



DCU

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Dublin City University



An tSeirbhís Náisiúnta Scagthástála
National Screening Service

Breaking Down Barriers:

An Assessment of the Needs
of Disabled People in Accessing
Population-Based Screening
Services in Ireland

Report Team

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Advisory Committee Members

Advisory Committee Members

- | | |
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Executive Summary

Introduction

In the Irish 2016 Census, 643,131 people stated they had a disability, accounting for 13.5 percent of the population. Advocating for disability inclusion in the health sector, the World Health Organization (WHO) states that in order to attain the highest possible standard of health and well-being for all, disability inclusion must be made intrinsic to health sector priorities, including public health, of which health screening is a part.

The Irish National Screening Service (NSS), part of the Health Service Executive (HSE), encompasses four national population-based screening programmes: BreastCheck for breast cancer screening, CervicalCheck for cervical cancer screening, BowelScreen for bowel cancer screening and Diabetic RetinaScreen for diabetic retinopathy screening. The proportion of the eligible population for cancer screening in Ireland with a disability is 19%, 12% and 22% for BreastCheck, CervicalCheck and BowelScreen, respectively.

To inform efforts to increase access to screening among disabled people in Ireland, this study sought to explore the needs of disabled people in accessing national screening services. This was the first study of its type to be carried out in Ireland. The study direction, scope and methodology was informed by NSS staff members and an advisory committee consisting of disabled people.

Study aim and Design

This study aimed to examine the perspectives and experiences of disabled people in accessing screening services and to assess factors that influence their uptake of, and participation of population-based screening programmes. The research was qualitative in nature, consisting of focus groups and interviews. Twenty disabled people participated in the study, representing those with Intellectual Disabilities, Autism, physical impairment, visual impairment, and the Deaf community. In addition, five healthcare professionals and five family carers were involved in the study. The data collected from the interviews and focus group discussions were analysed using thematic analysis.

Key findings of the research study

The findings from this study align with the findings in international literature. The findings are discussed in the context of each stage of the screening process, namely pre-screening, screening, and post-screening.

Pre-Screening Stage

Four out of eight people with intellectual disabilities stated they had never received a screening invitation for a particular service despite being eligible. Given the small sample, it is difficult to say if this is widespread; however, it merits further investigation.

Some disabled people expressed concerns about their dependency on others to make an appointment and attend the screening services.

Inaccessible communications (e.g., letters containing too much text) make it more challenging to decide whether to attend screening services or not.

A requirement to travel longer distances to attend screening, as opposed to accessing screening closer to home, was discussed as a barrier to screening (due to higher travel cost and other logistical difficulties).

Disabled people suggested that it would be helpful if they were able to view a video of a screening test involving someone they can identify with in information resources.

Screening Stage

Disabled people reported numerous positive experiences, such as the willingness of professionals to provide double appointments (e.g., appointments of longer duration), a supportive and compassionate approach, and the provision of information in Braille by request.

Some disabled people are concerned about negative attitudes among professionals involved in screening, such as assumptions regarding suitability for screening people with intellectual disabilities and the use of non-person-centred language.

Some disabled people prefer to have the screening test at a familiar place and with familiar people around them to provide support.

The screening professionals spoke of issues in relation to obtaining informed consent for screening, especially from people with intellectual disabilities.

Disabled people also expressed concern about the lack of accommodation and accessibility in screening settings, such as confined spaces and inflexible equipment.

Some disabled people reported that comorbidities make it challenging to access screening services.

Some disabled people expressed the need for support to collect the sample for bowel screening.

Post-Screening Stage

Some disabled people faced difficulties in amending the register to record their disability status.

Some disabled people are willing to disclose their disability and needs, but they would prefer to disclose this information electronically (e.g., via online web forms) rather than directly to screening staff.

Some participants reported pain and discomfort after the screening, and others felt irritation and sight disturbance after attending Diabetic RetinaScreen.

Disabled people had a positive experience in that they received their screening results in a format that was accessible to them. However, they had to request this service.

Recommendations

Involve disabled people in all aspects of screening service design.

Provide in-service disability awareness training to all staff involved in screening.

All communications should be made accessible at scale.

Develop a clear protocol for the chaperone process.

Provide guidelines and training on reasonable accommodations, to include travel; costs; equipment; appointment times, durations, and locations; physical accessibility, accompaniment, and support personnel.

Develop information and educational materials targeted at disabled people, their caregivers and family members, to include preparation for screening and what to expect.

Include disability status and needs as part of the health screening record.

Develop a platform/system to allow for feedback post-screening.

Provide clear information about screening location accessibility.

Establish/explore a system for sharing information between the four screening services.

Promote awareness of how to register and check the screening register.

Investigate the lack of invitations reported by people with intellectual disabilities.

Conclusion

This report identified the positive experiences of disabled people in accessing the screening services and the strategies the NSS adopted to improve access. Despite these efforts, disabled people still experience several issues and challenges in accessing screening services. The significant role of the NSS in promoting and implementing screening among eligible participants is highly valued among the participants. However, disabled people suggested the importance of collaborative work between the NSS, Disabled People's Organisations (DPOs), and disability services to improve access to screening services. There is an urgent need for the collection of information about disabled people who are eligible for screenings and have accessed to those services to help service improvement.

Chapter 1

Introduction to the report

1.1 Disability and Healthcare

According to the World Health Organization (WHO), disability results from the interaction between individuals with a health condition and personal and environmental factors, including negative attitudes, inaccessible transportation, and public buildings, and limited social support (WHO, 2022a). This model indicates that improving healthcare for disabled people requires careful examination of the interactions between healthcare providers and disabled people (WHO, 2022a).

A person's environment has a significant effect on the experience and extent of disability. Inaccessible environments create barriers that often hinder the full participation of disabled people in society on an equal basis with others. Progress in improving social participation can be made by addressing these barriers and supporting disabled people in their day-to-day lives, and facilitating access to community services (WHO, 2022a).

The WHO (2022a) has identified a range of barriers that disabled people encounter when they attempt to access healthcare, including;

- Attitudinal barriers
- Physical barriers
- Communication barriers
- Financial barriers.

Disabled people have the same general healthcare needs as everyone else, and therefore they need to access mainstream healthcare services (WHO, 2022a; NDA, 2012). There is some evidence to suggest that people with intellectual disabilities (ID) may be at greater risk of diabetes than those in the general population (McVilly et al., 2014). In addition, Jung et al. (2020) suggest that the prevalence of diabetes is higher for disabled people compared with non-disabled people. It is reported that the prevalence of cancer is higher among disabled people compared with the general population (Lezzoni et al., 2020; Xu et al., 2017; Newmann and Garner, 2005). Cervical cancer is a prevalent form of cancer among women, ranking as the third most common, with disabled people having a heightened susceptibility to developing this type of cancer (Saslow et al., 2012; Ferlay et al., 2008). In addition to cervical cancer, disabled people also have a high incidence of breast and bowel cancer (Sakellariou and Rotarou, 2017; Floud et al., 2017). Despite the high risk, disabled people have a low screening rate for cervical, breast and bowel cancer (Huang, Tsai and Kung, 2012; Armour, Thierry and Wolf, 2009).

Autistic people are particularly vulnerable, as they have a two-fold increase in the risk of dying from cancer-related causes (Hirvikoski et al., 2017). The main reason behind this is delayed diagnoses, which could have been prevented with early detection (Hosking, 2016). Early detection of cancers can significantly reduce the mortality rates, and it is crucial for disabled people to get screened regularly (Yang and Graves, 2022). However, late presentation to healthcare is a common issue among disabled people, and this is due to various reasons such as pre-existing mobility disabilities, lack of awareness about screening services, and underlying health conditions (Agaronnik et al., 2022). Similarly, autistic people face barriers in accessing healthcare, including communication difficulties, sensory barriers, mobility issues, and physical and mental health problems (Doherty et al., 2022).

To promote access and attain the highest possible standard of health and well-being for all, the WHO states that disability inclusion must be made intrinsic to health sector priorities such as:

- Universal health coverage
- Protection during health emergencies
- Public health interventions

The services provided by Ireland's National Screening Service (NSS) are examples of public health interventions.

1.2 Context of Disability

Over 1 billion people – about 15% of the global population – currently experience disability based on health conditions and the presence of social barriers. This number is increasing as the population ages and the prevalence of non-communicable diseases increases (WHO, 2022b).

In the Irish 2016 Census, 643,131 people stated they had a disability, accounting for 13.5 percent of the population. Among the disabled population, 48.4% were male, and 51.6% were female. Figure 1 charts disability percentage by age derived from Census 2016.

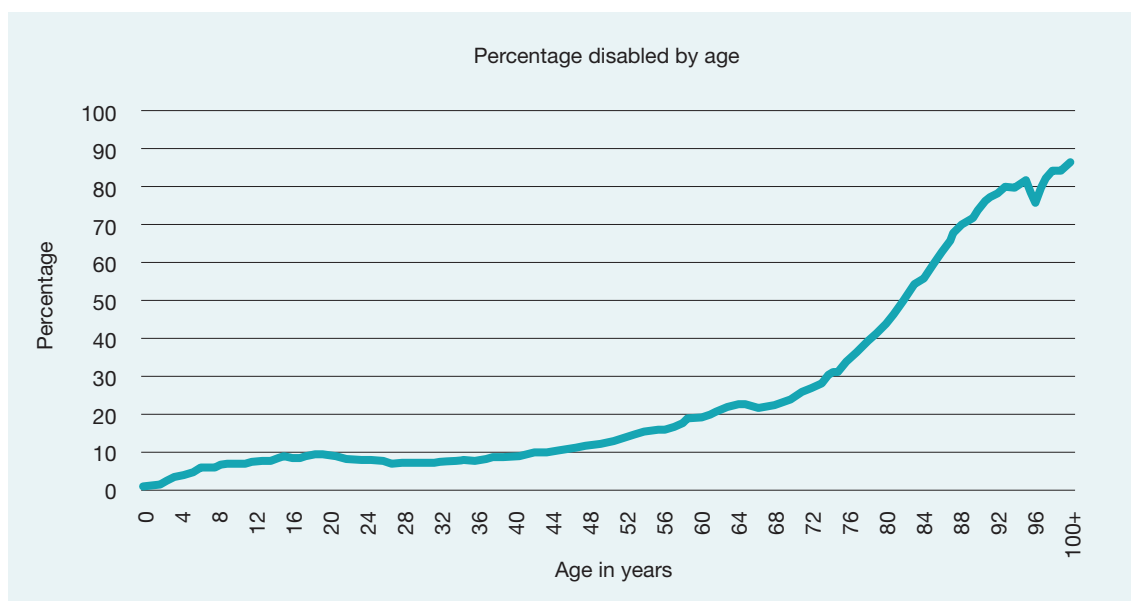


Figure 1 Percentage of Disability by age

‘Disability’ as a category is extremely diverse. While some health conditions associated with disability result in poor health and extensive healthcare needs, others do not. As reinforced by the WHO disabled people have the same general healthcare needs as everyone else and therefore need to access mainstream healthcare services (WHO, 2022b; NDA, 2012).

1.3 Research Terms of Reference

In November 2021, the NSS invited tenders of expressions of interest for carrying out a needs assessment for disabled people regarding access to the National Screening programmes. In response to the invitation, the DCU research team submitted a proposal which was subsequently successful.

The objectives of the needs assessment project were to:

- Document the size and demographics of the disabled population invited for screening in Ireland;
- Explore the current level of data captured by the NSS on disabled people;
- Review the health issues affecting disabled people as applied to screening services i.e. breast, cervical and bowel cancers, diabetes;
- Identify barriers and facilitators experienced by disabled people accessing screening;
- Consult with disabled people on their experience of screening;
- Consult with carers, family members and health professionals on their requirements to support disabled people to avail of screening;
- Provide recommendations for NSS based on findings.

1.4 United Nations (UN) Convention on the Rights of Persons with Disabilities

The UN Convention on the Rights of Persons with Disabilities sets out the rights of disabled people and serves as the basis for much legislation and governance currently in operation worldwide. Countries that ratify the convention agree to state, in writing, that they will do what the Convention requires and report to the UN Committee regarding progress.

Article 25 of the Convention relates to health. It recognises that disabled people have the right to the enjoyment of the highest attainable standard of health without discrimination based on disability; also, that state parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

The Convention specifically refers to population-based public health programmes, stating that parties shall:

“Provide persons with disabilities with the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes”.

This is of particular relevance to the current study as the health screening services under consideration here are examples of population-based public health programmes.

The Convention further states that these health services should be provided as close as possible to people’s own communities, including in rural areas, and requires health professionals to provide care of the same quality to persons with disabilities as to others. This includes raising awareness of the human rights, dignity, autonomy and needs of disabled people through training and the promulgation of ethical standards for public and private healthcare.

Ireland formally ratified the Convention in 2018, and it entered into force on 19 April 2018. Prior to this, in 1999, the Oireachtas (Irish parliament) enacted a bill to provide for the establishment of a body to be known as the National Disability Authority (NDA). The NDA is the independent state body providing expert advice on disability policy and practice to the government, the public sector and promoting Universal Design in Ireland. The functions of the NDA are set out in law. The main function of the NDA is to provide advice and information to the Minister for Justice and Equality on matters concerning policy and practice in relation to disabled people and to assist the Minister in the coordination of disability policy.

In 2017, the Irish Government produced “The National Disability Inclusion Strategy 2017-2021” (Department of Justice and Equality, 2017). This is the key framework for policy and action to address the needs of people with disabilities. Whilst this document calls for further development of the capacity of mainstream HSE funded services to provide accessible services and information to people with disabilities, it makes no specific mention of health screening. However, on foot of this strategy, the NDA produced a document entitled “An Indicator Set to Monitor the National Disability Inclusion Strategy 2017-2021” (National Disability Authority, 2017). This document presents a suite of indicators to monitor the National Disability Inclusion Strategy (NDIS). It states that indicators are regarded as playing a vital role in the identification of trends and issues, while contributing to the process of priority setting, policy formulation and the evaluation and monitoring of progress. It also states that the listed indicators will be used to assess the level of progress being made through the implementation of the Strategy to improve the lives of disabled people over time. Fifty-eight indicators are listed in total, with seven relating to health. Of the seven relating to health, one concerns health screening, namely indicator 5.1d, which states that “Rates of health screening in people with a disability compared to people without a disability” should be used as an indicator. It is evident from this that the provision of health screening for disabled people is a crucial aspect of the government’s strategy for disability.

1.5 The National Screening Service

The Irish National Screening Service (NSS), part of the Health Service Executive (HSE), encompasses four national population-based screening programmes. The programmes relate to breast cancer, cervical cancer, bowel cancer and diabetic retinopathy. Each year in Ireland, approximately 3,700 women are diagnosed with breast cancer, 300 with cervical cancer and 2,800 people with bowel cancer. The 5-year survival rates for these diseases are 84%, 65% and 64%, respectively. For diabetic retinopathy, between 2004 and 2013, the mean annual incidence of visual impairment due to the disease was 0.3 per 100,000 population, and the mean annual incidence of blindness due to the disease was 0.9 per 100,000 adults or 13 and 39 individuals per 100,000, respectively.

The four programmes of the National Screening Service are

- BreastCheck,
- CervicalCheck,
- BowelScreen and
- Diabetic RetinaScreen.

The eligibility criteria for the programmes at the time of publication are:

- women aged 50-69 years for BreastCheck,
- women and people with a cervix aged 25 to 65 for CervicalCheck,
- men and women aged 59 to 69 for BowelScreen and
- people with Type 1 or Type 2 Diabetes, aged 12 and over, for Diabetic RetinaScreen.

The proportion of individuals eligible for each cancer screening service who have a disability, based on the 2016 census, is shown in Figure 2.

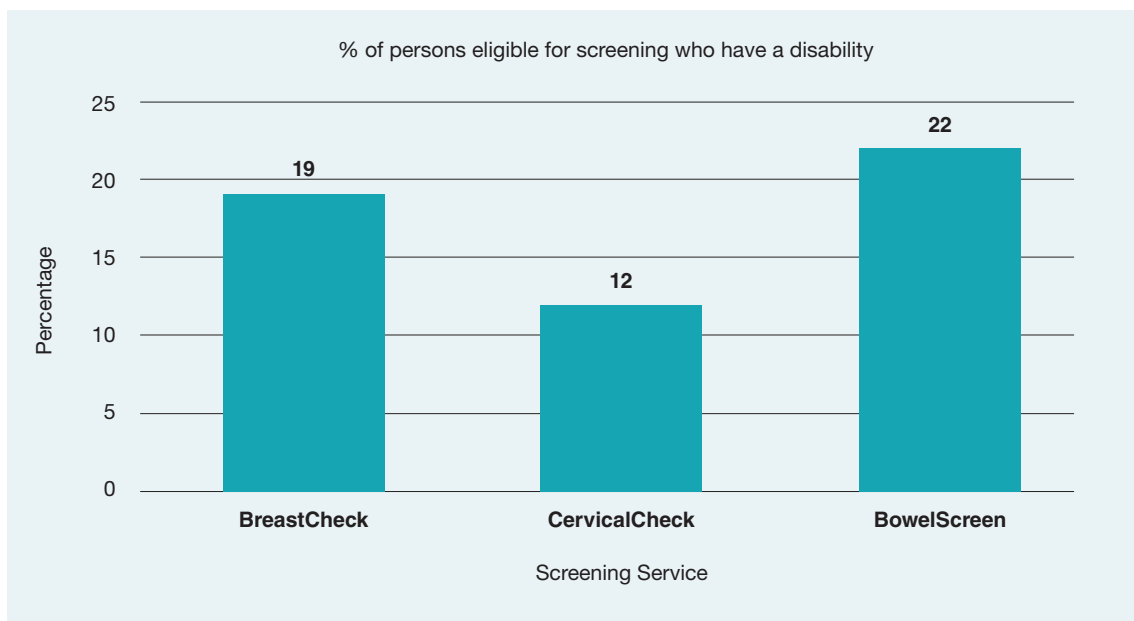


Figure 2 Percentage of Disabled people eligible for each cancer screening services based on the 2016 census

The current screening frequency is

- every 2 years for BreastCheck,
- every 3 years for women aged 25-29 and every 5 years for women aged 30-65 for CervicalCheck,
- every 2 years for BowelScreen and
- once a year for Diabetic RetinaScreen (unless the previous 2 screenings found no retinopathy, in which case the next screening invitation will be 2 years from the time of the last screen).

The uptake for the screening services was

- 73.8% for BreastCheck, with 167,575 eligible women attending in 2019.
- 78.7% for CervicalCheck, with an average of 295,000 screened each year for years 2017 to 2020.
- 41.9% for BowelScreen with 224,153 screened for years 2018 to 2019.
- 67.2% for Diabetic RetinaScreen with 105,475 attending for screening based on current programme data.

However, patterns of uptake suggest inequities. For instance, uptake for cervical screening ranged from 89.1% for women aged 25 to 29, to 59.7% for those over 60.

The NSS aims to address inequitable access and utilisation of screening, and works with communities to promote greater access to screening programmes. In 2021, the NSS undertook 22 projects under the umbrella of equity. All projects which fall under equity are aimed at increasing or supporting access to services and promoting the provision of more accessible information about NSS services (National Screening Service, 2021).

In 2021, the National Screening Service produced a document “Working to reduce inequity in screening” that outlined several projects aimed at reducing inequities based on sexual orientation, age, gender and disability status (National Screening Service, 2021).

1.6 Uptake of screening for people with disabilities

1.6.1 International

Several international studies have investigated the uptake of screening for disabled people. A recent systematic review and meta-analysis examined 29 quantitative studies comparing the uptake of breast or cervical cancer screening between women with and without disabilities (Andiwijaya et al., 2022). The reviewed studies were conducted in Canada, the USA, South Korea, the United Kingdom, Denmark, Northern Ireland, Sweden, and Australia. Compared to non-disabled women, the pooled estimates indicate that disabled women have lower likelihoods of undergoing breast and cervical cancer screenings. The odds of attending breast cancer screening are 0.78 (95% confidence interval: 0.72–0.84) lower and the odds of attending cervical cancer screening are 0.63 (95% CI: 0.45–0.88) lower for disabled women. The review concluded that disabled women face disparities in receipt of preventive cancer care and suggested that there is an urgent need to evaluate and improve the inclusivity of cancer screening programmes and thereby prevent avoidable morbidity and mortality. Similar disparities have been found for bowel cancer screening and diabetic retina screening.

One Belgian study examining screening uptake among 92,334 Flemish individuals registered as disabled in 2013–2015 found that 40.7% of disabled people had undergone a faecal immunochemical test (colorectal cancer screening) in the last two years compared to the overall Flemish uptake of 51.5%. The authors concluded that participation disparities in the Flemish cancer screening programmes between persons with and without disabilities require specific efforts to increase cancer screening among people with a disability (Kellen et al., 2020).

A Canadian study on bowel cancer screening found that the odds of having had a faecal occult blood test in the previous two years and being up-to-date with colorectal tests were 32% and 46% lower, respectively, for Ontarians with Intellectual and Developmental Disabilities compared to those without. The authors concluded that the findings underscore the need for targeted interventions aimed at making colorectal cancer screening more equitable (Ouellette-Kuntz et al., 2015).

Kreft and colleagues (2018) assessed factors associated with Diabetic Retinopathy (DR) screening uptake. The study, from Germany, concludes that a high proportion of newly diagnosed persons with type 2 Diabetes did not follow current German recommendations for DR screening. This was more apparent among persons who were men, older or had a disability. It found that the hazard ratio for disability was 0.30 [95%-CI: 0.25-0.36] (Kreft et al., 2018).

1.6.2 Ireland

A review of the literature failed to find any research studies on the uptake of screening for disabled people in Ireland. However, a report by the NDA included consideration of the rates of health screening in disabled people compared to non-disabled people in Ireland. It was reported that disabled people, as compared to non-disabled people, were less likely to receive a mammography (19% vs 14%, respectively). The prevalence of cervical screening among disabled and non-disabled people was approximately equal (20% vs 21%, respectively). These rates are based on data from the Irish Health Survey 2015 (Central Statistics Office, 2015).

A further report by the NDA (Overview of UNCRPD Article 25 in Ireland) stated that disabled people had higher or similar levels of health screening than non-disabled people, as per data from the 2015 Irish Health Survey. Nearly 14% of disabled woman had a mammogram in the previous 12 months compared to 13% non-disabled woman. Corresponding figures for cervical smear tests were 17% versus 20%. The report further stated that levels of breast checks among women with intellectual disabilities were comparable with the general older population, based on data from wave 3 of the IDS-TILDA study. These figures are at odds with international figures as outlined in the literature.

However, caution needs to be exercised in the interpretation of data on health screening among Irish disabled people. The Irish Health Survey considered a physical disability but not intellectual disabilities, and the IDS-TILDA study relates only to people with intellectual disabilities aged 40 years or over (McCarron et al., 2017).

1.7 Project Overview

This project seeks to further the aims of the NSS in addressing inequitable access to, or participation in, screening for disabled people. The project involved a five-stage process to achieve the objectives as stipulated by the NSS, as shown in the table below.

Table 1 Five-stage process to achieve the objectives

Stage	Actions
1	The research team met with NSS staff members to discuss their policy requirements and research expectations
2	Consultation with NSS staff to understand the existing data collection process, coverage gaps and expectations
3	Review of the peer-reviewed literature to explore national and international evidence to identify the barriers and facilitators for this cohort to access screening services and outline gaps in the current understanding of access to screening for disabled people
4	Data collection through focus groups and individual interviews with stakeholders. Data was analysed using thematic analysis
5	Preparation and dissemination of report

1.8 Advisory Committee

Early in the process, an Advisory Committee (Patient and Public Involvement) was established to guide the research project. An invitation to become an advisory committee member was sent to the Disabled People's Organisations (DPOs) through the Project Officer. We received an overwhelming number of responses requesting membership of the advisory committee. To provide an equal opportunity for the respondents to be involved in the committee while ensuring that there was at least one person to represent each category of disability, an individual was randomly selected from each category. The advisory committee consists of eight people, including two visually impaired persons, three persons with physical impairment, one Deaf person, one autistic person and one person with intellectual disabilities. The advisory committee comprises six women and two men.

1.9 Definition of Disability for this project

The project aimed to adopt a social model of disability, thus aligning with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) definition of disability that recognises that disability:

"...results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".

The powerful and liberating aspect of the social model is that it reflects disabled people's real-life experiences and proposes radical and practical recommendations to promote disabled people's inclusion, including in population-based screening programmes.

For the purpose of recruitment for this project, to increase the participants' representativeness, it was necessary to define disability categories and recruit a sample of individuals that represent these categories. Although this labelling /categorisation of individuals based on diagnoses/impairments contradicts the ethos of the social model of disability, where impairment type (e.g. intellectual impairment) is not the cause of the disability, but rather the environment, pragmatically it was necessary. We did, however, endeavour to maintain a social model of disability lens in data collection and analysis, and in our development of recommendations.

There is no definitive list of conditions that constitute a disability. Any such list could omit people with significant but rare conditions. There can also be a wide range of differences between how individuals experience a given disability condition, ranging from mild to severe difficulties. A person's environment, which includes the support they have and the physical or social barriers they face, influences the scale of the challenges they face in everyday life (National Disability Authority, 2022).

For this project, informed by the NSS disability steering group, we utilised the NASS's (National Ability Support System) and CSO's (Central Statistics Office) 'categories of disabilities' to define our sample for recruitment purposes. We invited people with intellectual disabilities, autistic people, physically impaired people, visually impaired people, and Deaf people. In addition to these being prevalent disabilities in Ireland, the peer-reviewed literature and preliminary data from prior NSS support requests suggest individuals with disabilities mentioned above may experience barriers to population-based screening programmes. We excluded psychological and emotional conditions, neurological disability, difficulty in learning, remembering or concentrating, and chronic illness, but anticipated that some disabled people included in the study may have these as secondary conditions.

1.10 Structure of the Report

This report is presented with an introduction and chapters addressing the background, literature, methodology, results, discussion, and recommendations as follows:

- Chapter One presents an introduction to the rights of disabled people, United Nations Convention of the Rights of Disabled People (UNCPRD), uptake of screening of disabled people, the definition of disability and overview of the project;
- Chapter Two reviews the scientific literature on the experiences and perceptions of disabled people, professional carers and family carers in accessing cancer and diabetic retinopathy screening;
- Chapter Three contains a discussion of the methodological approach and design utilised for the project;
- Chapter Four details the findings of the experiences and perceptions of disabled people, their family members and professionals when accessing National screening Services;
- Chapter Five provides a discussion of the findings and contextualises these into the broader literature; and
- Chapter Six concludes by offering recommendations for improving screening access and uptake by disabled people.

Chapter 2

Literature Review

2.1 Introduction

Cancer is a worldwide public health problem due to its high prevalence and high mortality, whilst Diabetic Retinopathy (DR) is a leading cause of blindness in working-aged adults in industrialised countries (Yau et al., 2012). It is projected that 27 million people will develop cancer globally, and 17 million deaths will result from this disease in 2030. The Irish Cancer Society (2020) reported in 2020 that there are 120 people diagnosed with cancer every day in Ireland, accounting for 44,000 people annually. The burden of cancer in Ireland is rising, driven mainly by population growth and an aging population. By 2045, the number of cases of breast, cervical, and colorectal cancer is expected to increase by 50%, 56%, and 113% respectively, compared to 2015 (National Cancer Registry Ireland, 2019). On average, between the years 2017-2019, there were 6,524 cases of breast, cervical, and colorectal cancers diagnosed (excluding male breast cancers 6,490) and 1,834 deaths due to these cancer types (excluding male breast cancers 1,828) each year in Ireland (National Cancer Registry Ireland, 2022). Although there is no official data of the incidence of cancer among disabled people in Ireland, it is widely recognised globally that disabled people have a higher prevalence of cancer and death from the disease compared to the general population (Iezzoni et al., 2020).

The higher prevalence of cancer and mortality among disabled people can be attributed to several factors, including late presentation, lower symptom recognition, and high pain thresholds. However, there is also a significant contribution from the low utilisation of screening services, which can be attributed to a lack of awareness about available programs and dependency on others to attend these services (Andresen et al., 2013). Insight into the experience of disabled people accessing the National Screening Services is key to promoting effective service planning and policy development. Meeting the needs of this population when accessing the National Screening Services requires a significant service redesign based on the individual's disability, current patterns of service delivery and usage, and the development of accessible support (Department of Health, 2019).

2.2 Aim of the Literature Review

This systematic literature review aimed to identify and synthesise the scientific evidence base about the barriers and facilitators experienced by the disabled population in accessing screening programmes.

The following research questions were the basis for the review:

- What does the published peer-reviewed literature tell us about the experiences of the disabled population, their carers and their professionals in accessing population-based screening programmes?
- What are the primary gaps in the literature that require attention to support disabled people in successfully accessing population-based screening programmes?

2.3 Search Strategy

This review uses the SPIDER (sample, phenomenon of interest, design, evaluation, and research type) acronym (Cook, Smith and Booth, 2012) to define the criteria for including studies (Table 2).

Table 2 Inclusion and Exclusion Criteria

Sample	<ol style="list-style-type: none"> 1. Disabled people who are eligible to access screening programmes. 2. Carers and professionals who are supporting disabled people to access screening programmes.
Phenomenon of Interest	Accessing screening programmes.
Design	Qualitative and mixed-method research designs.
Evaluation	Findings represent opinions, perspectives, views and experiences of the disabled population, carers and professionals in accessing screening programmes.
Research type	All published studies that report on the views or experiences of the disabled population, carers or professionals.

This review systematically searched the electronic databases to identify and retrieve primary research studies. The search was carried out using the following databases; Medline, CINAHL, Web of Science Core Collection (incorporating Social Science Citation Index) and Scopus. In addition, the review also searched grey literature websites (e.g., <https://www.greylit.org>) to include studies not listed in databases. Finally, the reference lists of any identified national guidelines regarding access to screening programmes by disabled people were reviewed.

We developed specific terms for elements of the SPIDER acronym (Table 3), and this was adapted as appropriate for searching the different databases. Once the articles were retrieved, we downloaded all the records from the databases to Zotero, a reference management software. Then, we uploaded these relevant articles to screen for eligibility using Covidence software (www.covidence.org). Two authors carried out the eligibility screening to check whether the articles were suitable for review. Initially, the suitability of the articles was screened based on their title and abstract. Then, after initial screening, articles that appear eligible were included for full-text review. The full-text review was carried out based on the inclusion and exclusion criteria, and then the eligible articles were retained for review. Any disagreement or uncertainty relating to including or excluding records was resolved through explicit discussion between the reviewers. In addition, to expand the scope of the review, we searched the reference lists of studies identified for inclusion in the review.

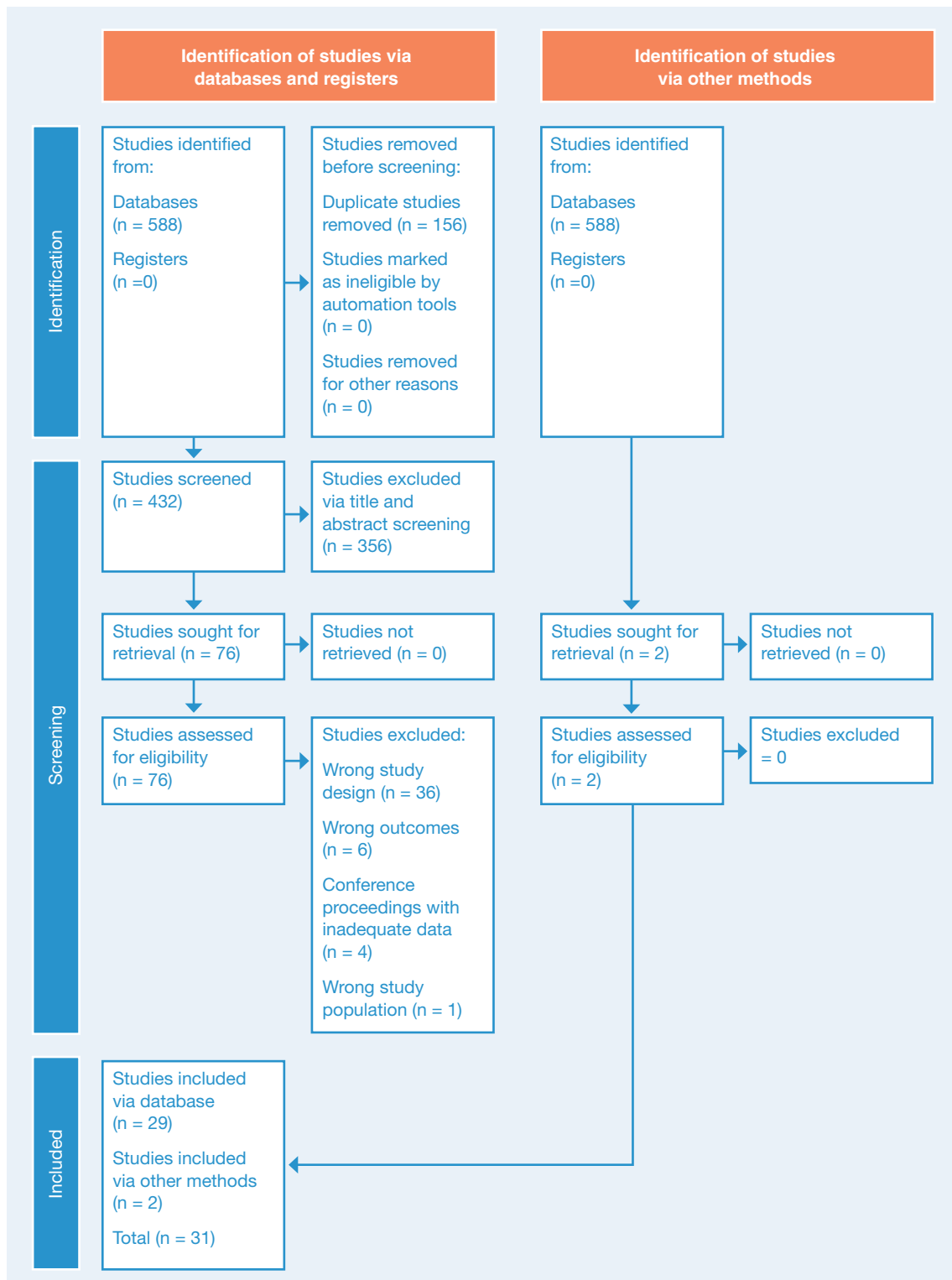
Table 3 Search Terms

Sample	Phenomena of Interest	Evaluation/Research Type
Learning disabilit* OR Intellectual disabilit* OR developmental disabilit* OR Sensory disabilit* OR Deaf* OR physical disabilit* OR disabilit* OR Blind* OR impairment OR autism OR ASD or autism spectrum disorder OR asperger's OR asperger's syndrome OR autistic disorder OR aspergers And carer* OR professional* OR relative* OR Sibling* OR nurse* AND	cancer screening* OR National cancer screening program* OR cancer screening program* OR Breast Check OR Breast screening OR Cervical screening OR Cervical Check OR Bowel screening OR Diabetic Retina Screen* OR retina screen* AND	Experience* OR view* OR perception* OR voice* OR narrative* OR qualitative OR mixed method* OR grounded theory OR phenomenology OR action research OR quantitative OR survey OR questionnaire*

2.4 Search and Selection

In total, 588 records were retrieved from the database searches. Out of these, 156 papers were duplicates and subsequently excluded. Of the 432 records screened on title and abstract, 356 were ineligible and thus excluded. The full texts of the remaining 76 records were retrieved and assessed for eligibility. Subsequently, 47 papers were excluded. Therefore, 29 records were included for the review from the databases. We sourced two records through a reference search. Thus, we included 31 papers for review (Fig-3).

Figure 3 Search and Selection flow diagram



2.5 Quality Appraisal of the Included Studies

Two authors conducted the quality appraisal of the included articles independently. This is an essential part of the review process to understand the quality of evidence included in the review (Noyes et al., 2019). For the purpose of this review, we utilised the tool developed by Evidence for Policy and Practice Information and Co-ordinating (EPPI) (Thomas et al., 2003). This quality appraisal tool comprises 12 criteria that measure quality on three domains, e.g.

- the quality of the study
- reporting, reliability and validity of data collection and analysis, and
- quality of the study methods.

2.5.1 Description of the included studies

A detailed summary of the characteristics of the included studies provides a comprehensive overview of the methodological quality of the included studies (Available on request). Of the 31 included studies, 13 were conducted in the United States of America, 6 were conducted in Australia, 3 were conducted in Canada and Northern Ireland, 2 were conducted in the United Kingdom (UK), 2 were conducted in Scotland, and 1 each in Turkey and New Zealand. The studies were conducted between 2000 and 2019 and published between 2003 and 2022. The number of participants across the 31 included studies was 802; in addition, one study had an undefined number of participants. The participants were disabled people, family members, care workers, nurses and technicians. For data collection, 19 studies used individual interviews, two studies used a mix of focus groups, and individual interviews, six studies used focus groups only, two used interviews and observation, and one used the individual barrier and solution profile form (IBSP). For analysing the data, sixteen studies used thematic analysis, six used thematic analysis guided by framework, one study used interpretive analysis, two studies adopted content analysis, 3 studies used constant comparison of grounded theory principles, one study used descriptive statistics and two studies did not clearly state the principles of data analysis.

2.5.2 Quality Assessment

A quality assessment of the included studies was carried out by two researchers. None of the 31 studies met all 12 quality criteria. Eighteen of the included studies (Willis et al., 2015; Willis, 2016; Truesdale-Kennedy et al., 2011; O'Farrell et al., 2012; Magasi et al., 2019; Agaronnik et al., 2021; Arana-Chicas et al., 2020; Kilic et al., 2019; Mcilpatrick et al., 2011; Mele et al., 2005; Peters and Cotton, 2016; Seaton et al., 2017; Shah et al., 2022; Sonalkar et al., 2019; Todd and Stuijbergen, 2011; Wilkinson et al., 2011; Sullivan et al., 2004; Taggart et al., 2011) met 11 of the 12 criteria. Four studies (Solenberg. et al., 2021; Breau et al., 2022; Angus et al., 2012; Peters and Cotton, 2014) met 10 criteria. Two studies met 9 of the 12 quality criteria and two criteria partially met (Swaine et al., 2013; Barr et al., 2008; Wood and Douglas (2007), Poulos et al. (2010) and Greenwood et al. (2014) met eight quality criteria. Wollin and Elder (2003) met seven of the 12 quality criteria. Sweeney and Suzuki., (2013) met five of the quality criteria. Lastly, Hanlon and Payne (2017) met four of the 12 quality criteria.

2.6 Data Extraction and Synthesis

The data from the study were examined based on the aim of the review, and the following information was extracted; the aim of the study, year published, funding details, recruitment information, sampling technique, participants' profile and description of the settings, duration of study/timeframe, data collection process and data analysis and the findings related to accessing screening programmes by the disabled people. The data were extracted using a standardised data extraction form by two reviewers independently (KC and KE), and then these were cross-checked independently.

The data were analysed using the five-step framework analysis (Goldsmith 2021). First, the data were read and re-read in full to gain familiarisation with the data, and then, second, key ideas and concepts in the data were coded independently by two reviewers (KC, and SH or KE). Third, the codes were assimilated together to develop sub-themes. Fourth, these sub-themes were then charted into the existing healthcare access framework (Levesque et al., 2013) systematically. Finally, the mapping of the codes and sub-themes into the healthcare access framework was extensively discussed among the research team until a consensus on the placement of subthemes within the framework was reached (Gale et al., 2013; Srivastava and Thomson, 2009).

2.7 Synthesis of Findings

The facilitators, experiences and needs of disabled people regarding accessing cancer screening services are presented for each domain of the Levesque framework (Levesque et al., 2013). Each framework domain is discussed and interpreted with reference from relevant literature.

2.8 Perceived Need for Cancer Screening

To engage in population-based screening, individuals must first perceive it as being a need, and a necessary and worthwhile activity. Twenty-two of the 31 studies included in this review demonstrated that an ability to “perceive cancer screening as a need” was a critical factor influencing disabled people’s uptake of this service. Data show that an individual’s perception of their need for cancer screening is determined by various factors, including their awareness of available screening programmes, reading and health literacy skills, and beliefs about the importance of population-based screening services. Reading literacy skills are frequently a barrier to interpreting population-based screening information and appointment invitations, especially for people with intellectual disabilities.

2.8.1 Ability to perceive cancer screening needs and services

This review revealed that many people with intellectual disabilities depend on professionals or family members to interact with screening services due to poor reading literacy (Llewellyn et al., 2011; McIlpatrick et al., 2011; Mele et al., 2005). Most often, people with intellectual disabilities find difficulty reading screening information, which leads to family members acting as gatekeepers (Llewellyn et al., 2011; McIlpatrick et al., 2011; Mele et al., 2005):

“Some women can’t read, they don’t know where to go, there’s no information. I think it’s very, very hard for them” (Llewellyn et al., 2011, p. 1760).

Health literacy was also identified as a barrier to population-based screening, influencing one's perception of the need for population-based screening. Reading literacy and communication issues with professionals were noted as reasons for lower health literacy. In addition, professionals find it hard to explain the need for screening programmes to disabled people, especially those with intellectual disabilities. This leads to a lack of participation (Arana-Chicas et al., 2020; Llewellyn et al., 2011):

“Participants who were severely impaired appeared not to have knowledge of mammograms, even after a mammogram picture was shown to them” (Arana-Chicas et al., 2020, p. 6).

The communication ability of people with intellectual disabilities also influences their perception of the available screening services; consequently, it affects uptake (Magasi et al., 2019; Seaton et al., 2018; Willis et al., 2015; Greenwood et al., 2014; Llewellyn et al., 2011). Disabled people may find it difficult to remember information provided to them that influences their decision to register for screening (Willis, 2016) and at times, professionals struggle to engage in appropriate communication to positively impact their decision to participate (Wood and Douglas, 2007):

“The particularly complex issues involved in explaining screening as opposed to therapeutic procedures, the need to enquire about sexual experience, and literacy issues in relation to invitation letters were seen as specific communication issues” (Wood and Douglas, 2007, p. 88).

2.8.2 Approachability of cancer screening services

In Levesque's framework, the approachability of healthcare access reflects how service providers make services more visible and prominent to the target population, including disabled and vulnerable populations. More often, this is related to the degree to which the functions of the screening services are transparent, can reach appropriate people, and provide relevant and accessible information (Levesque et al., 2013). The review highlighted three factors that appear to shape the approachability of population-based screening for disabled people.

First, health professionals were revealed to be key trusted sources of information about population-based screening for disabled people. Health education and health promotion activities carried out by professionals would create awareness of the importance of screening services among disabled people (Arana-Chicas et al., 2020; Hanlon and Payne, 2017; Breau et al., 2016; Taggart et al., 2011). Conversely, conflicting information from healthcare professionals regarding screening services for disabled people negatively influences their uptake of these services (Llewellyn et al., 2011):

“Improving the scope and frequency and of mammography recommendation by primary care providers is the single most important direct contribution the medical community can make toward increasing mammography use”

(Llewellyn et al., 2011, p. 1761).

Second, disabled people rely on the information they receive from well-established sources. Disabled people sometimes do not rely on their general practitioners (GPs) when making health decisions. Instead, they turn to the internet and trust information they receive from friends and media sources (Angus et al., 2012). The decisions they make are often influenced by the source of the information they receive. People typically value information from their caregivers, trustworthy media outlets, and the internet more highly (Arana-Chicas et al., 2020; Angus et al., 2012; Llewellyn et al., 2011). In contrast, people with intellectual disabilities tend to rely on day service programmes to create awareness. However, such programmes are not always available to them. (Arana-Chicas et al., 2020):

“I don't rely on my doctors for up-to-date information. I very much rely on what I hear from others, and the radio and internet. For me it's reflexive because if I hadn't been that way from a young age—we were all supposed to be dead”

(Angus et al., 2012, p. 69).

Third, this review highlighted the importance of screening services providing accessible information to facilitate disabled people to understand the nature and significance of cancer screening. Simple and easy-to-understand information using plain English and pictures are required to communicate screening information. In addition, the invitation that disabled people receive should meet their specific requirements (Wood and Douglas, 2007). They also want information in alternate formats such as Braille and audio tape (Mele et al., 2005):

“There was also agreement among the women that user-friendly leaflets or posters would be helpful in explaining breast awareness, breast screening and prevention albeit the information should be accessible with the writing’ big’ and “easy to understand” (Truesdale-Kennedy et al., 2011).

People with intellectual disabilities expect professionals to engage in an understandable conversation and want to hear adequate information to make the right decision (Arana-Chicas et al., 2020; Sonalkar et al., 2020; Willis, 2016; Swaine et al., 2013; Llewellyn et al., 2011; Taggart et al., 2011; Mele et al., 2005). In addition, the information professionals share regarding screening services influences disabled people’s decision to participate in the programme (Llewellyn et al., 2011):

“Caregivers emphasised the importance of talking to women with intellectual disabilities at the level of their understanding and showing them an educational film on mammograms” (Arana-Chicas et al., 2020, p. 8).

2.9 Seeking Cancer Screening

Twenty-six out of 31 included studies contributed to the cancer screening-seeking experience. The review found that the vulnerability and dependency of disabled people, previous experience while accessing screening services, professional attitude, and perception about screening were the influencing factors determining disabled people’s decision to seek cancer screening.

2.9.1 Ability to seek cancer screening services

Disabled peoples’ autonomy and capacity influence their ability to seek cancer screening services. Most often, disabled people depend on others to decide to participate, register and attend cancer screening services. In addition, multiple comorbidities experienced by disabled people can reduce their ability to seek screening services.

Disabled people depend on other people, frequently primary carers or family members, to make an appointment and travel. Many disabled people cannot attend the procedure if their support person fail to make an appointment or facilitate travel (Arana-Chicas et al., 2020; Kilic et al., 2019; Angus et al., 2012; Sweeney and Suzuki, 2013). Often, family members may decide for disabled people, especially those with intellectual disabilities. Family members think their loved ones with disabilities do not require screening services due to their assumptions in areas such as sexuality or are overwhelmed with other responsibilities that make them believe this is not a priority (Arana-Chicas et al., 2020; Greenwood et al., 2014; Swaine et al., 2013; Angus et al., 2012; McIlpatrick et al., 2011; Taggart et al., 2011):

“[my daughter] wasn’t sexually active, not dating, nothing like that, and having sex. It wasn’t really necessary to put her through it” (Swaine et al., 2013, p. 68).

However, some family members consider screening as an important preventive measures. Therefore, they act proactively in making an appointment, facilitating the screening visit and supporting them during the screening process (Arana-Chicas et al., 2020):

“...understood the importance of mammograms for their family member with intellectual disabilities and strive to keep them healthy. Family caregivers scheduled their family member’s mammogram appointments and provided support at the appointment” (Arana-Chicas et al., 2020).

In addition, the multiple health conditions and complex needs of disabled people are also important factors affecting their access to screening services (Arana-Chicas et al., 2020; Willis, 2016; Angus et al., 2012; Taggart et al., 2011):

“Many women had complex medical conditions, requiring attention to multiple issues during health appointments, additional time and assistance to move about and communicate. Participants’ anecdotes suggested that providers might assign low priority to health promotion or screening under these circumstances. For example, one woman was refused a colonoscopy because of her history of respiratory illness” (Angus et al., 2012, p.78).

2.9.2 Acceptability of cancer screening services

Acceptability of service is influenced by how service providers respect the needs of people who access the service and the satisfaction of people receiving care. Disabled people suggested a lack of acceptability for the screening services was significantly influenced by the professional attitude and previous experience when they engaged with screening services.

Some disabled people experience difficulties accessing screening due to co-existing medical conditions in addition to existing disability (Willis et al., 2015; Angus et al., 2012; Wood and Douglas, 2007). It is revealed that residential staff's poor engagement and lack of support create negative feelings among disabled people to attend screening services (Arana-Chicas et al., 2020; Peters and Cotton, 2015; Barr et al., 2007):

“Lack of sensitivity by facility staff was encountered throughout the process, from scheduling the appointment and undressing to receiving test results. The stress and burden of thinking about, arranging for, and actually having a mammogram was mentioned in the physical, psychiatric, and visual disability groups” (Barr et al., 2007, p.383).

Studies conducted by Peters and Cotton (2016) and Angus et al. (2012) found that the uncaring nature and assumptions of normalcy among professionals create a lack of awareness of the needs of women with disabilities who come for breast screening (Swaine et al., 2013), which leads to not knowing how to support them (Kilic et al., 2019):

“Assumptions of normalcy need to be replaced with an understanding of the nature of various disabilities and a focus on individualised care and reflective practice to combat oppression. The oppressive nature of both the machinery and the perceived uncaring environment led to participants feeling ‘put down’ and ‘powerless” (Peters and Cotton, 2016, p. 188).

There are positive experiences reported by disabled people where the professionals working in the screening services help them to relax, assist them in making appointments, make an effort to accommodate their additional needs, provide reassurance and allocate extra time (Arana-Chicas et al., 2020; Peters and Cotton, 2016; Taggart et al., 2011; Mele et al., 2005):

“These participants credit their nurses and mammogram technicians with preparing and communicating with them about mammograms prior to their appointment” (Arana-Chicas et al., 2020, p. 8).

While attending screening services, some disabled people often felt powerless, and the experience was precarious and embarrassing. For example, articles reviewed included instances of disabled people recounting how physical handling caused pain and humiliation (Arana-Chicas et al., 2020; Peters and Cotton, 2016 and 2015; Swaine et al., 2013; Angus et al., 2012; Sullivan et al., 2004). In addition, the specific needs of disabled people were often reported to be ignored, and often, disabled people won't ask for help due to fear and anxiety (Peters and Cotton, 2015; Poulos et al., 2011; Truesdale-Kennedy et al., 2011):

“Some participants felt healthcare professionals saw them as dehumanised, depersonalised, voiceless bodies, almost like robots, that could be manipulated and moved in any way they saw fit to meet the needs of the breast cancer screening procedure, without regard for the participant’s dignity or physical, emotional, psychological and communicative needs”

(Peters and Cotton, 2015, p. 567).

Sullivan et al. (2004) reported that some disabled people feel uncomfortable being screened by a male professional and this negative experience influences their decision to seek future attendance to the screening service (Poulos A et al., 2011). However, some women with cerebral palsy reported a positive experience of attending breast screening (Shah et al., 2022):

“Older women with different types of CP had positive experiences of mammograms. Even where the first mammogram was challenging, the barriers seem to be broken down by the time the women had their second”

(Shah et al., 2022, p. 829).

2.10 Ability of Disabled People to Reach Screening Services

Data from 25 papers contributed to how the ability of disabled people to reach screening services influences uptake. The ability to reach screening services pertains to disabled people's ability to physically access services based on disability and access to transportation. Also, it depends on how the service accommodates the needs of disabled people.

2.10.1 Physical ability to reach cancer screening

Disabled people's ability to reach screening services is determined by their travel ability and mobility issues. Often, disabled people depend on others to bring them to the screening services, and mobility issues make it difficult to travel. Disabled people experienced difficulties in availing of accessible transport to reach screening services. Consequently, this would be a barrier for many people to access screening services (Kilic et al., 2019; Angus et al., 2012; McIlfratrick et al., 2011; Mele et al., 2005):

“Transport and timing of the appointment were noted, which were seen to preclude women with intellectual disability access breast screening services: . . . access to the screening unit or mobile unit where the mammogram is going to take place. So a transport practicality may prevent them from coming” (McIlfratrick et al., 2011, p. 416).

In addition, the location and distance of the screening services make it difficult for disabled people to access them (Peters and Cotton, 2015; Sullivan et al., 2004):

“Graphically described her experience which has led her not to return for mammograms in the future” (Peters and Cotton, 2015, p. 568).

Disabled people identified physical mobility as a factor in their ability to attend services. Disabled people reported that they lack stamina which makes them difficult to stand (Agaronnik et al., 2021; Angus et al., 2012) and inability to stand still and to keep in a similar position for a short period that is required for a mammogram (Peters and Cotton, 2015; Greenwood et al., 2014; Poulos A et al., 2011). Additionally, being of small height and relying on a wheelchair intensifies the challenges during screening appointments (Llewellyn et al., 2011; Sullivan et al., 2004):

“One participant felt awful for a couple of hours because she had no control over her chair, while another was keen to take control and position herself which was more appropriate and more humane from her perspective than being pushed and pulled into the correct position. She felt that the radiographers should ask her to help them” (Llewellyn et al., 2011, p. 1764).

2.10.2 Availability and accommodation influence the ability to reach screening services

The availability and accommodation of screening services are related to their accessibility to disabled people both physical accommodation and accommodations regarding timing and duration of appointments. The included studies reported several accommodation issues encountered by disabled people, such as professional, mechanical and environmental accommodations.

Disabled people experienced a lack of strategies or facilities adopted by professionals to accommodate their specific needs while they attended screening services. Appropriate accommodation is essential to facilitate disabled people's specific needs and effective completion of the screening procedure (Agaronnik et al., 2021; Arana-Chicas et al., 2020):

“Appropriate patient positioning is critical for ensuring image quality—inability to accommodate mobility disability can interfere with diagnosis. Furthermore, attitudes of clinical staff about providing accommodations can be just as important as physical accessibility” (Agaronnik et al., 2021, p. 1254).

With appropriate accommodations and assistance, disabled people feel comfortable and safe. For example, the availability of attendant service when attending the screening facility provides support to push the wheelchair around the facility, using the toilet, bodily preparation and handling stool specimens (Arana-Chicas et al., 2020; Peters and Cotton, 2015; Angus et al., 2012):

“Accessible rooms and equipment, as well as attendant care enhanced comfort: Joining [accessible health centre] was very good for me... I feel very comfortable going there. The doctors I've dealt with, and the nurses are amazing. One lady comes to help you dress... This takes the stress off me for going to the doctor” (Angus et al., 2012, p. 80).

Disabled people are also concerned about a lack of flexible appointments while attending screening services, which causes frustration. They felt the routine timeframe that is offered is inadequate for establishing and engaging communication and physical preparation, which leads the professionals to rush the procedure and lack of information sharing before the procedure (Willis, 2016; Peters and Cotton, 2015; Greenwood et al., 2014; Angus et al., 2012; Llewellyn et al., 2011). In addition, disabled people prefer a shorter waiting time in hospital. Waiting for a long time created frustration and required to use additional facilities that are inaccessible (Kilic et al., 2019):

“For us, staying in the hospital for a long time means using the toilet there. It is really difficult to go to the toilet in the hospital. We need to finish our business and return as soon as possible” (Kilic et al., 2019, p. 1982).

Also, the timing of the appointment is vital as the early morning appointments may not be suitable for people with intellectual disabilities as they may require more time to complete their hygiene and other routine needs in the morning (McIlfatrick et al., 2011):

“Maybe timing of appointments because a lot of these women need care in the morning. By the time you get them washed, their hygiene and get them fed, . . . and you know again with the distance and maybe having to be there for 9 am, you know, to allow an appropriate time in the afternoon to suit them” (McIlfatrick et al., 2011, p. 416).

Some disabled people feel comfortable with being screened by the same gender professionals, especially cervical screening, as they think it reduces their anxiety (Hanlon and Payne, 2017; Greenwood et al., 2014; Swaine et al., 2013):

“Women prefer female practitioners for the delivery of women’s healthcare. Several women in our study shared this opinion. They attributed their engagement with screening to having a female practitioner available for the procedure” (Hanlon and Payne, 2017, p.24).

Several disabled people shared some positive accommodations when they attended screening services. When the staff attempt to accommodate their needs, felt they are treated equally and receive human treatment (Seaton et al., 2018; Llewellyn et al., 2011; Sullivan et al., 2004):

“Many women praised the facility staff for their helpfulness and support, unfortunately this praise was not universal” (Llewellyn et al., 2011, p. 1764).

Disabled people identified that the screening procedure was inappropriate for them due to unsuitable mammographic machines. They felt the device did not accommodate and was not flexible enough to meet the various needs of disabled people. The machine could not be lowered to be suitable for women in a wheelchair, could not be adaptable for people in a recliner wheelchair, the device is so high that disabled people cannot stand and breast squeezing by the machine is intolerable (Sonalkar et al., 2020; Willis, 2016; Peters and Cotton, 2015; Greenwood et al., 2014; Angus et al., 2012; Todd and Stuijbergen, 2012; Poulos A et al., 2011):

“The requirements of the mammography machine dictated breast screening staff procedures and practices. Women’s bodies were required to meet the machine’s needs, rather than the other way around. Their bodies had to contort and be contorted to accommodate its requirements” (Peters and Cotton, 2015, p. 186).

While attending the cervical screening, people expressed discomfort as the examination table was inaccessible or inappropriate. They need to be physically assisted to access the table (Solenberg et al., 2021; Kilic et al., 2019; Hanlon and Payne, 2017; Mele et al., 2005;):

“Having difficulty getting onto the table due to its height. She is reliant on others (a security guard) to lift her on and off the treatment table for the procedure. “The inability to be independent made her feel “manhandled” and caused a loss of personal dignity” (Hanlon and Payne, 2017, p. 22).

Some disabled people expressed the presence of poor physical facilities that fail to accommodate their specific needs causing discomfort and discouragement in revisiting the screening services. A small room space makes it challenging to move around the area, especially when they are using motorised wheelchairs in the mobile clinics; therefore, they suggested having bigger rooms that accommodate them and their accessible equipment (Solenberg et al., 2021; Sonalkar et al., 2020; Kilic et al., 2019). Furthermore, a number of disabled people are frustrated with the insufficient mobility accommodations at screening centers, including the absence of elevators and ramps, as well as the existence of revolving doors and doors that are heavily secured (Solenberg et al., 2021; Peters and Cotton, 2015; Mele et al., 2005):

“Needing better access. Participants who used wheelchairs had difficulties with access to BCS [Breast Cancer Screening] facilities. Using caravan facilities was generally prohibitive, and many clinic and hospital venues also posed access barriers in terms of lack of lifts and ramps” (Peters and Cotton, 2015, p. 186).

Some disabled people are unsatisfied with the changing and toilet facilities, as the changing rooms and toileting facilities may not be accessible or provide privacy (Peters and Cotton, 2015; Mele et al., 2005). The changing rooms are small and cannot accommodate their mobility device, which makes transfer difficult and unsafe (Angus et al., 2012; Mele et al., 2005):

“The bathrooms in their providers’ offices were not accessible. When they were, the doors did not lock automatically, increasing anxiety about privacy in those without the manual dexterity to lock the door. Toilets were also too close to the wall, making transfer difficult or unsafe” (Mele et al., 2005, p. 460).

It is shown that some of the facilities provide better accessibility but may not be visible; therefore requiring strategies to promote such facilities to make them the best model of service (Angus et al., 2012):

“Unfortunately, accessible, astute health services and providers were themselves invisible, because they were not widely publicised. The women wanted help to find reliable healthcare” (Angus et al., 2012, p. 80).

2.11 Cancer Screening Service Utilisation

Only four included studies discuss the issues around cancer screening utilisation. Firstly, utilisation is influenced by the ability of disabled people to pay a direct cost through either insurance or by themselves. Secondly, the utilisation of screening services is impacted by the affordability of disabled people to pay indirect costs such as organising transport and associated costs.

2.11.1 Ability to pay for screening services influence utilisation

Many countries including Ireland provide screening services free of charge as this is a fundamental right for their citizens. However, where the screening services are not free, they find it difficult to pay the direct costs involved in screening services. For example, disabled people pay for services they receive (Llewellyn et al., 2011; Barr et al., 2007):

“Women in four groups mentioned economic access barriers: problems paying for mammograms (e.g., inadequate insurance coverage, copayments”

(Barr et al., 2007, p.382).

2.11.2 Affordability to access cancer screening services-transportation

Taggart et al. (2011) reported that community ID nurses found difficulties supporting women with intellectual disabilities to attend screening services due to organising transport for her and her older family member:

“Many family carers were older than their daughter, additional issues arose pertaining to supporting both the woman with ID and also the elderly family carer along with transport: Very often the woman with the ID needs to be assisted to attend the breast screening clinic and there is no motivation in the part of the older family carer to bring them: so how can it happen?”

(Taggart et al., 2011, p. 47).

A Deaf woman who was required to pay for an interpreter service while attending the screening service caused financial implications in attending screening services (Llewellyn et al., 2011; Barr et al., 2007):

“A financial barrier unique to women with hearing impairments was the cost of interpreters at the mammography visit” (Barr et al., 2007, p.382).

2.12 Consequences of Screening Services Influence Uptake

2.12.1 Ability to engage

The ability of professionals and disabled people to engage with each other is essential while attending screening services. Disabled people feel a sense of ownership over the service they receive when they engage with professionals, enabling them to remain engaged with services in the future. However, the ability of professionals to engage with disabled people is affected by their lack of awareness and knowledge about disabled people’s specific needs. In addition, disabled people struggle to engage with the health professionals due to their lack of knowledge and perception of the screening services (Solenberg et al., 2021; Taggart et al., 2011; Sullivan et al., 2004).

Disabled people have questions about the value and effectiveness of undertaking mammograms and other screening procedures (Llewellyn et al., 2011; Barr et al., 2007; Sullivan et al., 2004). The consequences of screening services are influenced by the ability of disabled people and professionals to engage with each other and service provision and appropriateness of screening services to disabled people. In addition, they fear an unfavourable outcome after screening (Arana-Chicas et al., 2020; Kilic et al., 2019). This may make them reluctant to go for screening:

“Scepticism was mentioned in all groups except the two cognitive groups. Comments included doubts about the value and effectiveness of mammograms, and the need for yearly mammograms”

(Taggart, Truesdale-Kennedy and McIlpatrick, 2011; Willis, 2016).

A lack of awareness persists among disabled people about the timing of (at what age) undertaking specific screening services (Wollin and Elder, 2003). In addition, fear concerning the procedure and outcome often deter disabled people from attending screening services (Willis, 2016; Wilkinson et al., 2011).

2.12.2 Appropriateness of cancer screening services

Appropriateness of screening services provided to disabled people involves checking if the screening they receive meets established standards and procedures. Healthcare providers must consider the specific health needs of disabled people and their personal preferences and provide appropriate support during the screening process. This is important to maintain the quality of services for disabled people and reduce the risk of adverse outcomes. The quality of screening services for disabled people is greatly influenced by the technical and personal expertise of the professionals providing the screening (Solenberg 2021; Willis 2015; Toadd 2011; Poulous 2010).

Effective communication plays a crucial role in delivering screening services to disabled people. Building trust through communication is important, but when those conducting the screening struggle to communicate with disabled people, it becomes an issue. In addition, they do not understand the complex needs of disabled people. To address this, the professionals need to receive proper training (Solenberg 2021; Willis 2015; Taggart 2011; Toadd 2011; Poulous 2010):

“Need for radiographers to undergo specific training particularly in communicating with women with physical disability and ensuring their communication is effective. It seemed clear on one occasion that the radiographer’s verbal description of the process had not been entirely absorbed, and so the subsequent physical experience became an unexpected ordeal which they wished to end before the screening was complete”

(Poulous 2010, P.16).

The disabled people would highly appreciate if the screening procedure is completed with limited manipulation and in a timely manner (Poulous, 2010):

“Each radiographer would take on a specific role and focus which when combined would ensure that the mammogram is completed effectively and efficiently in minimum time and with minimal manipulation and discomfort/pain”

(Poulous 2010, p.18).

2.13 Overview of the Chapter

Chapter Two of the study reviewed existing literature on the experiences of disabled people during the cancer screening process. The review found that disabled people have varying views and experiences when it comes to accessing screening services. The findings revealed the factors that facilitate or hinder their use of these services, and the challenges they face. This information is valuable for those responsible for developing guidelines and providing cancer screening services, as it provides insight into the perspectives of disabled people, their families, and healthcare professionals.

Chapter 3

Methods

3.1 Introduction

In this chapter, the research aims and objectives are again stated. The research considerations surrounding the selection of study participants are discussed, and information is provided regarding the inclusion and exclusion criteria. Participant recruitment is explained, and ethical issues are identified and explored. Data collection and analysis are detailed and explained. The study participants' demographic information is provided with a summary of living arrangements and Disability.

3.2 Research aim

This study aimed to collect and analyse information on the experience and participation of disabled people in the Republic of Ireland's national screening services and assess the gaps between screening service delivery and the potential participation of disabled people.

3.3 Objectives

The objectives of the study were to:

- a. Document the size and demographics of the disabled population invited for screening in Ireland;
- b. Review the health issues affecting disabled people as applied to the four population-based screening programmes provided in the Republic of Ireland by the National Screening Service i.e., BreastCheck, CervicalCheck, BowelScreen and Diabetic RetinaScreen;
- c. Consult with disabled people on their experience of screening in the four programmes;
- d. Consult with carers, family members, and health professionals on their requirements to support disabled people to avail of screening;
- e. Identify barriers and facilitators experienced by disabled people accessing the four screening programmes;
- f. Provide recommendations for the NSS based on findings.

3.4 Consultation with National Screening Service Professionals

Through Zoom, the research team met with professionals from each of the four screening programmes and staff from the Communication Office. We found that the individual screening programmes do not systematically collect data regarding the attendance of disabled people. However, they extensively discussed the strategies to accommodate disabled people and the challenges encountered while supporting them. The data collected from the professionals were not included in the analysis for the report's main findings. However, the study's findings were discussed in light of the data from the professionals.

3.5 Research Design

A qualitative approach was chosen as the study method as it explores the experiences of disabled people, professionals, and family carers in accessing National Screening Services (Denzin and Lincoln, 2017). The strength of qualitative research is its ability to explore phenomena and provide rich information about them. In this instance, we chose this methodology to understand or explain disabled people's experiences, barriers, and facilitators in accessing the four screening programmes provided by the National Screening Service. We decided on interviews and focus group discussions, online or in person, as methods of data collection.

3.6 Questionnaire Development

We adopted a life cycle approach to developing the research question for the focus group discussions to capture the experience from pre-screening to post-screening. Initially, draft interview and focus group questions were developed through discussion within the research team. Then, we invited the advisory committee members to a Zoom meeting, introduced the study, and presented our draft questions. Each question was discussed with the advisory committee members who provided feedback and suggested additional topics for questioning. Next, we amended the questions and developed the interview/focus group questionnaire based on their feedback and suggestions. Finally, a focus group questionnaire (Appendix-1) and interview schedule for professionals (Appendix-2) were developed and agreed upon with the advisory committee members.

3.7 Selection and Recruitment of Participants

For the purpose of this study, as agreed by the steering committee, we planned to invite people with intellectual disabilities, autistic people, physically impaired people, visually impaired people and Deaf people. Therefore, the following inclusion criteria were used when recruiting participants.

Disabled people

1. Both males and females with intellectual disabilities, autistic people, physically impaired people, visually impaired people and Deaf people.
2. Aged 18 years to 70 years.
3. With and without having previous experience of attending screening services.
4. Who are willing and can provide informed consent.

Family members

1. Adult family members who support disabled people as stated above.
2. Who are willing to participate in the study.

Healthcare professionals

1. Healthcare professionals who support disabled people, as stated above.
2. Who are willing to participate in the study.

We adopted the following strategies to recruit participants for this study.

a. Disabled people

We developed our easy-read recruitment flyer and sent it to the advisory committee members for their input. Then, based on their feedback and suggestions, we finalised the easy-to-read recruitment flyer (Appendix-3). Next, we contacted NGOs and DPOs throughout Ireland, such as Diabetes Ireland, Voice of Vision Impairment, RehabCare, AsIAm, and Independent Living Ireland (ILM) etc., through email and requested them to share this flyer via their social media page and websites. Recruitment, conducted initially via social media, proved slow and difficult; therefore, we contacted the regional organisations of NGOs and DPOs by phone which subsequently proved more successful. The individuals who were willing and interested in participating in the study contacted us by email or phone. We later arranged a date and time suitable for the participants for the focus group discussion.

b. Professional Carers

We recruited professionals through the National Screening Service. First, we sent the participant information leaflet to the NSS, and they distributed it to the relevant professionals. The professionals who were willing and interested in participating contacted us by phone or email. Then, we arranged a date and time convenient for the participants for individual interviews.

c. Family carers

Family carers were recruited in association with Care Alliance Ireland, Family Carers Ireland and Family and Friends of Intellectual Disability Service. We sent out the information flyer (Appendix-4) to the organisations and requested that they distribute it to their members. The individuals who were willing and interested in participating in the study contacted us by phone or email. Then we arranged a date and time for a focus group discussion suitable for participants.

3.8 Participants' Profile

3.8.1 Disabled Participants

Twenty disabled persons were consulted via focus group. Demographics for this group are shown in Table 4.

Table 4 Demographics of Disabled participants

Disability	Number of Participants
Intellectual disabilities	8
Physical Impairment	6 (1 Diabetes)
Visually impaired	2 (1 Diabetes)
Deaf	1
Autism	3
Age Range	
20 to 29	1
29 to 30	0
30 to 39	2
40 to 49	4
50 to 59	7
60 to 69	4
70 to 79	1
Gender	
Male	4
Female	16

3.8.2 Family Carers

Five family carers were consulted via online interview. Information for this group is shown below.

Table 5 Family Carer Characteristics: Relationship details how carer is related to the cared for person. Disability, Age Range and Gender relate to the cared for person

Relationship	Disability	Age range	Gender
Mother	Autism	20 to 29	M
Mother	Intellectual Disability	30 to 39	F
Mother	Autism and Intellectual Disability	15 to 20	M
Sister	Intellectual Disability	50 to 59	M
Mother	Attention Deficit Hyperactivity Disorder Epilepsy Autism	30 to 39	M

3.8.3 Healthcare Professionals

Five healthcare professionals were interviewed via online. Information is provided below.

Table 6 Speciality of Healthcare Professionals

Profession	Number of Participants
Community Nurse	1
Residential Services Manager	1
Practice Nurse	1
Colposcopist	1
Diabetic Retina Screener	1

3.9 Data Collection

Irish sign language interpreters were included to facilitate communication during the data collection process to collect information from participants who communicate via Irish Sign Language. The focus group and interviews were audio-recorded. Interviews and focus groups took place between 21 June and 6 December 2022.

Data were collected from eligible disabled participants through focus group discussions through Zoom and phone. Before commencing the focus group discussion, the researcher explained the nature of the study and the rights of the participants and responded to the participants' questions. Then, informed consent was obtained from all participants. During the focus group discussions, each participant was offered an opportunity to give their perspectives and share their experience. The discussions were audio recorded, and each focus session ran between 60-95 minutes. In total, five focus group sessions were conducted with between two and six participants in each focus group.

An interview schedule guided the one-to-one individual interview with the professionals. Before the interview, the researcher provided information about the research project and the participant's right to withdraw from the study and also obtained informed consent. All interviews were conducted via Zoom and audio-recorded. Each interview lasted between 45-60 minutes.

Due to difficulties in arranging a focus group with family carers, online individual interviews with five family carers were conducted. Prior to commencing, the purpose of the study and the rights of the participants were discussed. The interviews were guided by the interview schedule. Each interview lasted for approximately 30 minutes.

3.10 Data Analysis

The audio recordings were downloaded to the password-protected DCU shared drive, and only the research team could access them. We used descriptive thematic analysis (Braun and Clarke 2022) to analyse data. First, the data were listened to and transcribed into a written document. Second, two researchers (KC and DJ) independently coded the data and generated initial themes. Third, the two researchers met and discussed the coding process and, through discussion, defined the initial themes. Fourth, the coding lists and the initial themes were presented to the research team. Then, we extensively discussed, reconstructed and re-arranged the themes based on the lifecycle of the screening process. Finally, the rearranged themes were presented to the team and agreed upon after discussion.

After agreeing on the findings with the team, we scheduled an advisory committee meeting and presented our interpretation of the focus group and interview data with the coding list and findings. During the meeting, the findings were presented to the advisory committee members who recognised their own experiences being reflected in several of the findings and agreed that they were consistent with their own observations. They added several suggestions, and thus the themes were subsequently modified.

3.11 Co-Designing Meeting

After amending the findings based on the advisory committee recommendations, we called the advisory committee to propose recommendations and solutions through a co-designing approach, as recommended by Chisholm, Holttum and Sprngham (2018). Each advisory committee member was asked to propose recommendations for each area of the screening process. The research team proposed additional recommendations. Then, recommendations were collated and finalised based on a discussion with the advisory committee members.

3.12 Consultation with the Advisory Committee Members

The Advisory Committee, developed at the start of the project, was consulted at each stage of the project. The advisory committee had key involvement during three phases of the project: (1) interview/focus group schedule development, (2) interpretation and refinement of results (thematic analysis findings), and (3) development of the recommendations.

3.13 Ethical issues

People with intellectual disabilities, physically impaired people, Deaf people, visually impaired people, and autistic people have been included in this study. Including these participants was essential to explore their experience and perceptions about accessing the National Screening Services. There is evidence of social exclusion of disabled people (Abbott and McConkey 2006) and exclusion from research (Iacono 2006). There is now a focus on addressing the need to translate research into practice, while also giving a “voice” to disabled people (Moulster et al., 2019; Lewis and Porter, 2004), who may traditionally have been marginalised (Northway, 2010). Disabled people, their families and professionals supporting them are central to this work. While proxy reporting on health issues was a feature of earlier disability research, it was vital to ensure that disabled people are supported to give their perspective on access to screening services instead of solely relying on a proxy respondent. Ethical approval for this study was obtained through the DCU Research Ethics Committee on 21st March 2022 Ref: DCUREC/2022/042. Ethical issues were considered throughout the study.

3.14 Challenges and Limitations

Recruiting disabled people for this research project was challenging, and the social media advertisement yielded limited success. We contacted some NGOs and DPOs to send the flyer to their members’ emails. In addition, we asked advisory group members and disability services to circulate the study information widely. Again, recruiting disabled people during the summer was difficult, leading us to extend the project’s timeline. It was clear from the participants that there was consultation fatigue. Initially, we decided to conduct a focus group session with the specific disabled group or a specific type of screening so that they could talk freely; however, this was difficult at times due to the lack of availability of participants.

The initial objective of documenting the size and demographics of the disabled population invited for screening in Ireland could not be achieved due to a lack of available comprehensive quantitative data. The 2016 census did not seek any information regarding screening. The Irish Longitudinal Study on Ageing (TILDA) collects data only from people over 50s, and Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) collects data only from people with intellectual disabilities who are over 40.

3.15 Chapter Summary

This section described the research framework and methodology used to achieve the research project’s aims and objectives. In addition, the research process was outlined, which includes an inclusive approach to the development of the focus group and interview questionnaire. Further, the study’s recruitment and data collection process was delineated, including the involvement of the advisory committee.

Chapter 4

Findings

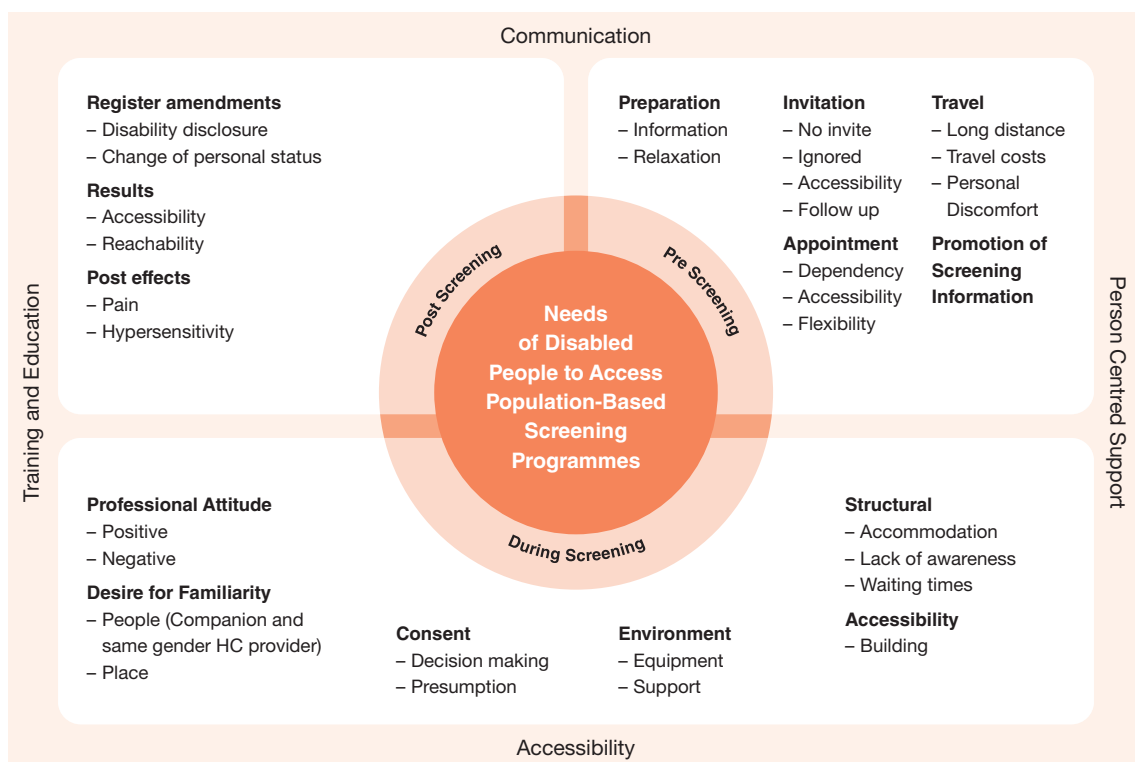
4.1 Introduction

Findings from the data collected from disabled people, professionals and Family carers pertaining to accessing National Screening Services are presented in this chapter. Quotes are included to support the findings. To contextualise the quotes, information is provided alongside each quote on the speaker's type of disability/professional category and screening programme being discussed.

4.2 Overview of the Findings

The research study adopted a life journey approach from invitation to screening to provision of the screening results to explore the disabled peoples' experiences in accessing screening services. The findings are grouped into themes according to the screening stage, namely pre-screening, during screening and post-screening. The issues identified in each stage of the screening process are grouped under each main theme as sub-themes. These are shown visually in Figure-4.

Figure 4 Themes and Sub themes



4.3 Pre-Screening

This section provides insight into the issues experienced by disabled people prior to attending the screening services. Prior to attending the screening services the disabled people found several issues which determine their attendance such as inaccessible invitation, difficult to make an appointment, challenges to travel to reach the screening site and inadequate preparation.

4.3.1 Invitation

The invitation is the primary point of contact between the screening service and the eligible participants. Unfortunately, the participants reported experiencing a number of issues in this regard. Several participants stated that they had never received an invite for any screening, with others stating that they had received an invite for one service but not another, despite being eligible. For example, some individuals received an invitation for a CervicalCheck but never received an invitation for a BreastCheck. This was particularly true of focus group participants with intellectual disabilities:

“So, you’ve never actually seen a letter to go for a cancer screening: NO”

(Intellectual disabilities, General).

“I haven’t. I never got a letter in my lifetime for the breast cancer screening”

(Intellectual disabilities, BreastCheck).

“And have you ever seen any? Has an invite for her to go for cervical check ever come to your house? No, no” (Family carer, CervicalCheck).

Meanwhile, some people who were receiving letters for a screening programme and poorly engaged with it, eventually stopped receiving invitations:

“The letters just stopped coming, because I wasn’t going for them at all, maybe”

(Intellectual disabilities, CervicalCheck).

Some participants noted that the current system of sending out the same invitation to all individuals presents problems in terms of accessibility for disabled people. For example, they expressed difficulties reading and understanding the content or dealing with the invite. Consequently, they require support from other people:

“I don’t understand. If I can’t get my cousin, I can bring the letter in here and ask them to tell me what the story is” (Intellectual disabilities, General).

Some good practice was noted within some residential care facilities, whereby healthcare professionals follow up for invitation letters if eligible residents do not receive invitations. In addition, on occasion, even if the residents receive invitations, they sometimes ignore them and do not tell anyone. Therefore, a community nurse looking after a group home expressed the desire to be kept in the loop regarding screening invitations for disabled persons in their care:

“They had got the letters and they’d just ignored them. But I think if they were to consent that a duplicate or a second copy could be sent to another person, I think that would work” (Community Nurse, General).

“They would have got the letters but didn’t tell us about them. So we rang the screening programme ourselves recently and got the bowel screening, the little packs sent out to them” (Community Nurse, General).

There is a claim that a lack of support contact in the invitation letter causes frustration. Despite the fact that the invitation includes a contact phone number and email for the various units and a toll-free number for the screening service, there seems to be a lack of knowledge among disabled individuals about these resources. It is necessary to increase awareness of their availability:

“There is an automatic assumption implied in the letter that people who are invited to screening would have no issue with screening. The impression I got was, you need to go for screening. There is no helpline for you to ring to say you might have difficulties with it, for whatever reason. It assumed that everyone was neurotypical. This applies, the sensory issues and stuff will apply for people who have been abused, who have experienced rape, incest, whatever you want to call it. The automatic assumption that everyone is 100% everyone is physically able is actually flawed” (Autism, CervicalCheck).

4.3.2 Appointment

The participants highlighted issues in making appointments to attend screening services. For some participants, their disability made it difficult for them to attend appointments, leaving them dependent on others. For example, some people with intellectual disabilities are dependent on carers or family members to make an appointment:

“My mother makes my doctor’s appointments for me and comes with me to them” (Autism, CervicalCheck)

“My key worker might make it with me” (Intellectual disabilities, BreastCheck).

For others, accessibility of technology was the issue, with phone conversation presenting difficulties. Finally, the lack of electronic communications in dealings with NSS was a particular issues raised:

“Yes, I struggle a lot with the phone. I think I would find text or email much easier” (Autism, General).

“If you have somebody who can answer the phone, I don’t know why you don’t have somebody who can answer an email” (Deaf, Diabetic RetinaScreen).

There was appreciation from the participants for the screening service’s flexibility in providing appointments. They acknowledged that if they request additional flexibility in terms of time prior to attending screening services, the NSS will offer it. For example, allowing additional time for a procedure was welcomed by participants:

“They asked had I specific needs. They said, ‘Yes, we will just book a little bit of extra time for you.’ That makes a big difference”
(Physical Impairment-Wheelchair User, BreastCheck).

4.3.3 Travel

The participants expressed their difficulties in travelling to attend the screening appointment. The vignette below illustrates some of the challenges voiced by a wheelchair user regarding distances required to travel for screening and associated costs:

“The first exam I had was in my doctor’s office, and she couldn’t find the cervix. Which is fine. I was sent then to another hospital, which is halfway across the country for me. I can’t drive, because of my medication. There are no buses from where I am to there, so, I would have to travel down to Dublin and all the way back up. Getting in there in the wheelchair was really, really difficult, Okay. I live in [town], and down to Dublin is €30. Back up to Drogheda was another €30. I am on disability allowance. That is not a viable thing for anybody. That is not acceptable” (Physical Impairment, Wheelchair User, CervicalCheck).

Again, one participant expressed her difficulties in attending the screening, which requires long travel. This will sometimes influence their decision to participate in the screening services:

“Most of the time, they will try to facilitate you in somewhere that is near you, if you have an issue, travelling is a problem. But to expect you to go that sort of distance is just brutally unreasonable”
(Physical Impairment-Wheelchair User, BreastCheck).

One individual living close to Carrick on Shannon was given a BreastCheck appointment in Sligo as no places were available at Carrick. However, travelling a long distance and the associated cost caused frustration and anxiety among some people:

“But you might have to go to Carrick or Sligo. You have to get a taxi down. That’s about €50 to go to Sligo in a taxi, so it would. It’s expensive”
(Intellectual Disabilities, BreastCheck).

“I went for a screening here last year. Not this year, last year. Breast screening. I had to go to Crumlin. I live in [town], but I had to go to Crumlin. I had to pay, I think it was, €20 there and back in the taxi to get there”
(Physical Impairment, BreastCheck).

However, people who live in residential services or who had family members to support them with transportation reported no issues related to travelling and associated costs but made other compromises:

“I don’t drive. My mam usually brings me. But that involves her taking time off work to bring me to an appointment. [laughing] I have sat the driving test six times. I don’t know. I have heard a lot of other autistic people say they struggle with driving, so I think it is probably a common enough issue”

(Autism, BreastCheck).

“All the services would generally have a vehicle, and for appointments we’ll just facilitate people to go” (Residential Service Manager, General).

4.3.4 Preparation

Preparing someone for screening by providing accessible information before attendance was seen as necessary to ease anxiety about screening. The vignette below shows how preparation was instrumental in ensuring a successful screening despite an unsuccessful prior attempt:

“We would have went the first time, and she wasn’t able to tolerate it, and we didn’t go through with it. ... It was just the thoughts of it. She was a very nervous kind of a person, she’d suffer a lot with anxiety, she had mental health diagnosis, and it was just the thought of it. ...”

[MODERATOR: And that person went back then and had it done ... And what was the difference then, the second time round?]

The difference was, we had more time in between and we had done a lot more work around why you do it, what it was for, how long it would take, that it would be short. We just had done more work around it”

(Residential Service Manager, CervicalCheck).

An autistic person spoke in favour of having visual information to understand the entire screening process. Specifically, it was noted that it would be helpful to receive information via video about what is happening during the screening:

“If I could visually see what you are about to use, and if I could know what exactly it is being used for, and what is happening, how long it is going to take, I know for me and for a lot of other autistic people, detail is important”

(Autism, CervicalCheck).

One participant mentioned using sedatives or other medication before attending the procedure to reduce anxiety to facilitate the successful completion of the screening, specifically noting cervical screening:

“We are going to have to look at you taking a Xanax or whatever the medication it is, or something stronger, before you go in, to help you relax”

(Autism, CervicalCheck).

“There could be issues to do with things like, being very dry down in that area, and the need to take oestrogen beforehand. But of course, no one actually raised that at the time. So, there was no consultation or thought about how to make it easier. As a result, I haven’t had a screening test in years

(Autism, CervicalCheck).

However, a professional raised concerns about using sedatives, which may interfere with informed consent:

“We don’t really offer sedation here. Now, sometimes patients will call us up and say, ‘Can I take something?’ I will say, ‘Yes, you can, but you are not to be driving. You are to have somebody with you.’ I said, ‘But you need to be able to say to me that you understand what it is that we are doing, and that you can give me verbal consent or written consent” (Colposcopist, CervicalCheck).

4.3.5 Promotion of Screening

Both healthcare workers and disabled participants mentioned the methods that would support their uptake of screening services. For example, they suggested that it would be helpful if they were able to view a video of a screening test appointment involving someone they can identify with:

“Now, we do send them a leaflet, and tell them this is what we will be doing, but maybe, if they could see it, and had the visualisation of it, it might reduce the fear a little bit, of it” (Colposcopist, CervicalCheck).

“I think sometimes videos can be very helpful to people, because it’s much easier than reading out something. So if they could see somebody, and particularly if they could see somebody who’s like them, if they could see somebody with an intellectual disability, who they would identify as a peer, maybe talking about it, that can be very powerful”

(Residential Service Manager, General).

“They really needed to do a video on all procedures. I said, it would be of benefit to everyone, whether or not they were autistic. But definitely, I would have benefited from it” (Autism, CervicalCheck).

There were also some concerns about the quality and accessibility of information provided by the HSE website:

“No. There’s bits and bobs with the HSE, but that end of the services they provide, it isn’t great, I’ll be honest. It would never be the first website that I’d go to, to look for something” (Residential Service Manager, General).

4.4 During screening

This section will present the issues experienced by disabled people during the screening process.

4.4.1 Professional Attitude

The participants expressed that both positive and negative attitudes of professionals had influenced their decision to attend the screening service. For example, a residential service manager expressed her concern about a GP refusing to provide cervical screening to a person with intellectual disabilities:

“But certainly, in other organisations that I’ve worked with, where there would have been people who had severe to profound intellectual disabilities, I don’t know that they did get cervical screening. I don’t think they did. And again, it was that kind of – I know certainly with the GP, because I remember asking the GP to provide me with a letter that I could have on file to state that this individual did not require cervical screening. And they did give me a letter.

[MOD: Did he say why, no?]

Oh, just that they didn’t require it. That’s what he said on the letter, “This individual does not require cervical screening.” I don’t know how he could make – and I asked for the letter in the hopes that I’d back him into a corner a bit, but no, he gave me the letter” (Residential Service Manager, CervicalCheck).

Another participant recalled both positive and negative experiences and concluded that the attitude shown by professionals towards disabled people would make them reluctant to return:

“I don’t know about XX and XX, but I have always felt that most healthcare, particularly in Ireland, seems to be run for the convenience of the staff. Whatever works for the stakeholders, as it is often described. [pause] I have had some very, very good experiences, and I have had some awful ones. I am sure I am not alone. But attitude will be enough to put off a lot of people”

(Physical Impairment, BreastCheck).

One participant was concerned about the inappropriate and non-person-centred language used to address her:

“The disabled woman, as opposed to, the person in that room with this, this and this. Our disability shouldn’t be the biggest thing, do you understand what I mean?” (Physical Impairment, BreastCheck)

However, very positive comments were also provided about professionals highlighting their professionalism and flexibility in supporting disabled people:

“You can have doctors who are just amazing, and will make all kinds of reasonable accommodations for people” (Residential Service Manager, CervicalCheck)

“The last time I had it done was great. The two ladies who did it were brilliant. They made sure there was a second person in the room, to actually support me, if I had to lean forward” (Physical Impairment-Wheelchair User, BreastCheck).

4.4.2 Familiarity

Serious concerns were expressed regarding people with intellectual disabilities being extremely anxious in unfamiliar surroundings during screening and the importance of having someone they know present during the procedure:

“If you have someone who has autism and you’re bringing them in here to this little space, you’ll do the work. You’ll do the social story, you’ll do the easy-reads, and they’re all fantastic resources. But then you’re standing outside a door and they’re going in on their own. And then the experience could be very traumatic” (Community Nurse, BreastCheck).

Autistic persons also emphasised the importance of having familiar healthcare professionals provide screening services. For example, an Autistic participant preferring a familiar doctor for her cervical screening. She found it uncomfortable to deal with unfamiliar medical personnel:

“For example, if my doctor wasn’t able to do my cervical smear, and they put in a locum, I could not have that cervical smear with the locum. There would just be no way. I would be walking out the door. That is it. There can’t be any changes to personnel for me” (Autism, CervicalCheck).

Another participant clarified her wishes to have a same-gender professional while accessing the screening programme. She has a presumption that male professionals would be unwilling to listen to her needs:

“I will not ever have a male doctor or a male nurse, ever, for a number of reasons. One is, they tend not to listen to women. So, I will always go with female medics” (Physical Impairment, General).

The desire for familiarity extended beyond the person to the place where the screening took place. For example, one participant with physical impairment noted a preference to be screened in a place where she is comfortable:

“It would be a very good idea. Now, I would like to receive it in such-and-such a place in such-and-such a way, please. I know it is probably a bit more expensive than your usual plan, but if I get a serious cancer and I am in hospital, not only do you have the expense of the cancer, but you have the whole lot of expense of looking after me too, and all the other things relating to disability, that go with it” (Physical Impairment, BreastCheck).

A family carer described what can happen when her daughter is faced with unfamiliar surroundings:

“She’d probably have a meltdown, yes. Everything with Name is organised, it’s all the same, nothing changes. And when things change, that really can have little issues. If it’s something different that she’s not used to, or if it’s a new place she hasn’t been before, she’ll panic until she knows the place” (Family Carer, General).

Another family carer suggested that a procedure like screening would not be possible without someone familiar in attendance:

“They do that at their peril. I would explain the situation that I have never been in a situation like that. It is non-negotiable. Usually, in hospitals and that, they understand. They just want to get the procedure done as easily and as swiftly as possible. If they are not willing to let one other person in, that is crazy”
(Family Carer, General).

4.4.3 Consent

The professionals raised issues of consent while providing screening, particularly in light of the new legislation on assisted decision-making. In addition, they are confused as to what consent entails:

“Years ago, we would have been able to go in, and it was brilliant. You could be in there with that person, but now they’re saying that we are... I suppose we’re greying the whole consent issue and it’s a big problem”
(Community Nurse, BreastCheck).

“Because all they do is mind their little child, even though the child is now 42, they’re minding them as if they’re 7 or 8. And it’s that, kind of to allow them to make decisions, that mightn’t be the best, it’s going to be very difficult”
(Residential Service Manager, General).

The right of an individual to refuse or provide consent may be considered usurped if consent is not asked for and screening does not occur based on a presumption by a medical professional or family member that screening is somehow inappropriate:

“Their attitude is, “Why does she need a cervical screening? Why would she need it?” There is that attitude” (Community Nurse, CervicalCheck).

“Totally depends. Totally depends on the day and who you get. You can have doctors who are just amazing, and will make all kinds of reasonable accommodations for people, and then there’s doctors who are on the other end of things. And they’re very much dismissive of people with an intellectual disability” (Residential Service Manager, CervicalCheck).

“No, she didn’t get any of them done because the doctor told me, she’s not going with anyone or anything like that and she wouldn’t really need...”
(Family Carer, CervicalCheck).

However, The CervicalCheck programme in the Republic of Ireland advises that those who have never engaged in sexual activity have a very low chance of getting cervical cancer. This is because the human papilloma virus, which is the primary cause of cervical cancer, is typically spread through genital contact during sexual activities like skin-to-skin contact. However, it can also be transmitted through oral sex or shared sex toys, so a thorough sexual history must be taken into account when deciding on cervical screening (Health Service Executive, 2023).

4.4.4 Accommodation

By law, accommodations are required to be made by health services to facilitate disabled people. Regarding the screening services, a lack of awareness of the specific accommodations required by disabled persons was raised:

“I think it is just more an awareness. If I was to see something be noted, it would be, with increased mask wearing, medics need to be aware that it can reduce effective communication, especially with patients who may be hard of hearing or deaf” (Deaf, CervicalCheck).

A participant recalled her experience of lack of awareness shown by the professionals in that they follow protocols rather than being flexible to meet the needs of disabled people:

“For them, this is just the way it is done. This is their protocol. This is how it is done, full stop. Yes, there was no, ‘Okay, let’s see how we can facilitate you in any way.’ It was, ‘No, this is how we do things, end of story”
(Physical Impairment-Wheelchair User, BreastCheck).

However, once attention is drawn to specific requirements, staff will make the necessary accommodations:

“I think, once you draw attention to these things, the staff, 90% of the time, are okay with it” (Physical Impairment-Non Wheelchair User, General).

Many disabled people requested shorter waiting times as an important reasonable accommodation. One autistic individual provided the example of not having to wait as an accommodation that would make a major difference to their screening experience:

“No surprises at all, because I will have a meltdown. Not in what you think, I will just end up pacing the floor for around 45 minutes, trying to calm myself down. But, no, no surprises. I can’t deal with them [waiting] when it comes to anything medical” (Autism, General).

It was noted, and appreciated, that the screening service accommodates additional time for screening appointments if they know prior to the appointment. disabled people did, however, emphasize the importance of a longer appointment:

“If people have some mental health issues, giving them that extra time is handy because sometimes just not to have a rushed appointment makes a huge difference” (Visually Impaired, General).

“We have been told by the National Screening Programme that if we have someone who has additional supports, that we get a double appointment” (Visually Impaired, BreastCheck).

4.4.5 Accessibility

Wheelchair accessibility is an obvious requirement to allow wheelchair users access to screening services. Nonetheless, some issues were outlined:

“I wasn’t able to manoeuvre the chair into place for me to move over. I wasn’t able to manoeuvre the chair into the changing rooms, or anything. So, a lot of it was hobbling around, very undignified, [laughing]”
(Physical Impairment-Wheelchair User, CervicalCheck).

“No. They say that the powered chair is too heavy for the lift on the mobile units. Well, to my mind, that is absolutely appalling. Because bear in mind, it is the HSE who is supplying most of these wheelchairs”
(Physical Impairment-Wheelchair User, BreastCheck).

However, not all battery-powered wheelchairs are compatible with the lift on the breast mobile clinic but some are. Therefore, the breast screening staff assesses each situation individually and request that people contact them prior to their appointment to discuss the specifics of their wheelchair mode.

The disabled participants, particularly those who use wheelchairs, expressed worry about instances when they are unable to use their wheelchairs due to limited space. This leads to frustration and a sense of loss as they are highly reliant on their wheelchairs:

“Space is a huge thing for people with mobility issues. A wheelchair does take up an awful lot of space. Not having our wheelchair, when we are so used to it, it is terrifying. How do we do anything without the wheelchair? It is our legs”
(Physical Impairment-Wheelchair User, CervicalCheck).

The environment within a building can also present difficulties. For example, for autistic people with sensory issues some spaces were over-stimulating:

“Yes, not specific to screenings themselves, but doctor’s offices. They are usually very brightly lit, and generally loud. I don’t really know what could be done about that. That is part of it. It kicks up the anxiety when you are overloaded with sensory issues” (Autism, CervicalCheck).

There were particular issues raised by a professional with bowel screening concerning self-sampling. She was certain that some disabled people required support to collect the sample to ensure this was taken correctly:

“If you just handed them that and went, “Off you go now,” the sample you’ll get might not have been taken properly, or you know, there are probably a lot of issues with it. So no, staff would support them”

(Residential Service Manager, BowelScreen).

While some individuals felt confident about doing it on their own and suggested this was a dignified way of doing it, the sample kit’s design made it difficult for them to engage. Therefore, they require support in collecting the sample:

“It was idiot-proof. It was very, very easy to do. I would suggest that maybe the option be given for bottles that are larger and easier to grip”

(Physical Impairment-Wheelchair User, BowelScreen)

The difficulty for someone with mobility issues to access postal services in rural areas was also raised. On some occasions, their medical conditions prevent them from getting to a post office irrespective of where they live. This poses an additional barrier for them. Therefore, disabled people who face barriers in reaching the service require adequate support to successful participation:

“I was saying, access, especially in rural areas like me, getting to the Post Offices can be near impossible” (Physical Impairment-Wheelchair User, BowelScreen).

“Where your Post Office might be more of an issue, because some people whose Post Office is right around the corner, but because of chronic pain or access or even just a really poor footpath, you couldn’t make that kind of trip. Whereas somebody else can go 10km away without issue. So, I think it needs to be more dependent on the needs of the person, rather than the location”

(Physical Impairment, BowelScreen).

4.4.6 Equipment

An incompatibility between the equipment provided to disabled people and the requirements for screening, particularly regarding BreastCheck was noted. For example, a community nurse expressed that people with intellectual disabilities who are in a moulded wheelchairs find difficulty with Breast screening:

“There really wasn’t, when she was in there. She could not actually physically, you know, they couldn’t get the lateral views or they couldn’t get her in position for actually getting any kind of good visual images at all. And we would have a good few people in those chairs. They are moulded wheelchairs especially for our people” (Community Nurse, BreastCheck).

A person with physical impairment expressed her difficulties when she attended her BreastCheck appointment as she noted the limitation of the machine that is not adapted to the needs of some disabled people who use a wheelchair:

“Needs this high-tech or very, very fancy, it’s not even that fancy, to be honest, but it demands an awful lot of... I mean, you’ve got to fit into the machine, rather than the machine fitting to... you know, adapting to you. You’ve got to sit in and then you’ve got to turn this way and the machine has to come this way. But that’s another example of where you just can’t... The limitations of, I suppose, these machines are just so inflexible, they’re so rigid. And even people have to sit on here and, you know, it’s fine, but, I mean, if you have somebody in a wheelchair and they’re all strapped in, it can be very, very difficult for them” (Physical Impairment – Wheelchair User, BreastCheck).

An individual with physical impairment found it difficult to handle the bowel screening sample bottle. They felt a larger size lid would help them to handle it effectively:

“That was a big, big problem. Maybe as an alternative, ‘Do you need a larger size lid,’ or whatever. I did find it a little bit awkward to handle. But apart from that, it was very good. It was a very dignified way of screening as well” (Physical Impairment-Non Wheelchair User, BowelScreen).

4.4.7 Health Conditions

Some participants felt additional health problems, in addition to their disability, affects their attendance for screening programmes. This has a huge impact on screening:

“I have hyperalgesia and allodynia on my legs, so I cannot be touched whatsoever. I cannot even be breathed on. She accidentally grabbed the leg as she slipped. So, yes. [laughing] That pain lasted for about three days”

(Physical Impairment-Wheelchair User, CervicalCheck).

A person with intellectual disabilities recalled her experience of difficulties having an additional health problem that makes her anxious going again for the screening:

“The doctor put something into me. But it was terrible. I never... I have a weak gallbladder. I'd be afraid I'd go to the toilet in the middle of it, yes”

(Intellectual Disabilities, CervicalCheck).

Another individual with physical impairment expressed her difficulties attending screening services due to her multi-morbidity:

“It's a collagen defect. So, I would tear very easily, skin tears easily. I have got heart problems, joint dislocations, visual, all that kind of... Anything connected with collagen is affected by EDS. [pause] ... So, things were rather difficult, and it just didn't happen” (Physical Impairment-Wheelchair User, CervicalCheck).

4.5 Post Screening

This section details the experiences and issues faced by disabled people after the screening procedures.

4.5.1 Register amendments

The requirement, as noted by some, to repeatedly inform screening services of their disability as their disability status was not registered in the relevant NSS database was stated:

“The only concern I ever have in those kinds of appointments, especially when my eyesight gets blurry, is, will I hear them come out and call my name? Every damn time, I have to say, ‘Can you please note on my file that I am deaf, and I may not hear you?’” (Deaf, Diabetic RetinaScreen).

An Autistic person declared that she is willing to inform services regarding disability and how this might be done was also touched upon:

“Yes, if there was just a space to put it in, I would feel... I am also very open about it, but I also feel like I talk about it a lot. So, I would be very hesitant to just announce it at medical professionals. But if there was a space on a form to give details about that, it would be easier” (Autism, General).

4.5.2 Result

As with invitations and communications in general, issues regarding accessibility when receiving results were noted:

“They were quite prepared to send out the results to me, for somebody else to read” (Visually Impaired, BowelScreen).

“I am not dyslexic, but I do get tired from reading stuff. It kind of goes into white noise, is the best description of it. I am going... It is not produced in a way that is actually easy to read. That is my issue. Lack of paragraphs, lack of colour, you name it. It just makes it very, very difficult to read” (Autism, CervicalCheck)

However, there is a positive experience shared by one participant who stated that she received all communication in Braille when she requested for it:

“General manager, who happened to be the access officer as well, in my local primary care. She took charge of the whole thing. She made sure that all the information was sent out to me in braille” (Visually Impaired, BowelScreen).

Misunderstanding results that might be verbally communicated was also a concern:

“Again, if there is further information, it is really helpful if it can be provided in writing, if anything needs to be taken away, by way of information. So, that’s the other reason why I really like getting a report or something afterwards. It is confirmation to me that I heard correctly” (Deaf, General).

In one particular instance involving diabetic retina screening, a participant was left trying to find out where communications regarding tests had been sent:

“Most of these don’t have or advertise email addresses. I work full time. There is a piece of me that just goes, ‘I shouldn’t have to chase this.’ I don’t particularly want to pick up the phone and say, ‘You did something last time I was in. I want that report.’ You don’t know that it hasn’t been sent to your clinic, because usually, I don’t” (Deaf, Diabetic RetinaScreen).

4.5.3 Post effects

Dealing with the after effect of screening was also discussed. A person with intellectual disabilities stated that undergoing a cervical screening is inconvenient and painful:

“It is painful alright. It is very painful, yes” (Intellectual Disabilities, CervicalCheck)

The diabetic retina screening test was also described as being uncomfortable. A participant discussed difficulties regarding physical sensations such as pain, explaining absences for screening to employers or coping with sight disturbance post retina screening:

“Well, the eye screening is, quite frankly, inconvenient. It is a pain in the neck. Your sight can be blurred for hours. I used to be uncomfortable about taking that time off work, and uncomfortable about explaining why I needed the time, uncomfortable about asking at the desk for a letter”

(Deaf, Diabetic RetinaScreen).

“Yes. Because you go in. You wait to get seen. You get your drops. You wait 20 minutes for the drops to work. You get seen by somebody else. That is fine. That is, maybe 45 minutes. But the drops, I can’t see properly for maybe 4 hours after. I can’t do any of my work on the computer” (Deaf, Diabetic RetinaScreen)

4.6 Enablers and Barriers

The findings from the literature review and the research have been considered in constructing the table below (Table-7) showing enablers and barriers for accessing the national screening services by the disabled people.

Table 7 Enablers and Barriers

Enablers	Barriers
Promotion of available services and facilities to disabled people through a targeted campaign.	Lack of Awareness and understanding of the importance of screening.
Creating Awareness among disabled people by using images of disabled people receiving screening.	Dependency on others.
Accessible information <ul style="list-style-type: none"> • Multi-mode and multi-format communication • Screening simulations • Readily available information (easy to locate). • Point of contact to answer concerns and queries. 	Inaccessible information <ul style="list-style-type: none"> • Quality of information • Difficulty finding information • Limited formats of information • Limited modes of communication

Provision of proactive support <ul style="list-style-type: none"> • Prepare to accommodate needs on short notice. 	Presence of Co-morbidities.
Facilitation of reasonable accommodations <ul style="list-style-type: none"> • Flexible appointments • Tailored environment • Suitable space • Flexible equipment • Accessible buildings • Person-centred waiting arrangements 	Lack of Accommodation <ul style="list-style-type: none"> • Inaccessible buildings • Confined space • Lack of accessible equipment (hoist, exam table)
Good professional attitude <ul style="list-style-type: none"> • Disability Awareness • Compassionate approach • Understanding HSE consent policy 	Negative professional attitudes <ul style="list-style-type: none"> • Lack of disability awareness • Medical personnel presumptions • Lack of consistent support framework
Reimbursement of expenses	Expenses
Presence of familiarity <ul style="list-style-type: none"> • Allowing familiar people to accompany • Facilitation of service at the local level 	Travel (Lack of service provision at close proximity) <ul style="list-style-type: none"> • Unfamiliar personnel • Unfamiliar locations
Ability to amend the register (about personal needs and information)	Reluctance to disclose disability status/needs.
Preparation <ul style="list-style-type: none"> • Provision of information prior to screening • Awareness of professionals of medications that can facilitate screening in certain circumstances. 	Obtaining consent
Coordination with primary care and disability services	Family member's presumptions
	After Effects <ul style="list-style-type: none"> • Pain • Eye irritation
	Prior negative experiences

4.7 Overview

The findings presented above highlight the issues faced by disabled people when accessing population-based screening programmes in the Republic of Ireland. The findings suggest that disabled people and their carers have some positive experiences with the four programmes provided by the National Screening Service but they also have several issues and challenges in accessing screening services including: inaccessible information, travel challenges, negative personal and professional assumptions and attitudes, lack of screening preparation material, structural issues preventing access, consent issues, and difficulty with making amendments to the register. In the following section, we provide recommendations that can address the issues raised.

Chapter 5

Discussion

5.1 Introduction

This was the first study carried out in Ireland to explore the needs of disabled people in accessing the four population-based national screening programmes provided by the National Screening Service. The previous chapter presented findings from focus group discussions with disabled people and family carers and interviews with professionals on the experiences of disabled people accessing the National Screening Services. Much of what has been disclosed in the course of the focus groups and interviews are mirrored in the academic literature, this chapter will discuss the findings in light of existing literature.

5.2 Pre-Screening

The dependency of disabled people on others for some or all aspects of screening, from invitation through to attendance and interpretation of the result, is well documented in the literature (Arana-Chicas et al., 2020; Kilic et al., 2019). Some aspects of the screening mentioned during discussions in this study, contribute to this dependency. For instance, invitations are sent as standard letters that are inaccessible to some.

BreastCheck provides pre-arranged appointments at local breast screening centers. They have incorporated text message communication with service users. Despite the successful implementation of the text messaging system, BreastCheck still uses letters, which are sent before the texts, to give users the option to reschedule. BreastCheck emphasises that their text messages are a supplement to letters and not everyone may have access to a mobile phone. In addition, the CervicalCheck programme is exploring the viability of using text messaging services through a feasibility study.

Despite advancements to enhance communication and accessibility, there is currently no option for text-back, which is preferred by several disabled people.

However, for an invitation to be sent, disabled people must be on the register in the first case. Notably, some of the people with intellectual disabilities consulted said they had never received an invite for a screening service they are eligible for. Given the small sample, it is difficult to say if this is widespread and what factors cause this to occur. It may be an absence from the register, or a gatekeeper did not pass on the invitation. This apparent lack of invitation is not widely reported in the literature. The Health Information and Quality Authority (HIQA) directive

stating that care home residents must be registered with screening services encourages a degree of access to national population-based screening programmes for residents. Consequently, care home residents are registered with the NSS and receive invitations for screening.

The need for trusted, accessible information was noted in discussions and in the wider literature (Hanlon and Payne, 2017; Breau et al., 2016; Wu et al., 2012). Flexibility regarding content format and mode of communication was called for, particularly electronic communication in a format accessible to assistive technologies. Difficulty in accessing the information on HSE websites was also mentioned by some participants. There appears to be a lack of awareness of information regarding screening, such as the existence of the screening register for the four programmes and how to amend or check for inclusion on the screening register. Some carers preferred to use other websites, such as those provided by the United Kingdom National Health Service or National Disability Organisations, to obtain information in multiple formats. However, the NSS staff reported that information from the NSS is available in various forms such as easy read, Braille, large font, video, video with subtitles and photo story depending on the specific screening services. In addition, the staff stated that the communication team currently advertise on various platforms and media (press media, radio campaigns, and social media) and is working on providing information through other platforms like Twitter, Instagram, TikTok etc. They also share personal stories through radio and TV to advertise the various screening services offered and use formal advertisement strategies such as placing information at GP surgeries, supermarkets and public places. Despite all these efforts, disabled people are not represented in ad imagery and there is a lack of awareness among disabled people about the available information.

The topic of travel was an issue for some disabled participants, including the need to travel long distances to appointments; this is also represented in the literature (Kilic et al., 2019; Peters and Cotton, 2015; Angus et al., 2012; McIlpatrick et al., 2011; Mele et al., 2005; Sullivan et al., 2004). The NSS staff acknowledged the issue that disabled people experienced difficulties around travel and stated transport could be a problem, with some people having to take multiple buses, for example, from some areas of Dublin. Transport in rural areas is a major issue. To reduce the difficulty of travelling long distances and to increase accessibility, the NSS have mobile units for breast screening. Unfortunately, not all battery-powered wheelchairs are suitable for the lift on the mobile screening units and some are too large to fit. As a result, BreastCheck conduct an individual assessment and have a discussion with the person before the screening appointment to determine what would be best for the individual. Additionally, the space in the mobile units is limited, which means that some disabled people still need to attend a static unit for breast screening.

5.3 During Screening

Screening is a source of fear and anxiety for disabled people in this research. This is also highlighted in the literature (Kilic et al., 2019). Unfamiliar surroundings can be difficult for disabled people, particularly people with intellectual disabilities and autistic people. This may be mitigated somewhat if the person is accompanied by someone known to them, a family member or carer. However, the participants in this research suggest major difficulties from the service provider side regarding accompaniment. It may also be mitigated by preparation, whereby familiarisation regarding the procedure, location and personnel is conducted before the appointment (Watts, 2008). In addition, creating awareness of bringing the Health Passport (HSE, 2019) while attending screening services may help the professionals in the screening service to understand the personalised needs of disabled people, especially people with intellectual disabilities. The Health Passport serves as a means of communication to assist individuals with intellectual and cognitive disabilities in expressing their health and social care requirements. It helps healthcare professionals comprehend the capabilities and requirements of individuals with intellectual disabilities who encounter healthcare services. The use of medication to alleviate anxiety was also raised during discussions along with the practical difficulties such use may pose (Norway et al., 2017). Flexible appointments may also help. For example, the Diabetic Retina Screening service attempts to accommodate anxiety issues by giving the individual the first appointment of the day.

Accommodations provided to disabled people regarding appointment duration and double appointments, were appreciated by the participants. Pain and discomfort are factors that influence screening for disabled people (Verger et al., 2005). Prior experience has been shown, in this study and others (Arana-Chicas et al., 2020; Peters and Cotton, 2015) to be a factor in the decision to attend for screening or not. This relates particularly to cervical screening and is an issue for all women in general, not just those who are disabled. However, for disabled people, this issue appears to be compounded by the attitude of some healthcare professionals (Kung et al., 2012). This was particularly noted in focus group discussions with people with intellectual disabilities.

Negative professional attitudes towards disabled people in cancer screening is a recognised issue internationally within the literature (Ramjan et al., 2016). The negative attitude against disabled people goes beyond just the barriers they face in accessing screening services and encompasses their overall healthcare experience. Unfortunately, 80% of physicians acknowledged that disabled people have a lower quality of life compared to those without disabilities, and just 40% felt confident in their ability to deliver equal care to disabled patients (Lezzoni et al., 2021). The data collected in this study suggests this can also be a barrier to accessing the population-based screening programmes in Ireland. In the course of the discussions, participants discussed the examples of positive and negative attitudes from staff working in screening. It may be that some of these negative attitudes reflect a lack of awareness of the needs of disabled people (Lloyd and Coulson, 2014). However, several individuals suggested that professionals were happy to facilitate the needs once they were made aware of the accommodations required.

Similar to Kilic et al. 2019 study, some disabled participants in this study expressed that when they get to the appointment, the location is inaccessible, the physical space is restrictive, and the equipment is inflexible. The finding is consistent with other literature that wheelchair accessibility is an obvious requirement to access screening services (Agaronnik et al., 2021). An incompatibility between the equipment provided to disabled people and requirements for screening, particularly regarding BreastCheck also were an issue. In addition, an individual with

physical impairment found it challenging to handle the bowel screening sample bottle. The NSS staff highlighted that the bowel kit itself is very small, dexterity problems can be a barrier for some disabled people, especially individuals with vision impairment. However, a larger pack does not exist as the laboratory processes the current standard one. The environments that contribute to sensory overload within screening spaces can also present difficulties; for instance, autistic people feel uncomfortable with excessive sensory overload (Breau et al., 2022). Doherty et al. (2022) highlight that the waiting room environment, such as noise, crowd, and lighting, was a barrier for autistic people to access healthcare.

Many of the participants we spoke to experienced health conditions unrelated to their disabilities. The literature equally emphasises that multiple health conditions and complex needs of disabled people are important factors affecting their access to screening services (Yang and Graves, 2022; Nandam et al., 2018), some people are even refused screening because of these co-occurring conditions (Willis et al., 2015). We did not, however, encounter any concern from the participants of such refusal for screening but several individuals raised fear of incontinence during screening, with two others expressing that their conditions required sensitive and gentle physical support to avoid causing additional pain.

Personal and professional attitudes and assumptions may also impact whether or not a screening invite is acted upon, particularly regarding cervical screening (Sakellariou and Rotarou, 2017). Health professionals and/or family members may decide that the risk of cancer may not justify the burden or distress involved in screening for disabled people, especially for people with intellectual disabilities. This was particularly likely if there was a belief about the absence of sexual activity among disabled people, from family members or caregivers. According to the CervicalCheck recommendations, if someone has never had sex or sexual contact, the risk of developing cervical cancer is very low. If they do become sexually active, they should begin having screening tests. Sexual contact includes: any skin-to-skin contact of the genital area vaginal, oral or anal sex sharing sex toys (HSE, 2023). In contrast to this, some family members and carers proactively seek to obtain screening for people with intellectual disabilities and advocate for their rights (Breau et al., 2022). In the course of discussions, we heard of cases where invites would not have been acted on were it not for the intervention of carers.

The difficulties with the process of obtaining consent for screening for people with intellectual disabilities was raised by participants in this study and this issue features noticeably in the literature also (Willis et al., 2015; McIlpatrick et al., 2011; Wood and Douglas, 2007). It is worth noting that the NSS recommends that all staff involved in the screening process undertake the training on the HSE consent policy.

5.4 Post-Screening

On several occasions, disabled people discussed how their screening result was returned in an inaccessible format, such as a letter that was difficult for some disabled people to read. Difficulty in reading and/or interpreting the screening results meant some disabled people required assistance from others, which led to feelings that their privacy and dignity was compromised. Participants suggested that this could be prevented by sending electronic communication from the NSS compatible with assistive technologies as preferred by disabled people. For this to occur, the NSS register would have to include a request for a preferred communication format for each individual.

There was some discussion regarding the disclosure of disability status with the NSS. As two individuals with the same disability could have different needs, the possibility of recording needs as well as disability status was broached; this will enable the NSS to provide reasonable accommodations as required. Some individuals felt anxious about disclosing a disability in person but would more readily declare it on a form. The NSS has a facility to capture any access issues they are made aware of on the system for the person's next appointment by sending out an initial letter asking them to identify any access issues. For example, people may need an interpreter. The NSS will then put the appropriate supports in place when that person comes for their appointment. Despite these efforts, some disabled people are reluctant to disclose their needs.

The participants in this study did not report on follow-up issues regarding additional tests following a positive screening result, but there is a risk that disabled people, especially autistic people, may not pursue a positive screening result due to executive functioning difficulties and previous negative healthcare experiences. Barriers to accessing healthcare for autistic people include a lack of understanding of where to seek help, a complicated and confusing process to access help, and negative experiences with healthcare professionals (Mason et al., 2019; Vogan et al., 2017). To improve the success of the screening process, it is essential to provide clear and accessible information on how to access help, simplify the process, and foster a positive attitude among healthcare professionals. If the screening experience is unsatisfactory, it may discourage autistic people from pursuing necessary treatment in the future.

5.5 Limitations

The findings discussed here are the results of a study involving twenty disabled people, five family carers, five healthcare professionals and the literature. The fact that the findings closely align with findings from similar studies from other countries suggests that we may take the learning from these sources to improve population-based screening access issues for disabled people in Ireland. However, future studies involving larger samples of disabled people are urgently required to provide a more comprehensive, generalisable understanding of screening experiences among disabled people in Ireland. This is required to inform targeted interventions and programme modifications.

5.6 Chapter Summary

The findings from the study are discussed in light of existing international literature. The discussion with the NSS staff suggested an overwhelming willingness to adapt and make specific efforts to cater for people's particular needs but a lack of awareness of the potential supports available was noted among some disabled people and their carers. The findings from this study may inform the development of a system-wide framework for considering disabled people within the four screening programmes organised by the NSS. In the next section, we provide recommendations which can form a basis for such a framework.

Chapter 6

Conclusion and Recommendations

6.1 Introduction

This chapter summarises the conclusions of this report on the needs assessment of disabled people in accessing the four programmes (BreastCheck, BowelScreen, CervicalCheck and Diabetic RetinaScreen) of the National Screening Service. This report identified some aspects of current accommodations and measures the NSS provides to make population-based national screening available to disabled people. Participants acknowledged the value of many of these accommodations. However, disabled people, professionals and family carers highlight some issues and challenges. Based on these findings, recommendations are made to improve the screening access of disabled people.

6.2 Conclusions

The findings of this report concerning the screening access needs of disabled people in Ireland draw similarity to international evidence; however, the findings cannot be broadly generalisable because of the study design and the small sample size, but still may be transferrable. Accessing the population-based national screening programme is an essential health promotion activity for the early identification and prevention of disease, which reduces morbidity and mortality. This report identified positive experiences of disabled people in accessing the screening services and the strategies NSS adopted to promote their access, for example, facilitating double appointments and organising Irish sign language Interpreters (if requested prior to the appointment). Despite these efforts to promote access, disabled people experience several issues and challenges in accessing screening services: inaccessible information, travel challenges, negative personal and professional assumptions and attitudes, lack of screening preparation material, structural issues preventing access, consent issues, and difficulty with making amendments to the register. Overall, the significant role of the NSS in promoting and implementing screening among eligible participants in Ireland cannot be understated. However, consideration must be given to ensure that they develop an inclusive approach consistent with the suggestions of participants in this study. Reaching out to disabled people, explaining the benefits and facilitating this population to attend for their screening appointments is a crucial consideration in promoting better health for disabled people. The NSS, DPOs and disability services have a role in improving access to screening services through co-ordinated work, planning and implementing a person-centred approach tailored to the needs of disabled people and their carers.

There is no dataset available in the NSS on disabled people's utilisation of screening services to document the size and demographics of the disabled people invited for screening and explore the current utilisation level. However, there are recording difficulties in the NSS because of factors such as GDPR regulations, technical limitations in recording information, stigma, prejudice, and the reluctance of disabled people to disclose their status. We suggest that collecting this data and periodical reviews would help develop a timely and appropriate service mechanism contributing to service improvement, meeting the needs of disabled people and their families to access screening services, and reducing health disparities. Reducing disparities and addressing communication issues to attract disabled people to access screening requires systemic change, and the role of all agencies is pivotal to driving this systemic change in conjunction with disabled people and their families. As presenting issues and challenges are individual and different for each disabled person, all measures to promote screening must be targeted with both universal and specific unique measures.

As mentioned by many disabled people, the media is a powerful tool to acquire information. Therefore, this should be utilised more to promote screening among disabled people and to develop the accommodations and resources needed to facilitate disabled people to attend for screening. However, such strategies need to be co-designed by both communication specialists and disabled people. Crucially, involving disabled people and their carers in service planning, development, and evaluation is necessary because they are the experts in their own lives.

6.3 Recommendations

These recommendations and conclusions were drawn from the literature review, consultation with participants, and research advisory committee. The study recommends focusing on initiatives that have both a high impact and are realistically achievable. These top priorities include:

1. Staff training and education to enhance their understanding of disabilities and improve their interactions with disabled people.
2. A campaign to verify registration as a disabled people in population- based screening programmes to improve access to services and benefits.
3. An IT system with a disability marker to efficiently track and provide services to disabled people.

6.3.1 Training and Education

1. Provide in-service disability awareness training for health and social care professionals involved with National Screening Service (NSS).
 - a. Awareness training should be co-produced and co-delivered with disabled people.
 - b. There are good examples of effective screening for disabled people within the NSS programmes; we recommend these ‘successful’ case studies can be collected from the screening staff and integrated into training.
2. Provide guidelines and training on reasonable accommodations for providers of screening services, e.g., GP surgeries, Diabetic Retina Screening providers.
3. For any individual with a disability and individuals in community/residential care, promote screening as a part of their regular healthcare.

6.3.2 Person-Centred Approach

1. Ensure reasonable accommodations are made for each individual.
2. Conduct a review regarding who can accompany the disabled person during NSS screening procedures to offer increased flexibility for disabled people.
3. Provide additional and flexible appointment times where this is a requirement for disabled people to participate in the screening for all screening programmes.
4. Develop guidelines for carers to support the disabled person to prepare for a screening appointment for all screening services.
5. Provide clear, detailed and accessible information about what can be expected during the screening appointment for all screening services.
6. Ensure health professionals are aware of medications that can be used to facilitate screening in certain circumstances.
7. Develop an accessible platform/system to allow for feedback after screening procedures for all screening programmes.
8. Facilitate person-centred waiting time arrangements, for example, a quiet waiting area or the facility to text/call someone waiting in their car.
9. Consider providing a support person for disabled people to assist during appointments should this be required.
10. Involve disabled people in all aspects of screening service design. Ensure disability representation on the PPP (Patient and Public Partnership) panel.

6.3.3 Communication

1. Ensure all promotional and educational materials provided by the National Screening Services are readily available in easy read/audio/video format with Irish Sign Language interpretation.
2. Utilise easy read/audio/video with ISL interpretation for the invitation, information, and result for each screening service. Provide a QR code in all documentation to access multiple electronic formats and multimedia information about a specific screening they are invited to.
3. Offer content in multiple electronic and multimedia formats, compatible with assistive technologies.
4. Expand the current system to allow invitations, information and results to be sent in Braille format to visually impaired people.
5. Elicit the preferred content format and mode of communication for each disabled person through an initial invite asking for the disabled person's preferred format.
6. Develop a "check the screening register campaign" to increase awareness of the register and how to register for the different screening programmes.
7. Develop a facility to allow all registers to be checked on inputting personal information once rather than requiring each register to be checked separately.
8. Conduct person-centred communication in a manner appropriate to the disability. For example, people who lip-read require face-to-face communication.
9. Conduct formal usability testing of HSE screening websites with disabled people and carers.
10. Incorporate a QR code into the invitation to link the user to an online form where they can ask for specific needs in advance of the screening appointment rather than disability because the same disability has different needs.
11. Add "disability status" and "additional needs" as fields to the screening record.
12. Develop promotional and educational materials targeted at disabled people, their caregivers and influencers. For instance, provide examples of disabled people undergoing screening and highlight the importance of regular screening.

6.3.4 Accessibility

1. Ensure that clear and detailed information about the accessibility of screening locations is made available, including directions with a map, video, or virtual tour.
2. Ensure disabled persons are preferentially offered appointments close to home.
3. Provide convenient parking near the screening centers that has a level entrance to the building. This includes providing designated wheelchair spaces even for those who do not have a wheelchair registration as long as they can demonstrate their needs.
4. Consider transport as part of reasonable accommodation, including consideration for reimbursing travel costs.
5. Consider providing personal support to disabled people to use a bowel screening test kit if required.
6. Consider options for alternative screening methods where conventional tests are not accessible, if available. e.g. self-sampling.
7. Assess different types of accessible equipment available for different screening programmes such as hoists, rise and fall beds, wheelchairs etc. and communicate these available supports to disabled people.
8. Introduce accessibility rating (1 to 5) for screening sites.
9. Establish/explore a system for sharing information, in compliance with GDPR, between the different screening services about access needs.

6.3.5 Further Research

1. Based on qualitative data obtained from this research, develop a survey for distribution to a large sample of disabled people, carers and family members to be quantitatively analysed and subjected to a Theoretical Domains Framework analysis to further develop interventions to overcome barriers to screening, using a behaviour change methodology.
2. Conduct a comprehensive analysis of the Irish Health Survey, 2019 database to determine if rates of screening for all disabilities are as previously reported.

6.4 Chapter Summary

This chapter concludes by discussing the project's contribution and presenting recommendations to support the NSS, disabled people and other agencies to increase the uptake of screening services by disabled people to improve their quality of life and reduce morbidity and mortality. This report highlights the importance of embedding authentic consultation with disabled people, their families and other organisations working for disabled people in the culture, values and practice of the NSS.

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Appendix 1

Focus group guide

1. What do you know about cancer screening services in Ireland?

Potential Prompts

- a. How do you know?
- b. Where do you get that information?
- c. Was it accessible and easy to use?
- d. How do you want the screening information to be available to disabled people?
- e. Where do you normally get the health-related information?

2. How did you feel when you received the invitation for the screening test?

(Facilitator shows invites)

Potential prompts

- a. Was it accessible?
- b. Did you need to discuss this with anyone else, were you comfortable in doing so?
- c. What are your initial impressions of this invite?
- d. How would you react?
- e. How did you react?
- f. What could it be made better?
- g. How do you want to receive the information?

3. How did you make an appointment?

Potential prompts

- a. What difficulties would you foresee in making an appointment?
- b. Did you make an appointment?
- c. Was it easy to make, and how could it be made easier?
- d. How would you like to receive reminders about your appointments?
- e. Were your needs met?

4. Could it be costly for you to attend the screening service?

Potential prompts

- a. How did you travel?
- b. Did transport affect your decision to attend the screening service?

5. Did you attend the screening service?

Potential prompts

- a. If not why not?
- b. If Yes, why and how did you find the experience??
- c. How could your experience be made improved?
- d. What difficulties would you face trying to attend the screening? What problems have you had when you attended?
- e. Who would / do you discuss screening with or seek further advice from?
- f. What type of assistance – Formal/Informal. Who are they getting assistance from and for what exactly?
- g. What were your experiences in accessing the place (physical structure)?
- h. What was your experience with the procedure while undertaking a breast check and cervical check?
- i. How did the healthcare providers respond to your needs?
- j. Did you feel that the healthcare providers took your needs seriously?
- k. Did the healthcare providers provide enough information about the procedure? Was it accessible for you?
- l. Did you have any trouble understanding what was said about the screening procedure?
- m. Did you like to have someone who can assist you in the screening?
- n. Are you likely to attend when next invited?
- o. Why or why not?

6. For bowel screening

Show instructions for bowel screening

- a. What are your initial impressions of these instructions?
- b. How would you react?
- c. How did you react?
- d. What could be made better?
- e. Did you take a sample at a previous invite? If Yes, what could be done to improve- Did you need help or support?
- f. Would you take a sample?
- g. If not, why not?
- h. How could the procedure be made easier for you?
- i. How would you like to receive reminders?
- j. Did you return the sample?
- k. Would you return the future sample?
- l. If not, why not?
- m. How can the return procedure be made easier?
- n. Are you likely to complete the screening next time you are invited to go?
- o. Why, Why not

7. Were there any issues in getting consent?

Potential prompts

- a. How do you think to manage the situation if someone cannot provide consent?

8. What were your experiences in receiving the report?

Potential prompts

- a. Was it clear/Easy to read and understand? Do you need support to access, understand, and explain?
- b. How did you want your result to be sent to you?

9. Do you feel (concern about) unmet needs had an effect on attending? If yes, please describe.

10. Do you have any final comments?

11. Is there anything additional that you would like to say that you feel has not been said today or anything additional that needs clarification?

12. Do you have any recommendations?






Appendix 2

Interview Schedule

1. Would you like to tell us about your experience supporting disabled people in your care to attend the screening services?
2. What did you find helpful and what was the good system in place to support disabled people to attend screening services?
3. What barriers do you think affect disabled people attending the screening services?
4. What supports do you think need to be put in place to facilitate/attract disabled people to access screening services?

Appendix 3

Recruitment Flyer for Disabled People



Research on Health Screening for Disabled People

Dublin City University (DCU) has been asked by the National Screening Service (NSS) of the HSE to carry out research on health screening for disabled people and to provide advice to the NSS to make screening easier for disabled people.

We would like to talk to:
Disabled People: people with an intellectual disability, Persons with Physical Impairment, DEAF people, Visually Impaired People and Autistic People.

What is Health Screening?
NSS (www.screeningservice.ie) provides four types of screening services for the Irish population. These are

- Breast Cancer Screening – for women aged between 50 and 69
- Cervical Cancer Screening – for women aged between 25 and 65
- Bowel Cancer Screening – for all individuals aged between 60 and 69
- Diabetic Retina Screening for people with Diabetes – for all individuals with diabetes aged 12 and over.

Screening services can catch signs of an illness early and greatly improve outcomes, reducing the numbers of deaths due to cancer and blindness due to diabetes.



However, for disabled people there may be issues that make Population Screening more of a challenge.

Have Your Say: We will shortly be conducting focus groups lasting about 1 hour, in person or via zoom, for carers of people with a disability. We want you to tell us what the challenges are and how you think they can be overcome.

Interested in taking part or finding out more?




Contact us at:

Tel: 087 222 111 5;
Email: david.joyce@dcu.ie OR kumaresan.cithambaram@dcu.ie



Appendix 4

Recruitment Flyer for Family Carers



Family Carers: Research on Health Screening for Disabled People

Dublin City University (DCU) has been asked by the National Screening Service (NSS) of the HSE to carry out research on health screening for disabled people and to provide recommendations to the NSS to make screening easier for disabled people.

We would like to talk to:
Family members or carers of disabled people

What is Health Screening?
NSS (www.screeningservice.ie) provides four types of screening services for the Irish population. These are

- Breast Cancer Screening – for women aged between 50 and 69
- Cervical Cancer Screening – for women aged between 25 and 65
- Bowel Cancer Screening – for all individuals aged between 60 and 69
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Screening services can catch signs of an illness early and greatly improve outcomes, reducing the numbers of deaths due to cancer and blindness due to diabetes.

However, for disabled people there may be issues that make Screening more of a challenge.

Have Your Say
We will shortly be conducting focus groups lasting about 1 hour, in person or via zoom, for carers of people with a disability. We want you to tell us what the challenges are and how you think they can be overcome.

Interested in taking part or finding out more?
Contact us at:

Tel: 087 222 111 5;
Email: david.joyce@dcu.ie OR
kumaresan.cifhambaram@dcu.ie





DCU
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Dublin City University



An tSeirbhís Náisiúnta Scagthástála
National Screening Service