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Barriers to, and facilitators of, access to cancer services and experiences of cancer care for adults with a physical disability; a mixed methods systematic review

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Abstract

Background

Cancer services need to be inclusive and accessible by everybody, including people with disabilities. However, there is evidence suggesting that people with disabilities experience poorer access to cancer services, compared to people without disabilities.

Objectives

To investigate the barriers and facilitators of access to cancer services for people with physical disabilities and their experiences of cancer care.

Methods

A mixed-method systematic review was conducted following the Evidence for Policy and Practice Information and Co-ordinating Centre approach. We used the Mixed Methods Appraisal Tool (MMAT -Version 11) to assess the quality of the included studies. We employed thematic synthesis to bring together data from across both qualitative and quantitative studies and we assessed the strength of synthesised findings using the Confidence in the Evidence from Reviews of Qualitative Research (CERQual) approach.

Results

Seven quantitative studies and 10 qualitative studies (across 18 publications) were included. The findings highlighted a dearth of research on the experiences of men with disabilities. Furthermore, only one study explored experiences of cancer treatment, with all other studies focusing on cancer screening. Five synthesised findings were identified that reflected barriers and facilitators, highlighting both what makes access to services difficult and what are the strategies that could improve it.

Conclusions

Knowing what works for people with disabilities can enable the delivery of appropriate services. The findings of this review suggest that the mere existence of services does not guarantee their usability. Services need to be relevant, flexible, and accessible, and offered in a respectful manner.

Key words: Cancer services, physical disability, barriers, facilitators

Introduction

Cancer services, like all healthcare services, need to be inclusive and accessible by everybody, including people with disabilities. However, there is evidence suggesting that people with disabilities experience poorer access to cancer services, compared to people without disabilities.¹⁻³ For example, there is an increasing body of research suggesting that people with disabilities have a low uptake of bowel cancer screening,⁴ colorectal cancer screening,⁵ and breast or cervical cancer screening,⁶⁻¹⁰ especially when compared to screening recommendations,^{11,12} the general population¹³ or when compared to cohorts of non-disabled women.² However, for prostate cancer screening, the evidence is inconclusive.^{14,15} Within the research literature, a large number of predictors of decreased participation have been identified; for example, increased disability severity has been found to be a predictor of decreased participation for all types of cancer screening.^{4,5,9,10,14,16-22} For people with breast cancer, other disability related predictors of decreased participation include having major lower limb difficulties,²³ being non-ambulatory,²⁴ using mobility aids,²⁵ living farther from facilities that offer mammography²⁶ or having a relative as the main caregiver as opposed to a spouse/partner caregiver.²⁷ For women with cervical cancer, other disability related predictors of non-participation include having multiple disabilities,¹⁶ having lower limb difficulties,²³ having a relative caregiver as opposed to a spouse/partner caregiver²⁷ and requiring caregiving for activities of daily living.²⁷ The evidence also suggests that there are a wide range of other socioeconomic predictors of decreased participation, which are displayed in ancillary material 1.

It has been suggested that as a consequence of lower screening uptake, people with disabilities are more likely to be at a higher risk of delayed diagnosis and cancer mortality.^{1,13} With regard to diagnosis, patients with disabilities tend to be diagnosed at later

stages for lung and prostate cancers²⁸ but not for colorectal cancer.²⁸ The evidence as to whether women with disabilities are diagnosed at later stages of breast cancer is inconclusive; one study found that women with disabilities tend to be diagnosed at a later stage with breast cancer²⁹ while another two studies did not.^{30,31}

The literature that has investigated cancer specific mortality rates is also inconclusive. Roetzheim and Chirikos²⁹ analysis did not identify any differences in breast or lung cancer-specific mortality between people with and people without disabilities, whereas two other studies found that cancer-specific mortality was higher among people with disabilities for breast,^{28,32} colorectal²⁸ and lung cancer.³³ However, the study conducted with lung cancer patients by Iezonni et al.³³ found no difference in cancer mortality between women with disability and women without disability.

A number of studies have explored disparities with regard to the receipt of treatment between people with and without disabilities.^{30,32-34} One study found that people with musculoskeletal disorders were significantly more likely to have radiotherapy for their lung cancer than those without disabilities.³³

The studies that explored the likelihood of women with disabilities receiving breast cancer surgery, chemotherapy or radiotherapy have shown conflicting results. The main points were that:

- Women with disabilities were significantly less likely to undergo standard therapy after breast-conserving surgery than women without disabilities.³²
- There were no significant differences in the likelihood of women with and without disabilities undergoing surgical treatment for breast cancer^{30,34}.

- Compared to women without disabilities, women with disabilities were significantly more likely to receive the less aggressive treatments of breast conservation surgery alone or mastectomy rather than the more aggressive treatment of breast conservation surgery with radiotherapy.³⁴
- There was no significant difference in the likelihood of receiving neoadjuvant chemotherapy followed by breast cancer surgery between women with and women without disabilities.³⁰

In order to improve access to cancer services for people with disabilities, it is important to explore barriers to, and facilitators of access to cancer services and experiences of cancer care for adults with a physical disability. There is a wealth of literature that explores these issues for the general population.³⁵⁻⁴⁶ Barriers are the factors that reduce the likelihood that a person will access cancer services and facilitators are the factors that enhance the likelihood that a person will access such services. Although several previous reviews have investigated barriers to screening or preventive care for people with disabilities,^{13,47-51} no attempt was made to determine the quality of the included studies or the confidence level of the evidence in these reviews. In addition to qualitative studies exploring barriers and facilitators to cancer care for people with disabilities, several quantitative studies have also been conducted, using cross sectional surveys to collect data on cancer care and services. We therefore undertook a mixed-method systematic review using a comprehensive search strategy and assessed the methodological quality of the included studies. The objectives were:

- To investigate the barriers and facilitators of access to cancer services for people with physical disabilities.
- To investigate the experiences of cancer care for adults with a pre-existing physical disability.

Methods

This systematic review was conducted following the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) approach⁵² for mixed methods reviews and was reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.⁵³ The study protocol was registered in PROSPERO (Prospective Register of Systematic Reviews) database (CRD42018102626), University of York.

Inclusion criteria

Research studies were included if they fulfilled all the criteria below, based upon a modified SPICE (Setting, Perspective, Intervention, Comparison and Evaluation) framework, where we used *Issue of Interest* instead of *Intervention*.

1. *Setting*: The review considered all research studies that were conducted across both primary or secondary healthcare settings.
2. *Perspective*: This review considered all research studies that explored the perspectives of participants who were over 18 years, with any physical disability existing prior to the cancer, and linked to any underlying conditions, such as, for example, cerebral palsy, multiple sclerosis, or spina bifida. Disability was defined broadly, based on the conceptual domains of the International Classification of Disability, Functioning, and Health(ICF)⁵⁴. The ICF defines disability as an umbrella term for impairments, activity limitations, or participation restrictions. We did not limit the search to any particular type of physical disability.
3. *Issue of Interest*: The review considered all research studies that focused on barriers and facilitators of access to cancer services or experiences of cancer care.

4. *Comparison*: Not applicable. If a paper also reported on the differences between people with and people without disabilities as part of the study, then this information was synthesized as part of the analysis.

5. *Evaluation*: The review considered all research studies that specifically addressed cancer services and cancer care in any primary or secondary healthcare setting, which for the purposes of this review included screening through to post-treatment rehabilitation. We were also interested in any cancer-related preventive healthcare seeking behaviour, such as breast self-examination (BSE) or attending pelvic screening, mammography screening, or having a Papanicolaou (Pap) test. We did not limit the search to any particular of type of cancer.

Types of studies: All qualitative study designs were included if they reported on barriers to, and facilitators of, access to cancer services or experiences of cancer care using open discussion, focus groups, observations, or semi-structured interviews. Quantitative cross-sectional studies were included if they reported on barriers to, and facilitators of, access to cancer services or experiences of cancer care using self-reported measures.

Exclusion criteria

This review excluded research studies

- that reported on the experiences or opinions of healthcare providers (HCPs);
- that reported surveillance data or that were based on secondary analysis of data focusing on prevalence, uptake, or on disparities in screening;
- where the participants were people with a learning disability, a sensory impairment, dementia, short term physical impairment following injury, mental health issues where there was no physical impairment, and people with frailty associated with increasing age.

Search strategy

Seven databases were searched for English language citations from database inception. On Ovid platform: Medline, PsycINFO and EMBASE; on the EBSCO platform: CINAHL; on the ProQuest platform: British Nursing Index, ASSIA and Web of Science. The same three-arm search approach was conducted across all databases, whereby keywords were coupled with the relevant MeSH/thesaurus terms and truncated as appropriate. The keywords used as the basis of each search were cancer OR tumour OR neoplasm OR malignancy or carcinoma AND disabled OR disability or mobility impairment or functional limitation AND screening OR surveillance OR detection OR prevention) OR diagnosis OR treat OR therapy OR follow up OR rehabilitation OR cancer service/delivery/network OR oncology service OR radiotherapy OR chemotherapy OR surgery.

The search strategy, including all identified keywords and index terms was adapted for each included information source. The full search strategy for Medline can be found in Ancillary material 2.

Along with hand searching, recent issues of Disability and Health Journal, the American Journal of Preventive Medicine, the Journal of Women's Health and reference lists of included publications were scanned, experts were contacted, and forward citation tracking was performed using the ISI Web of Science.

Screening

All the citations that were retrieved were imported into EndNote and duplicate references were removed. All the remaining items were then independently assessed for relevance by two members of the review team using the information provided in the title and abstract.

Next, the full text was retrieved for all citations that, at that stage, appeared to meet the review's inclusion criteria. To achieve a high level of consistency, two reviewers screened each retrieved citation for inclusion using a purposely-designed form. In order to be included a study had to have met all of the criteria as laid out using the SPICE framework as stated above. Disagreements between the reviewers were resolved through discussion with a third reviewer.

Quality assessment

Study quality was assessed using the Mixed Methods Appraisal Tool (MMAT-Version 11⁵⁵). Each study included in the quality assessment was evaluated by two independent reviewers with any discrepancies mediated by a third reviewer. Each study was assigned a score based on the number of criteria met (25%—one criterion met; 100%—all criteria met). Studies were excluded from the review if they scored 0%, meaning that they fulfilled none of the criteria, as this was indicative of poor research quality/ poor rigour.⁵⁶

Data extraction and data synthesis

All demographic data was extracted directly into tables by one reviewer and checked by another, following the format recommended by the Centre for Reviews and Dissemination (CRD).⁵⁷ We employed thematic synthesis to bring together data from across both qualitative and quantitative studies.⁵⁸ The descriptive codes generated were organised into descriptive thematic codes, which were developed inductively based on close reading of the content of all items included. We used these thematic codes to categorise barriers, facilitators, and

experiences into themes across quantitative studies. Barriers, facilitators, and experiences from qualitative and quantitative studies were then compared and integrated into a final narrative synthesis.⁵⁹

Assessing Confidence

The strength of the synthesised qualitative and non-intervention findings were assessed using the GRADE-CERQual (The Confidence in the Evidence from Reviews of Qualitative research) approach.⁶⁰ The original CERQual approach was designed for qualitative findings, but has previously been used by members of this research team in mixed methods studies by adopting CERQual for the assessment of the confidence of synthesised findings from surveys and other non-intervention quantitative studies.^{61,62} The confidence of individual synthesised review findings is based on the assessment of four components: the methodological limitations of the qualitative studies contributing to a synthesised review finding, the relevance to the review question of the studies contributing to a synthesised review finding, the coherence of a synthesised review finding, and the adequacy of data supporting a synthesised review finding. Four levels are then used to describe the overall assessment of confidence as high, moderate, low or very low. When a synthesized review finding is assessed as being 'high confidence', this indicates that this synthesized review finding should be seen as a reasonable representation of the phenomenon of interest. If there are concerns with regard to any of the above four components, then this indication is weakened and a lower level of confidence attained (see Figure 1).

Results

A total of 5368 potential citations were identified in database searches and 17 through additional sources. The PRISMA diagram is presented in Figure 2 (details of excluded citations can be found in ancillary material 3). Eighteen citations underwent quality

assessment with the MMAT and all scored above 50%. Eighteen articles were therefore included in this systematic review. There were 7 quantitative studies and 10 qualitative studies (across 18 publications).

Study characteristics

Tables 1 and 2 summarize the characteristics of the 17 included studies involving 11,929 participants that met the inclusion criteria for the review. The studies were conducted in USA (n=11), Australia (n=2), Canada (n=2), Taiwan (n=1), and South Africa (n=1). The earliest and latest articles fulfilling the inclusion criteria were published in 1997 and 2015. The seven quantitative studies were all cross-sectional studies. The qualitative studies used a variety of methods which included interviews (n=5), focus groups (n=4), and observations (n=1). The participants in all of the studies, except one, were just women.⁶³ The study by Sweeney and Suzuki 2013⁷⁵, which the authors described as a case study, was included within table 1 as a quantitative study, as we only extracted the findings from the structured 37-item survey they used, which was completed through interviewing two women and descriptive statistics obtained.

The majority of the studies focused on either breast cancer screening (n=8),^{23,30,64-69} cervical cancer screening (n=2)^{70,71} or both (n=2)^{72,73}, with one study focusing on three cancer types: breast, cervical, and colorectal cancer screening.⁷⁴ The remaining four studies focused on preventive healthcare services.^{63,75-77}

Definitions of disability also varied across studies, with the majority of studies (n=9)^{23,63,68,69,71-73,76,77} using categorical approaches associated with specific conditions (such as multiple sclerosis, cerebral palsy, or spina bifida) or impairment (such as mobility impairment). Four studies adopted functional approaches where disability was centred around

broad limitations, such as a lack of mobility that came from an underlying condition or impairment.^{64,74,75,78} A further four studies included participants with a range of disabilities (physical, sensory, and cognitive disabilities) but reported separate findings for people with physical disabilities.^{65–67,70}

Thirteen studies presented information regarding the specific age ranges that formed part of the inclusion/exclusion criteria. This varied widely across the studies, for example: including only women over 40⁷⁷ or over 65 years of age,⁷⁸ or including only women under 40⁶⁶ or 60^{23,79} or 65 years of age⁷³ or including women aged 49 to 69 years,⁶⁷ 35 to 64 years,⁶⁴ 18 to 80 years⁷⁰ or 18 to 90 years⁷⁶ or including all women over 18 years of age.^{63,68,72,74}

Methodological quality

Five out of eleven of the qualitative studies fulfilled all four quality criteria on the MMAT,^{23,63,64,72,74} while the remaining six did not report whether the researchers' role might have influenced the outcome of the study.^{23,67–69,76,77} All the quantitative studies fulfilled three out of the four quality criteria, failing to report an acceptable response rate (60% or above).

Narrative synthesis

For the first objective (barriers and facilitators of access to cancer services for people with physical disabilities) five synthesized findings along with the detailed assessment of confidence is presented in table 3 (with greater detail being provided in ancillary material 4). With regard to the second objective, only one study was found, which reported findings across two publications, looking at the experiences of women with disabilities who had early stage breast cancer and a summary of this evidence is presented.

The majority of women with disabilities made decisions with regard to which treatment to undergo based on their concerns as to how the different options would affect their arms. Several were concerned about lymphoedema post-operatively and would not contemplate undergoing breast cancer surgery. Women with mobility impairments felt that they experienced more side effects as a result of chemotherapy than women without mobility impairments.²³ For example, women with mobility impairments who underwent radiation therapy reported difficulties getting onto the table for the procedure.⁷⁹

Barriers and facilitators of access to cancer services for people with physical disabilities

Five synthesised findings were identified that reflected barriers and facilitators surrounding access to cancer screening services. These were: i) reasons for not engaging in preventive healthcare seeking behaviours, ii) interactions between healthcare providers and women with disabilities, iii) external factors that influence preventive healthcare seeking behaviours, iv) factors that influence the accessibility of facilities, offices, and equipment and v) positioning concerns.

The first synthesised finding explored the wide range of reasons for not engaging in preventive healthcare behaviours as described by people with disabilities. Such reasons included individual factors (CERQual: Moderate); lack of knowledge (CERQual: High); belief systems (CERQual: High); time constraints and competing priorities (CERQual: High) and not remembering (CERQual: High). Receiving letters, postcards, or phone calls were suggested as ways to remind women with disabilities to attend mammography appointments (CERQual: Moderate).

The interactions between healthcare providers and individuals with disabilities was the second synthesised finding that this review identified. For people with disabilities their previous negative experiences of interactions with healthcare providers often prevented them from returning for further cancer screening appointments. These experiences included poor attitudes and behaviours (CERQual: High), lack of knowledge (CERQual: High) and lack of sensitivity (CERQual: High) by HCPs, HCPs not making referrals (CerQual: High) or not providing information (CerQual: Moderate), or not valuing patient as experts in their conditions (CerQual: Moderate). When women with disabilities experienced care from HCPs who were sensitive and responsive to their needs, they were more likely to return for repeat mammograms (CERQual: Moderate).

Men and women with disabilities felt that they knew more about their disabilities than their providers but this knowledge and expertise was often disregarded (CERQual: Moderate). To overcome this, men and women with disabilities felt that being proactive and demonstrating assertive communication skills was important (CERQual: Moderate). Education of HCPs was identified as being important (CERQual: Moderate) to improve healthcare interactions between HCPs and people with disabilities.

The third synthesised finding was around external factors that influence preventive health seeking behaviours and included financial concerns and difficulties with transportation. Organising transport to appointments was a concern along with unreliability, long waits, dealing with rude drivers, getting into and out of the vehicles, and having to cancel at short notice, along with having to take public transport which could often exacerbate existing symptoms (CERQual: High). Improved and reliable transport services or obtaining a referral

to a closer clinic or other facility could reduce some of the barriers associated with transport problems (CERQual: Moderate).

The fourth synthesised finding was around factors that influenced the accessibility of facilities, offices, and equipment, such as lack of ramps, lack of automatic doors, as well as parking issues (CERQual: High) as well inaccessible examination tables that could not be lowered (CERQual: High). Men and women with disabilities described the many facilitators that did or could improve their experience of screening such as:

- disabled parking spaces, handrails by entrance, level or ramped entrances, and accessibility buttons on doors (CERQual: High); and
- clinics that have adaptive equipment to meet their needs, such as mammography machines which can lower to wheelchair height and/or accommodate positioning needs and adjustable height tables for easy transfers (CERQual: High).

Having assistance which could be provided from a variety of sources was important so that men and women with disabilities could attend appointments, get around buildings, undress, transfer, and do paperwork (CERQual: High).

For women with disabilities, finding an experienced provider who understands their disability was difficult (CERQual: High). Men and women with disabilities found it hard to find accessible facilities as these were not widely advertised (CERQual: Moderate). Advertising accessible facilities through a variety of different sources such as word of mouth or support groups could overcome this barrier (CERQual: Moderate). Standard appointment times also posed a challenge as extra time is often needed during appointments for a thorough examination, undressing or finding accessible rooms (CERQual: Moderate). Having

appointments scheduled by the physician's office was reported as a positive experience (CERQual: Moderate) and having additional time was appreciated and was often available to those who attended accessible health centres, if requested on scheduling the appointment (CERQual: Moderate).

The final synthesised finding was that of positioning. Women with disabilities, especially wheelchair-users, reported difficulty in getting their bodies into the positions required for mammography. Other positioning concerns included not being able to stand, being unable to grip the handles or hold onto the rail of the mammography machine for support, being unable to raise arms above their breast and having to stay still due to involuntary head movements (CERQual: High).

A number of suggestions were given by women with disabilities to help with positioning concerns and included having a second technician to help them hold their head in position (specifically in relation to cerebral palsy), being able to sit during mammography, whether this was in a specially-designed seat or using their own scooter with an electric seat that could be moved up or down. Other women with disabilities found holding onto handrails helpful (CERQual: High).

In terms of experiences of cancer services, women with disabilities described experiencing both psychological and physical discomfort when undergoing mammogram, Pap tests or pelvic examinations, which dissuaded them from returning for future screenings (CERQual: High). Safety issues were a concern for many women with disabilities, especially when being left unattended or when being assisted with transfers (CERQual: High). The evidence

suggests that appropriate assistance could improve screening experience and improve safety of women with disabilities (CERQual: Moderate).

Discussion

The objectives of this mixed methods systematic review were to investigate the barriers and facilitators of access to cancer services for people with physical disabilities and to investigate the experiences of cancer treatment for this population. Only one study explored experiences of cancer treatment and the authors suggested that clinicians need to consider the women's mobility functioning when making recommendations regarding treatment options.⁸⁰

Previous reviews focused on just barriers to either site-specific cancer screening or preventive healthcare screening, in general, for people with physical and in some cases also intellectual disabilities.^{13,47-51} This is the first review that has included findings from people with a range of physical disabilities across all cancer diagnoses. This mixed methods review highlights the importance of engaging in preventive healthcare seeking behaviours and the interactions that take place during clinical encounters. It also highlights the facilitators that could help improve access to such services, from the perspective of people with disabilities.

The reasons given by people with disabilities for not engaging in preventive health care are the same as those commonly cited by the general population.³⁹⁻⁴⁴ A further reason that this current review identified, which was unique to women with disabilities, was their perspective that having to address their pre-existing conditions was enough to deal with. Other studies of women with chronic conditions have found that as comorbidities increase, the likelihood of partaking in cancer screening decreased.^{35,36} The strategies that have been shown to be effective for increasing the uptake of a variety of screening procedures in the general

population are the same as those suggested by people with disabilities and identified within this review.^{35–38,45,46}

The importance of the interactions that take place during clinical encounters has previously been highlighted for people with^{13,47–51} and without disabilities.³⁷ Clark and Reeves³⁷ in their review of women's experiences of mammography, found that often the ways women reflected upon their mammography experience was largely dependent on the interpersonal skills of the radiographer; in some instances radiographers were not always seen to be as calm, empathetic, gentle, sensitive, and professional as the women would have liked.³⁷

Of particular concern across a number of previous reviews was the fact that people with disabilities reported lack of information regarding preventive healthcare screening and being denied access or referral to such screening by HCPs.^{13,47,51} We concur with this finding; as our findings show that HCPs often acted as gatekeepers. Not all providers suggested or recommended referrals for preventive healthcare procedures for women with disabilities. Furthermore, although women and men with disabilities get preventive healthcare information from a variety of sources this is rarely provided by their HCPs.

Education of HCPs was identified as being important and this corresponds with recommendations made in previous reviews.^{47,49} We found that this was suggested to be necessary for both office support staff and HCPs. This review also found that a facilitator of this process would be for HCPs and people with disabilities to work together to ensure that optimal screening experiences take place. One suggestion as to how this could be facilitated would be to involve people with disabilities in undergraduate and continuing education programmes.

Financial concerns such as insurance coverage and costs of healthcare are particularly a US concern and along with transport issues have been highlighted frequently in the literature.^{13,48-51} Marrocco and Krouse⁴⁸ reported that people with disabilities experience poverty more than any other minority group. Having higher odds of having low-income, people with disabilities sometimes need to choose between paying for healthcare or daily living expenses.⁴⁸

This review has shown a wide range of factors that influence the accessibility of facilities, offices, and equipment for people with disabilities, impacting on decisions as to whether or not they feel able to attend screening appointments. This concurs with findings from previous reviews that found that physical barriers were another hurdle that could hinder access or repeat visits for women with disabilities.^{13,48-51} What this review adds to the literature is that both men and women with disabilities reported a number of concerns with regard to arranging assistance and the actual process of being given assistance, including attendant services being difficult to organize, a lack of continuity in carers, inappropriate transfers and undesirable levels of physical handling, and concerns regarding privacy.

The final synthesized finding was that of positioning, which was most problematic for women undergoing mammograms. Poulos et al.⁵¹ in their review of women with cerebral palsy and breast cancer screening reported that positioning is particularly difficult for women with cerebral palsy.⁵¹ Women with disabilities described experiencing both psychological and physical discomfort when undergoing mammograms and Pap tests and pelvic examinations, which dissuade them from returning for future screenings. This is also the case for women without disabilities who experience painful mammograms.³⁸ For women with disabilities

having appropriate assistance could improve the screening experience and improve safety. Iezonni et al^{23,79} recommended having policies, procedures, and guidelines in place for diagnostic radiographers to overcome this problem.

Of particular note is that this review highlighted the absence of research focusing on access to cancer services for men with disabilities. The majority of the published evidence focuses on breast and cervical cancer screening with very limited evidence regarding access to services for other cancers. Since the health-seeking behaviour between men and women may differ, and the barriers and facilitators to cancer screening may be different for men and women, it is necessary for research to focus on the experiences of men with disabilities who get diagnosed with cancer. This review also highlighted a dearth of research on experiences of cancer treatment, with the majority of the research conducted focuses on access to breast and cervical cancer screening. Whether chemotherapy, radiotherapy, immunotherapy, surgical or any other type, cancer treatment is often accompanied by side-effects, which may include fatigue, pain, and oedema. Such side-effects may disproportionately impact people with disabilities who, for example, use a manual wheelchair for mobility.

Furthermore, the findings of this review suggest that the mere existence of services does not guarantee their usability. Services need to be relevant, flexible, and accessible, and offered in a respectful manner. It is important that healthcare professionals work towards inclusive healthcare provision, enabling the utilisation of services by all. Necessary steps to be taken include better communication between the various professionals and across the different teams involved in a patient's care, raising awareness of how physical disability can affect or interact with cancer-related treatment, and creating more accessible physical environments.

Limitations and strengths

This review has a number of limitations. First, is the search for English-language only materials. Another limitation is the fact that all the participants for all of the studies except one were women, due to the focus of the published research on breast and cervical cancer. This is of particular note, and the reasons why men with disabilities appear to be under-included in research on cancer screening need to be explored. This review found that there is a large degree of heterogeneity in the way that the studies describe disability which is in keeping with findings from previous reviews.^{1,3,48} This makes it difficult to make conclusions on the unique needs of individuals with specific impairments such as multiple sclerosis, cerebral palsy or spina bifida, which was also highlighted as being a problem in the review by Marraco and Krouse.⁴⁸ Finally, only one study explored the experiences of cancer care for people with physical disabilities.

A unique feature of this review was the use of the CERQual approach. This allowed us to highlight barriers for which there is a high level of evidence, for example poor attitudes and behaviours by healthcare professionals, limited information on preventive healthcare by people with disabilities, and transportation barriers, among several others. Knowing which are the barriers that affect people's engagement with cancer services, including the uptake of preventive services, can inform and guide policy by, for example, producing disability-awareness educational material for healthcare professionals.

Conclusions

This review has focused on the variety of barriers and facilitators that people with physical disabilities face in accessing cancer services. Such barriers are not only related to the physical accessibility of spaces, financial issues, and transportation concerns but also to attitudes

during clinical interactions. Existing literature suggests that people with disabilities have lower uptake of preventive services, compared with people without disabilities. The findings highlighted a dearth of research on the experiences of men with disabilities. Furthermore, only one study explored experiences of cancer treatment, with all other studies focusing on cancer screening, with an emphasis on breast and cervical cancer screening.

There are a large number of wide-ranging factors that act as barriers which can influence the decisions of individual with disabilities to utilise cancer screening. Although several of these barriers are similar to those reported by the general population, there are a number of disability-specific barriers that HCPs need to be made aware of so that adequate cancer screening services can be provided to people with disabilities.. Using the CERQual approach enabled us to ascertain barriers to access to cancer services for which there is a high level of evidence for example poor attitudes and behaviours by healthcare professionals, limited information on preventive healthcare by people with disabilities, and transportation barriers, among several others. Knowing which are the barriers that affect people's engagement with cancer services, including the uptake of preventive services, can inform and guide policy by, for example, producing disability-awareness educational material for healthcare professionals. This Furthermore, this is the first systematic review that has explored facilitators from the perspective of individuals with disability. By highlighting facilitators for which there is a high level of evidence, the results of this review can help inform policy, and improve access to cancer services for people with disabilities.

Figure captions

Figure 1: CERQual: applying High, Moderate, and Low confidence to evidence

Figure 2: PRISMA 2009 Flow Diagram

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Figure 1: CERQual: applying High, Moderate, and Low confidence to evidence




High confidence in qualitative evidence	A review finding drawn from generally well-conducted studies with few methodological limitations and showing high levels of coherence	
Moderate confidence in qualitative evidence	A review finding where there are concerns regarding <i>either</i> the methodological limitations of the studies <i>or</i> the coherence of the review finding	
Low confidence in qualitative evidence	A review finding based on studies with important methodological limitations <i>and</i> where there are concerns regarding the coherence of the review finding	
Coherence	<p><i>The extent to which a clear pattern can be identified across individual study data. This pattern could include, for example:</i></p> <ul style="list-style-type: none"> * circumstances where the review finding is consistent across multiple contexts <i>or</i> * where the review finding incorporates explanations for any variations across individual studies <p>Coherence may be further strengthened if the individual studies contributing to the finding are drawn from a wide range of settings</p>	

Figure 2: PRISMA 2009 Flow Diagram

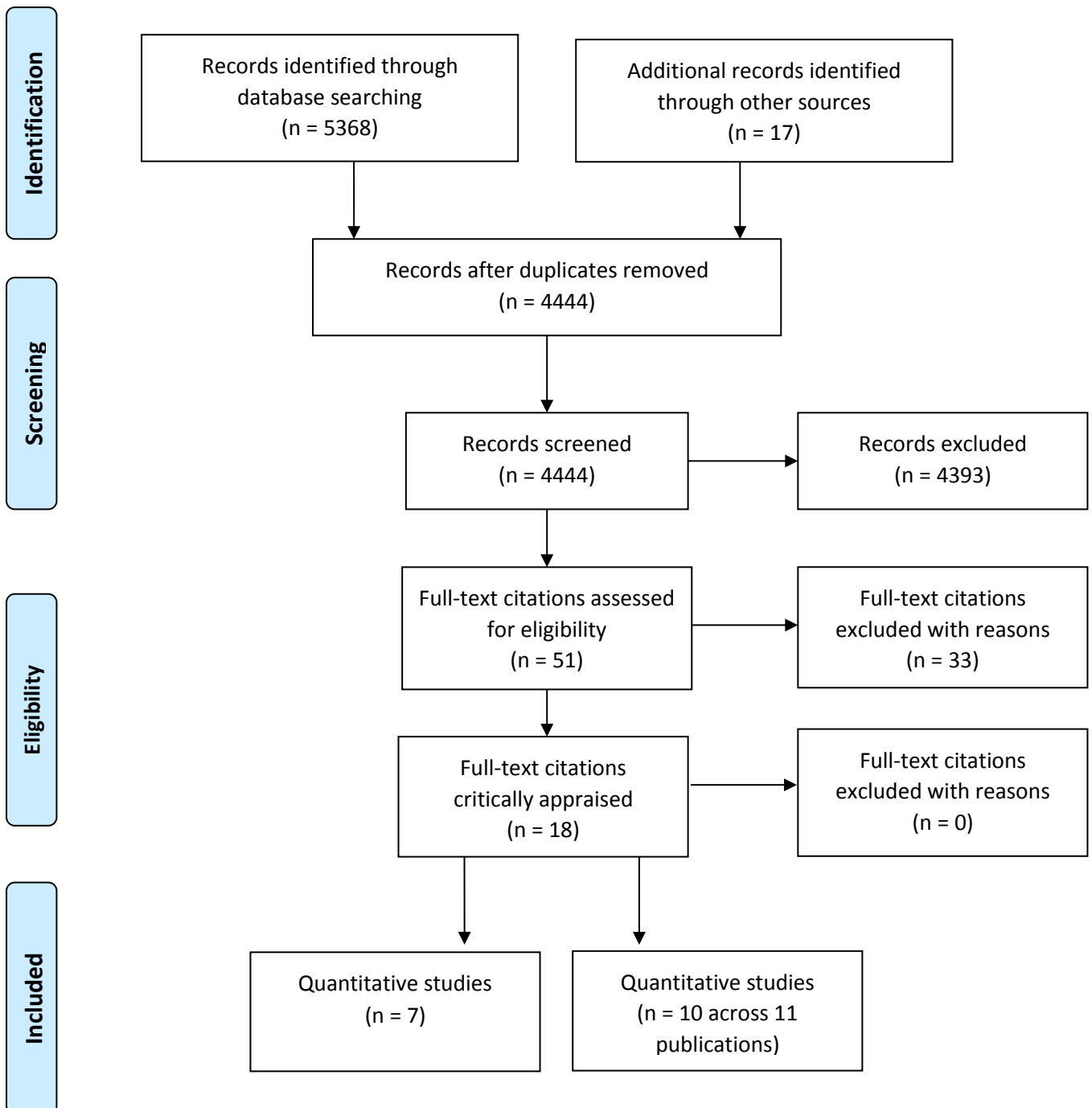


Table 1: Included studies table for quantitative studies

Author, Year, Country	Participant details	Disability	Outcome of interest
Aims			MMAT Score (%)
Cross sectional surveys			
<p>Study 1: Cooper and Yoshida 2007; Canada</p> <p>To report the prevalence and factors associated with ever having had a Pap test or pelvic examination among women with physical disabilities and the barriers to having the tests</p>	<p>Women with disabilities over 18 years (n=1095; RR 53%), recruited from mailing list of subscribers to the <i>Abilities</i> magazine</p> <p>Mean age(years) 49±14.3 SD</p>	<p>Musculoskeletal (44%)</p> <p>Neurologic (17%)</p> <p>Sensory (13%)</p>	<p><u>Outcome/s of interest</u></p> <p>Reported barriers to having a regular (once a year) Pap test or pelvic examination</p> <p><u>MMAT Score: 75%</u></p>
<p>Study 2: Jarman et al 2012; USA</p> <p>To ascertain the needs of women with disabilities who were being screened for cancer and explore whether these needs were being met</p>	<p>Women with disabilities (n=739; (RR 54.8%) recruited from mammography registry practices (n=9/34) who were >40 years and not had a mammogram during time period assessed by the study</p> <p><50 years (18.1%) / 50-59 years (29.6%) 60-69 years (25.9%) / 70-79 years (20.4%) 80+ years (6.0%)</p>	<p>Physical (59.4%)</p> <p>Hearing (8.7%)</p> <p>Visual (6.6%)</p> <p>Multiple disabilities (25.3%)</p>	<p><u>Outcome/s of interest</u></p> <p>Women were asked if they needed any of 28 accommodations during their last mammography appointment, and if their need was met</p> <p><u>MMAT Score: 75%</u></p>
<p>Study 3: Sweeny and Suzuki 2013; USA</p> <p>To obtain information regarding institutional barriers, especially regarding the physical accessibility of one outpatient health care centre</p>	<p>Women with disabilities (n=2) recruited from waiting room in health centre, who were uninsured and aged 19 to 64 years</p>	<p>Mobility impairments (100%)</p>	<p><u>Outcome/s of interest</u></p> <p>Accessibility of the health centre via building inspection</p> <p>Patient-reported</p>

			accessibility <u>MMAT Score: 75%</u>
Study 4: Wu et al 2012; Taiwan To explore knowledge and attitudes regarding cervical cancer screening and to examine its determinants based on the perspectives of women with physical disabilities living in the community	Women with disabilities (n=498; RR NS) recruited via a list of those registered as having physical disabilities and aged > 15 years Mean age (years) 49.97 ± 12.36 SD ≥ 50 years (46.5%)	Lower limb impairment (72.8%) Upper limb impairment (31.8%) Spinal cord injury (10.5%) Other nervous system impairment (7.3%) Accompanied with another disability (85.5%)	<u>Outcome/s of interest</u> Respondent knowledge and awareness of cervical cancer screening <u>MMAT Score</u> 75%
Study 5: Yankaskas et al 2010; USA To examine barriers to mammography adherence among women with disabilities, in order to reduce such barriers and promote regular screening in this population	Women with disabilities (n=1915; RR 45.6%) recruited from mammography registry practices who were aged >40 years and not had a mammogram during time period assessed by the study 40-64 years: 62.7% and ≥ 65 : 33.4%	Physical limitations (64.4%) Visual limitations (22.1%) Hearing limitations (7.9%) Multiple limitations (22.1%)	<u>Outcome/s of interest</u> Reasons cited by women for not returning for screening <u>MMAT Score: 75%</u>
Study 6: Nosek and Howland 1997; USA To explore the reasons women with disabilities offer for not receiving regular cancer screenings	Women with disabilities (n=475; RR 45%) recruited from centres of independent living and announcements and aged between 18-65 years. Mean age 39.1 years	Spinal cord injury (26%) Poliomyelitis (18%) Neuromuscular disorders (12%) Cerebral palsy (10%) Multiple sclerosis (10%) Joint and connective tissue disorders (8%) <u>Severity of disability</u> Measured using SF-36 Severe functional limitations (22%)	<u>Outcome/s of interest</u> Reasons for not receiving regular pelvic exams or mammograms <u>MMAT Score</u> 75%

		Moderate disabilities (52%) Mild disabilities (26%)	
Study 7: Caban et al 2011; USA To determine the factors associated with mammography use among Medicare beneficiaries and reasons for non-use	Women with disabilities (n=2281; RR NS) retrospective analysis of secondary data from the 2004–2005 Medicare current beneficiary survey who were aged > 65 years	Moderate disability (58.1%) Severe disability (41.9%)	<u>Outcome/s of interest</u> Reasons for not having mammography <u>MMAT Score: 75%</u>

Key: ADL: activities of daily living; IADL: instrumental activities of daily living; MMAT: Mixed Methods Appraisal Tool; NS: not specified; Pap: Papanicolaou; RR: response rate; SD: standard deviation.

Table 2: Included studies table for qualitative studies

Author, Year Country Aims	Participant details	Disability	Methods MMAT Score (%)
Community-based participatory research			
Study 8: Angus et al 2012; Canada To obtain views from women with mobility disabilities about breast, cervical, and colorectal cancer screening and to illuminate constraints and facilitators to screening access	Women with disabilities (n=24) recruited via community organizations, including advocacy and support groups (n=44), older than 18 years. 20-39 years (29%); 40-59 years (50%) and 60-76 years (21%)	Congenital (50%) Acquired (50%)	<u>Methods</u> Focus groups (n=5) <u>MMAT Score: 100%</u>
Qualitative descriptive			
Study 9: Barr et al 2008; USA To identify barriers to mammography screening among women with different disabilities and to suggest interventions to address barriers	Women with disabilities (n=42) recruited via direct mailings; meeting announcements; newsletters; Web postings; personal calls. Participants were non-institutionalized women aged between 40 to 69 years, who self-reported one or more disabilities Average age 52 and 40-49 years (38%); 50-59 years (48%); 60-69 years (14%)	Physical impairment (12%) Hearing impairment (10%) Visual impairment (12%) Psychiatric impairment (12%) Cognitive impairment (living independently) (17%) Cognitive-Intellectual impairment (Living in group homes) (19%)	<u>Methods</u> Disability- specific focus groups (n=6) <u>MMAT Score: 75%</u>
Study 10 : Iezzoni et al 2010; USA To explore the perceptions of breast cancer patients with mobility impairments of the	Women with disabilities (n=20) recruited from oncologist panels and from nationwide informal networks of disabled women with chronic mobility impairments who developed early-stage breast cancer	Poliomyelitis in childhood or post-polio syndrome as an adult (45%) Spinal cord injury (15%) Cerebral palsy (15%)	<u>Methods</u> Interviews <u>MMAT Score: 100%</u>

physical accessibility of health care equipment and facilities	before age 60. Age at time of diagnosis was 30-39 years (15%); 40-49 years (35%) and 50-59 years (50%)	Multiple sclerosis (10%) Other (rheumatoid arthritis, degenerative disk disease, and surgical complication in childhood (15%)	
Study 10: Iezzoni et al 2011; USA To explore how women's mobility difficulties affected the diagnosis and treatment of early-stage breast cancer	See Iezonni et al 2010 Age (years) at time of interview was 40-49 years (5%); 50-59 years (55%)	See Iezonni et al 2010	<u>Methods</u> Interviews <u>MMAT Score: 75%</u>
Study 11: Kroll et al 2006; USA 1) to investigate access barriers to obtaining preventive healthcare services for adults with physical disabilities and (2) to identify strategies to increase access to these services	Those with a physically disabling condition (n=36) recruited through announcements in e-newsletters, flyers, and word-of mouth. Female (44.5%) with a median age 46 years (min 20 years max 65 years)	Spinal cord injury (19.5%) Stroke (16.5%) Multiple sclerosis (14%) Other (50%)	<u>Methods</u> Focus groups (n=5) <u>MMAT Score: 100%</u>
Study 12: Persaud 2000; USA To identify barriers to preventive health practices for women with spinal cord injury	Women with disabilities (n=28) recruited from a private physician, an independent living centre, disabled student services, a home health agency, and peer support groups who aged between 18 to 90 years	Spinal cord injury (100%)	<u>Methods</u> Interviews <u>MMAT Score: 75%</u>
Study 13: Peters and Cotton 2015; Australia To explore breast and cervical screening practices women with physical disabilities in New South Wales and the barriers and facilitators to them accessing preventative	Women with disabilities (n=12) recruited via women's health organisations, through websites and newsletters. Participants were women who had undertaken breast cancer screening and self-identified as having a permanent physical disability	Mobility impaired due to a range of conditions including : - Incomplete paraplegic, - Arthritis - Back injuries - Multiple sclerosis	<u>Methods</u> Interviews <u>MMAT Score: 100%</u>

screening		<ul style="list-style-type: none"> - Congenital hip disorder - Double amputation - Poliomyelitis - Peripheral vascular disease 	
<p>Study 14: Poulos et al 2011; Australia</p> <p>To identify barriers and facilitators experienced by women with physical disability when having a mammogram</p>	<p>Women with disabilities (n=13) recruited for the study from a group of 75 women with a range of physical disabilities who volunteered to participate in phase 1 of the larger study. Aged 51-64 years</p>	<p>Cerebral palsy (n=5)</p> <p>Multiple sclerosis (n=1)</p> <p>Quadriplegia (n=1)</p> <p>Rheumatoid arthritis and quadriplegia (n=1)</p> <p>Blind, double amputee (n=1)</p> <p>Stroke (n=1)</p> <p>Paraplegia, spinal tuberculosis (n=1)</p>	<p><u>Methods</u></p> <p>Non-participant direct observation</p> <p><u>MMAT Score</u></p> <p>75%</p>
<p>Study 15: Smeltzer et al 2007; USA</p> <p>To gain insight into the perceptions of women with mobility and sensory limitations about several healthcare issues that may affect them</p>	<p>Women with disabilities (n=6) recruited through organizations serving them, with the exception of the college-aged women, who were part of an informal social network at a local college, and of whom one had attended health education programs run by the project team</p>	<p>Cerebral palsy or spina bifida (n=6)</p>	<p><u>Methods</u></p> <p>Focus groups (n=6)</p> <p><u>MMAT Score</u></p> <p>75%</p>
<p>Study 16: Suzuki et al 2013; USA</p> <p>To determine which barriers prevented women with mobility limitations who had already participated in an educational workshop from following through in obtaining a mammogram</p>	<p>Women with disabilities (n=47) recruited via Medicaid managed care organisation and a durable medical equipment vendor. Participants were aged between 35-64 years and had a mobility limitation as identified by an activity limitation due to physical, mental, or emotional problems or a health problem that required the use of special equipment. Self-reporting as not meeting Pap testing or mammography screening guidelines and</p>	<p>Limitations with motor skills to be their most limiting condition (83%)</p> <p>Limitations with hearing (6%)</p> <p>Limitation with cognition (4%)</p>	<p><u>Methods</u></p> <p>Interviews</p> <p><u>MMAT Score</u></p> <p>100%</p>

	having health insurance coverage Mean age (years) 50.87±5.74 SD		
Study 17: Todd and Stuijberger 2011; USA To identify barriers and facilitators related to breast cancer screening among women with multiple sclerosis	Women with disabilities (n=36). No other details provided Mean age (years) 55.03±10.56 SD	Multiple sclerosis (100%)	<u>Methods</u> Interviews <u>MMAT Score</u> 75%

Key

MMAT: Mixed Methods Appraisal Tool; Pap: Papanicolaou

Table 3: CERQual Summary of Findings table

Summary of review finding	Studies contributing to review finding	CERQual Confidence
Reasons for not engaging in preventive health care seeking behaviours		
Individual factors Women with disabilities gave multiple individual reasons for not engaging in PHC seeking behaviours, there were similar to those identified by women without disabilities (B)	Studies 5, 6, 18	M
Knowledge Women with disabilities were knowledgeable about their own health issues but had limited knowledge regarding PHC care (B)	Studies 4, 5, 8, 12, 17	H
Beliefs A number of different belief systems prevented women with disabilities from engaging with PHC services (B)	Studies 1, 5, 7, 9, 17	H
Coping with existing conditions: Women with disabilities do not engage with PHC screening as they report that having to cope with their pre-existing conditions is enough to deal with (B)	Studies 12, 17, 18	M
Time constraints and priorities Not having the time and not seeing PHC as a priority are given as reasons for non-adherence (B)	Studies 1, 8, 17, 18	H
Remembering to schedule mammography appointments Receiving letters, postcards or phone calls were suggested as ways to remind women with disabilities to attend mammography appointments (F) Women with disabilities reported that they do not remember to attend mammography appointments (B)	Studies 14, 18	M
	Studies 7, 9, 14, 18	H
Interactions between health care providers and women with disabilities		
Attitudes and behaviours When women with disabilities experienced positive interactions with HCPs, they were more likely to	Studies 13, 18	M

return for repeat mammograms (F)		
HCPs often exhibited poor attitudes and behaviours towards men and women with disabilities and such negative experiences often prevented them for returning for repeat mammograms (B)	Studies 8, 11, 13, 15, 18	H
Knowledge and communication		
Men and women with disabilities reported that training in communication skills could be useful in improving patient-provider interaction (F)	Study 11	VL
Men and women with disabilities reported that HCPs lacked knowledge about disabilities, which often resulted in poor communication (B)	Studies 11, 15, 17, 18	H
Sensitivity		
Men and women with disabilities reported that HCPs lacked sensitivity, evidenced throughout their encounter, from booking appointments to receiving test results (B)	Studies 8, 9, 11, 12, 15	M
Some women with disabilities had experienced HCPs who were sensitive and reactive to their needs (F)	Studies 13, 18	M
Gatekeeping		
Not all providers suggested or recommended referrals for PHC procedures for women with disabilities (B)	Studies 5, 6, 7, 15, 17, 18	H
Providing information		
Women and men with disabilities get PHC information from a variety of sources and reported that such information is rarely provided by their HCPs (B)	Studies 8, 11, 12	M
Valuing the patient as expert		
Office staff and HCPs need to be well educated about disability issues and PHC needs and that HCPs and people with disabilities need to work together to ensure that optimal screening takes place. One suggestion as to how this could be facilitated, was to involve those with disabilities in continuing education programmes (F)	Studies 8, 11, 12, 13, 14, 15	M
Men and women with disabilities felt that they know more about their disabilities than their providers but this knowledge and expertise is often disregarded (B)	Studies 8, 11	M

<p>Being proactive and demonstrating assertiveness</p> <p>Men and women with disabilities felt that being proactive and demonstrating assertive communication skills was important (F)</p>	<p>Studies 11, 13, 14, 17</p>	<p>M</p>
<p>External factors that influence preventive health seeking behaviours</p>		
<p>Economic concerns</p> <p>Women with disabilities in the US suggested that the availability of free screenings would improve their mammogram use (F)</p> <p>For women with disabilities in the US, concerns about insurance coverage and costs (relating to the procedure itself or to transport) influenced their preventive health care seeking behaviours (B)</p>	<p>Study 17</p> <p>Studies 5, 7, 9, 12, 17, 18</p>	<p>VL</p> <p>H</p>
<p>Transportation issues</p> <p>Improved and reliable transport services or obtaining a referral to a closer clinic or other facility would reduce the barriers associated with transport (F)</p> <p>Organising transport to appointments was reported to be a concern along with unreliability, long waits, dealing with rude drivers, getting into and out of the vehicles, and having to cancel at short notice.</p> <p>Having to take public transport was also difficult and could often exacerbate existing symptoms (B)</p>	<p>Studies 9, 13, 17</p> <p>Studies 1, 5, 7, 8, 9, 12, 13, 15</p>	<p>M</p> <p>H</p>
<p>Factors that influence the accessibility of facilities, offices, and equipment</p>		
<p>Finding a suitable health care provider</p> <p>finding an experienced provider who understands their disabilities was found to be difficult for women with disabilities (B)</p>	<p>Studies 1, 6, 8, 15, 17, 18</p>	<p>H</p>
<p>Appointment practicalities</p> <p>Having appointments scheduled by the physician's office was reported as a positive experience. Having additional time was appreciated and was often available to those who attended accessible health centres, if requested on scheduling the appointment (F)</p> <p>Scheduling appointments with primary care providers or with screening facilities was felt to be</p>	<p>Studies 2, 9, 12, 14</p> <p>Studies 8, 11,</p>	<p>M</p> <p>M</p>

stressful. Standard appointments time pose a challenge as extra time often is needed during appointments for a thorough examination, undressing or finding accessible rooms (B)	14, 17	
Availability of accessible facilities		
Advertising accessible facilities through a variety of different sources such as word of mouth or support groups (F)	Studies 8, 12, 15	M
Men and women with disabilities found it hard to find accessible facilities as they were not widely advertised (B)	Studies 8, 11, 15	M
Physical access and parking issues		
Men and women with disabilities described the many facilitators that did or could improve their experience, such as disabled parking spaces handrails by entrance, level or ramped entrances, and accessible handicap buttons on doors (F)	Studies 2, 3, 11, 12, 13	H
Barriers to accessing buildings, such as lack of ramps, lack of automatic doors as well as parking issues were reasons for not returning for screening (B)	Studies 5, 11, 12, 13, 15, 18	
Accommodating needs through adaptive equipment		
Some clinics had adaptive equipment to meet the needs of people with disabilities, such as mammography machines which could lower to wheelchair height and/or accommodate positioning needs and adjustable height tables for easy transfers. Some women had wheelchairs that reclined (F)	Studies 10,11, 12, 13, 18	H
Men and women reported that many facilities had inaccessible examination tables that could not be lowered for patient transfer. This meant that they had to bring a friend or family member to assist with the transfer or rely on staff who were often reluctant to help (B)	Studies 1, 6, 10, 11, 12, 15	H
Assistance		
Having assistance which could be provided from a variety of sources was important so that men and women with disabilities could attend appointments, get around buildings, undress, transfer, position themselves, and complete paperwork (F)	Studies 1, 2, 3, 8, 9, 10, 11, 12, 13, 14	H
Men and women with disabilities reported a number of concerns with regard to arranging assistance and	Studies 4, 8, 10,	H

the actual process of being given assistance, which included: attendant services difficult to organize, a lack of continuity in carers, inappropriate transfers and undesirable levels of physical handling, and concerns regarding privacy (B)	11, 12, 14	
Positioning concerns		
Physical positioning A number of suggestions were given by women with disabilities to help with positioning concerns and included having a second technician hold head in position, being able to sit during mammography, whether this was in a specially designed seat or using their own scooter with an electric seat that could be moved up or down. Others found holding onto a handrail helpful (F) Women with disabilities reported difficulty in getting their bodies into physical position required for mammography images, and this was especially so for wheelchair-users. Other positioning concerns included not being able to stand, grip the handles or hold onto the rail of mammography machine for support, raise to lift arms above breast, and having to stay still due to involuntary head movements (B)	Studies 2, 8, 10, 14 Studies 1, 3, 6, 8, 10, 13, 14	H H
Physical pain and discomfort Women with disabilities often received information from their peers about the mammography procedure, however but this was often negative in nature. They experienced both psychological discomfort and physical discomfort when undergoing mammogram and Pap tests and pelvic examinations, which dissuaded them from returning for future screenings (B)	Studies 1, 5, 7, 14	H
Compromised safety Appropriate assistance could improve the screening experience and improve safety of women with disabilities (F) Safety issues were a concern for many women with disabilities, especially when being left unattended or during transfers (B)	Studies 9, 13 Studies 10, 13, 14	M M

Key: Barrier: B; F: Facilitator; H: High confidence; HCPs: Health care professionals; L: Low confidence; M: Moderate confidence; PHC: Preventive health care; Pap: Papanicolaou; VL: Very low confidence

Ancillary material 1: Table of demographic predictors of decreased participation in cancer screening

Colorectal cancer screening

Women aged 18-64 years¹⁵

Men aged >65 years¹⁵

Cervical cancer screening

Not having a child²⁸

Never having been employed²⁸

Illiterate / intellectual disability / lower education level^{13,28,31,33}

Underweight²⁸

20 to 30 years²⁸

Older age^{9,24,29,33}

Lower income^{13,33}

Residing in area of higher urbanisation³³

Residing in rural areas²²

Unmarried^{31,33}

Not diagnosed with cancer³³

Not diagnosed with diabetes³³

Lower economic status²⁹

Breast cancer screening

Younger age^{9,21,29}

Living in rural/non metropolitan areas^{10,21}

Lower levels of education^{4,21,29}

Lower income levels²⁹

Not married or living with partner²⁹

Not having private health insurance^{21,23}

Not having an usual source of medical care^{21,23}

Ancillary material 2: Medline search strategies

Database: Ovid MEDLINE(R) ALL <1946 to May 23, 2018>

Search Strategy:

-
- 1 (cancer* or tumor* or tumour* or neoplas* or malignan* or carcinoma* or adenocarcinoma* or adeno?carcinoma* or choriocrcinoma* or leukemia* or leukaemia* or metastat* or sarcoma* or teratoma* or lymphoma).ti,ab. (3155062)
 - 2 exp neoplasm/ (3049417)
 - 3 oncology.ti,ab. (76979)
 - 4 (disabled or disabil* or "mobility adj1 impair*" or "functional adj1 limitation*").ti. (46333)
 - 5 exp Disabled Persons/ (59546)
 - 6 exp MOBILITY LIMITATION/ (3798)
 - 7 (mammogram* or breast examination).ti,ab. (9680)
 - 8 exp Mammography/ (27752)
 - 9 exp Mass Screening/ (116432)
 - 10 exp "Early Detection of Cancer"/ (18334)
 - 11 (screen* or surveillance or detect* or prevent*).ti,ab. (3734194)
 - 12 (Smear* or endoscop* or proctoscop* or colonoscop* or sigmoidoscop* or rectosigmoidoscop* or proctosigmoidoscop*).ti,ab. (252303)
 - 13 (faecel occult* or fecal occult* or FOBT or FOB).ti,ab. (3741)
 - 14 ("Prostrate specific antigen" or PSA).ti,ab. (30653)
 - 15 ("CA 125" or "blood tests").ti,ab. (12784)
 - 16 (ultrasound or x?ray*).ti,ab. (209986)
 - 17 (Diagnosis or treat* or therap* or follow?up or rehab*).ti,ab. (6859891)
 - 18 ("Cancer service*" or "cancer delivery" or "cancer network" or "oncology service*" or "clinical adj2 trial").ti,ab. (4082)
 - 19 (Radiotherapy or chemotherapy or surgery).ti,ab. (1334442)
 - 20 exp Cancer Care Facilities/ (4813)
 - 21 exp RADIOTHERAPY/ (168104)
 - 22 exp chemoradiotherapy/ or exp chemotherapy, adjuvant/ (46333)
 - 23 exp General Surgery/ (37247)
 - 24 exp IMMUNOTHERAPY/ (251977)

- 25 1 or 2 or 3 (3940001)
- 26 4 or 5 or 6 (91417)
- 27 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 (4134962)
- 28 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 (7675515)
- 29 25 and 26 and 28 (846)
- 30 25 and 26 and 27 (466)
- 31 29 or 30 (1117)
- 32 31 not developmental.ti,ab. (1084)
- 33 32 not intellect*.ti,ab. (1004)
- 34 33 not child*.ti,ab. (890)

- 1 (disabled or disabil* or "mobility adj1 impair*" or "functional adj1 limitation*").ti. (46368)
- 2 (prevent* adj3 service*).ti,ab. (10527)
- 3 (Breast adj3 service*).ti,ab. (709)
- 4 (prevent* adj3 care).ti,ab. (17090)
- 6 2 or 3 or 4 (26609)
- 7 1 and 5 (224)
- 7 6 not development*.ti,ab. (176)
- 8 7 not intellect*.ti,ab. (154)
- 9 8 not child*.ti,ab. (135)

Ancillary material 3: Excluded studies

1. Allen et al 2009: Continuity in provider and site of care and preventive services receipt in an adult Medicaid population with physical disabilities
Reason for exclusion: Not cancer preventative services
2. Andresen et al 2013: Pap, mammography, and clinical breast examination screening among women with disabilities: A systematic review:
Reason for exclusion: Review article all relevant articles retrieved
3. Brown and Kalitizidis 2013: Barriers preventing high-quality nursing care of people with disabilities within acute care settings: a thematic literature review
Reasons for exclusion: Not about cancer services
4. Buckley et al 2012: Does a standard measure of self-reported physical disability correlate with clinician perception of impairment related to cancer screening?
Reason for exclusion: Health professional views
5. de Castro et al 2013: Persons with disabilities, cancer screening and related factors
Reasons for exclusion: Sample included those with visual and hearing disabilities and analysis was conducted across all participants with no separate data reported just for mobility disabilities
6. Gibson et al 2010: Access to health care for disabled people: a systematic review
Reason for exclusion: Review article all relevant articles retrieved
7. Izano et al 2013: The impact of functional limitations on long-term outcomes among African-American and white women with breast cancer: A cohort study
Reasons for exclusion: Focus of research was on mortality and survival
8. Kim et al 2009: Lifestyle risk factors and utilization of preventive services in disabled elderly adults in the community
Reasons for exclusion: No results for cancer screenings even though they talk about cancer screenings under preventive services
9. Marrocco and Krouse 2017: Obstacles to preventive care for individuals with disability: Implications for nurse practitioners
Reason for exclusion: Review article all relevant articles retrieved
10. McCarthy et al 2006: Disparities in breast cancer treatment and survival for women with disabilities
Reasons for exclusion: Women who qualified for Social Security Disability and no details of physical disabilities provided
11. Merten et al 2015: Barriers to cancer screening for people with disabilities: A literature review

Reason for exclusion: A scoping review article, all relevant articles retrieved

12. Peterson-Besse et al 2014: Clinical preventive service use disparities among subgroups of people with disabilities: A scoping review
Reasons for exclusion: Scoping review all relevant references retrieved
13. Poulos et al 2006: Women with cerebral palsy and breast cancer screening by mammography
Reasons for exclusion: Discussion article
14. Ramjan et al 2016: Barriers to breast and cervical cancer screening for women with physical disability: A review
Reasons for exclusion: Narrative review all relevant articles retrieved
15. Roetzheim et al 2008: Managed care and cancer outcomes for Medicare beneficiaries with disabilities
Reasons for exclusion: Type of insurance arrangement and outcomes
16. Schopp et al 2002: Removing service barriers for women with physical disabilities: promoting accessibility in the gynecologic care setting
Reasons for exclusion: Discussion article
17. Seaton et al 2017: "I want to help, but what do you do in a situation like that?" Health care providers' qualitative perspectives on working with disabled women in breast cancer screening
Reasons for exclusions: Heath care providers experiences
18. Smeltzer 2006: Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities
Reasons for exclusion: Review all relevant articles retrieved
19. Thierry 2000: Increasing breast and cervical cancer screening among women with disabilities
Reasons for exclusion: Discussion article
20. Todd and Stuijbergen 2012: Breast cancer screening barriers and disability
Reasons for exclusion: Discussion article
21. Turk 2013: The ACA and preventive health care services for people with disabilities
Reasons for exclusion: Editorial
22. Verger et al 2005: Women with disabilities: general practitioners and breast cancer screening
Reasons for exclusion: General practitioners experiences

23. Welner et al 1998: Screening issues in gynecologic malignancies for women with disabilities: critical considerations
Reasons for exclusion: Editorial
24. Welch Saleeby and Hunter Jones 2016: Identifying barriers and facilitators to breast health services among women with disabilities
Reasons for exclusion: No separate findings reported for women with physical and mobility disabilities.
25. Mele et al 2005: Access to breast cancer screening services for women with disabilities
Reasons for exclusion: No separate findings reported for women with mobility disabilities.
26. Llewellyn et al 2011: Disability and mammography screening: intangible barriers to participation
Reasons for exclusion: No separate findings reported for women with mobility disabilities.
27. Drainoni et al 2006: Cross-disability experiences of barriers to health-care access
Reasons for exclusion. No separate findings reported for women with physical and mobility disabilities
28. Steele et al 2017: Prevalence of cancer screening among adults with disabilities, United States, 2013
Reasons for exclusion: No separate findings reported for women with mobility disabilities
29. Sakallerious and Rotarou 2017: Utilisation of cancer screening services by disabled women in Chile
Reasons for exclusion: No separate findings reported for women with physical disabilities
30. Riveria Drew and Short 2010: Disability and Pap smear receipt among U.S. Women, 2000 and 2005
Reasons for exclusion: No separate findings reported for women with physical and mobility disabilities
31. Liu and Clark 2008: Breast and cervical cancer screening practices among disabled women aged 40-75: does quality of the experience matter?
Reasons for exclusion. No separate findings reported for women with physical disabilities
32. Proulx et al 2012: Access to breast cancer screening programs for women with disabilities
Reasons for exclusion. No separate findings reported for women with physical disabilities

33. Peterson et al 2012: Improving cancer screening among women with mobility impairments: randomized controlled trial of a participatory workshop intervention
Reasons for exclusion. Not about barriers and facilitators

Ancillary material 4: CERQual Summary of Findings table			
Summary of review finding	Studies contributing to the review finding	CERQual assessment of confidence in the evidence	Explanation of CERQual assessment
Reasons for not engaging in preventive health care seeking behaviours			
Individual factors: Barriers Women with disabilities gave multiple individual reasons for not engaging in preventive health care seeking behaviours which were similar to those identified by women without disabilities	Studies 5, 6, 18	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence Moderate concerns regarding adequacy as only three studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Knowledge: Barriers Women with disabilities were knowledgeable about their own health issues but had limited knowledge regarding preventive health care	Studies 4, 5, 8, 12, 17	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy, and relevance
Beliefs: Barriers A number of different belief systems prevented women with disabilities from engaging with preventive services	Studies 1, 5, 7, 9, 17	High Confidence	No or very minor concerns regarding methodological limitations, coherence and adequacy. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Coping with existing conditions: Barriers Women with disabilities do not engage with preventive health care screening as having to cope with their pre-existing conditions is enough to deal with	Studies 12, 17, 18	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence Moderate concerns regarding adequacy as only three studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Time constraints and priorities: Barriers	Studies 1, 8,	High Confidence	No or very minor concerns regarding

Not having the time and not seeing preventive health care as a priority are given as reasons for non-adherence	17, 18		methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Remembering to schedule mammography appointments: Facilitators Receiving letters, postcards or phone calls were suggested as ways to remind women with disabilities to attend mammography appointments	Studies 14, 18	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only two studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Remembering to schedule mammography appointments: Barriers Women with disabilities reported that they do not remember to attend for their mammograms	Studies 7, 9, 14, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Interactions between health care providers and women with disabilities			
Attitudes and behaviours: Facilitators When women with disabilities experienced positive interactions with health care professionals they were more likely to return for repeat mammograms	Studies 13, 18	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only two studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Attitudes and behaviours: Barriers Health care professionals often exhibited poor attitudes and behaviours towards men and women with disabilities and such negative experiences which often prevented them for returning for repeat mammograms	Studies 8, 11, 13, 15, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence and adequacy. Minor concerns regarding relevance as only one study which represented males

<p>Knowledge and communication: Facilitators Men and women with disabilities reported that training in communication skills could be useful in improving patient provider interaction</p>	Study 11	Very low Confidence	No or very minor concerns regarding methodological limitations and coherence. Serious concerns regarding adequacy and relevance as only one study representing one country contributed to this finding
<p>Knowledge and communication: Barriers Men and women with disabilities reported that health care professionals lacked knowledge about disabilities which often resulted in poor communication</p>	Studies 11, 15, 17, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males
<p>Sensitivity: Facilitators Some women with disabilities had experienced HCPs who were sensitive and responsive to their needs</p>	Studies 13, 18	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only two studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
<p>Sensitivity: Barriers Men and women with disabilities reported that HCPs lacked sensitivity from booking appointments to receiving test results</p>	Studies 8, 9, 11, 12, 15	Moderate Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males
<p>Gatekeeping: Barriers Not all providers suggested or recommended referrals for preventive health care procedures for women with disabilities</p>	Studies 5, 6, 7, 15, 17, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
<p>Providing information: Barriers Women and men with disabilities get preventive health care information from a variety of sources and reported that such information is rarely provided by their health care</p>	Studies 8, 11, 12	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only three studies contributed to this finding.

professionals			Minor concerns regarding relevance as only one study which represented males
Valuing the patient as expert: Facilitators It was felt that both office staff and health care professionals need to be well educated about disability issues and preventive health care needs and that health care professionals and those with disabilities need to work together to ensure that optimal screening takes place. One suggestion as to how this could be facilitated would be to involve those with disabilities in continuing education programmes	Studies 8, 11, 12, 13, 14, 15	Moderate Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males
Valuing the patient as expert: Barriers Men and women with disabilities felt that they know more about their disabilities than their providers but this knowledge and expertise is often disregarded	Studies 8, 11	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only two studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Being proactive and demonstrating assertiveness: Facilitators Men and women with disabilities felt that being proactive and demonstrating assertive communication skills was important	Studies 11, 13, 14, 17	Moderate Confidence	No or very minor concerns regarding methodological limitations, coherence and adequacy. Minor concerns regarding relevance as only one study which represented males
External factors that influence preventive health seeking behaviours			
Economic concerns: Facilitators Women with disabilities in the US suggested that the availability of free screenings would improve their mammogram use	Study 17	Very Low Confidence	No or very minor concerns regarding methodological limitations and coherence. Serious concerns regarding adequacy and relevance as only one study representing one country contributed to this finding
Economic concerns: Barriers Women with disabilities in the US expressed concerns about insurance coverage and costs (procedure itself or	Studies 5, 7, 9, 12, 17, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance

transport) influenced their preventive health care seeking behaviours			
Transportation issues: Facilitators Improved and reliable transport services or obtaining a referral to a closer clinic or other facility would reduce the barriers associated with transport	Studies 9, 13, 17	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only three studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Transportation issues: Barriers Organising transport to appointments was reported to be a concern along with unreliability, long waits, dealing with rude drivers, getting into and out of the vehicles, and having to cancel at short notice. Having to take public transport was also seen as difficult and could often exacerbate existing symptoms	Studies 1, 5, 7, 8, 9, 12, 13, 15,	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy, and relevance
Factors that influence the accessibility of facilities, offices, and equipment			
Finding a suitable health care provider: Barriers For women finding an experienced provider who understands their disabilities was difficult	Studies 1, 6, 8, 15, 17, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Appointment practicalities: Facilitators Having appointments scheduled by the physician's office was reported as a positive experience. Having additional time was appreciated and was often available to those who attended accessible health centres if requested on scheduling the appointment	Studies 2, 9, 12, 14	Moderate Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Appointment practicalities: Barriers Scheduling appointments with primary care providers or with screening facilities was felt to be stressful. Standard appointment time poses a challenge as extra time often is needed during appointments for a thorough examination, undressing or finding accessible rooms	Studies 8, 11, 14, 17	Moderate Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males

<p>Availability of accessible facilities: Facilitators Advertising accessible facilities through a variety of different sources such as word of mouth or support groups</p>	Studies 8, 12, 15	Moderate Confidence	No or very minor concerns regarding methodological limitations, coherence, and relevance. Moderate concerns regarding adequacy as only three studies contributed to this finding
<p>Availability of accessible facilities: Barriers Men and women with disabilities found it hard to find accessible facilities as these were not widely advertised</p>	Studies 8, 11, 15	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only three studies contributed to this finding. Minor concerns regarding relevance as only one study which represented males
<p>Physical access and parking issues: Facilitators Men and women with disabilities described the many facilitators that did or could improve their experience such as disabled parking spaces handrails by entrance, level or ramped entrances, and an accessible handicap button on doors</p>	Studies 2, 3, 11, 12, 13	High Confidence	No or very minor concerns regarding methodological limitations, coherence and adequacy. Minor concerns regarding relevance as only one study which represented males
<p>Physical access and parking issues: Barriers Physical access to buildings such as lack of ramps, lack of automatic doors as well as parking issues were reasons for not returning for screening</p>	Studies 5, 11, 12, 13, 15, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence and adequacy. Minor concerns regarding relevance as only one study which represented males
<p>Accommodating needs through adaptive equipment: Facilitators Clinics that have adaptive equipment to meet their needs such as mammography machines which could lower to wheelchair height and/or accommodate positioning needs and adjustable height tables for easy transfers. Some women had wheelchairs that reclined</p>	Studies 10, 11, 12, 13, 18	High Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males
<p>Accommodating needs through adaptive equipment: Barriers Men and women reported that many facilities had</p>	Studies 1, 6, 10, 11, 12, 15	High Confidence	No or very minor concerns regarding methodological limitations, coherence and adequacy.

inaccessible examination tables that could not be lowered for patient transfer. This meant that they had to bring a friend or family member to assist with the transfer or rely on office staff who were often reluctant			Minor concerns regarding relevance as only one study which represented males
Assistance: Facilitators Having assistance which could be provided from a variety of sources was important so that men and women with disabilities could attend appointments, get around buildings, undress, be transferred, positioned correctly and helped with paperwork	Studies 1, 2, 3, 8, 9, 10, 11, 12, 13, 14	High Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males
Assistance: Barriers Men and women with disabilities reported a number of concerns with regard to arranging assistance and the actual process of being given assistance which included: attendant services difficult to organize, a lack of continuity in carers, inappropriate transfers and undesirable levels of physical handling and concerns regarding privacy	Studies 4, 8, 10, 11, 12, 14	High Confidence	No or very minor concerns regarding methodological limitations, coherence, and adequacy. Minor concerns regarding relevance as only one study which represented males
Positioning concerns			
Physical positioning: Facilitators A number of suggestions were given by women with disabilities to help with positioning concerns and included having a second technician hold head in position, being able to sit during mammography, whether this was in a specially designed seat or using their own scooter with an electric seat that could be moved up or down. Other women with disabilities found holding onto the handrail helpful	Studies 2, 8, 10, 14	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy and relevance
Physical positioning: Barriers Women with disabilities reported difficulty in getting their bodies into physical position required for mammography images especially wheelchair-users. Other positioning concerns included not being able to stand, being unable to grip the handles or hold onto the rail of mammography	Studies 1, 3, 6, 8, 10, 13, 14	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy, and relevance

machine for support, being unable to raise to lift arms above their breast and having to stay still due to involuntary head movements			
Physical pain and discomfort: Barriers Women with disabilities often received information from their peers about the mammography procedure, however this was often negative in nature. Women with disabilities described both psychological discomfort and physical discomfort that they experienced when undergoing mammogram and Pap tests and pelvic examinations, which dissuaded them from returning for future screenings	Studies 1, 5, 7, 14	High Confidence	No or very minor concerns regarding methodological limitations, coherence, adequacy, and relevance
Compromised safety: Facilitators Appropriate assistance could improve screening experience and improve safety of women with disabilities	Studies 9, 13	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only two studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread
Compromised safety: Barriers Safety issues were a concern for many women with disabilities especially when leaving them unattended or when providing assistance with transfers	Studies 10, 13, 14	Moderate Confidence	No or very minor concerns regarding methodological limitations and coherence. Moderate concerns regarding adequacy as only three studies contributed to this finding. Minor concerns regarding relevance as all studies directly relevant but very limited geographical spread

