of independent*

> *disabled people you know or who have a partner who is also disabled it's*
>
> *just not really taken into account at all.*

Radiotherapy

Radiotherapy followed Sarah's chemotherapy. Radiotherapy was described by Sarah as the most emotionally and physically challenging part of her cancer journey. As with visiting the chemotherapy unit, Sarah and her husband had the struggle of parking for every visit. Sarah describes the additional physical difficulties associated with inappropriate equipment:

> *In many ways, it was radiotherapy that nearly broke me really and it was*
>
> *just the sheer…um…physical difficulty of actually hauling myself up out of*
>
> *my wheelchair and on to that radiotherapy bench…every day for 15 days*
>
> *was an absolute killer, an absolute killer.*

Sarah went on to describe that along with the physical challenges of radiotherapy, she also faced staff that weren't knowledgeable about her physical abilities, which added to the stress of the experience. Sarah gave an example of an interaction with a member of staff during radiotherapy treatment:

> *…others just didn't get it no matter how many times I told them, so they'd*
>
> *say things like "just hitch your bottom up a little bit, hitch up a little bit*
>
> *you're not quite right" … I couldn't, you know! You may as well tell me to*
>
> *try a bit harder and grow a third leg, I can't do it.*

Searching for support

After describing the emotional challenges of her radiotherapy, Sarah went on to tell me that she attempted to access services geared toward emotional wellbeing when going through cancer which were provided at the local Maggie's centre. Like her experiences of hospital

parking, Sarah found that while her local Maggie's centre had technically provided accessible parking, it was inaccessible for her. Sarah explained:

> *they've got two accessible spaces outside their building, so you know,*
>
> *they've provided access for disabled people. But my husband and I couldn't*
>
> *get our wheelchairs out of the car from those spaces because the car was*
>
> *not on flat ground, it was halfway up a hill. (laughter)*

This meant that Sarah couldn't access vital services to support her mental wellbeing. Sarah told me that she communicated this to her breast care nurse who then made a referral to mental health services and Sarah was provided with a counsellor to speak to. After her radiotherapy Sarah went on to have targeted therapy and reports that she is now cancer free. She has had subsequent MRI scans at the hospital to check for recurrence. Whilst Sarah said that these were still technically and emotionally challenging at times, she now had a mental health professional to talk through difficulties with. Sarah expressed how much the mental health support helped her:

> *I think I would have really, really struggled to cope if I hadn't had that*
>
> *support, if I hadn't accepted that support that was offered to be honest, it*
>
> *was massively helpful, just having somebody to talk to was really, really*
>
> *helpful.*

Lasting effects

As well as the emotional and mental health impacts of the difficulties Sarah had been through during her cancer journey, due to the lack of practical support after her mastectomy, Sarah felt she had put unnecessary pressure on her upper body during this time. Sarah told me that the result of this was a tightening of the muscles under her arms which has led to long term

damage, known as chording. At the time of our interviews, Sarah felt she still hadn't regained full range of movement in her arms. Despite this, Sarah told me she was still glad to have returned home soon after the surgery rather than stay in the hospital for longer as she had felt very unsafe there.

Summary of Sarah's story

Sarah's story is one of resilience and adaptability in the face of a stream of barriers to safe and accessible healthcare. Sarah's story was deliberately written to encompass the array of challenges she faced during her cancer journey. Sarah's story speaks to the notion that whilst cancer is a life-threatening disease, people with disabilities have an extra, arguably unnecessary threat to their lives- unsafe care. Sarah was left with a feeling that she would be safer at home despite having no care package or adaptive equipment made available to her. Sarah and her husband were forced to think quickly and find a way to meet Sarah's needs at home with limited resources available to them. Sarah's voice went unheard on multiple occasions in her story, demonstrating a power struggle in her interactions with the healthcare system. Sarah's voice went unheard when she spoke up in advance of her surgery, when staff did not understand her needs in radiotherapy and when faced with the barrier of inaccessible parking. The structural inequalities such as the inaccessible parking highlighted in Sarah's story show an assumption in the planning of services that all disabled people will have an able-bodied carer with them to navigate the system, rendering those who don't choose to or need a carer further disabled by the built environment.

Narrative synthesis

This section pulls together findings from the five narratives presented in the previous chapter. The synthesised qualitative findings will be used to contextualise the quantitative findings from this thesis but does not attempt to amalgamate the five participants experiences in to

one. Rather, it is an attempt to draw together some threads from the stories which when brought together might help to explore some of the wider issues, power dynamics and inequalities experienced. The synthesis will explore two main thematic threads that appear congruent across some or all the narratives, such as not feeling seen or heard and feeling unsafe. Under the theme of not feeling safe issues such as the participants not being treated as credible witnesses to their own bodily needs is discussed and how this led to needs being ignored. Lack of equipment and accessibility, staff lack of knowledge around disability related health needs, lack of preparation and unsafe hospital conditions are discussed under the theme of not feeling safe. This theme is argued to be connected to the quantitative findings that people with disabilities are less likely to utilise screening services. It is argued that these findings, in collaboration with the quantitative findings point towards disability-based discrimination in accessing and receiving cancer care for people with disabilities.

Before diving into some of the possible threads to pull out across these narratives the contextual commonality of receiving their cancer care in the National Health Service space should be discussed. The well documented struggles of the NHS such as understaffing (Picker, 2020), complex care pathways (Haste et al, 2020), long waiting times (CQC, 2015) and lack of communication between services (Ryan, Pope and Roberts, 2020) play a part in all the narratives presented. As Ann puts it in her narrative, they all experienced the 'usual gripes' of being a cancer patient in the NHS. There was a sense of shared understanding of this across all five of the interviews. Further, there was a sense that while each participant was sensitive to the needs of the service, staff and grateful for this free at the point of care system, the care they receive simply wasn't good enough. At times this not being good enough manifested in the form of an expected irritation such as an overcrowded waiting room to unacceptable and unsafe care. It is arguable that although any cancer patient in the NHS could be exposed to a system that struggles to meet their needs, people with physical

disabilities might be disproportionately negatively affected by things such as delays to treatment or crowded waiting rooms. As we saw in Sarah's story, the overcrowded waiting room for her chemotherapy meant there was no space for her, and her husband's wheelchairs and they therefore had to wait in the corridor.

The shared context of all the participants identifying as women also contributes to the backdrop of the narratives. This is pertinent in obvious ways such as Lisa's surgeon not knowing she had had children and the fact that four out of five of the participants experienced breast cancer, which is more common in women than men. The experience of being a woman with a disability going through cancer is also significant in less obvious ways such as the fact that a diagnosis of ME is more common amongst women; this is significant because of the stigmatization that often comes with an ME diagnosis (Raine et al, 2004). Feminist viewpoints on healthcare suggest that women historically have experienced more dismissal of health symptoms as compared to men (Samulowitz et al, 2018., Andrist, 1997). Literature on experiences of healthcare as someone with ME point to the idea that ME symptoms are trivialized and psychologized (Anderson et al, 2012). This intersection of ME dismissal and cancer care is the most pertinent in Claire's story. We see through Claire's retelling of her experience that she repeatedly telling cancer care staff of her disability related needs which are dismissed and belittled. This leaves Claire dealing with both her cancer care and pre-existing health related needs without support from healthcare staff.

Not feeling seen or heard

This leads to the first thread to be discussed, not feeling seen or heard. There were many instances across the five narratives that left each woman feeling that her needs were not seen or heard. This sentiment was expressed directly and through examples of actions each person took as a result of this feeling. For example, Lisa expressed a very clear feeling that she was not seen when she was on the ward and the staff were walking by without acknowledging her

or communicating what was happening with her care. There were instances in all the narratives where each person's disability was rendered invisible as their needs were not acknowledged. In the cases of Susan and Sarah, they both told me they spoke up in advance of hospital care to express their need for a care package post-surgery, their voices here went unheard, and the care packages never materialized or were given too late. Claire, being non-ambulatory most of the time prior to her cancer diagnosis said she had to use a wheelchair to get around the hospital and was repeatedly challenged on her need for this, demonstrating staff's lack of belief in her disability. Ann felt her voice was not heard on occasions such as her interaction with the surgeon, where she tried to voice her concerns but felt dismissed.

There were varying results of this feeling of needs not being heard, this ranged from actual delays to diagnosis, in the case of Susan and Jane not feeling heard over Jane's earlier symptoms of breast cancer to emotional challenges, such as Claire recalling she had to call the meeting with the oncologist that made her feel uncomfortable. There was a sense across all participants of not being believed or not credited as reliable witnesses to their own bodily needs which negatively affected their relationship and trust with the healthcare system. Previous research suggests in interactions with healthcare providers trust and communication are important factors in facilitating access to healthcare for people with physical disabilities (Walji, Carroll and Haber, 2021). The additional emotional burden of navigating the system and fighting for their right to be seen and treated with respect during an already highly stressful life event came across in all the interviews.

The sense of not being seen or heard as someone with a physical disability undergoing cancer care can relate to the cancer outcomes explored in the quantitative portion of this thesis. Not feeling respected and listened to can contribute to a lack of trust in the healthcare system, which could lead to people with disabilities not wishing to interact with healthcare providers and ultimately missing vital health services like cancer screening. Similarly, if people with

disabilities feel as though their needs are not being communicated to healthcare staff this could lead to healthcare staff missing key information in consultations that could lead to an earlier cancer diagnosis.

Feeling unsafe

The second theme or thread covers the feeling that came through strongly in all the interviews, that of not feeling safe. There were accounts of times where participants did not feel safe or that their care was inadequate while in hospital. The idea of safety was discussed in relation to delays to treatment and diagnosis, feeling unsafe as an inpatient and staff lacking knowledge of health conditions resulting in lack of confidence in the care being received. Examples of participants feeling unsafe whilst under hospital care came from Lisa, Susan (regarding Jane's care) and from Sarah. All three accounts conveyed a sense that they were at risk as an inpatient as care was deemed inadequate and dangerous. Sarah expressed this succinctly when she discussed the fact that she was not being turned or toileted properly which put her at risk of pressure sores. This finding adds to the literature on care experiences for people with physical disabilities and adds to the limited qualitative research on inpatient cancer care for people with physical disabilities.

Feeling unsafe was also expressed in relation to delays to diagnosis and treatment. The healthcare system acting in an efficient way when going through a life-threatening diagnosis such as cancer is of high importance as time delays can mean later diagnosis and higher risk of mortality. The feeling of waiting and delay compounded some participants feelings that not enough was being done on their behalf, putting them at risk of their cancer developing more than it should have done if things were happening quicker. Delays to diagnosis and treatment can occur for anyone in the NHS pathway for cancer care. However, evidence from these narratives suggests that the delays to diagnosis and treatment were related to the presence of a physical impairment. For example, Lisa felt her diagnosis was delayed because

her GP surgery did not have appropriate equipment to examine her when her symptoms first arose. Lisa also felt that staff were not acting quickly enough on her behalf due to negative attitudes towards her as a woman with a visible physical disability. These findings also add to the existing body of literature citing lack of suitable equipment as a barrier to healthcare generally for people with physical disabilities (Stillman et al, 2017., Iezzoni, 2006) and for access to cancer services (Agaronnik et al, 2021).

Further to this, examples from Ann and Claire demonstrated how staff's lack of knowledge about their condition led to feelings of being unsafe. For example, in their stories Ann and Claire told me they came to multiple members of staff to discuss concerns with their condition's interaction with specific treatments due to concerns that this was not being considered. Similarly, Jane felt that during her interactions with staff that they were unprepared and lacked knowledge of her daughters care related needs. It could be argued that staff lacking knowledge or failing to prepare for patient's disability related needs negates from their duty to provide safe and effective care for all patients. Failure to provide this basic level of care for people with disabilities due to either lack of preparation or suitable equipment arguably constitutes disability discrimination. The theme of feeling unsafe could arguably link to all three of the cancer outcomes explored in the quantitative portion of this thesis.

Feeling unsafe was expressed in relation to perceived delays to diagnosis in Lisa's case, where she did not feel staff valued her life enough to expedite her care and an opportunity to diagnose her cancer early was missed due to lack of suitable equipment to examine her. This insight, along with lower uptake of screening services found in the thesis could help us to understand the quantitative finding from this thesis that people with disabilities were more likely to have a later stage at diagnosis than people without disabilities.

Chapter summary

This chapter has presented the narratives of the five participants that took part in the qualitative interviews for this thesis, along with a synthesis pulling together themes seen across the five narratives.

Chapter 11: Reflections

Introduction to chapter to chapter 11

It is important to be a reflexive researcher in order to learn from experiences and apply lessons learned in future research. This chapter will reflect on experiences of conducting research during the COVID-19 pandemic, use of routine data in healthcare research, the experience of conducting the qualitative interviews for this PhD, my positionality as a researcher and the potential impact on findings.

Impacts of COVID-19

On this research

This research began in October 2018, so much of the planning and development stage was done pre-pandemic. The first lockdown in the U.K. started in March 2020 when I was due to begin recruitment for the qualitative interviews. The plan had been to conduct the interviews in person, so this of course had to change to remote interviewing. The pandemic also changed the course of the quantitative part of the research as the company responsible for providing the data channeled their focus to prioritize COVID-19 data projects. This resulted in a delay to accessing the data. Due to these changes and the general stress of the pandemic, at various times my own mental health suffered which resulted in me working at a slower pace and with less focus than I would have liked. On reflection, in many ways the pandemic has made this PhD experience more difficult than it might have been it has also taught me a lot as a researcher, to expect the unexpected and develop resilience to change and uncertainty.

On the cancer pathway to care in the UK

The COVID -19 pandemic changed the way healthcare was delivered during the height of the pandemic but has also had lasting effects on cancer care and the system as a whole. During the pandemic many services moved to remotely delivering care and some non-urgent services were paused. This has caused a backlog of unmet healthcare needs in the general population as many people may not have sought care during the pandemic for fear of becoming ill with the virus (BMA, 2022). At the time of writing during summer 2022, NHS patients are seeing long waiting times for essential services and services are struggling with recruitment and catching up with the post-pandemic backlog of patients (BMA, 2022). It is worth noting these changes to the healthcare and cancer care landscape as the changes brought on by the pandemic may mean that the NHS discussed in the interviews and observed through the quantitative data is quite different to the one delivered now. The differences can be seen in the way care is delivered, with more online appointments and increased difficulties e.g., longer waiting times for cancer referrals. It is likely that the increased difficulties experienced in the NHS are impacting on patient care and that people with disabilities may be disproportionately affected by these changes.

Recruiting for qualitative interviews

As mentioned, recruitment for the qualitive interviews took place during Spring 2020, during lockdown. This meant shifting the recruitment strategy to recruit solely online and interviews were conducted via phone or zoom. As the situation with the pandemic happened quickly and I was at a key stage of the PhD process, decisions had to be made relatively quickly. On reflection, this led to an online recruitment strategy that lacked clear direction and planning. Despite the challenges, I managed to recruit enough participants to glean some meaningful information. However, with more time to prepare an online recruitment strategy the volume of participants may have been higher. The timing of the recruitment was also difficult

because at the time, information about COVID -19 was prioritized by charity organizations, so many of them responded saying they could not put my recruitment poster on their social media platforms. I also suspect that during that time, as people were anxious about the virus, attracting attention to anything that was not COVID -19 related was somewhat difficult.

Undertaking of qualitative interviews

As this was my first time undertaking qualitative interviews for research, I was nervous going into my first interview. As an early career researcher, I felt unqualified to be conducting such an interview, which I later identified as imposter syndrome. The quality of the first interview may have been impacted by this anxiety as I feel I asked some questions that were possibly too directed. In my later interviews, as I became more comfortable, I feel I was more conscious of my question wording and asked more open questions.

There were other factors at play that added to this feeling of nervousness. For example, the first interview was via Zoom, and I was unsure how we would connect about a sensitive topic without being face to face. As the first interview progressed however, it became clear that connection was possible over video call, albeit in a different way to face-to-face discussion. With the subsequent interviews I gave each participant the option of doing the interview via phone, online call or online call with video. Each of the participants chose an option that felt comfortable to them which I believe helped them to feel comfortable and open.

I would hope that the interview participants gained something from being part of this research process and a few shared that telling their story felt therapeutic for them. In some of the interviews it felt difficult to keep participants on the topic of cancer care, rather than their general healthcare experiences. I found it difficult to decide when or if to redirect someone as I was unsure if I might miss some vital information if I interrupted their flow. I generally chose to stand back and let the participants discuss what felt important to them to stay true to

the narrative interview style I had chosen, and I believe the outcome was an abundance of useful and insightful information.

Conducting an interview that was done via proxy was also a new experience for me. I found challenges in conducting the interview and interpreting the data. Prior to the interview I had planned for the focus to be Susan discussing Jane's experience and I had consulted Jane on whether she had anything to add via email after the first interview. I chose the wording of the questions to reflect that I was interested in Susan's perspective of Jane's experience. However, during the transcription process I had a sense that the data reflected more Jane's experience of being a carer and family member of someone with a disability going though cancer. I shifted the focus of the analysis to reflect this in the writing up phase. This was also a particularly emotional interview to conduct as Jane was having a difficult time due to the pressures of the pandemic and Jane's ongoing cancer journey. I tried to show an awareness of the stress Jane was under and communicated to Jane on a few occasions that if she didn't feel able to carry on with the interview we could stop at any time.

Use of routinely collected data

The use of linked routinely collected data used in this PhD was a particular challenge for me. This was my first experience of data management and regression analysis. The skills I had to develop to successfully complete this part of the PhD project included use of statistical software, data cleaning, data linkage and knowledge of data science. The quantitative part of this PhD was the greatest challenge for me as a researcher and I began with very little confidence in the area. However, it is a challenge I feel I met and have gained valuable skills as a researcher as a result. On reflection, I would have started the application to access the data earlier to maximize the time I could spend understanding the data and recoding. The process of linking the data together successfully was a time-consuming challenge and there were several delays with accessing the data although this may have been impacted by the

pandemic. As I gained confidence in the area I began to enjoy the process of figuring out the data puzzle I was putting together so more time to complete this part of the project would have been useful in hindsight.

Researcher positionality

There are several facets of my identity as a researcher that could have had an impact on the interpretation of findings and therefore need to be unpacked and reflected upon. Firstly, my professional background of Occupational Therapy could have had an impact on the lense through which I interpreted results. My experience as an Occupational Therapist has mainly been in mental healh inpatient settings and brain injury rehabilitation so my training post registration has been largely focused on mental health, however, as Occupational Therapists are training to think holistically about a person's individual needs physical health and ability to physically carry out day to day activities always factors into clinical decision making. I feel this holistic, person centered approach followed me into my research activities, particularly when interpreting the narratives. When constructing and analysing each person's narrative I considered the mental health impacts of physical access issues. Further to this, things that jumped out at me when analysing the narratives may have been influenced by my professional background such as the focus in Sarah's story being on her adapting in order to meet her self care needs when, as she recalled, the hospital did not provide her with care at home post discharge.

Secondly, my identity as a non-disabled woman will have played a role in my interpretation of findings. As a woman interviewing other women about their I believe there was a shared understanding and a certain level of comfort between myself and the participants. However, my own experience as a woman could have influence the way I which I interpreted results. To combat this, I kept a reflective journal to document how I felt after each interview and when analysing results. The interviews were highly emotive at times and this was a healthy

practice to ensure I was processing the traumatic stories I was hearing from particiapnts, as well as ensuring I was taking myself out of the narratives as much as posssible. Aswell as my indentity as a woman playing a role in the research process, my identity and experience as a non-disabled person will have also had an impact. I was intent from the offset of this research project that I would strive to do research 'with' not 'on' a population with disabilities. So, in the same way that I used a reflexive journal to reflect on my positionality as a woman conducting this research, I also ensured I was reflecting on my worldview as a person without disabilities and the ways this could influence the research. I found that at times things I was hearing that the participant put down to discriminatory staff attitudes I on first glance I put down to NHS staffing and funding pressures. Whereas, after reflection I focused on reflecting the story as told by the participant as someone with lived experience of having a disability.

Chapter 12: Discussion Chapter

Introduction to chapter 12

This chapter summarises the key findings of the thesis along with the unique contribution this thesis makes. How this thesis fits in to the literature review gap, implications of the findings for education, practice and further research are also discussed.

Summary of key findings

This section will summarize the key findings from this PhD study and relate them to the aims outlined in chapter 3. The broad aim of this PhD study was to investigate disparities in cancer care for people with physical disabilities. The research questions were aimed at illuminating various areas of inequality that could exist for people with disabilities. The first step in establishing if there could be inequalities in cancer outcomes for people with disabilities was to identify the population required to answer this question. Therefore, research question one asked: what are the characteristics of the population with physical disabilities in the National Survey for Wales population? Findings from this part of the research showed that the NSW population self-identifying as having a physical disability were broadly in line with the characteristics of populations with disabilities in the wider literature and national statistics. For example, the population self-identifying as having a long-term limiting illness or disability were more likely to be older, living in urban areas and have higher levels of deprivation compared to the population without a disability. Findings also showed that most of the people self-reporting as having a disability considered their disability to be physical and the majority of respondents identified as having two or more limiting illnesses or disabilities. The effects of wording of disability related questions on population captured was

also explored and findings showed that the two distinct disability related questions captured similar populations, but the way respondents categorized the severity of their disability differed between the two disability related questions.

Research question 2 asked are there disparities in cancer outcomes for people with physical disabilities in Wales? To answer this question data from the National Survey for Wales was linked with routinely collected cancer outcome data. This research found that individuals self-reporting physical disability experienced significantly more delays, were less likely to attend screening, were diagnosed with cancer at a later stage and had a higher risk of cancer related mortality than those without a physical disability. Findings from the three screening services investigated: breast, bowel and cervical, showed that people with disabilities were less likely to attend screening services and more likely to experience a delay in uptake of screening services. Results from this thesis also showed that people who self-reported as having a physical disability had higher odds of having a later stage of cancer at diagnosis. Results from the binary regression model showed a significant relationship between self-reported disability status and later stage at diagnosis (stage 3 or 4). Results of the ordinal regression showed people with disabilities had higher odds of having a later stage at diagnosis, although this relationship was not significant (p value= 0.049). Descriptive results also showed that a higher percentage of people with disabilities had a stage 4 diagnosis (14.2%) compared to the non-disabled population (11.2%). Results from the cox regression analyses in this thesis show that people with self-reported physical disabilities have a higher risk of death with cancer as the underlying cause, compared to the population not considered to have a disability. The hazard ratio for disability status from the unadjusted cox regression model was 1.67 (95% CI=1.34 to 2.08), with physical disability being a significant predictor in the model. After adjustment for relevant confounders, results showed a higher hazard ratio

for people with a physical disability compared to the population without (HR= 1.14, 95% CI= 0.76 to 1.69). Although, disability status was not a significant predictor in the adjusted model.

Research question 3 was 'what is the experience of cancer care for people with physical disabilities?' This was investigated using qualitative interviews with people with lived experience of cancer care who identified as having a physical disability prior to their cancer diagnosis. Results showed that participants felt that their disability related needs were not acknowledged or catered for in general. Several participants reported feelings of not being safe in that their basic needs were not being met while in hospital and when returning home post op. There was a sentiment across the narratives that the participants felt their lives did not matter to the individual healthcare staff and to the wider system, for example by literally being ignored by staff or a lack of equipment leading to preventative healthcare services being missed. Overall, the experiences captured in this research illustrate a system which deprived the participants of their basic right to lifesaving healthcare that is safe, efficient, and caring. Results of the deprivation of quality care experienced by these participants ranged from delayed diagnosis, physical damage (as a result of lack of homecare services), mental health impacts and worsening of disability related symptoms.

Discussion

Main findings- breast and cervical screening

Findings from this thesis looking at the uptake of breast screening in the NSW population demonstrated that 81% of the population had been screened in the five-year period. 76% of the population with a self-reported disability had been screened, compared to 84% of the population without a disability. The results of the logistic regression analysis showed that people with disabilities had 34% reduced odds of having a mammogram in the study period (OR=0.66, 95% CI=0.58 to 0.74) after adjustment for confounders.

The CSW screening data was linked with the invitation data. Findings from this thesis showed that 82% of those invited for a cervical screen completed a screen in the five-year study period. Of the population considered to have a disability, 77% had a cervical screen, compared to 83% of the population without a disability. The logistic regression analyses showed that people with disabilities had 21% reduced odds of having a cervical screen (OR=0.79, 95% CI= 0.70 to 0.87) and 13% reduced odds of having been screened in 6 months of invite (OR=0.87, 95% CI= 0.78 to 0.97), both of which were statistically significant.

Comparisons with the literature

Published uptake results from Public Health Wales show that in the year 2016 to 2017, 70.4% of women invited for a mammogram were screened in the preceding 3-year period (PHW, 2018). The difference in percentage uptake between PHW results and results from this thesis could be due to the inability to link invitations to screens within the BTW datasets. Therefore, it wasn't possible to look at the uptake of invitations in this analysis, which can be considered as a limitation for this analysis. The findings from this thesis may demonstrate disparities in coverage over the five-year period rather than uptake.

Evidence from Public Health Wales suggests that the coverage for cervical screens in 2018 to 2019 was 73.2%. (PHW, 2020). The difference in percentage in uptake could be because the analysis from this thesis looked at a wider timeframe for analysis. There could also be potential selection bias as the people included in this analysis were only those who completed the National Survey for Wales. A limitation of this analysis is that it was not disaggregated by age range. As people with a cervix aged between 25 and 49 are invited every three years and those over 50 are invited every five years, it would have been a useful insight to understand the effect of the length of the invitation cycle on uptake for women with disabilities. As of 2022 the Welsh Government have announced that women of all ages

eligible for cervical screening will be on a five-year cycle however, which reflects this research timeframe (PHW, 2022).

International literature corroborates the findings from this thesis that women with disabilities are less likely to take up breast and cervical screening services. The literature on this area of health disparities for people with disabilities is growing and literature to date has explored breast and cervical uptake by type of disability and severity (Martin et al, 2013., Floud et al, 2017., Bussiere et al, 2015). Several studies have also shown that factors such as age, education level, deprivation status and living in rural areas can have an impact on uptake rates of screening services for women with disabilities (Horner-Johnson, 2015., Kung et al, 2012., Courtney-Long et al, 2011). Most research on breast and cervical screening uptake utilizes self-report data, so this thesis adds to the limited body of research using linked routinely collected healthcare data. Research from Woodhead et al (2016) used linked primary and secondary healthcare data from the London borough of Lambeth. Their study looked at the impact of serious mental illness on breast and cervical screening uptake. In their adjusted logistic regression models, they adjusted for socio-demographic factors and for primary care contact. Eligible patients with serious mental illness diagnoses were less likely to have received breast (OR=0.69, 95% CI=0.57 to 0.84) or cervical screening (OR=0.72, 95% CI=0.60 to- 0.85). Primary care contact was found to be a significant mediator in the relationship between cervical screening uptake for women with serious mental illness. Primary care contact was not adjusted for in these analyses due to the large amount of missing data for the variable. Future research in this area would benefit from the inclusion of primary care contact data and from information on mental health of women with disabilities as both can influence uptake of breast and cervical screening services.

Findings from this thesis add to the existing literature surrounding access to screening services for women with disabilities as evidence of delay between invitation and screen is

presented alongside evidence of decreased uptake of screening services. These findings also add to the international literature which suggests disparities in breast and cervical screening access for people with disabilities but from a geographically defined population with free at the point of access healthcare and organized cervical and breast screening programmes. Although, Wales has areas with high deprivation which could limit generalizability elsewhere. Future research into cervical and breast screening inequities for people with disabilities could include evidence of the type of disabilities present in the dataset as this was missing from this research. A meta-analysis is also needed to synthesize the growing body of evidence for cervical and breast screening disparities for people with disabilities.

Main findings- Bowel screening

Findings from this thesis show that females had a slightly higher percentage of returning a bowel screening kit (65%) compared to males (62%). Those who self-reported a physical disability had a lower percentage who returned a kit (60%) compared to people without a disability (66%). The results from the adjusted logistic regression showed that people with a disability were significantly less likely to have taken up bowel screening, with a 20% reduction in odds, even after adjusting for measurable confounders. Results from the logistic regression looking at delay in uptake of bowel screening showed that people with a disability had 70% increased odds of having over a 6-month delay in returning their bowel screening test but this was not significantly different from patients with no physical disability. Findings from this thesis show a rate of uptake of bowel screening of 82% for the NSW population.

Comparisons with the literature

Historically, in Wales uptake of bowel screening has consistently been below the national uptake standard of 60%, with data from 2015-16 showing an uptake rate of 54%, with uptake as low as 38% in some health boards (PHW, 2017). Findings from this thesis show a higher percentage rate of uptake overall at 82%; this could be because our measure for uptake was

any time within a five-year period. Whereas bowel screening invitation is on a two-year cycle. Therefore, we could have included up to three invitation cycles for everyone and preference was given to any uptake of bowel screening within the study period.

Published research in the domain of bowel screening for people with disabilities is sparce and results vary in terms of impact of disability status on bowel screening. Research from Iezzoni et al (2016) and Steele et al (2017) showed that people with disabilities were more likely to have received a bowel screening test than people without disabilities. Some evidence contradicts with findings from this thesis that women are more likely to take up bowel screening services. Research from Lo et al (2013) demonstrated that women were less likely to return a bowel screening test compared to uptake of breast or cervical screening. Similarly, research from McCowan et al (2019) utilized routinely collected data in Glasgow to compare uptake of bowel screening for women compared to uptake of breast and cervical screening. Their results showed that the lowest uptake of screening services was for bowel screening and the presence of moderate comorbidities was associated with lower uptake of bowel screening. In support of the results from this thesis that people with disabilities were less likely to take part in bowel screening, a study from Floud et al (2017) found that women with disabilities were less likely to take part in bowel screening than women without disabilities. Further investigation into the intersection between gender, disability status and bowel screening uptake is needed.

As far as the researcher is aware this is the first study to report on the participation in all three screening programmes for people with disabilities in a large geographically defined area. This adds to the evidence base for bowel screening uptake in the U.K. and Wales specifically, where bowel screening uptake is lower than the rest of the U.K. Furthermore, it is believed this is also the first study to look at delay in screening uptake for people with disabilities. It also adds to the limited evidence base for bowel screening uptake for people self-reporting as

having a disability. In 2019 the test kit (gFOBT) was phased out and replaced by the FIT kit which is reportedly easier to use. Since the FIT kit has been introduced, the Welsh population is reportedly consistently exceeding the national uptake target of 60% (Welsh government, 2021). As part of the optimization of bowel screening in Wales programme, bowel screening invitations are also gradually being offered to 50- to 59-year-olds in Wales (Welsh government, 2021). Future research into the impact of the new FIT kits on uptake of bowel screening for people with disabilities would be useful to assess if increased uptake has also been achieved for this group.

Main findings

Results from this thesis show that people who self-reported as having a physical disability had higher odds of having a later stage of cancer at diagnosis. Results from the logistic regression model showed a significant relationship between self-reported disability status and later stage at diagnosis (stage 3 or 4) when compared to earlier diagnosis (stage 1 or 2). Results of the ordinal regression showed people with disabilities had higher odds of having a later stage at diagnosis, although this relationship was not significant (p value= 0.049). Descriptive results also showed that a higher percentage of people with disabilities had a stage 4 diagnosis (14.2%) compared to the non-disabled population (11.2%).

Comparisons with the literature

There is a significant gap in the literature surrounding stage at diagnosis for people with disabilities, as far as the researcher is aware this is the only piece of research investigating stage at diagnosis for people with disabilities using self-report measures and linked routine data. Findings from research into comorbidities and stage at diagnosis and emergency presentation for cancer diagnosis will be explored in this discussion, however, it is noted that none of the studies cited use an approach to capturing a population with disability that falls in line with the approach taken in this research.

There are some studies that arguably go some way in supporting findings from this thesis, there are several studies that demonstrated an association between presence of comorbidities and later stage at cancer diagnosis (Young-Choi, 2021., Shin, 2021). As discussed in the previous chapters however, the presence of an illness or condition does not necessarily mean someone identifies as having a disability. Findings from Park (2017) into the influence of socio-economic status, co morbidities and disability on late-stage cancer diagnosis showed that both comorbidities and disability were associated with later stage at cancer diagnosis. Their measure of disability status came from the EQ-5D, a measure of health-related quality of life. They identified an individual as having a disability if they rated themselves as having a problem in domains such as mobility, daily activities, pain and discomfort and anxiety/depression. Their findings showed that for both genders, the presence of a disability resulted in a higher risk of cancer diagnosed at a later stage (men OR=1.64, 95% CI=1.23 to 2.17, women OR= 1.52, 95% CI=1.09 to 0.10). When comparing this with their findings on comorbidities and late-stage cancer diagnosis risk, results show a decreased risk in comparison to disability status (men OR=1.48, 95% CI=1.11 to 1.97, women OR=0.72, 95% CI=0.50 to 1.04). This demonstrates the need to research comorbidities as well as disability status in stage at diagnosis work as both can capture varying populations.

Research from McCarthy et al (2007) investigated the relationship between disability and stage at diagnosis in the U.S. The basis of disability definition in this study was medical/condition based. The researchers identified those who had social security disability insurance on Medicare as disabled. The results from this study showed that those considered to have a disability presented with a similar stage of cancer at diagnosis to those without a disability. One critique of the approach to disability definition in this study is that by using a medicalized/insurance-based definition of disability they may have been excluding those who would consider themselves to have a disability but were undiagnosed or could not afford

medical insurance. Therefore, they could be excluding those at the intersection of disability and poverty or unemployment. Furthermore, this study collapsed the four cancer stages into binary categories; early (in situ or local) and late stage (regional or distant) which reduces the capacity to assess the distribution of the cancer stages fully.

A study from Renzi et al (2019) looked at the effect of pre-existing comorbidities such as diabetes, cardiac and respiratory diseases on the risk of presenting with colon cancer via emergency presentation in England. Results showed that those with severe comorbidities were more likely to present via emergency routes despite contrasting findings that people with comorbidities were more likely to have consulted their GP with colon cancer symptoms in the year preceding their diagnosis. This study was a data-linkage study linking cancer registry data with primary and secondary care data. As this study was investigating the effects of comorbidity and not specifically those considered to have a disability, the application to this thesis is limited. However, the findings do present an insight into the potential relationship between having a disability, route of cancer diagnosis and therefore stage of cancer at diagnosis. This study also generates a discussion around the argument that people with comorbidities/disabilities might have more interaction with primary care services than those without and therefore cancer symptoms might be more likely to be identified earlier. The findings from this study suggest the opposite however, as despite increased interaction with primary care services, those with comorbidities in this population were more likely to be diagnosed via emergency presentation. These findings therefore support the 'competing demands' hypothesis (Mounce, 2017), that argues that people with comorbidities or disabilities are more likely to have their cancer symptoms overlooked and/or classified as a symptom related to their illness/disability.

Future research in this area is needed to add to the resources for understanding the relationship between disability status and stage of cancer at diagnosis. Evidence is lacking

from the viewpoint of self-reported disability status and medically diagnosed limiting conditions. Research that gathers knowledge disaggregating type and severity of disability and by type of cancer would also be useful to further understand the relationship between disability status and stage of cancer at diagnosis. This information is key to understanding the full picture of cancer care for people with disabilities. In order to understand the impact of known inequalities in cancer care such as low uptake of cancer screening services and lack of environmental access to healthcare that has been evidenced in previous literature (Iezzoni, 2000., Merten, 2015., Horner-Johnson, 2015), evidence on inequalities on stage of cancer at diagnosis is needed.

Main findings- cancer related mortality

Results from the cox regression analyses show that people with self-reported physical disabilities have a higher risk of death with cancer as the underlying cause, compared to the population not considered to have a disability. The hazard ratio (HR) for disability status from the unadjusted cox regression model was 1.67 (95% CI=1.34 to 2.08), with physical disability being a significant predictor in the model. After adjustment for relevant confounders, results showed a higher hazard ratio for people with a physical disability compared to the population without (HR=1.14, 95% CI= 0.76 to 1.69). Although, disability status was not a significant predictor in the model. Late stage at diagnosis and age were significant predictors in the adjusted model, however. As people with disabilities are more likely to be older and have a later stage at diagnosis (as findings from this thesis have demonstrated), it is arguable that people with disabilities are at increased risk of mortality with cancer due to disability being associated with these factors.

Comparisons with the literature

Research into cancer-related mortality and physical disability is scarce in the literature. As with stage at diagnosis, research looking at mortality risk associated with cancer and

'disability' are mostly related to comorbidities as the marker of disability. For example, Boakye et al (2018) undertook a systematic review and meta-analysis investigating the impact of comorbidity and frailty on colorectal cancer survival rates. The systematic review included thirty-five studies related to comorbidity and colorectal cancer survival and two related to frailty. The meta-analysis included 13 of these studies and results showed that people with severe comorbidities had a hazard ratio of 1.14 for colorectal cancer specific mortality. The meta-analysis included only research that identified comorbidities from standardized comorbidity registers, limiting the findings in relation to this thesis as the presence of a comorbidity does not determine the presence of a disability. The collection of comorbidity information from national registers also could have missed the population that might have a medical diagnosis but do have a form of impairment/disability.

Research from Shin et al (2021) and Park (2012) go some way to support the findings from this thesis, both studies demonstrated increased risk of all-cause mortality for people with disabilities but did not investigate cancer specific mortality. Park (2012) investigated short- and long-term mortality for Korean cancer patients. The research used self-report data on disability status and data was disaggregated by disability type. Their findings showed that people with disabilities had a higher risk of all-cause mortality compared to people without disabilities. Of the population with disabilities identified, 75% identified as having a mobility difficulty. Of the population with mobility difficulties, five years post cancer survival, males with mobility difficulties had a HR of 1.56 (95% CI=1.38–1.75) and females had a HR of 1.54 (95% CI=1.28–1.86). This has its limitations however, the analysis lacked information on stage of cancer at diagnosis, a key confounder of cancer-related mortality. Research from Shin et al (2021) investigated stage at diagnosis, treatment and survival for men with disabilities and a prostate cancer diagnosis. The study had a large sample size as they utilized Korean cancer registry data linked with disability status from national disability registers.

Results from cox regression analysis showed that people with disabilities had higher all-cause mortality (HR=1.20, 95% CI=1.15 to1.25), and slightly higher risk of prostate cancer specific mortality (HR=1.11, 95% CI=1.04 to 1.1).

One study looked at colorectal cancer specific and all-cause mortality for people with Multiple Sclerosis (Marrie et al, 2021). Diagnosis of Multiple Sclerosis was identified from administrative data from two provinces in Canada and linked with cancer registry data. Results from the adjusted cox regression model showed that people with Multiple Sclerosis had an increased risk for cancer specific death compared to people without (HR=1.47, 95% CI=1.02 to2.12). In the cox regression model for one province, disability status was included as a covariate alongside Multiple Sclerosis status. Disability status was defined as receipt of home care or admission a long-term care facility. After adjustment for disability status, the cancer-specific mortality hazards ratio reduced to 1.34 (95% CI=0.91to1.97). This study had a relatively small sample size and specifically refers to one condition and one cancer type, limiting applicability to the results from this thesis. Brown et al (2018) investigated the association between self-reported major mobility disability and cancer related mortality. Major mobility disability in this study referred specifically to walking ability. Participants were asked how much difficulty they had in walking a quarter of a mile, if participants reported having "much difficulty" or "unable to do" they were classified as having a major mobility disability. Results showed that people with a self-reported major mobility disability had higher risk of cancer-specific mortality (HR=2.49; 95% CI=1.53 to 4.07). While the approach to defining disability does not align completely with the approach taken in this thesis, the results go some way to support the findings in this thesis of association between self-reported disability status and cancer specific mortality.

The cancer specific mortality cox regression analysis in this thesis at present seems to be the only study looking at self-reported disability and mortality with cancer as the underlying

cause (including various types of cancers). In this way this analysis significantly adds to the literature in this area. Further research on cancer-related mortality and disability status is needed to further understand the relationship between these two factors. Strengths of this analysis are the inclusion of stage at diagnosis information, although information of type of cancer was missing from the analysis. Further limitations of this analysis include the lack of information on lifestyle factors such as smoking status and comorbidities which may have an influence on mortality risk from cancer.

Qualitative findings

The main themes identified in the qualitative findings were that people who have experienced cancer care as someone with a pre-existing physical disability often felt unheard and unsafe when in receipt of cancer services. There were examples in the narratives of participants feeling their disability related needs were not considered on a personal level (via healthcare staff interaction and poor care planning), and on a structural level (seen through lack of suitable equipment. Similarly, participants felt unsafe at multiple points in their journeys. This manifested in times where participants felt emotionally unsafe, for example that their lives did not matter to the staff as a person with disabilities and feeling unsupported emotionally. There were also examples given where participants felt physically unsafe, by healthcare staff appearing to overlook interactions of cancer related care and their disability and lack of safe levels of care and attention while staying in hospital as an inpatient.

Qualitative discussion

It can be argued that examples given in the qualitative results could constitute disability-based discrimination. Discrimination can occur on many levels and some forms can be more overt that others. Discrimination has been defined as unjust treatment of a group of people on the grounds of categories such as race, age and disability (Equality Act, 2010). Discrimination can occur on different levels, for example direct/ indirect discrimination or

institutional discrimination (Gov.uk, 2022). On the personal level, examples of discrimination participants received can be seen in the assumptions that were made regarding both Sarah and Lisa's narrated experiences. Lisa contemplated whether the staff thought her life was worth saving and whether they assumed she didn't have children due to her disability. Sarah recalled that staff assumed that she would always have an able-bodied carer with her and found this led to her feeling excluded from certain aspects of care such as accessing mental health support.

The stigma that Claire and Lisa perceived over their hidden disability can also be seen as discrimination on the personal level. On a wider level, institutional discrimination can be described as "policies and practices that impact differently or harm non-dominant groups based on language, country of origin, culture, relationship-based working, gender, income, ability, thinking style, and religion, resulting in differential access to goods, services, and opportunities" (Lim et al, 2021, p. 3). In this thesis, an example of institutional discrimination can be seen in the examples given of lack of accessibility with regards to parking and lack of accessible equipment, which was noted in most of the narratives presented. It is argued here that in various ways the participants in these narratives experienced disability discrimination.

To unpack this further the Levesque framework of determinants of healthcare access introduced in chapter 1 will be utilised. Under the Levesque framework there are five dimensions of accessibility that intersect with corresponding abilities of individuals, which results in healthcare access or lack of access. The five determinants discussed under the framework are approachability, acceptability, availability, affordability and appropriateness.

Approachability refers to whether people are able to identify that a service exists, people are able to reach the service and for the service to have an impact. In the narratives presented in this thesis we see the participants repeatedly struggle to reach the potentially life saving

services they require, for example Lisa's perceived struggle to receive an assessment due to the lack of suitable equipment at her GP surgery.

Acceptability under the Levesque framework refers to cultural and social factors that may render services inequitable for certain subsections of society. The perceived stigma that Lisa felt serves as an example of this. Lisa felt staff didn't think her life mattered, this could be seen as a way in which the services explored in the narratives were inequitable for people with disabilities.

Whether services can be reached physically and in a timely manner is encapsulated by the 'availability' theme in the Levesque framework. In several of the narratives, participants relayed difficulties with accessible parking. This was particularly pertinent in Sarah's story, where she found that accessible parking was only accessible should one have an able bodied carer with them. As this was not the case in Sarah's story, she said she spent valuable time and energy trying to physically access her cancer treatment. This arguably could render the services described in this narrative as less than accessible for this population.

Affordability was not explicitly explored in the narratives presented. However, it ties in somewhat with the example given above. Affordability under the Levesque framework refers to the people's economic capacity to spend resources (including time) to use appropriate services. As extra time was taken in some of the narratives to find appropriate accessible parking this could be another way cancer services were not accessible in the qualitative findings.

Lastly, appropriateness of services refers to the fit between patient need and services offered (including timeliness, time spent and interpersonal quality of care). It could be argued that the services presented in the narratives above were not appropriately accessible for the five participants. Timeliness as an identifier or appropriateness of services in particular can be

seen as an area of improvement identified in the narratives. Both Lisa and Jane experienced delays to their diagnoses and all participants referred to long waiting times in their experiences. Some delays, as discussed, could be down to NHS waiting times, however there were some instances where delays to treatment or post discharge care were perceived to be because of physical accessibility or lack of preparation from staff to provide appropriate care at the correct time for the participants.

Triangulation of results

When triangulating the quantitative results with the qualitative results of this thesis, it is necessary to discuss the comparability of the respective populations. The quantitative and qualitative approaches to definition were derived from the same theoretical background and both attempted to address the physical, environmental, and functional aspects of disability. The quantitative population was captured using the chosen disability related questions identified from the National Survey for Wales and participants therefore self-identified as having a long-term illness or disability that affected their ability to carry out their day-to-day activities. The qualitative participants were recruited using language that reflected a holistic understanding of physical disability and self-identified as having a physical disability also. While the qualitative population covered a narrower, more homogenous group (White women, ages approximately 40-60), it is arguable that both parts of this study captured similar populations in terms of disability related needs and that given more recruitment time/ a different recruitment context, a more representative population may have been recruited for the qualitative portion.

The quantitative findings of lower screening uptake, increased likelihood of delay to screening and later stage of cancer at diagnosis can be used to illuminate and contextualise the consequences of the experiences of discrimination captured in the qualitative part of this

thesis. As the quantitative findings from this thesis show, people with physical disabilities had lower uptake of screening services across bowel, cervical and breast screening. Experiences from the qualitative research demonstrated that participants often found interactions with healthcare staff difficult, uncomfortable, or potentially discriminatory. Positive interactions with healthcare staff can impact on health protective behaviours like cancer screening as negative interactions can result in people avoiding interacting with the healthcare system. Further to this, participants in the qualitative research discussed experiences where there was unsuitable equipment available for them, meaning they could not be examined safely. When applied to uptake of cancer screening this finding could go some way to explain why people with disabilities may be less likely to attend screening services.

The quantitative finding that people with disabilities were more likely to have a later stage of cancer at diagnosis can also be expanded upon using the qualitative findings. As mentioned, there were instances where the participants were unable to be examined appropriately due to unsuitable equipment, this is a finding that could explain the later stage at diagnosis for people with disabilities as vital opportunities to diagnose cancer at an earlier stage could be missed. There was also a general sense of not feeling seen or heard across the narratives, this finding could also contextualise the later stage at diagnosis finding as it is possible people with disabilities are not feeling seen or heard pre-cancer diagnosis also, therefore resulting in cancer symptoms being missed.

There were instances in the five narratives presented where the participants felt physically unsafe while in hospital and were discharged without an appropriately safe care package. There were also instances where participants felt that their disability related needs were not considered along with their treatment, for example, Ann felt that her ME was not considered in its potential interaction with the anaesthesia. Examples were provided in the interviews of

times where participants felt that they were being discriminated against as a person with a physical disability and therefore that their treatment was possibly delayed as a result. These factors, along with the lower screening uptake and later stage of cancer at diagnosis findings could all be contributing factors towards increased risk of cancer related mortality for people with disabilities.

Unique contribution of this research

This thesis explored in depth the application of ICF informed disability definition as applied to a national survey. This included an exploration of alternatively worded disability related questions and how different phrasing can impact on the population captured.

This thesis used routinely collected data and linkage to national survey to explore cancer outcomes. As far as the researcher is aware this is the first piece of research to identify a population self-identifying as having a disability and linkage with cancer outcome data from routinely collected sources. Other research linking national survey data and routinely collected data does often include a disability related variable, however this is often related to comorbidities when researching a different health-related topic. The benefit of this approach over defining disability using medically diagnosed disability from routine data (e.g., GP data) is that it avoids over medicalizing disability status and allows for self-identification of disability status.

The stage at diagnosis disparities for people with disabilities was a previously under researched area. As far as the researcher is aware this is the only research that uses the methods outlined above to look at stage at diagnosis as an outcome for people with disabilities. Previous research has looked at specific populations with disability related illnesses such as multiple sclerosis, however, this is the first research study that looks at stage at diagnosis for a broad population who self-identify as having a disability.

This thesis adds valuable insight into the experience of cancer care for people with disabilities in relation to inpatient services. The qualitative exploration on inpatient cancer care in this study showed disparities and unsafe care that may exist for this population that has not been identified by the researcher in other literature.

Strengths and limitations

Strengths:

This thesis used self-reported physical disability status as a means of identifying the population in both the quantitative and qualitative part of the thesis. This is a more holistic approach to the concept of disability and is arguably a more reliable source of disability status than a medicalized approach e.g. identifying disability from GP records. Furthermore, the extensive descriptive analysis completed on the NSW data, characterising the population with self-identified disability status adds to the scant literature on disability statistics in national surveys.

This thesis provided evidence on disparities on cancer outcomes and cancer experience from both the quantitative and qualitative perspective. This meant that cancer disparities were considered on both the micro and macro level, adding towards a more comprehensive picture of cancer services for people with disabilities,

Limitations- Quantitative results:

There were some limitations to the use of linked survey data. The fact that disability status was only captured at one point in time over the five-year survey period meant that I could not say for certain whether each respondent identified as having a disability for the whole five-year period. Not being able to confidently ascertain whether participants considered

themselves to have a disability for the duration of the five-year period reduced confidence in the applicability of results.

Analyses lacked information on disability severity and type of disability. Although some descriptive analysis was undertaken when the derived variable stating type of disability was available (survey year 2016/17), which provided some insight into the broad types of disability we might be capturing, this was limited information. Having access to information on type of disability/impairment or illness type would have meant the results could be more targeted towards specific groups. Including information on severity of disability would have further characterised the population captured. Further to this, analyses could have been split by severity type, providing more detailed insights. This would have been possible by creating two disability variables by not combining the 'yes, a little' and 'yes, a lot' response options in response to the question 'Does your disability, illness, or limitation affect your ability to carry out day-to-day activities?'. However, this was an oversight during the creation of the statistical analysis plan.

The quantitative analysis could have been strengthened by including unadjusted, adjusted (multivariable analysis) and a further age-adjusted analysis. Age was included as a confounder in the DAG models created when deciding which variables to include in the statistical models. However, it has since been reflected on that age and disability may have a causal relationship, therefore, including a model that was only age adjusted would have meant a clearer understanding of the effect of disability status on the outcomes explored. In addition, the mortality analysis was adjusted for stage at diagnosis as well as the other confounding factors. It has been reflected on post-analysis that this may have resulted in an over-adjusted model when considering mortality risk for people with disabilities in the sample.

This PhD included information on screening services, stage of cancer at diagnosis and mortality as a result of cancer diagnosis. If more time and resources had allowed analysis of cancer outcomes past stage at diagnosis would have provided valuable insight. Analysis of the type of treatment offered for people with and without disabilities and point of access of cancer care e.g., prevalence of emergency routes in the population with a disability would provide valuable insight into further potential disparities in cancer outcomes.

Limitations- Qualitative results:

The number of qualitative interview participants was relatively small, and the initial recruitment plan had accounted for more participants. Although the interviews and resulting analysis have allowed for an in-depth exploration of each person's experience, the small sample size means that results may not have reached full data saturation. Further interviews would have possibly led to more themes being identified in the data.

The qualitative sample was a homogeneous group as it was all white women and included two types of disability: ME and Spina Bifida. This means that the experiences of people from minority ethnic groups and people with other conditions were not accounted for in this research. Having a less homogenous sample may have illuminated themes and trends across groups of people. Having participants that identified as being from ethnic minority communities also would have added to the literature on intersectional identities and how these impact on cancer care experience.

The qualitative part of this thesis could have been strengthened if it had included interviews with healthcare professionals as well as patients. This would have allowed for an exploration of the barriers faced by staff when trying to deliver care, leading to a more rounded understanding of the issue and more refined suggestions for improvement.

Implications of this research

Implications for education

This thesis highlighted the need for healthcare staff to have more awareness of the needs of patients with disabilities going through cancer care. In particular needs identified were: Accessibility (including appropriate equipment), staff lacking knowledge of conditions, staff taking the time to ensure the needs of people with disabilities are heard and catered for where possible.

Higher education establishments can also go some way in tackling disability discrimination and stigma early on in healthcare staff's careers. This can be done by educating students on the stigma and discrimination people with disabilities may face in the healthcare landscape and indeed, in other areas of society.

Implications for practice

As mentioned, having staff that are knowledgeable about disability related health conditions was an area of potential improvement identified in this research. Where possible, healthcare providers could provide opportunities for staff to improve their knowledge of the needs of people with a range of health conditions.

Integrated services would also be of benefit to people with disabilities going through cancer care. Where cancer care staff may lack specific knowledge related to individuals' health conditions or disability, increased communication with a specialist in that area when specialist knowledge is required could improve the experience of cancer care for people with disabilities.

Lack of time and staff burnout are issues seen frequently in today's NHS landscape. Therefore, the issue of people with disabilities feeling time was not taken to account for their

needs is a difficult one to address. Where possible, it would be beneficial for staff to take additional time and space to listen to the needs of people with disabilities going through cancer care and take additional time to read through patient information in advance of surgery for example. However, this is not always possible in practice due to a number of factors. Where this is not possible, an awareness of how general NHS pressures might disproportionately impact people with disabilities in cancer care should be acknowledged by NHS trusts.

Several issues were identified in this thesis relating to later stage at diagnosis for people with disabilities. In the qualitative findings participants felt their concerns were not listened to or investigated regarding early signs and symptoms of cancer. An awareness in primary health services around this issue may lead to earlier diagnosis of cancer for people with disabilities. Several participants also discussed lack of equipment leading to aversion to attending screening services, this should be addressed in primary health services to increase accessibility and therefore uptake of screening services for people with disabilities.

Implications for future research

Future research on the impact of approach to definition of disability in quantitative research would be of benefit. Investigations into how best to capture populations with disabilities and exploration of the characteristics of the populations under study would be beneficial to understand the generalizability of findings.

Further research is needed into the impact of intersectional identities on healthcare/cancer inequalities as this thesis showed that other socio-demographic factors can impact cancer outcomes alongside disability status.

This thesis has provided some evidence of the experience of cancer care post diagnosis (treatment and aftercare), however further research is needed to further understand the experience of people with disabilities in this area of cancer care.

Research and initiatives are needed that are aimed at reducing the gaps in cancer outcomes between people identifying as having a physical disability and those who do not. An initiative similar to the LeDeR project (https://leder.nhs.uk/) would be a positive step in the direction of improving healthcare for people with physical disabilities. The LeDeR project collated information on deaths of people with learning disabilities to explore areas where care can be improved for this population. A similar initiative that collates experiences of cancer care for people with physical disabilities and deaths related to cancer for people with physical disabilities would create a more expansive evidence base upon which to base decisions on improving care for this group.

Conclusion

From the three disparate but linked research questions presented in this thesis, this PhD paints a picture of the landscape of cancer care for people with disabilities. The key thesis being put forward is that inequalities in cancer care exist for people with disabilities. These inequalities exist on the wider level, shown through the examination of routinely collected electronic health records and on a personal level, shown through the in-depth interviews.

Chapter 13: References

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Chapter 13: Appendix

Appendix 1: Literature review data collection spreadsheet:

Author(s)	Year	Origin (published or conducted)	Aims/purpose	Study population and sample size	Methodology	Outcomes and measurement criteria	Key findings rel to review Q	Key themes
Clark et al	2009	U.S.A, Rhode Island	Comp B screening rates WWD & WWND	F, 93 matched cohort WWD &WND	matched cohort study, multivariable and univariable analysis, phone int, second survey data, descriptive analysis	Mammog exp by disab status, rates of repeat screening, identify factors assoc w repeat mm screening	pos exp of mm WWD more likely to return, WWD lower screening rates, access influences reason for choosing mamm facility	Exp of screening, sc repeat screening
Iezzoni et al*	2010	U.S.A	perceptions of WMI with breast cancer of accesibility of h/c facilities & equip during diagnosis, treatment and follow up	F, 20 ps with MI who developed BC before 60,	individ int, qual analysis to identify themes	extent and nature of mobility impairments, concerns about barriers to care	Innaccesable equip incl. mammog machines, examining tables and weight scales. Issues with transfers by medical staff, positioning and handling uncontrollable movements. Accesible equip sometimes unavailable	Exp of screening, ph screening, accessibili Exp of therapy (che
Rivera Drew and Short	2019	U.S.A	Explore the relationship between disability and pap smear reciept	20, 907 women aged 21-64, 2000-2005 national health interview survey	Logistic regression analysisto assess assoc between disab and C C screening	Disab negatively assoc w/ pap smear test	31% WWD cited lack of insurance as reason, 'putting it off',	scr uptake, reasons
Banks et al	2010	Australia	investigate whether elevated levels of psych distress= cancer diagnosis, treatment or disability	89574 m&w over 45, respondents of '45 and up study'	Self-reported questionnaire dat on demog, health and lifestyle, mental health. Unconditional logistic regression	High psychological distress	Risk of psychological distress in individ w/ cancer relates more strongly to their level of disability than it does to the cancer itself	Psychological distres and disability
Iezzoni et al*	2011	U.S.A	Implications of mobility impairment on diagnosis, therapy and recovery of women with breast cancer	*same as prev Iezzoni study	*Same as prev Iezzoni study		treatment decisions related to how various therapies would affect their arms, anaesthaesis concerns related to underlying condition, clinicians not considering post-op needs,	exp of screening, lo outcomes, treatmer experiences of treat
Llewellyn et al	2011	Australia	Investigate intangible barriers to participation of WWD in mammog screening	F, 75 ps, WWD ages 50-69	Interviews	Barriers to active involvement to manage their disability and take control over their experience of mammog	Expectations= be kept informed, actively involved in mammog procedure and to be treated with respect. Barriers to this= lack of info and consistency, difficulty expressing needs and not feeling listened to, pain, staff knowledge and stigma	Exp of screening, ba
Courtney-Long et al	2011	U.S.A	Expand knowledge of assoc between mammog use and having a disability	F, over 40 and women between 50-74	Self reported mammog use from national survey, logisitic regression analysis,	Mammog screening rates	WWD lower odds of mamog use for both age cohorts compared to WND	Scr uptake
Weir et al	2011	U.S.A	Examine disparities in routine mammog for medicaid managed WWD	F, between ages of 42-69, 35 171	Healthcare effectiveness data and information set and individual level data from medicaid managed care plans. Multivariate logistic regression analysis.	Mammog screening rates	WWD (defined by being on medicaid managed care plans defined as disabled) disability status had negative assoc with screening mammog after adjusting for confounders	Scr uptake, demog v far from screening c
			determine if there are disparities in long and short	93758 cancer patients over 20	survival analyses	gender, type of cancer, type of disability,	Short term mortality, no significance with	Mortality rates

#	Author	Year	Country	Aim	Sample	Method	Variables	Findings	Focus
12	Park et al	2012	Korea	determine if there are disparities in long and short term mortality between cancer patients with and without preexisting disabilities	93758 cancer patients over 20 years old, ICD-10 coded as having cancer	survival analyses	gender, type of cancer, type of disability, sociodemog	Short term mortality- no significance with disabled pop. Preexisting disability higher long term mortality than nondisabled group. Short term mortality higher for males with impaired communication and females with internal disability. Impaired mobility associated with higher long term mortality.	Mortality rates
13	Angus et al	2012	Canada	document challenges for women with disabilities in access and experiences of screening for colo, cerv and breast	24 women with mobility difficulties	peer led focus groups	qual	Ares 'of complex work' identified: arranging and attending screening appointments, assumptions about womens bodies, health information	Exp of screening
14	Kung et al.	2012	Taiwan	Examine determining facrtors for low use of mamm, identify barriers to scr for WWD	F, 50 to 69,	Logistic regression analysis,	scr rates, demog charact, health status, classification of disability, utilization of other preventative health services	Higher edu and income= higher, severe and multiple disab= lower, use of other services= higher	Scr uptake, demog to scr
15	Lin et al .	2012	Taiwan	Examine factors related to hysterectomy in WWD	F, 502, age 15 and over, reg disabled	Multilevel logisitc regression analysis,	hysterectomy prevelance	50 years plus, had CC, not had pap smear in last 3 yrs= more likely to accept hyster than counterparts	Treatment options
16	Jarman et al	2012	U.S.A	Accomodations seen as neccesary for WWD who have had screenings	739 WWD	Survey	qual	Needed accomodations: accesible changing area, oral description of procedure, accesible parking (parking most likely need to go unmet)	Accomodations for services
17	Volker et al .	2013	U.S.A	Explore the exp of pre-exisiting functional disab and a cancer diagnosis	19, F cancer pt with pre-existing functional limitations	Qualitative, descriptive focus groups,	qual	care providers unable to accom or understand additional needs, oncologists ability to recommend cancer treatment that took underlying disab in to account, fatigue and treatment decisions, advocating for self, imp of health promotion strategies,	Exp of living with ca and cancer treatme cancer
18	Martin et al .	2013	U.S.A	CC screening rates for W in Ohio and relationship with sociodemo factors to participation	350, age 20-80, women	Descriptive stats, logistic regression models,	scr rates, demog charact,	only 50% had had scr, likelihood decreased by 20% if ADL imitation present	scr rates, sociodemo

#	Author	Year	Country	Aim	Sample	Method	Variables	Findings	Themes
19	Horner-Johnson et al	2013	U.S.A	Further examine disparities in screening in relation to severity of disability	for groups of women aged 18 to 64	logistic regression analysis	categorized by presence and complexity of disability, pap or mamms received within recommended timeframe	WWD less likely to be up to date with b and c scr, disparities greater for owmen with complex limitations	scr rates, sev of dis
20	Guilcher et al.	2014	Canada	Level of disability and multi-morbidity on screening	10, 363 (4660 reported some level of disability),	multivariate regression	scr rates, level of disability	women with moderate disab more likely to scr than women without, women with severe disab less likely than both	scr rates, level of dis
21	Peters and Cotton	2014	Australia	Explore the experiences of breast scr for WWD	12 WWD aged between 50 and 75 yrs	face to face or telephone interviews	qual	Feeling out of control, not being lsitened to, feeling helpless, alone and afraid and exp pain, torture and humiliation	exp of screening
22	Bussiere et al .	2015	France	rate and determinants of likelihood of cc scr WWD in institutions	f, 1052 WWD inst	multivariate regression	scr rates, sociodemo, health related variables, sev of dis	higher the functional limitation level, the lower the likelihood of cancer screening	scr rates, level of dis
23	Horner-Johnson et al.	2015	U.S.A	Examine combination disab status and rurality in assoc with b and c scr	F, age 18-64, 65 506,	logistic reg analyses	dep variable= scr, indep v= disability, covariates= sociodemog	WWD less likely to be up to date with b and c scr + women in rural areas less likely. W with both least likely	Scr rates, sociodemo
24	Iezzoni et al .	2016	U.S.A	Examine whether disab disp in scr pap tests have diminished over time	F, age 21-65,	multivariable logistic regression	scr uptake, disability levels	statistically significantly lower rates of pap testing for women with disab ompared to women without	Scr rates
25	Welch Saleeby et al .	2016	U.S.A	Explore barriers and facilitators to breast health services for WWD	F, 10, self identified as disabled	Focus groups, purposive sampling	qual	envi, cost, equipment, better info, unwelcoming facilities (staff), training of staff in working with PWD, perceptions and attitudes of staff, lack of policies and procedures around PWD, equip availability,	exp of scr, barriers a quality care
26	Iezzoni, Kurtz et al .	2016	U.S.A	Examine if there are disparities in colorectal cancer screening for PWD and if these have changed over time	non-inst u.s residents aged 50-75	bivariable and multivariable logistic regression m & w seperately looked at assoc with colo cancer screening with sociodemog factors and disability type	scr uptake, disability levels, sociodemog	Few statistically significant differences in colo cancer screening uptake over time between PWD and those without	Scr rates, sociodemo
27	Steele et al	2017	U.S.A	Look at reciept of cancer screening by disability status and type	respondents of national health interview survey, adults 21 to 75, 15 079 adults	multivariable logistic regression analysis	screening uptake, sociodemog, disability type, recommendation for tests, barriers to health-care access	WWD less likely to receive pap and mamm, PWD more likely than those without to be up to date with CR screening	screening uptake, sc disability type, recor tests, barriers to hea
28	Deroche et al	2017	U.S.A	Investigates whether adults with disability receive CR screening at equivalent rates to those without disability	Medicaid/Medicare data linked with hospital discharge data	Descriptive stats	Scr uptake	Less likely to be up to date with CR screening; spinal cord injury (44.14% vs 48% in non disabled population	Scr uptake
29	Sakellariou and Rotarou	2017	Chile	examine utilisation of pap and mammog scr for WWD in Chile	Cross-sectional linked data from national survey	Logistic regressions	pap and mammog scr uptake and socieodemog	Disabled women less likely to receive scr than non-disabled women. Being single, inactive in terms of employment assoc with lower scr rates	Scr uptake, socioder
				investigate whether cer cancer scr differed by	Linked administration database in	multivariate logistic regressions	presence, type and severity of disability	Disability assoc with a lower screening rate	Scr uptake, disability

#	Author	Year	Country	Aim	Sample	Analysis	Outcomes	Findings	Theme
30	Wook Shin et al	2018	South Korea	investigate whether cer cancer scr differed by presence and varying degrees and types of disability	Linked administration database in Korea	multivariate logistic regressions	presence, type and severity of disability . Factors assoc with cerv cancer scr rates	Disability assoc with a lower screening rate. Markedly lower in women with severe disab	Scr uptake, disability
31	Nandam et al	2018	U.S.A	evaluate mammog rates in women with CP	WWCP, 40 yrs or older, respondents of a cross sectional survey. N= 118	Chi-square tests, logistic regression to look at effect of functional factors on screening	Scr status, imaging modality and accom needs	65.3% had mammograms within last 2 years, severity of fien motor deficits assoc with lower scr, needs least often met included: accomodations for standing, arm positioning and wheel-chair accesible mammogram machines	Scr uptake
32	Puts et al	2010	Canada	describe the health and functional status of patients who refused cancer treatment	112 men and women, newly diagnosed cancer patients, over 65, had not received cancer treatment in last 5 years	descriptive stats	health and functional status, sociodemog, treatment decisions	Participants who refused treatment often lived alone, were less often married and had ADL disability	treatment decisions
33	Puts et al	2017	Canada	how comorbidities, frailty and functional impairment are considered during treatment decision making process for Cancer	Older adults with cancer, 70 plus, with advances breast, prostate, colorectal and lung cancer and made a treatment decision about palliative chemo in last 6 months. 32 ps,	mixed-method longitudinal mixed methods study; two semi-structured interviews and surveys (one after treatment decision and one 3-6 months later). Multi-perspective interviews (family, caregiver, practitioner)	survey data- all participants satisfied with their treatment decision making process	Factors that influence treatment decision making process: relationship with oncologist, benefits vs harm, comorbidity and functional status did not play a role in treatment decision making process, treatment exp of others considered	treatment decisions
34	Floud et al (hs)	2017	England	to gather info on participation in population wide screening programmes ny people with disabilities	473 185 women offered b and bowel screening	data from NHS routine screening programme linked with info on disability reported by the Million women study.	Participation in screening	WWD less likely to participate in breast and bowel screening, varies by type of disability	Scr rates

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Appendix 2: Statistical Analysis Plan:

1. Purpose and scope of the plan

This document details the proposed presentation and analysis for the main paper(s) reporting results for the 'disparities in cancer care for people with physical disabilities in Wales' study. The results reported in these papers should follow the strategy set out here. Subsequent analysis of a more exploratory nature will not be bound by this strategy, though they are expected to follow the broad principles laid down here. The principles are not intended to curtail exploratory analyses (for e.g. to decide cut points for categorisation of continuous variables), nor to prohibit accepted practices (e.g. data transformation prior to analysis), but they are intended to establish the rules that will be followed, as closely as possible, when analysing and reporting the study.

The analysis strategy will be available on request when the principal papers are submitted for publication in a journal. Suggestions for subsequent analyses by journal editors or referees, will be considered carefully, and carried out as far as possible in line with the principles of this analysis strategy; if reported, the source of the suggestion will be acknowledged. Any deviations from the statistical analysis plan will be described and justified in the final report of the study.

2. Statistical analysis plan authorship

Alice James is the project lead and the author of this SAP. All statistical analyses will be carried out by Alice James and supervised by Rebecca Cannings-John. This SAP will be

finalised for presentation to the Study Steering Group and will be agreed by them and signed off by the author and statistics supervisor. A copy will then be sent to the Study Steering Group.

3. Study overview

Research evidence suggests that people with physical disabilities are likely to be diagnosed with cancer at a later stage, are less likely to access screening services and have poorer outcomes when it comes to cancer survival. This study aims to look at whether people with and without physical disabilities have the same access to cancer care in Wales. We will be using responses from the National Survey for Wales to identify respondents who self-report having a physical disability and compare their data on cancer care with those who didn't identify as having a physical disability. We will get our data on cancer care from registry and hospital data, on screening services, cancer treatment given, the stage at diagnosis and outcomes of cancer treatment. We are hoping to combine results from this part of the study with interviews with people with physical disabilities and cancer to get an idea of what the experience of cancer care is like for this group. We are aiming to get a deeper understanding of the differences in cancer care there might be between people with and without physical disabilities and, through the interviews, identify the problems or barriers people with physical disabilities might face in accessing cancer care. With this information we will create guidance and publish our findings to hopefully improve cancer care for this group.

3.1 Study aim and objectives

The aim of the study is to investigate disparities in cancer diagnosis and care for people with physical disabilities in Wales.

The objectives of the study are to:

A. Identify a cohort of people in Wales with a physical disability and a comparable cohort without

B. Investigate disparities in cancer care between people with and without physical disabilities looking at the following stages of the cancer journey:
    1. Screening uptake for breast, bowel and cervical screening services
    2. Stage of cancer at time of diagnosis
    3. Time to death (Mortality)

C. Explore the combined influence of disability and other demographic and socio-economic variables and other confounders of outcome.

3.2 Study population

Our study population will be participants responding to the National Survey for Wales (NSW) between 2012/13 and 2016/17 (one survey per year). For objectives B2-3 the study population will be further refined to respondents of the national survey who went on to receive a cancer diagnosis in the follow up period (2012 to 2017), were 18 years or older and living in Wales at the time of diagnosis (see table 1 below). Those self-reporting a mental health disability only will be excluded from the analysis as this research focuses on physical disability and those with a mental health disability may experience a different set of challenges to accessing care (see appendix 1 for more details on defining mental health disability). The study population will be followed up to first cancer diagnosis, death, migration out of wales, or last follow-up date.

We will attempt to characterise the 'exposed' population using health-related data and co-morbidities from the NSW. We will characterise our population by exposure using baseline demographics from the NSW (Age at survey completion, ethnicity, gender), health data and health service use (Wellbeing questions, number of carer hours, GP (seen a GP in the last 12 months) and lifestyle behaviours (Smoking, alcohol, fruit and veg intake and exercise) using summary statistics such as mean (standard deviation), median and interquartile range and N(%).

Table 1. Eligibility criteria and verifying data field

A. Inclusion criteria	B. Dataset and fields inclusion criteria
For all objectives	
1. Adults aged 18 years or older at time responded to the National Survey for Wales between 2012/13 and 2016/17	
For objectives B2-3	
2. Cancer diagnosis	WCISU: Date of clinical staging – We will use this as the date of cancer diagnosis. We will be interested in the cancer diagnosis closest to the survey date where multiple diagnoses of cancer exist.
3. Living in Wales at time of cancer diagnosis	NSW: Geographical location
4. Aged 18 years or older at the time of diagnosis.	Derived variable based on date of birth (NSW) and date of clinical staging (WCISU)
Exclusion criteria	
1. Only has a mental health disability (no physical) (appendix 1)	NSW: Derived variables that detail type of disability.

Exposure

Cases will be those fitting the inclusion criteria above that self-identify as having a physical disability.

The definition of disability for this study is a physical impairment that has a substantial and long-term (more than 12 months) negative effect on people's ability to carry out their usual daily life activities (table 2). Presence of a limiting illness/condition that limits activity identified by answers to the following NSW questions:

-LIIILIMIT (Do you have any physical or mental illnesses lasting or expected to last for 12 months or more)

-LONGIIILIMIT (Does your condition or illness reduce your ability to carry-out day-to-day activities?) /OR DisabLimit (Does condition limit activities in any way?)

Those that answer yes to LIIILIMIT and yes to either LONGIIILIMIT OR DisabLimit will be considered to have a disability.

The type of limiting complaint/illness/disability (mental or physical/ acute or chronic) will be identified from the derived variables created from answers to the preceding questions. Those considered to have a physical illness/complaint (See Table 2.) will be included in the exposed population, those who identify as having a mental health disability or acute illness/complaint will be removed from the analysis.

Controls will be those fitting with the inclusion criteria above that did not self-identify as having a disability

Table 2. Physical disability definition

Physical Disability definition	Disability definition applied to fields within NSW
Physical impairment that has a substantial and long-term (more than 12 months) negative effect on ability to	-LIIILIMIT (Do you have any physical or mental illnesses lasting or expected to last for 12 months or more)

carry out their usual daily life activities at time of diagnosis.	-LONGIIILIMIT (Does your condition or illness reduce your ability to carry-out day-to-day activities?) /OR DisabLimit (Does condition limit activities in any way?) **Derived variables used to identify physical illness (grouped limiting illnesses):** -Musculoskeletal complaints limit individual - Blood and related organs complaints limit individual - Endocrine and metabolic diseases limit individual - Nervous system complaints limit individual -Heart and circulatory complaints limit individual -Respiratory system complaints limit individual -Digestive system complaints limit individual

Screening population

The study population for the screening outcome will be all participants responding to the National Survey for Wales (NSW) between 2012/13, living in Wales and over 18 years of age at time of survey. The population will be narrowed down to those who were invited for a routine screening appointment (respectively for breast, bowel and cervical) in the years 2012/13. The follow up time period for attendance at routine screening appointments will be from NSW participation year (2012/13) to 2016/17. The time period for recommended screening will depend upon Public Health Wales guidelines on recommended frequency for each screening service (please see table 3 below).

The study population for screening services will be further refined by age and gender dependent on the type of screening service e.g. breast, cervical or bowel.

Those with a physical disability within this cohort will be identified and compared with the population without a physical disability.

Table 3. Screening services inclusion criteria

Screening service	Age range (years)	Gender	Recommended time frame for screening invite
Breast screening	50-74	Female	Every 3 years
Bowel screening	60-74	Male and female	Every 2 years
Cervical screening	25-64	Female	Every 5 years (50-64 age group) Every 3 years (25-49 age group)

4. Study design

This is a retrospective electronic cohort (e-cohort) study utilising datasets held in the Secure Anonymised Information Linkage System (SAIL databank; www.saildatabank.com) developed in the Health Information Research Unit (HIRU) at Swansea University. A linked anonymised cohort will be accessed to compare routinely available health and social care data on outcomes such as attendance rates of cancer screening services, cancer stage at diagnosis and cancer mortality between people who self-identify with a pre-existing physical long term limiting illness (physical disability) and those who do not.

5. Study outcomes

Outcomes follow the cancer treatment timeline. We will be looking at outcomes at three points:

1. Screening – Did patients attend/partake in screening appointments/tests?

We will be interested in the relationship between having a physical disability (and relevant sociodemographic/lifestyle factors) and attendance at routine screening appointments within the recommended clinical time frame. The outcomes are all binary (Did they attend a screening appointment within the recommended time frame following a routine screening invite?)

Table 4.

Variable/Outcome	Hypothesis	Outcome Measure	Method of Analysis
Breast Screening [Dataset: Breast Test Wales]	Physical disability leads to lower attendance at routine breast screening appointments within recommended timeframe	Invited for screening (routine invitations) [INVITE_DATE] and was screened [SCREEN-DATE]	Logistic Regression
Cervical cytology test [Dataset: Cervical Screening Wales]	Physical disability leads to lower attendance at routine cervical screening appointments within recommended timeframe	Invited for screening (routine or first call invitations) [INVITE_DATE] and was screened [TEST-DATE]	Logistic Regression
Bowel Screening [Dataset: Bowel Screening Wales]	Physical disability leads to lower adherence to routine bowel screening tests within recommended timeframe	Invited for screening (routine invitations) [SENT_DATE] and was screened [RECEIVED-DATE]	Logistic Regression

2. Stage – What stage of cancer at diagnosis?

We are interested in the relationship between having a physical disability and the stage of cancer at diagnosis. To investigate this, we will use Ordinal regression to estimate the likelihoods of diagnosis at each stage (1 to 4) for people with physical disabilities compared with those without.

3. Mortality – Likelihood that the patient died as a result of cancer?

We will be interested in the relationship between having a physical disability (and relevant sociodemographic/lifestyle factors) and the risk of dying as a result of a cancer diagnosis. We will exclude those from the analysis who are still alive or died from another cause in the follow up period (2012 to 2017). In the event where someone has two diagnoses of cancer, the first diagnosis will be taken as the time to event date.

Table 5.

Variable/Outcome	Hypothesis	Outcome Measure	Method of Analysis
Clinical Stage	Physical disability leads to cancer diagnosis at a later stage	CLINICAL_STAGE (WCISU) (Post survey response)	Ordinal Regression

		CLINICAL DATE (Date of clinical staging)	
Mortality	Patients with physical disability are more likely to die as a result of cancer	CAUSED_DEATH (WCISU- information on whether neoplasm was the cause of death) Field_3 Date of death	Cox Regression

See Appendix 2 for WCISU variable codes and descriptions

5.1 Datasets, linkage and handling

Table 3 lists all the outcomes and data sources that will be utilised in the study along with

the Data Controller and the relevant panel to approve data access.

Table 6 Source datasets, controller and approval panel

Source datasets	Data Controller	SAIL IGRP	Data controller approval
WCISU	Welsh Cancer Intelligence & Surveillance Unit (WCISU)	✓	✓
Cervical screening Wales	Public Health Wales NHS Trust	✓	✓
Bowel cancer screening Wales	Public Health Wales NHS Trust	✓	✓
Breast cancer screening survey (breast test Wales)	Public Health Wales NHS Trust	✓	✓
National survey for Wales	Welsh government	✓	✓
PEDW	NHS Wales' Informatics Service (NWIS)	✓	✓
ONS deaths	Office for national statistics	✓	✓
Welsh demographic service data	NHS Wales' Informatics Service (NWIS)	✓	✓

National Survey for Wales

Table 7. NSW Baseline characteristics

Variable	Variable type
Age at survey response (years)	Categorical: age bands
Gender	Binary: Male, female
Marital status	Categorical: Married, single etc
Level of education	Categorical: Highest Qualification
Geographical location	Categorical (Urban/ Rural classification)
Self-rated wellbeing	Categorical
Seen a GP in last 12 months	Binary (yes/no)

Smoking	Binary (current smoking status at time of survey)
Fruit and vegetable intake	Categorical
Exercise	Categorical
LIIILIMIT- Do you have any physical or mental illnesses lasting or expected to last for 12 months or more?	Binary
LONGIIILIMIT- Does your condition or illness reduce your ability to carry-out day-to-day activities?	Binary
Disablimit- Does condition limit activities in anyway?	Binary
SCneed 1-8. Social care needs (available years 2016/17)	Binary
Derived variable: Dvlimnum (Number of limiting illnesses)	Numerical
Derived variable: Dvlimnumgrp (Number of limiting illnesses grouped)	Categorical

Bowel, breast and cervical screening variables

All variables related to invitations, tests/screens and assessments requested

5.2 Missing data

We will describe the rate of missing data descriptively. Where numbers are large, we will investigate whether imputation is necessary.

5.4 Outliers

Values identified as possible outliers will be cross-checked with other data sources/variables if possible. The influence of these outlier values on analyses will be checked. Any significant influence detected will be reported and discussed with the Study Steering Committee.

5.5 Analysis Time Frame

Baseline data for cases and controls will be analysed in early 2020. The main analysis will be carried out after outcome data is received from SAIL (estimated around March 2020) and will last until the final report is published in October 2021.

6. Statistical analyses

6.1 Data cleaning of outcome data

Once the outcome data has been received, we will describe all datasets received by SAIL. This will include (but not exhaustive) for each dataset:

-checking that the requested fields have been received.

-reporting the completeness of requested fields based on total eligible NSW records.

Describe the study population

1. Describe the numbers from each NSW received. How generalizable is the survey against the Welsh population of wales?

Describe the exposure

2. Define exposure groups (PD or no PD) using the 3 different fields: LIIILIMIT, LONGIIILIMIT and DisabLimit. Do they correlate and how does PD differ using each of the fields? What is the best approach?

3. Characterise these groups (PD/no PD) with respect to NSW data – are they comparable.

4. Does the rate of PD change over time, by age/time, gender/time etc

Outcome: Screening

5. For each screening population (specific gender/age groups) we will describe by PD/no PD

6. Characterise these groups (PD/no PD) with respect to NSW data – are they comparable?

Outcome: Cancer

7. what % had cancer within a certain time frame following the survey?

8. of those that do have a cancer, describe PD/no PD groups by cancer type, stage at diagnosis, time from diagnosis to death if applicable.

6.2 Main analysis

There are no pre-specified primary outcome(s) and thus equal importance will be given to each outcome, although, this depends on coverage, data quality, and completeness.
We will also produce Directed Acyclic Graphs to examine the causal pathway to an outcome, examining relationships between variables and outcomes and potential mediators of outcome e.g. uptake of screening or attendance at outpatient or GP and risk of cancer diagnosis.

We will follow up this cohort over a maximum 5-year period (or until the event e.g. cancer, death, or date of last follow-up) examining the following outcomes: (a) screening attendance;(b) stage of cancer at diagnosis; and (d) survival. We will develop regression models to explore the influence of having a physical disability on these outcomes.

Outcomes are likely to be binary (uptake or not, cancer diagnosis or not) and we will employ a logistic regression model with risk of event presented as odds ratios (ORs) (alongside 95% Confidence intervals (CIs) or time to event (time to death) and will employ Cox regression model with estimates given as hazard ratios alongside 95% CIs. Stage of cancer is categorical, and an ordinal regression model will be performed. Confounders of outcome will also be pre-hypothesised and adjusted for in the regression models (lifestyle factors etc).

6.3 Bias

The National Survey for Wales is a cross-sectional survey of the adult population in Wales. A sample of addresses is selected at random from the Royal Mail's Postcode Address File (PAF), stratified by local authority. Survey data are collected in face-to-face interviews with one randomly selected adult in each selected household. Each year, the survey is completed by around 12,000 people aged 16 and over (Statistics for Wales, 2016). There is opportunity for potential bias as the survey is based on face-to face interviews, samples for face-to-face surveys are often geographically clustered to keep travel costs to a minimum, this can lead to a less varied sample (Nicolaas, 2012). Data collected using face-to-face interviews may also be subject to interviewer effects such as social desirability bias and interviewer error. There is a risk of coverage bias if portions of the population are not included or they do not have access to the mode of data collection, for example, the survey does not cover people living in communal establishments (e.g. care homes, residential youth offender homes, hostels, and student halls). The survey is weighted to adjust for non-response, which helps make the results as representative as possible (Statistics for Wales, 2016).

6.4 Software

SPSS version 25i will be used for all statistical analyses

7. Appendices

7.1 Identification of mental health disability

We will identify those who have a mental disorder that limits their daily activities using the code: Dvlimillchap3 Mental disorder (limiting) No Mental disorders, from the National Survey for Wales.

7.2 WCISU variables

The following codes were used to select events from data sources for outcomes Table 8.

Code	Description
CATEGORY	Type of treatment
TREAT_DATE	Date of treatment
TREAT_NEOP_NO	Neoplasm number
FIELD_3	Date of death
FIELD_4	ICD9 code for cause of death
CAUSED_DEATH	Information on whether neoplasm was cause of death
GRADE	Neoplasm grade
CLINICAL_STAGE	Clinical stage value
SITE	ICD10 code for neoplasm
CLINICAL_DATE	Date of clinical staging

8. References

Statistics for Wales (2016) Quality Report. Accessed (10/02/2020) Via:

https://gov.wales/sites/default/files/statistics-and-research/2019-02/national-survey-wales-quality-report-2016-17-onwards.pdf

Nicolaas, G (2012) Mixing Modes within a Social Survey: Opportunities and constraints for the National Survey. National Centre for Social Research. Accessed: (10/02/2020) Via:

Mixing Modes within a Social Survey: Opportunities and constraints for the National Survey

Appendix 3: Recruitment poster for qualitative interviews

Appendix 4: The School of Healthcare Sciences research ethics committee approval January 2020.

School of Healthcare Sciences
Head of School and Dean Professor David Whittaker

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

19 July 2019

Cardiff University
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Cardiff   CF24 0AB

Tel Ffon: +44 (0)29 20 688559
Email E-bost HCAREEthics@cardiff.ac.uk

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35 – 43 Heol Casnewydd
Caerdydd   CF24 0AB

Alice James
Cardiff University
School of Healthcare Sciences

Dear Alice

An exploration of disparities in cancer care for people with physical disabilities in Wales and how these are experienced.

At its meeting of *9 July 2019,* the School's Research Ethics Committee considered your research proposal. The decision of the Committee is that your work should:

Pass –and that you proceed with your Research in collaboration with your supervisor

The Committee has asked that the lead reviewers' comments be passed onto you and your supervisors, please see attached.

Please note that if there are any subsequent major amendments to the project made following this approval you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Mrs Liz Harmer – Griebel
Research Administration Manager

Cc : Sally Anstey, Dikaios Sakellariou, Rebecca Cannings-John

Appendix 5: The School of Healthcare Sciences research ethics committee approval January 2020.

School of Healthcare Sciences
Head of School and Dean Professor David Whittaker

Ysgol Gwyddorau Gofal Iechyd
Pennaeth yr Ysgol a Deon Yr Athrawes David Whittaker

CARDIFF
UNIVERSITY

PRIFYSGOL
CAERDYⱭ

14 January 2020

Cardiff University
Ty Dewi Sant
Heath Park
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Alice James
Cardiff University
School of Healthcare Sciences

Tel *Ffôn* +44(0)29 20687552
E-mail E-bost harmerl@cf.ac.uk
Prifysgol Caerdydd
Ty Dewi Sant
Mynydd Bychan
Caerdydd CF14 4XN

Dear Alice

An exploration of disparities in cancer care for people with physical disabilities in Wales and how these are experienced.

I am writing to inform you that the Chair of the Research Ethics Committee has, following consultation, **approved** your revised research proposal. The Committee will ratify this decision at its next meeting.

Please note that if there are any major amendments to the project you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Liz

Mrs Liz Harmer Griebel
Research Administration Manager

c.c. Sally Anstey

Appendix 6: The School of Healthcare Sciences research ethics committee approval May 2020.

School of Healthcare Sciences
Ysgol y Gwyddorau Gofal Iechyd

Cardiff University
Eastgate House
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Interim Head of School and Dean /Pennaeth yr Ysgol Dros Dro a Deon Professor David Whitaker

7 MAY 2020

ALICE JAMES
CARDIFF UNIVERSITY
SCHOOL OF HEALTHCARE SCIENCES

Dear Alice

Research project title: An exploration of disparities in cancer care for people with physical disabilities in Wales and how these are experienced.

SREC reference: 663

The School of Healthcare Sciences Research Ethics Committee Chair has reviewed the above application amendments via its proportionate review process.

Ethical Opinion
The Committee Chair gave a favourable ethical opinion of the above application on the basis described in the application form, protocol and supporting documentation.

Additional approvals
This letter provides an ethical opinion <u>only</u>. You must not start your research project until all appropriate approvals are in place.

Amendments
Any substantial amendments to documents previously reviewed by the Committee must be submitted to the Committee HCAREEthics@cf.ac.uk for consideration and cannot be implemented until the Committee has confirmed it is satisfied with the proposed amendments.

You are permitted to implement non-substantial amendments to the documents previously reviewed by the Committee but you must provide a copy of any updated documents to the Committee at <u>HCAREEthics@cf.ac.uk</u> for its records.

Monitoring requirements
The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.

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Appendix 7: Secure Anonymised Information Linkage Databank (SAIL) Information Governance Review Panel (IGRP) application:

> **SAIL**

SAIL IGRP Application Form

The following form has been designed to collect the information needed for the information governance approval process for work involving the SAIL databank. The information you provide will facilitate consideration of your enquiry. Guidance notes on completing this form can be found at: https://www.saildatabank.com/wp-content/uploads/Guidance_Notes_for_SAIL_IGRP_Application_4-1.docx

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SAIL Feasibility Agreement

All projects require a SAIL Feasibility Agreement to be completed and signed before proceeding to IGRP. This agreement will have been developed as part of the initial project scoping process with a SAIL analyst. Do not continue with this form until you have had your project scoping discussion.
Please provide the agreement number: 0761

1a. Provide contact details of project lead:

Name: Alice James
Job title: PhD student, School of Healthcare Sciences
Organisation: Cardiff University
Address: Eastgate House, 35-43 Newport Road, Cardiff
Tel:
Fax:
Email: jamesal4@cardiff.ac.uk

1b. Provide contact details of the lead contact from any other organisation who will be accessing the data:

	Name	Job title	Organisation
1			
2			
3			
4			

2. Provide full title of the project: An exploration of disparities in cancer care for people with physical disabilities in Wales and how these are experienced

3. Provide details on who is commissioning the project: Kess 2 (Knowledge Economy skills scholarships)- European Social Fund, in partnership with Tenovus Cancer Care

4. Provide the aim of the project, including anticipated outcomes:

1

The aim of the study is to investigate disparities in cancer care for people with physical disabilities in Wales.

The objectives of the study are to:

1. Identify a cohort of people in Wales with a physical disability and a comparable cohort without;

2. Investigate disparities in cancer screening, diagnosis (including cancer stage at diagnosis), treatment, and survival, between people with and without physical disabilities.

3. Explore the combined influence of disability and other demographic and socio-economic variables and other confounders of outcome, as evidence suggests these might also have an effect.

Anticipated outcomes:

The study will identify factors that should be taken into account in the planning and in the provision of cancer care for people with phsyical disabilities, considering the potential impact of demographic and socio-economic variables. It will then, based on peoples' experiences, propose ways to address the specific needs of this population. It is an exploratory study where the purpose is to generate understanding of the disparities in care experiences of this population group.

Please include a copy of the protocol/plan for the proposed work with SAIL, including the contact details of any co-applicants when you return your completed form.

5. Provide a lay summary of the project: Research evidence suggests that people with physical disabilities are likely to be diagnosed with cancer at a later stage, are less likely to access screening services and have poorer outcomes when it comes to cancer survival. This study aims to look at whether people with and without physical disabilities have the same access to cancer care in Wales. We will be using responses from the National Survey for Wales to identify respondents who self report having a physical disability and compare their data on cancer care with those who didn't identify as having a physical disability. We will get our data on cancer care from registry and hospital data, on screening services, cancer treatment given, the stage at diagnosis and outcomes of cancer treatment. We are hoping to combine results from this part of the study with interviews with people with phsyical disabilities and cancer to get an idea of what the experience of cancer care is like for this group. We are aiming to get a deeper understanding of the differences in cancer care there might be between people with and without physical disabilities and, through the interviews, identify the problems or barriers people with physical disabilities might face in accessing cancer care. With this information we will create guidance and publish our findings to hopefully improve cancer care for this group.

6. Provide an outline of the public engagement strategy for the study, or a brief explanation why there is not public engagement: Public engagement in this study is of vital importance. Disability rights

2

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scholars have emphasised the need to conduct research with people with disabilities and not on them. The aim of public engagement for this study will be to collaborate with people with a pre-existing physical disability that went on to get cancer in designing and carrying out the research. We will recruit people with a pre-existing physical disability who have had cancer through our close links with one of our funders, Tenovus Cancer care. The project supervisors also have exisiting links with individuals with a pre-existing physical disability who have had cancer that have been involved in previous studies. We will aim to involve 2-3 individuals throughout the research process and responsibilities will include providing their feedback on the way we are representing people with disabilities and all aspects of the project from their individual perspective.

---

7. Provide information on the relevant permissions you have obtained or that are being sought:

	Obtained	Being sought	Not required
Research ethics	[☐]	[☒]	[☒]

Please state the name of the committee that is being applied to/ has given approval, as applicable:
Research ethics committee: The quantitative element of this mixed methods study will use ony anonymised data, the school of Healthcare Sciences school at Cardiff University ethics approval is being sought for the project.

If you have ticked 'not required' please specify the reasons:
☒ The project will use only anonymised data, and therefore research ethics review is not required.
☐ Other: ▢

	Obtained	Being sought	Not required
Independent peer review	[☐]	[☐]	[☒]

Please state the name of the peer reviewing organisation that is being applied to/ has given approval, as applicable:
Peer reviewing organisation: The application was peer reviewed by Tenovus and KESS as part of the funding application.

If you have ticked 'not required' please specify the reasons:
▢

	Obtained	Being sought	Not required
Permission from data-holding organisation to use their datasets	[☐]	[☒]	[☐]

Please state the name of the data provider that is being applied to/ has given approval, as applicable:

3

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Data organisation: We need to gain approval from WCISU and screening datasets as these have restricted access.

If you have ticked 'not required' please specify the reasons.

☐ The project uses only SAIL unrestricted core datasets and/or data held by the project.

☐ Other: ▢

Please note that it is the responsibility of the project lead to ensure that the relevant permissions are obtained.

8a. Provide a prospective start date for the work involving SAIL: (dd/mm/yy) Upon approval

8b. Provide anticipated end date of the project: (End date OR time duration after approval) 01/01/2022

9a. Provide details of data you require access to for the proposed work with SAIL?

Please list:

The SAIL datasets you require information from

National Survey for Wales

PEDW

WCISU

Colorectal cancer screening suvey

Breast cancer screening survey

Bowel cancer screening survey

ONS deaths

The information needed from each dataset

Please see attached variables table for more detail.

▮

From National Health Survey 2012/13 through to 2016/17 survey year: Age, ethnicity, gender, marital status, employment status, income, level of education, geographical location (urban/rural), self- assessment of health (mental and physical), wellbeing questions, number of carer hours, BMI, GP-seen a GP in the last 12 months.

Lifestyle behaviours: Smoking, alcohol, fruit and veg intake and exercise

National health survey years 2012 to 2015: Answers to Survey questions related to disability. National Health survey variable LIIILIMIT (Do you have any physical or mental illnesses lasting or expected to last for 12 months or more?) and LONGIIILIMIT (Does your condition or illness reduce your ability to carry-out day-to-day activities?)

DisabLimit (Does condition limit activities in any way?)

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National health survey years 2016-2017: 2016/2017 national health survey variables- same as above plus:
Variables SCneed1 through to SCneed8

Plus all derived variables related to the above questions.

From WCISU- Treatment type: Type of treatment (CATEGORY), date of treatment (TREAT_DATE), Neoplasm number (TREAT_NEOP_NO). Treatment outcomes: Date of death (FIELD_3), ICD9 code for cause of death (FIELD_4), information on whether the neoplasm was the cause of death (CAUSED_DEATH). Cancer stage at diagnosis: Neoplasm grade (GRADE), Clinical stage value (CLINICAL_STAGE), ICD10 code for neoplasm (SITE), Date of clinical staging (CLINICAL_DATE).

Colorectal cancer screening suvey-All variables related to Invitations,tests/screens and Assessments required.

Breast cancer screening survey-All variables related to Invitations, tests/screens and Assessments required.

Bowel cancer screening survey-All variables related to Invitations, tests/screens and Assessments required.

ONS deaths for time period 2012-2019

Please indicate the time period for which data is requested

National survey for Wales data from surveys from 2012 to 2016-17

Follow up period for other datasets; PEDW, WCISU, Colorectal cancer screening suvey, Breast cancer screening survey, Bowel cancer screening survey, ONS deaths- data from 01/01/2012 to 31/12/2018

Please indicate the geographic area for which data is requested

All of Wales

Please indicate demographic criteria for the data requested (age, gender, etc.)

Adults ages 18 upwards living in Wales at time of survey. Our population for comparison will be those not deemed to have a physical disability derived from responses to the National survey for Wales.

9b. Will you be providing any other dataset(s) to be incorporated into the SAIL databank?
Yes   [☐]   No   [☒]
If yes:
Provide the name of the dataset(s):
Provide details of the contents of the dataset(s):

9c. Provide an outline of your analysis plan including the anticipated outputs:
We will develop regression models to explore the influence of having a disability on outcomes such as screening uptake, stage of cancer at diagnosis, treatment options and outcomes/mortality rates.

9d. Are the results/methods developed likely to have other potential applications?
Yes   [☒]   No   [☐]
If yes, please specify: The methods for identifying individuals with a physical disability within the data will be able to be applied to other national surveys.

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10a. Please indicate your plans for publishing the results of your project, e.g. target journal or intended recipients of report:

The findings will be widely disseminated through European and global professional groups, for example the European Organisation for Research and Treatment of Cancer and Multinational Association of Supportive Care in Cancer among others, and through publication in international journals, such as the following, among others: BMC Cancer, European Journal of Cancer Care, and Journal of Cancer Care. An executive report will be produced to submit to the Wales Cancer Network, so that outcomes from the thesis can inform the development of the Welsh Cancer delivery plan workstreams.

10b. What are the potentially sensitive issues that need to be taken into account when publicising the findings of the project?

Please outline the issues and your proposed solutions:

Possible sensitive issues that we might entail during this project and the use of SAIL data include;
- The study is using protected characterisitic demographic data such as race, age and disability. The study focuses on a sensitive topic also, the topic of cancer care, including stage at diagnosis and survival rates. It is possible that the sensitivity of the topic of the data combined with the demographic criteria could increase the consequences of any potential disclosure. We will mitigate this risk by following SAIL and avoiding disclosive results.
-We will be using geographic information in the study as the study looks at all of Wales, and socio-economic status within geographic locations, however we will mitiagate the risk of disclosure by reporting results at an all Wales level. Our default position will be to consider all information as sensitive and potentially confidential so the same standard will be applied to all the information we come into contact with.

What to do next

Please return your completed form and supporting documents by email to Cynthia McNerney, Information Governance Coordinator c.l.mcnerney@swansea.ac.uk Thank you.

Appendix 8: Consent form for qualitative interview participants:

CONSENT FORM

Title of Project: An Exploration of Disparities in Cancer Care for People with Physical Disabilities in England and Wales and how These are Experienced

Name of Researcher: Alice James (Cardiff University), Dr Sally Anstey (Cardiff University)

Please initial box

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

4. I agree for the conversations that take place during interviews to be audio recorded and analysed.

5. I agree for the use of quotations from my statements to be used in research reports, any quotations will be anonymised.

6. I give my consent to the use of a written account of my experiences to be made available to others anonymously via the project web site or in research publications

7. I understand that all personally identifiable information about me will be kept in a secure place and in a confidential way and destroyed once the study is completed.

8. I understand that the findings and potentially secondary analysis of the findings and associated data from the study may be presented at conference and in scientific journals. I understand that these will be used anonymously and that no individual respondent will be identified in such report.

9. I agree to take part in the above study.

Name of Participant

Date

Signature of Participant

*Please fill in below if you are signing on behalf of the participant

Name of person signing on behalf of participant	Signature of person signing on behalf of participant

*For use of researcher

Name of Person taking consent:	Date:	Signature:

When completed: 1 for participant; 1 for researcher site file; 1 to be kept in medical notes (if appropriate).

Appendix 9: Information pack for qualitative interview participants:

PARTICIPANT INFORMATION SHEET

Title of Project: An exploration of disparities in cancer care for people with physical disabilities in England and Wales and how these are experienced.

Name of Researchers: Alice James (Cardiff University), Dr Sally Anstey (Cardiff University), Dr Dikaios Sakellariou (Cardiff University) and Dr Rebecca Cannings-John (Cardiff University).

You are being invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

Thank you for reading this.

What is the purpose of the research?

The project aims to investigate cancer care access and experiences of cancer care, including diagnosis and screening, for people with physical disabilities in England and Wales.

The project is a response to previous research that has suggested that people with physical disabilities don't always get the same level of access to cancer care compared to people without physical disabilities.

We want to find out more about the experience of cancer care for people with physical disabilities to identify factors that should be taken in to account in the planning and provision of cancer care for disabled people. Based on people's experiences, possible ways to address the specific needs of physically disabled people in relation to cancer care will be proposed.

Why have I been invited?

You have been invited because you have identified as having a physical disability and experience of having a diagnosis of cancer and cancer care.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part, we will ask you to sign a consent form. If you decide not to take part, you do not have to explain your reasons and it will not affect your legal rights.

You are free to withdraw your consent at any time, without giving a reason, even after signing the consent form. If you would like to withdraw your data after taking part, you can do so by contacting Alice James, jamesal4@Cardiff.ac.uk

What would taking part involve?

Taking part in the study would involve completing one telephone or skype interview with a researcher which will last roughly one hour and one follow up telephone interview, one month later, which will last roughly 30 minutes. The interviewer will ask you some questions related to your experience of cancer care and give you time to answer each question. We are aiming to interview 10- 15 people. All material will be anonymised to protect your identity.

Will I be paid anything for taking part?

No, there is no payment for this stage of the research.

What are the possible benefits of taking part?

There are no specific benefits to you in taking part, but the research will help us to understand the experience of cancer care for people with physical disabilities and help us to raise awareness among decision-makers, clinician and researchers. This will, overtime, improve the experience of patients and help us to understand the barriers to accessing care.

What are the possible disadvantages and risks of taking part?

There are no specific risks in taking part in this research.

How will my information be kept confidential?

Disclosed information will be stored securely and used solely for research purposes. All Information which is collected about you during the course of the research will be kept strictly confidential. All data collected will be anonymised and will not be individually identifiable. Pseudonyms will be used in any oral or written reports or presentations from the study, including any direct quotations from your questionnaire.

Only the research team will have access to the information that can identify and link you to your data. All electronic data will be kept on a password-protected server at Cardiff University. Any paper-based material will be kept in a locked filing cabinet. The original data collection sheets will be kept under lock and key in accordance with the Data Protection Act and will only be accessible to the research team and regulatory authorities. Data will be kept for five years and then disposed of securely and may be used for additional analyses related to other aspects of cancer care for people with physical disabilities.

What will happen if I don't want to carry on with the study?

If you wish to withdraw from the study at any time, then we will all destroy data that we have collected from you.

What will happen to the results of this study?

We plan to present the findings of this research at scientific meetings and publish in academic journals. The results of this research will also be included in the PhD theses of one member of the research team. Participants will not be identifiable in any report/publication but that we may use some of the comments that you have provided in reports, publications and presentations.

What if there is a problem?

If you have any concerns about any aspect of the way that you have been approached or treated during the course of the study please contact Alice James (jamesal4@cardiff.ac.uk) who is part of the research team. Should you require independent advice, please contact Dr Kate Button, Director of Research Governance, School of Healthcare Sciences (buttonk@cardiff.ac.uk). If you are harmed by taking part in this research study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action, but you may have to pay for it.

Who is organising and funding this research project?

The project is being undertaken by researchers at the University of Cardiff. Dr Sally Anstey, Dr Rebecca Cannings-John and Dr Dikaios Sakellariou are supervising the research. Other members of the research team are Alice James (PhD candidate, School of Healthcare

Sciences, Cardiff University). The research is funded by the Knowledge Economy Skills Scholarships and Tenovus Cancer Care.

Who has reviewed this study?

The study has been given ethical approval by the Research Ethics Committee of the School of Healthcare Sciences, Cardiff University.

Further information and contact details

If you have any further questions about the research, please contact Alice James, jamesal4@cardiff.ac.uk

We would like to thank you for considering taking part in this study. If you decide to participate you will be given a copy of the information sheet and a signed consent form to keep.