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1 **Abstract**

2 **Objectives:** To understand knowledge of, attitudes towards, and decision making around  
 3 cervical and breast cancer screening in women with learning disabilities, family carers and  
 4 paid carers. **Methods:** A Q methodology study involving 13 women with learning disabilities,  
 5 three family carers and five paid care workers, from the North-East of England. A Q-sort, of  
 6 28 statements was completed with all participants completing a post-Q-sort interview to  
 7 understand the reason behind the card placements. Factor analysis was completed using  
 8 PQMethod and interpreted using framework analysis. **Results:** Factor one, named 'Personal  
 9 choice and ownership', explores how women with learning disabilities want to be supported  
 10 to make their own decision to attend cancer screening and explored their preferred support  
 11 needs. Factor two, named 'Protecting vs enablement', portrayed the battle family carers and  
 12 paid care workers felt to protect women with learning disabilities from harm, whilst feeling  
 13 that they were supporting women with learning disabilities to decide to attend cancer  
 14 screening. Eight consensus statements were identified indicating a shared perspective.  
 15 **Conclusions:** Cancer screening services should ensure that women with learning  
 16 disabilities are supported to make informed decisions to attend cancer screening and then  
 17 be further supported throughout the cancer pathway.

## 1 **Introduction**

2 In the United Kingdom (UK), a learning disability can be broadly defined as those who  
3 struggle with learning new skills, understanding complex or new information, and coping  
4 independently (Department of Health, 2001). Having a learning disability can mean that the  
5 individual faces multiple health inequalities which can put the person at risk of disease and  
6 premature death (Emerson & Baines, 2011). There are three screening programmes, in the  
7 UK, aiming to detect the early presence of cancer of the cervix, breast, and colon (Cancer  
8 Research UK, 2018). Statistics published by NHS Digital (shown in supp file 1) show that  
9 cancer screening uptake is vastly different when comparing people with learning disabilities  
10 and those without learning disabilities (NHS Digital, 2020), with the largest difference in  
11 uptake being for cervical and breast cancer screening (NHS Digital, 2020).

12 Research has highlighted multiple barriers to decision-making, and access to cervical and  
13 breast cancer screening by women with learning disabilities (WwLD), including mobility  
14 issues, communication difficulties (Turner, Emerson, & Glover, 2012), fear and being  
15 embarrassed about going to screening (Connolly, 2013), family carer and paid care workers  
16 may lack understanding cancer (Tuffrey-Wijne et al., 2013) and having poor health literacy  
17 (MENCAP, 2019). Even with these known barriers to cancer screening, uptake remains  
18 consistently lower than the general population (NHS Digital, 2020). Even with the  
19 acknowledgement of the range of barriers that WwLD face in deciding to attend, and then  
20 access cervical and/or breast cancer screening, there is a need to identify the most  
21 influential factors that can facilitate or hinder WwLD. Research to date tends to involve  
22 WwLD alone (Truesdale-Kennedy, Taggart, & McIlfatrick, 2011; Willis, Kennedy, & Kilbride,  
23 2008) or their carers (Hanna, Taggart, & Cousins, 2011; McIlfatrick, Taggart, & Truesdale-  
24 Kennedy, 2011; Willis, Kilbride, Horsburgh, & Kennedy, 2015; Wyatt & Talbot, 2013), with  
25 very few accounting for all their perspectives in the same study (Levi, Kimpton, & Sim,  
26 2006). The combined perspectives on factors that influence access can then be utilised to  
27 make recommendation for policy and cancer screening practice to limit the inequalities faced

1 by WwLD. Due to this, this research aimed to further understand the range of knowledge,  
2 attitudes towards, and decision-making around cervical and breast cancer screening in  
3 WwLD, family carers and paid carers.

#### 4 **Methods**

5 Approval to complete a Q methodology study (which is a way of systematically studying a  
6 person's beliefs and attitudes (Brown, 1993; Cross, 2005; Stenner & Rogers, 2004)) was  
7 received from a University, and the Health Research Authority. The following subsections  
8 explain the methods used to employ the Q methodology study.

#### 9 ***Identifying a concourse and developing the Q-set***

10 A concourse consists of the range of possible opinions regarding the topic in question (S.  
11 Brown, 1993), that can be written or spoken about a topic that can be contested and  
12 debated (Smith, Harré, & Van Langenhove, 1995). A concourse is usually identified through  
13 interviews, focus groups (Gubrium, Holstein, Marvasti, & McKinney, 2012), and conducting  
14 literature reviews (Chee et al., 2015). For this study, the results of a systematic review  
15 (Byrnes et al., 2019) were collated with reports and websites. From this, 128 statements  
16 were identified (supp file 2).

17 The concourse is then synthesised to develop a set of statements called a Q-set (Watts &  
18 Stenner, 2012). The Q-set aims to cover the full range of opinions in the concourse (Brown,  
19 1993), and tends to range from 20 to 100 statements (Watts & Stenner, 2005). The Q-set  
20 was developed through thematically clustering the concourse statements together, based on  
21 if they had a similar meaning. All authors (KS, ELG, GJM, HC) were involved in this process.  
22 Based on this, 28 statements were developed (supp file 3). Each Q-set statement started  
23 with "Women with a learning disability...", to provide consistency (Watts & Stenner, 2012),  
24 and allowed the WwLD to think about themselves or other WwLD if they had not attended  
25 cancer screening previously.

## 1           ***Specifying the participants***

2   Participants were identified using purposive sampling of three non-NHS day centre  
3   providers; an NHS Foundation Trust; and a GP practice in the North-East of England.  
4   Gatekeepers in each location initially identified WwLD as meeting a set of inclusion criteria  
5   (supp file 4). One co-author (HC) acted as a gatekeeper for one site and was the only author  
6   who had any involvement in identifying eligible participants. The gatekeepers discussed the  
7   study with the WwLD, using an information sheet (written in an Easy Read format which was  
8   developed through Patient and Public involvement and consultation between KS with HC). If  
9   WwLD were interested in taking part, they were either given the researcher's details or their  
10   contact information was passed onto the researcher (KS). The WwLD were also asked if  
11   they were happy for their family or paid care workers to be contacted to take part. If so, the  
12   WwLD provided their details. Family carers and paid care workers were provided with  
13   information by the researcher (KS) or information was sent to the WwLD to then pass on.  
14   Written informed consent was obtained from all participants.

## 15           ***Administering the Q-sort and analysis***

16   The fourth step was to administer the Q-sort. This is the process where participants rank-  
17   order the Q-set based on their preferences, or feelings towards the Q-set statements (Cross,  
18   2005). The researcher (KS) was present during all data collection activities. To complete the  
19   Q-sort, a specific grid was developed (supp file 5). The grid ranged from -4 (representing  
20   strongly disagree) to +4 (representing strongly agree) with 28 spaces for each Q-set  
21   statement.

22   Participants started by sorting the Q-set into three piles (agree, disagree or neutral/unsure),  
23   each pile was taken in turn, and the cards were sorted onto the Q-grid to indicate the  
24   participant's level of agreement, or disagreement, with the card. The sorting process was  
25   completed under a forced-choice condition, where participants were required to place a  
26   specific number of statements under each column of the Q-grid. This instruction can make

1 the sorting process a more manageable conceptual task, where participants can carefully  
2 consider all statements concerning each other (McKeown & Thomas, 2013). However,  
3 participants could place cards outside the predetermined grid structure, if they strongly felt  
4 that the remaining spaces did not reflect their views. Following the Q-sort, each participant  
5 completed a brief post-Q-sort interview to explain their reasons for the card placement and  
6 to understand their experiences of screening. All Q-sorts were audio recorded and  
7 transcribed by KS.

8 The final step was to analyse the Q-sorts and interpret the output. The Q-sorts were input  
9 onto PQMethod (Schmolck, 2021). The sorts were analysed using Principle Component  
10 Analysis (PCA) with varimax rotation. This maximised the variance and provided the best  
11 mathematical solution or best fit (McKeown & Thomas, 1988). The correlation matrix  
12 generated, is subjected to the varimax rotation to optimise the separation between factors  
13 and clarified the factor structure (Rogers, 1991). A factor array was also produced, which  
14 represents a 'mean' Q-sort of the shared viewpoint of participants, this can then be  
15 interpreted (Watts & Stenner, 2005). Framework analysis was completed so the authors  
16 could interpret the factor arrays. A Microsoft Excel spreadsheet to replicate the polar ends of  
17 the factors (statements under columns +4, +3, -3 and -4). Quotes from the transcript were  
18 identified to understand the reasons behind the card's placement. The researcher (KS)  
19 interpreted the meaning of the factors and discussed the interpretation in detail with co-  
20 authors (ELG, GJM, HC) and two independent Q methodologists for sense checking.

## 21 **Results**

22 A total of 13 WwLD, three family carers and five paid care workers took part (N=21; 20  
23 female, one male). Ages ranged from 20 to 69 (mean = 47.3 years). A two-factor solution  
24 accounting for 46% of the variance and that explained the views of 19 participants was  
25 chosen (Per participant factor loadings shown in supp file 6). Two WwLD did not load  
26 significantly onto either factor and were classed as 'null loaders'. Their views indicate a

1 different and unique viewpoint to others. Factor arrays are presented in Table 1 (depicted in  
 2 supp file 7), with the polar ends of the factors shown in Figure 1. In the results that follow,  
 3 statements will be identified in brackets by (statement number: ranking in factor array).

4 [Insert Table 1]

5 [Insert Figure 1]

### 6 ***Factor 1: Personal choice and ownership***

7 Factor one accounted for 28% of the total variance, with the Q-sorts of 11 WwLD and two  
 8 paid care workers defining this factor. This factor highlights a narrative of personal choice  
 9 and WwLD having ownership over their healthcare decision, including whether to attend  
 10 cervical and breast cancer screening or not. The importance of awareness and knowledge of  
 11 cancer screening was present with participants agreeing that WwLD “need to know the  
 12 symptoms of cancer” (8: +4) with multiple participants strongly agreeing that it was  
 13 important. However, some WwLD did not know the specific symptoms of cervical cancer:  
 14 *“it’s your ovaries or the part down below, the cells and stuff”* (woman with learning disabilities  
 15 3). Whereas, more participants knew about breast cancer: *“lumps in my boobs”* (woman with  
 16 learning disabilities 10), *“and bumps or things”* (woman with learning disabilities 12).

17 Participants felt WwLD still needed to go to cervical cancer screening if they are not or have  
 18 not been sexually active (11: -4). This emphasises that WwLD’s sexual status should not  
 19 hinder their uptake of cervical cancer screening. A paid carer highlighted that WwLD’s  
 20 sexual status should not be used to determine eligibility for screening: *“...you can’t just say*  
 21 *‘you’re not sexually active, you don’t need to go to screening’, because you know there could*  
 22 *be something underlying there that it could pick up”* (paid carer 01). It was also felt that  
 23 WwLD know screening is an important appointment to attend (10: -3); *“it is important to stop*  
 24 *you getting cancer”* (woman with learning disabilities 12). Some indicated how they were  
 25 made aware of its importance as *“it’s been on the News”* (woman with learning disabilities 4),

1 and *“the lady staff say”* (woman with learning disabilities 5). However, there was a  
 2 perception that even though WwLD knew screening was important there were other factors  
 3 that influence uptake; *“they know it is important but they won't go so what is the use”*  
 4 (woman with learning disabilities 5).

5 It was perceived that WwLD are not stopped from going to screening by doctors (5: -3); *“It is*  
 6 *up to us”* (woman with learning disabilities 12). With WwLD being perceived to be “supported  
 7 to make their own decisions about going to screening” (19: +3) and do not “have carers who  
 8 make decisions without speaking to them first” (28: -3) as *“it's up to them if they want to go*  
 9 *or not”* (woman with learning disabilities 4), *“I make my own decisions. I have my mind.*  
 10 *Parent and staff haven't got my mind”* (woman with learning disabilities 12).

11 The need for relaxation, and how this could lead to successful screening, was acknowledged  
 12 as the participants felt that WwLD “are helped to relax during cancer screening” (23: +3):  
 13 *“they [screening staff] talk to you don't they, the people talk to you”* (woman with learning  
 14 disabilities 4). Alongside talking, participants highlighted the importance of a female nurse  
 15 completing the screening (24, +3); *“I would feel more comfortable with a lady nurse, and not*  
 16 *a man”* (woman with learning disabilities 3). However, it should be noted that not everyone  
 17 agreed with this, for instance, one WwLD highlighted she would prefer a man to complete  
 18 the screening as her doctor is male and there was an element of trust.

## 19 **Factor 2: Protecting vs enablement**

20 Factor two accounted for 18% of the total variance, with the Q-sorts of three family carers  
 21 and three paid care workers loading heavily onto this factor. The protectiveness of family  
 22 carers and paid care workers to support WwLD in deciding to attend cancer screening is  
 23 clear. However, this protection goes hand in hand with enablement. Family carers and paid  
 24 care workers discuss multiple methods that can support WwLD. They also highlighted how  
 25 changing or amending their perceptions and beliefs could greatly support WwLD to make an  
 26 informed decision to attend a screening or not.



1 Participants that aligned to this factor, perceived that WwLD need the support of paid care  
2 workers, family carers (3: +3), as well as nurses and doctors (26: +3) to support them in  
3 deciding to attend cervical and breast cancer screening or not. Specifically, WwLDs rely on  
4 them to help and support them in being aware of cancer screening (3: +3). This emphasises  
5 the need for multiple parties to be involved in supporting WwLD, However, a family carer did  
6 highlight how there was a specific reliance on them as a family to support WwLD: *“once that*  
7 *letter comes it's just it's up to us to explain to them”* (family carer 2). It was also noted the  
8 importance of healthcare professionals knowing about how to support and help WwLD:  
9 *“Because it comes up with every aspect of somebody with learning disability’s life. People*  
10 *need to know about the extra help they need... I mean you do have your specialist nurses*  
11 *like [name] but they've even tried in the past doing like little passport books that's supposed*  
12 *to take with them and give to somebody if they've got learning difficulties at the hospital, but*  
13 *they don't have time to look at them because it could be ‘wait there’ and nobody comes.”*  
14 (family carer 3). This quote from a family carer also highlights how reasonable adjustments  
15 may not be effective in supporting WwLD through screening appointments, due to a lack of  
16 additional time in appointments but also lack of staffing. This again then increases the  
17 responsibility of the carers to support the WwLD.

18 There was a perception that WwLD were less likely to know what cervical cancer is (1: -4),  
19 know what breast cancer is (2: -1), or know how to check their breast (13: -3). These were  
20 felt to be reasons that could influence a decision to uptake cancer screening or not: *“I don't*  
21 *think they will know what lady bit cancer is because I just don't think people will talk to them*  
22 *about it at all”* (paid carer 2).

23 There was a consensus that WwLD were unaware of specific aspects of cancer screening  
24 such as symptoms, yet participants highlighted WwLD do need to know what the symptoms  
25 of cancer are: *“think it's something we should all know. We should all know what we're*  
26 *looking for... You know, she might not recognize the symptoms. But I certainly should”*  
27 (family carer 2). However, this carer specifically links the symptoms (and awareness of

1 symptoms) for cervical cancer screening to sexual activity. Carers typically agreed that  
 2 WwLDs do need to go for cervical screening even if they have not had sexual activity (11: -  
 3 3); *“I think everybody should go for it”* (family carer 2).

4 Methods of improving decision making, and experiences during cancer screening included  
 5 ensuring that WwLDs are told about other positive experiences of screening (22: +4); *“if they  
 6 are hearing it from their friends at day centres and things like that. It builds more of a  
 7 confidence”* (paid carer 4), having doctors and nurses that know about the extra help and  
 8 support the WwLD needs (26: +3); *“they've even tried in the past doing like little passport  
 9 books that's supposed to take with them and give to somebody if they've got learning  
 10 difficulties at the hospital, but they don't have time to look at them”* (family carer 3) and  
 11 ensuring that WwLD “are asked about what would make it easier for them to go to cancer  
 12 screening” (15: -2) could help WwLD decide to attend cancer screening or not, and then feel  
 13 supported throughout the screening process.

#### 14 ***Items of consensus across factors one and two***

15 Across both factors, there were eight consensus statements. The consensus statements will  
 16 be identified in brackets by (statement number: ranking in factor one, ranking in factor two).  
 17 All participants perceived that WwLD: “do not attend cancer screening because they are  
 18 scared” (4: +1, +2); “need to know the symptoms of cancer” (8: +4, +3); need to attend  
 19 cervical cancer screening even when they are not sexually active (11: -4, -3); are not “asked  
 20 about what can help them attend cancer screening” (15: -2, -2); “would like a female nurse to  
 21 complete their screening” (24: +3, +1); “find screening painful” (25: +1, +1) and do not “know  
 22 about what will happen in the screening appointment before they go” (21: -1, -1). Participants  
 23 held a neutral perspective to the statement, WwLD “speak to paid carers more than their  
 24 family about their health” (9: 0, 0), indicating that WwLD will speak to either their family or  
 25 paid carers regarding their health.

## 1           **Null loaders**

2   As mentioned previously, two participants (both WwLD) were classed as ‘null loaders’. This  
 3   indicated that they may hold a different perspective to the WwLD, family carers and paid  
 4   care workers who load onto one of the two factors. Due to this difference in perspective, the  
 5   views of both participants were not included in the final factor analysis. Some key differences  
 6   between these two participants perspectives, and that of the other participants were: their  
 7   preference for a male to do the screening, *“Paid carer: you would prefer a man to look at*  
 8   *your lady bits and your boobies? Interviewee: yes”* (woman with learning disabilities 11), not  
 9   needing to go to cervical cancer screening if WwLD are not sexually active, *“Paid carer: do*  
 10   *you think you should go for your lady bits checked? Interviewee: no”* (woman with learning  
 11   disabilities 11), more unsure that WwLD would know what cervical cancer is, *“Interviewee:*  
 12   *some people do it depends on their needs and their learning disability they might not know*  
 13   *about it”* (woman with learning disabilities 2), WwLD not knowing how to check their breast,  
 14   *“Researcher: Ok so do you think most women would know? Interviewee: no”* (woman with  
 15   learning disabilities 2) and not feeling that WwLD are helped to relax during cancer  
 16   screening, *“Paid carer: Did you feel worked up? Interviewee: yeah Researcher: So you didn’t*  
 17   *feel chilled? I: no”* (woman with learning disabilities 2).

## 18           **Discussion**

19   This study aimed to understand the knowledge of, attitudes towards, and decision making  
 20   around cervical and breast cancer screening in WwLD, family carers and paid carers. From  
 21   completing a Q methodology study, two accounts were identified that reflect the attitudes  
 22   and perspectives relating to WwLD accessing cervical and breast cancer screening.

23   Factor one highlighted that WwLD should have ownership over their healthcare decisions,  
 24   including whether to attend cervical and breast cancer screening or not and that this was  
 25   their decision to make. NHS England (2017) explained that there is a need to focus on what  
 26   is important to the person within healthcare services, shifting from *“what is the matter with*

1 *you?’ towards ‘what matters to you?’ “ (pg. 3). Specifically for WwLD, understanding what  
2 matters to them and how they can be supported to make their own decision to access  
3 cancer screening services can aid in the screening services becoming more person-centred  
4 and flexible (based on the needs of the WwLD), as opposed to being a ‘one size fits all’  
5 system (Kaehne, 2018).*

6 This supports research which also identified WwLD are fearful of the mammogram exam and  
7 find breast cancer screening painful (Arana-Chicas et al., 2020) as well as the pain attributed  
8 to the speculum and taking of cells during cervical cancer screening (Broughton & Thomson,  
9 2000). However, other populations of women including women with physical disabilities  
10 (Kilic, Tastan, Guvenc, & Akyuz, 2019) and women of Black African origin (Bamidele, Ali,  
11 Papadopoulos, & Randhawa, 2017), have reported fearing the potential for pain, fear of the  
12 results and fear of cancer. This highlights that fear and pain are factors for women overall,  
13 which may hinder or prevent them from attending cervical and/or breast cancer screening. It  
14 is important to understand the reasons WwLD may experience fear and anxiety, especially  
15 towards cervical cancer screening, which could be due to the invasive nature of the test  
16 (Plourde, Brown, Vigod, & Cobigo, 2018), lack of knowledge of what screening entails, as  
17 well as the impact potential previous sexual violence has had on the individual (McCarthy,  
18 Hunt, & Milne-Skillman, 2017). This specifically reinforces the need for WwLD to attend  
19 cervical cancer screening irrespective of their sexual status. It has been documented  
20 previously that some, including healthcare professionals, may perceive WwLD should only  
21 attend cervical cancer screening if they have had sexual activity (Watts, 2008). However,  
22 WwLD should be supported to make an informed decision to attend cancer screening or not,  
23 and their sexual status should not be considered as an eligibility criterion (Lloyd & Coulson,  
24 2014; Public Health England, 2020).

25 Factor two highlighted the protectiveness of family carers and paid care workers to support  
26 WwLD to decide to attend cancer screening. Research by Willis (2015), highlighted that  
27 family and paid carers found it difficult to explain health problems and different tests that

1 have been completed for the person. If this is the case, supporting WwLD understand  
2 screening, may not be easy for family and paid carers (Willis, 2015). In 2019/20, 104,723  
3 adults with learning disabilities were living in their own homes or with their families in  
4 England (Nuffield Trust, 2021), and for those who do not live at home various family  
5 members are typically involved in their lives and may provide care and support alongside  
6 paid carers (NHS England, 2015), this indicates the reliance and input family and paid carers  
7 could have in supporting WwLD.

### 8 ***Study limitations***

9 Viewpoints may not be generalisable given the small sample (Brown, 2002), and that the  
10 sample were white British. This may mean that the factors reported may not account for  
11 those of WwLD, family carers or paid carers from other cultures. In addition, only one male  
12 took part, therefore the perspectives of males who are in relationships with WwLD or male  
13 carers is missing.

### 14 ***Clinical implications***

15 For WwLD to make an informed decision, and then be supported to access cervical and  
16 breast cancer screening, reasonable adjustments should be identified and implemented  
17 throughout the cancer screening pathway. Proactively identifying the needs of WwLD before  
18 the invitation to attend cervical and breast cancer screening, can help implement  
19 adjustments based on the WwLD needs. However, this requires WwLD to be 'flagged' as  
20 having learning disabilities to the screening programmes so adjustments can be made. For  
21 instance, offering a desensitisation appointment so the WwLD is familiar with the  
22 environment and equipment. Similarly, support for family carers and paid carers to ensure  
23 their perspectives are informed by evidence, rather than personal thoughts, so they can  
24 support WwLD before they are invited to screening.

### 25 ***Conclusions***

26 The findings from this study highlight multiple factors that may influence decision-making

1 and subsequent uptake of WwLDs to cervical and breast cancer screening. This included  
 2 using easy-read documentation throughout the screening process and inviting WwLD to  
 3 attend cancer screening, ensuring WwLD know the symptoms of cancer and ensuring carers  
 4 are informed and supportive of WwLDs decisions. Specific clinical implications have been  
 5 identified, including offering reasonable adjustments throughout the cancer screening  
 6 pathway from invitation through to receiving the results.

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