

Attitudes and perceptions of people with a learning disability, family carers and paid care workers, towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation

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**Running Title-** A systematic review of attitudes towards cancer screening

## **Abstract**

*Objective:* Evidence suggests that people with a learning disability (PwLD) are less likely to attend cancer screening than the general population in the United Kingdom. The aim of this systematic review was to identify and synthesise qualitative studies reporting the attitudes and opinions of PwLD, family carers and paid care workers, towards national cancer screening programmes.

*Methods:* Five electronic and two grey literature databases were searched. 14,846 papers were reviewed against pre-determined inclusion criteria. Included papers were critically appraised. Findings were synthesised using meta-aggregation.

*Results:* 11 papers met the inclusion criteria, all related to cervical and breast screening. No papers were related to colorectal cancer screening. Findings were clustered into four synthesised findings: 1) Supporting women with a learning disability (WwLD) to attend screening; 2) WwLD's awareness of screening, and their psychophysical experiences; 3) Professional practice barriers including the need for multidisciplinary working and an understanding of the needs of WwLD, and 4) Approaches to improve the uptake of cervical and breast cancer screening. The synthesis highlights the significance of WwLD having support to understand the importance of screening to be able to make an informed choice about attending.

*Conclusions:* WwLD may not attend cancer screening due to fear, concerns over pain, and the potential influence of family carers and paid care workers. The review identified practical mechanisms which could help WwLD attend screening. Future research should focus on identifying potential barriers and facilitators as a proactive measure to promote colorectal cancer screening.

**Keywords:** attitudes, cancer, screening, oncology, learning disability, meta-aggregation, qualitative, systematic review

## **Background**

The World Health Organisation estimate that there were 9.6 million deaths in 2018 caused by cancer (1). Given recent global trends, it is projected that by 2030, there will be 23.6 million new cases of cancer each year (2). An effective way to improve survival from cancer and reduce mortality is through cancer screening. Screening aims to identify and diagnose cancer at an early stage (3) by identifying healthy members of the population who may be at increased risk of a disease or condition (4).

In the United Kingdom (UK), the National Health Service (NHS) run three cancer screening programmes for the early identification of cervical, breast, and colorectal cancer. The cervical screening programme invites women aged 25 to 64 to have a sample of cells taken from their cervix to identify any changes within the cells (5). Women aged between 25 and 49 are invited to attend every three years, and women aged between 50 and 64 every five years (6). For breast screening, women are invited to attend a mammogram from 50 to 70 years old, every three years however, women can opt to continue screening after their 71<sup>st</sup> birthday, every three years. During the mammogram, an X-ray of the breast is taken (7). Across England, 65 NHS Breast Cancer Screening units are trialling an age range extension to include women from 47 to 49, and 71 to 73 (8). Colorectal screening invites men and women, in England, Wales, and Northern Ireland, aged from 60 to 74, and 50 to 70 in Scotland (9), to complete a home-screening kit collecting stool samples to detect the presence of blood (10).

The UK National Screening Committee stipulate national targets for cancer screening coverage; this measures the proportion of eligible people who have been screened (11). Cervical screening has a standard target of 80% uptake (11), 70% for breast cancer screening (12), and 75% for colorectal cancer screening (13). The target for colorectal screening will rise to 80%, as the Faecal Immunochemical Test (FIT) is expected to simplify the process thereby increasing patient uptake (14). The FIT has been implemented in Scotland. This is due to healthcare being a devolved issue, each constituent country of the UK has some responsibility for their own healthcare provision (15). Due to this screening uptake may differ per country, please refer to supplementary material 1.

Cervical cancer screening is a clinical indicator in the Quality and Outcomes Framework (QOF). The QOF is a voluntary programme for General Practices across the UK (16) and is designed to encourage services to offer cervical screening, for a financial reward in order to maintain and improve the levels of uptake (17). Due to the reliance on QOF income from

cervical screening, this could mean practices prioritise QOF-related activities over other aspects of care (18). The Confidential Inquiry into Premature Deaths (CIPOLD) of people with a learning disability (PwLD) identified that cancer was one of the most common underlying causes of death, with the uptake of cancer screening differing from that of the general population (19). NHS digital shows 83.6% of men and women with a learning disability aged 65-69 had received colorectal cancer screening in 2015 (20). In the same year, 24.8% of women with a learning disability (WwLD) aged 55 to 64, received their cervical screening (20) and 44% of WwLD aged 50 to 54 received breast cancer screening (20). Key barriers for PwLD accessing cancer screening include: scarcity of information, fear of medical intervention and embarrassment (21), a lack of easily comprehensible invitations, time pressures limiting the length of appointments, a lack of reasonable adjustments (22), and poor awareness of cancer screening prior to invitation (23, 24). There is a reliance on family or paid care workers to take a primary role in promoting healthy lifestyles, ensuring healthy choices (25, 26) and to be aware of cancer signs and symptoms as PwLD may not identify these themselves (27). However, family and paid care workers may not perceive cancer screening for PwLD as important (25, 26) or appropriate (28, 29).

Multiple theoretical models of behaviour change suggest that attitudes are significant including: the theory of reasoned action (29), the theory of planned behaviour (TPB) (30) and the persuasion theory (31). Previous research utilising TPB with PwLD, has examined the intentions of paid care workers to support engagement in physical activity (32) and encourage healthy eating behaviour (33). Both of these studies highlight that attitudes have an influential role in intentions to change behaviour, however this has not yet been established for cancer screening. As attitudes are central to influencing decisions and potential behaviour change, it is vital that attitudes towards cancer screening are understood. Therefore, the aim of this systematic review was to identify and synthesise the best available evidence on the attitudes and perceptions of PwLD, family carers and paid care workers, towards the cervical, breast and colorectal cancer screening programmes in the UK.

## **Methods**

A qualitative systematic review was undertaken using the Joanna Briggs Institute (JBI) approach. This approach was chosen as it offers an internationally recognised, rigorous pathway for systematic reviewing of qualitative research evidence (34). In particular, the JBI approach utilises meta-aggregation which offers a method to obtain usable data, allowing for

A systematic review of attitudes towards cancer screening

easy application to clinical settings enabling clinical improvements (35). The protocol was registered with PROSPERO (CRD42018093967) and no substantive changes have been made. The review is reported in line with PRISMA reporting guidelines (36).

### *Inclusion criteria*

Papers were included if they reported qualitative research about the attitudes, perceptions or beliefs towards cervical, breast, and/or colorectal cancer screening of PwLD, or family carers/paid care workers of PwLD. Mixed methods papers were included if the qualitative element could be isolated, papers employing quantitative methods alone were excluded. Predetermined definitions were used to differentiate each population (table 1). Papers were included if published after 1988 as this was when the first cervical and breast cancer screening programmes were introduced (37), prior to this date screening was not a national agenda (5). Only studies conducted in the UK were included, as the NHS screening programmes are free of charge at the point of delivery, which is not the case in other countries which could alter factors influencing uptake. It is envisaged that due to differences in the way services are organised in other countries it may influence the experiences of cancer screening (38).

### *Search Strategy*

To identify relevant papers, multiple search terms were utilised which related to: attitudes and opinions, cancer, cancer screening programmes, PwLD or Intellectual Disabilities (ID), family carers and paid care workers (supplementary material 2). Both PwLD and intellectual disabilities were included as the terms are used interchangeably depending upon the location of the research. Five electronic databases were searched: MEDLINE, CINAHL, PubMed, Scopus, and PsycInfo. An unpublished grey literature search of MEDNAR and Google Scholar was conducted with the first 100 listed records being retained. To ensure all relevant papers were captured within the search, key indicator papers (KIPs) were identified prior to running the search which should meet the inclusion criteria. Upon retaining the results of the search, the KIPs were identified. This demonstrates that the search was robust (39). The same search terms were used for grey literature, and electronic database searches. The reference list of all included reports and articles were searched. All searches were conducted in April 2018. The five electronic databases were re-searched in February 2019. No language restrictions were applied as all papers would be written in English as this is the main language of the UK.

### *Paper selection*

## A systematic review of attitudes towards cancer screening

References were downloaded into Endnote version X7.01 for storage, duplicate removal and sifting. One reviewer (KB) sifted all titles and abstracts against the inclusion criteria. Two additional reviewers independently sifted 10% each of the titles and abstracts (CO'M, JM). Any discrepancies were discussed between reviewers. Papers which were included following the first sift, had the full paper assessed for eligibility. Attempts were made to obtain all papers through the British Library and contacting authors; one paper was unavailable after these attempts. One reviewer sifted all remaining papers (KB), with two reviewers independently double sifting 50% each (ELG, GJM). There was a 68.75% agreeance rate between reviewers, which presented a fair agreement when converted into Kappa statistics for inter-rater reliability (40). Discrepancies were caused by the country being outside of the UK and unclear categorisation of participants. Discrepancies were discussed between reviewers of the paper until a consensus was reached on all papers.

### *Assessing methodological quality*

All papers that met the inclusion criteria were quality assessed independently by two reviewers (KB, ELG), using the JBI Quality Appraisal Review Instrument (QARI) for qualitative studies (34). Any discrepancies between the two reviewers were resolved through discussion.

### *Assessing data quality*

All extracted findings from the papers were graded on a scale of plausibility, either 'unequivocal', 'credible', or 'unsupported' (41). The grading related to the assessment of the congruency between the finding from the paper and the accompanying illustrative quotes. An 'Unequivocal' finding is one that is supported by at least one illustrative quote and is not open to challenge; 'credible' findings are those where the finding and quote are not so strongly linked and therefore open to challenge; and the 'unsupported' findings are not supported by the quotes (41). No unsupported findings were identified.

### *Data extraction*

Data from the included papers were extracted using a pre-developed Excel data extraction table. This replicated the format of the JBI-SUMARI software (42). The extracted data included information regarding the author(s), year of publication, country, methodology, sample size and participant characteristics (age, gender, location, and demographics), key findings, and main conclusions. One reviewer (KB) undertook data extraction and for quality assurance

A systematic review of attitudes towards cancer screening

purposes, were checked by a second reviewer (CO'M). No discrepancies were identified. All extractions were uploaded to the JBI-SUMARI software for analysis (42).

### *Data synthesis*

Meta-aggregation was used to synthesise the qualitative findings (34). A strength of meta-aggregation is that the study findings from all included qualitative papers can be synthesised, irrespective of the method used to collect the original data. The theme and one quote from the included paper (combined to create illustrations) were used to generate a set of findings. These were categorised by the leader reviewer (KB), based on similarity in meaning (34) to form categories. Subsequently, the categories were grouped into similar themes, and an initial series of statements, known as “synthesised findings” (SF) were devised. Four members of the research team (KB, ELG, GJM, SH) read the synthesis created by the lead reviewer (KB) to reduce interpretation bias and to obtain a consensus of the final SF.

## **Results**

The initial searches yielded 14,747 references. After title and abstract sifting, 22 full papers were assessed, 11 papers based on ten projects were included in the review (24, 43-52) (Figure 1).

### *Study Characteristics*

The characteristics extracted from the 11 papers are presented in supplementary material 3. Four papers reported on cervical cancer screening (43, 45, 46, 52), five reported on breast cancer screening (24, 47-49, 51) and two reported findings on cervical and breast cancer screening (44, 50). No papers reported on colorectal cancer screening. In total, 93 women with a learning disability (WwLD), 81 paid carer workers and three family carers were included as participants (24, 43-52). Two papers (43, 44) failed to detail whether 110 people were family or paid care workers, thus they have not been included in the total participants. The studies were conducted in England (43, 44, 46), Scotland (24, 45, 50-52), and Northern Ireland (47-49). Six papers did not report participant ages (24, 44, 45, 47, 50, 52). In those that did, categories of ages were provided. Ages ranged from 20 to 69 years of age.

### *Critical Appraisal*

The agreement rate between reviewers for the critical appraisal was 87%. The results from

applying the JBI QARI tool is documented in supplementary material 4. No papers were excluded based on the quality assessment. All included papers met criteria 2, 3, 4, 5, 8 and 10. However, the philosophical perspective (criteria 1) was unclear in all papers, as papers did not highlight the philosophical or theoretical premise on which the study was based (34). None of the papers, except Willis (2016), met criteria 6 (locating the researcher culturally or theoretically). The only paper to document the influence of the researcher (criteria 7) was Willis et al. (2015); it was unclear whether Langan et al. (1994) met criteria 7. It was not evidenced in Wood et al. (2007) whether the research had received ethical approval (criteria 9).

### **Meta-aggregation findings**

All findings that directly related to cancer screening were extracted; 59 illustrations were identified. The majority of the extracted findings were rated 'unequivocal' with three being 'credible'. Findings were aggregated into ten sub-categories, then further aggregated into four SF. No papers reported on colorectal screening therefore the SFs concentrate on the experiences of women with a learning disability (WwLD) in relation to cervical and breast cancer screening. Each SF has a supplementary table reflecting the contributing papers, a full list of illustrations and credibility ratings.

### **SF 1: Supporting women with a learning disability to attend screening (Supplementary material 5)**

#### *Making decisions in the best interest of the women*

Family and paid care workers expressed how they tried to balance their decision about supporting cancer screening, and the likelihood of distress against the benefit to the WwLD. Findings highlighted that specific characteristics attributed with the learning disability may result in screening causing distress, for instance "*Some women with autism...tactile defensive issues, the smell, the curtains, the buzzing and the machinery. They just can't cope with it...*" (Paid care worker) (48). There were multiple indications that family/paid care workers were making decisions on behalf of WwLD, with no evidence of previous discussion with them. An example of this is when a WwLD was deemed to require breast cancer screening but "*...there might never be a reason for her to have the cervical smear*" (Family carer) (51).

#### *Creating a positive and encouraging environment for screening*

Cancer screening can be a physically uncomfortable experience. However, by acknowledging



the preferences of WwLD, it could help them to attend screening; *“I wouldn't have a man...”* (WwLD) (43). This includes using appropriate language for the women and mannerisms to help build rapport. The demeanour of the staff was also referenced as important, specifically screening staff should be *“chirpy”* (WwLD) (49), and have a happy and positive nature to make the experience less traumatic. Staff demeanour is important for ensuring trust is developed so the WwLD, *“...feel comfortable about what is going on.”* (WwLD) (45). Additionally, encouragement was another attribute highlighted to help show WwLD that the staff have confidence in the women overcoming their apprehensions to complete screening, and feel supported throughout the process, for example; *“... ‘we can do this’...”* (Paid care worker) (46).

#### *Prior preparation*

There is a need to ensure WwLD know the symptoms of cancer, for example *“check them for lumps.”* (WwLD) (24). Although not part of the screening programmes, this can be beneficial to help understand, demystify and reduce fears around cancer screening. There is also a need to ensure the WwLD are familiar with the screening environment and the equipment used: *“...sit on the couch you know look at the speculum all those kind of things, you know the little brush that actually takes the specimen you know takes the cells away...”* (Paid care worker) (46). This may be a single visit, but may require multiple visits, to ensure the WwLD are prepared and that screening staff implement reasonable adjustments; *“she would need to go several times: first to get to know the nurse or doctor; also the procedures.”* (Family carer) (43).

## **SF 2: Women with learning disabilities awareness of screening, and their psychophysical experiences (Supplementary material 6)**

#### *Women lacking understanding and awareness of screening*

*“I suppose there's a lack of understanding you know about what the procedure is, why you have the procedure and an understanding of cancers [...] and I suppose the ability to understand the consequences of actions”* (Paid care worker) (46). This quote from a paid care worker highlights an assumption that the WwLD do not have the knowledge and understanding of cancer screening, including how important it is and the potential consequences of not attending. This was reflected by other carers who doubted the WwLD's ability to know how to complete breast self-checking or what to look for: *“what she says and what she does are two*

A systematic review of attitudes towards cancer screening

*different things.*” (Family carer) (51). In contrast to this, there were examples where WwLD did have some knowledge of cancer including how it spreads and its potential severity: “...*It’s like a germ in your blood.....you could be very sick with it...*” (WwLD) (49). Some WwLD knew what cancer screening is “...*to check for abnormal cells that could lead to cancer and if they catch it early, it can prevent cancer.*” (WwLD) (45).

The current invitation process for cervical and breast cancer screening is through individual invitation letters, but this requires the ability to read and understand the information within, to make an appointment for screening; “*something comes in the post and they are not able to read, they may not even be aware that they have been invited to breast screening*” (Paid care worker) (47) which suggests that some WwLD may not make an appointment to attend screening or understand the contents of the invitation letter to know they have been invited to screening.

#### *Feelings of anxiety and fear throughout the screening programme*

Women with a Learning Disability did not know what they would experience or what to expect including the pain they could face, or raised anxiety levels. One WwLD believed she would need an injection; indicating a lack of knowledge; “*Does it hurt? How long would it be uncomfortable? Do you have to have an injection?*” (WwLD) (43). This posed a problem during screening as the heightened state of anxiety meant the cervical screening was not completed because the WwLD were too tense.

Fear was also heavily influential in the experience of cancer screening. Family carers and paid care workers stated that the fear of the unknown may be a barrier to screening, by believing the WwLD may think they need their breast removed. Positively, a WwLD explained when she had received screening it was “...*nothing to worry about*” (WwLD) (49).

The screening experience does not end after the person has attended their screening appointment, as there is then a wait for the results. A WwLD recalled:

*“the letter came back and I didn’t know what it was. It just said there is some abnormality and you need to have another test and I was like, why another test? And it must mean that I have cancer!....”* (WwLD) (45).

This quote evidences that this particular WwLD may not have been prepared for what would

A systematic review of attitudes towards cancer screening

happen after screening, especially as the woman believed that the abnormalities definitely meant she had cancer. Furthermore, she did not know the possible reasons why she needed another test.

#### *Experiences of pain during and after screening*

Women with a Learning Disability described experiencing pain during and after cervical and breast cancer screening (24, 43). The pain during screening was attributed to the speculum in cervical screening and the mammography machine in breast screening being cold and applying pressure to the breast.

### **SF 3: Professional practice barriers including the need for multidisciplinary working and an understanding of the needs of women with a learning disability (Supplementary material 7)**

#### *Paid care workers knowledge*

A General Practitioner (GP) stated “*I would like to think that the staff and medical staff would think that these things are worth it rather than not worth it*” (Paid care worker) (47). This highlights that some healthcare professionals may doubt that screening is beneficial or appropriate for WwLD. Family carers reported that some GPs held the misunderstanding that if a WwLD has not been sexually active then cervical screening is not required, due to a lower level of risk. This reflects the limited understanding of the needs of WwLD attributed to a lack of “*experience or skill or confidence*” (Paid care worker) (46). This can impact upon the ability to implement reasonable adjustments or make an informed decision that is suitable for WwLD.

#### *Importance of multidisciplinary working to ensure health of women with a learning disability*

A family carer highlighted that paid care workers potentially have issues with sharing information in the best interest of the women; “*...They went upstairs, and made it clear it’s Holly they were here to see. So if we don’t know, how can we help?*” (Family carer) (50). This suggests that the nurse in this case focused solely on the WwLD and excluded the family carer, who felt they should have been involved in healthcare decisions relating to their relative.

### **SF 4: Approaches to improve the uptake of cervical and breast cancer screening (Supplementary material 8)**

### *The need for educational training provided to everyone*

There was an emphasis on the need for an educational provision given to WwLD themselves, as well as family carers, and paid care workers including GPs and screening staff. There is a responsibility of “... anybody who is physically working with people with an ID” (Paid care worker) (48) to know about cancer and cancer screening. It was not explained how this training should be implemented. Yet, there were three suggestions to aid WwLD to understand screening. Suggestions included a pictorial leaflet given to carers to help explain the need for breast cancer screening: “A leaflet that has pictures on, that I could actually explain along with the pictures of what it entails...” (Paid care worker) (51). In addition to information on “the worst case scenario... Maybe a story of somebody that has had an abnormal result.” (WwLD) (45). As well as a leaflet, methods which do not rely on the women reading were identified “including a DVD... something women focussed using pictures, signs and symbols (Makaton) where necessary” (Paid care worker) (48). An opportunity to discuss cancer screening with someone not related to the WwLD care was also suggested: “I think maybe if there is more people coming in... and talking to women with ID and their carers and explain to them what it’s about and how often they have it done and whatever” (Paid care worker) (48).

### *Having learning disability friendly healthcare*

The screening programmes were not accounting for the WwLD needs due to minimal reasonable adjustments being implemented. For example, it was highlighted that if WwLD are rushed during appointments and are pushed into ‘the one size fits all’ system then WwLD may be less likely to attend screening, thus putting their health at risk; “...if the five minute appointment doesn’t suffice, then that’s you know where people drop through the net” (Paid care worker) (46). This highlights a much wider problem that “there is a need to look at the whole process for a woman with a learning disability...try and see where it could be improved... sort of inter-group discussions...” (Paid care worker) (47). This highlights a need to review the screening programmes from the start of the invitation process to the end of the screening pathway, to ensure that the screening programmes are accessible to WwLD.

## **Discussion**

To our knowledge this is the first systematic review to identify and synthesise qualitative evidence on the attitudes of WwLD, family carers and paid care workers towards the cervical and breast cancer screening programmes in the UK. Eleven papers met the inclusion criteria,

A systematic review of attitudes towards cancer screening

none of which focused on colorectal cancer screening. This could be attributed to the higher uptake rates of colorectal screening as it is less invasive and more acceptable to complete (53), also family and paid care workers can help PwLD collect their samples (54), therefore it may not be seen as an area to focus research.

The consent process may also influence uptake of colorectal screening, as by completing and returning the testing kit, valid consent is demonstrated (55). However, family and paid care workers may complete the kits on behalf of the PwLD who may not have known this has been done. This highlights the need to ensure PwLD are supported to make an informed decision to accept or decline the invitation to colorectal cancer screening, rather than have a decision for them, determined by their ability to access accurate and evidence based information (56).

Maximum accessibility to screening for all women, can be ensured through providing information in the most appropriate method by using easy read information and videos, for example, to maximise understanding (57). This will enable women to make an informed choice about whether to participate or not (57). A key finding from this review is that the cervical and breast cancer screening programmes may be inadvertently excluding WwLD due to having poor health literacy (58), especially as 42% of adults without a learning disability are unable to understand or make use of everyday health information, and are therefore less likely to act upon preventive measures for their health (59). This will require support from family and paid care workers to help WwLD understand the standard screening information sent to all invitees, this can be achieved through providing easy read information, photo stories, or short films (60). However, the level of support required will depend upon the level of learning disability as some WwLD will be able to process and retain a greater level of understanding.

In addition, it is vital that family and paid care workers do not have an unfavourable opinion towards screening. This can influence the WwLD's subjective norms (29) (thinking how a particular behaviour is perceived by others)(61), which may affect the likelihood of WwLD feeling supported to engage in cancer screening (62). All of which supports the need for proactive, person-centred invitations to cancer screening which does not rely on literacy and family or paid care workers, but empower WwLD to make an informed decision on whether to attend cancer screening.

Psychosocial support to help alleviate WwLD anxiety, fear, and pain towards screening is needed. Anxiety was a significant emotion affecting the screening experience which was also associated with anticipated pain. This can greatly affect whether WwLD attend any subsequent

appointments or screening invitations. It also directly relates to Perceived Behavioural Control, within the TPB (30), which proposes that the reflection on previous experiences and anticipated inhibitors of the behaviours will affect whether behaviour change occurs (63). This evidences the importance of having a positive screening experience for all women, not just WwLD. Women without a learning disability have expressed pain (11, 64) fear, discomfort, and anxiety (11) as being a barrier to them attending cervical and breast cancer screening. However, women without a disability are more likely to understand the screening procedure, and potentially use Anticipated Regret (AR) (65) to make an informed decision to attend screening. However, AR argues that someone can anticipate how they will feel and through this, the individual can avoid actually experiencing regret (66). Anticipated Regret has been researched in relation to the TPB (30), to increase intention pre-behaviourally (67) and has shown that women who completed either a TPB questionnaire or TPB combined with AR questionnaire, were significantly more likely to attend cervical screening (67). The AR questions motivate the individual to move from intention to action to avoid the negative feelings of regret (68). However, having a learning disability can make it difficult to understand new or complex information (69) or use complex forward thinking such as AR. Nevertheless, this strengthens the need for WwLD to have adjustments in place, if they wish, to alleviate pain during screening, but be provided with information and support prior to screening to reduce fear and anxiety. This can ensure an informed choice is made.

This review highlights WwLD should be made aware of, and educated on screening in a proactive, multidisciplinary approach involving WwLD, family carers and paid care workers including screening staff and GPs. However, it was highlighted that in some cases a multidisciplinary approach is not adopted by all. It is important that all relevant parties involved with WwLD know about screening and have informed attitudes towards it. Deficits in understanding by GPs, primary health care staff and screening staff, of the needs of PwLD, and the screening inclusion criteria may be a barrier to being fully informed on cervical and breast cancer screening. This could be putting WwLD at further risk. For example, there is a common misconception that the presence of human papillomavirus (HPV), detected by cervical screening, is relevant only to sexually active women, however it should be considered for all women as it can be passed through skin-to-skin contact, not just sexual intercourse (70). This emphasises an inequality, as every eligible woman should be invited and be supported to be screened (if they wish) regardless of their perceived risk (57).

### *Clinical Implications*

People with a Learning Disability need the same opportunities as the general population in accessing healthcare system, including cancer screening. As previously discussed, the findings from the review suggest that the health care of WwLD needs to be proactive and person centred throughout the cancer screening pathway. This can include modifications to the invitation process, to not rely on literacy alone and utilise various communication aids including Makaton (71) or through additional resources such as visual recordings (60). However, there is a need for paid care workers including nursing staff and screening staff, to be confident in implementing reasonable adjustments which could help WwLD attend cervical and breast cancer screening. This will ensure that WwLD are given every opportunity to make an informed decision about whether they attend cancer screening or not. To aid WwLD making an informed decision, carers need to be aware of the needs of PwLD generally, and specifically the needs of WwLD to attend screening. This will aid in the implementation of reasonable adjustments such as providing information in easy read and/or providing multiple appointments to understand the screening procedure. However there is little best practice guidance available to hospital staff to implement adjustments for PwLD (72).

Additionally, PwLD should be informed that further tests may be required when cancer screening is explained. This will ensure that PwLD are informed of the positive and potential negative aspects of screening (73), including over-diagnosis which could lead to unnecessary treatment (73). These factors can help to ensure informed attendance at initial screening, for all three screening programmes, and continued engagement in subsequent screening invitations (74, 75).

Future research should concentrate on involving WwLD, family carers and paid care workers, to account for all three groups' attitudes and opinions together to obtain an in-depth understanding, via qualitative methods. This can provide a holistic approach to identify how to ensure WwLD are supported to make an informed decision on whether they take up, or not, their screening invite for cervical and breast cancer screening. This can highlight any ill-informed attitudes towards screening that could impact upon uptake, and also account for the potential influence of family and paid care workers. Similarly, more research is needed to better understand attitudes towards colorectal screening, as this review identified a lack of evidence. This can aid in identifying potential gender specific barriers to accessing colorectal screening, but also identify the potential issues around PwLD making an informed choice to attend colorectal screening. This will facilitate in understanding the wider perspectives of why PwLD chose to take up, or not, their cancer screening invite. From this, reasonable adjustments can

A systematic review of attitudes towards cancer screening

be proposed and implemented, which do not place the onus on family or paid care workers, and encompass the multidisciplinary nature of healthcare required for PwLD whilst also meeting their needs and preferences.

### *Study Limitations*

A number of limitations need to be considered. This review focussed only on UK populations due to unique screening programmes offered by the UK NHS, therefore, the experiences within the SFs may not be generalisable to other countries. The level of severity of the learning disability was not accounted for in the majority of papers, so the findings of the review may not be generalisable to all WwLD. However, the definitions used within the systematic search were aimed to be all encompassing of PwLD. In addition, the JBI approach of meta-aggregation has been scrutinised, with it being noted that aggregation is not possible (76). However, this review has shown that aggregation is possible and suggestions have been made to improve learning disability practices.

### **Conclusion**

This qualitative systematic review highlights that there are various psychosocial factors which can contribute to WwLD's attitudes towards attending cervical and breast cancer screening. This in conjunction with ill-informed attitudes and a lack of awareness on the need of PwLD and the screening inclusion criteria which may be held by family and paid care workers, could be inhibiting WwLD in taking up cancer screening invitations. This review also highlighted that WwLD may not have the opportunity for additional support to help attend screening, especially relating to the invitation process. It is vital to ensure that healthcare provision accounts for the general need of WwLD, but also specific needs of WwLD to enable them to make an informed choice about attend screening or not.

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Table 1: Population definition

Terms used in the review	Definition
People with a learning disability	Someone who have a significant reduced ability to understand new or complex information, to learn new skills with a reduced ability to cope independently which started before adulthood, with a lasting effect on development (Department of Health, 2001).
Family carers	Referring to parent, family members, neighbour, friends, anyone who does not get paid for caring for people with a learning disability*
Paid care workers	Referring to anyone who is paid for caring for a person with a learning disability such as support workers, learning disability nurses, community nurses and doctors. **

\*Adapted from the Care Act (2014) definition of ‘carer’

\*\* Adapted from the International Labour Office (2018) definition of ‘Paid care work’