

## **Exploring the Impact of Mental Capacity on Breast Screening for Women with Intellectual Disabilities**

### **Abstract**

This study explores the impact of mental capacity in relation to breast screening for women with intellectual disabilities (ID) in the UK. Participation in breast screening is considerably lower for women with ID compared to the general population. Barriers to screening include poor mobility and behavioural difficulties. There is currently no research which primarily explores the relationship between mental capacity and breast screening for this group of individuals. This paper presents the results of a cross sectional survey of 131 women with ID supported by eight Social Care Providers within England and Wales. The data was collected between January 2017 and July 2017. The current research explores the decision-making process surrounding breast screening, considering the impact of associated risk factors during this process. Participants completed a specifically created survey addressing the aforementioned issues. The results indicated that women who lacked capacity, were less likely to engage in breast screening. It was also demonstrated that the process outlined in the Mental Capacity Act (MCA) (2005) was not always followed; women were not routinely assessed if there were doubts regarding their decision-making ability around breast screening and best interest meetings (BIM) were not always held if the person lacked capacity. In order to be able to generalise the current findings, further research is needed to gain a broader understanding of how professionals make decisions surrounding breast screening for women with ID if the individuals are unable to decide this independently.

*Keywords: Intellectual disability, learning disabilities, screening, breast cancer, decision making, health and social care*

What is already known about this topic

- Women with ID are less likely to engage in breast screening than the general population.
- Women with ID who have more complex needs, mobility issues or do not use speech to communicate are even less likely to engage in breast screening.
- Women with ID typically display two risk factors associated with developing breast cancer: obesity and living a sedentary lifestyle.

## What this paper adds

- The principals of the MCA are not being routinely followed in relation to breast screening
- Women with ID who lack capacity are less likely to engage in breast screening
- There is considerable variation regarding who participates in best interest decisions regarding breast screening and who makes the final decision regarding screening participation

## Background

Breast cancer is the seventh leading cause of death among British women (Office for National Statistics, 2015), with 11,433 deaths resulting from the disease in 2016; from which 27% were considered preventable (Cancer Research UK, 2016). The UK has a free national screening program to assist with the early detection of breast cancer, available to all women between the ages of 50 and 70 who are registered with a doctor (GP). Medical advances have led to an increase in life expectancy for people with ID (Tuffrey-Wijne *et al.* 2007), who are now typically living to an age where they are at an increased risk of developing breast cancer and therefore should be accessing screening services (Willis *et al.* 2008). Women with ID are less likely to access breast screening than the general population. This has been demonstrated in Britain (Osborn *et al.* 2012; Glover *et al.* 2014), Ireland (Reidy *et al.* 2014), Canada (Cobigo *et al.* 2013) and Australia (Sullivan *et al.* 2003). However, no definitive statistic exists depicting the number of women with ID who have developed breast cancer in Britain (Willis *et al.* 2008).

In the UK, 37% of women with ID access breast screening (Glover *et al.* 2014) compared to 71% of the total population (Institute for Public Policy Research, 2018). This is marginally higher compared to screening rates in Australia of 34% (Sullivan *et al.* 2003). However, screening rates are higher in Canada at 42% (Cobigo *et al.* 2013) and 53% in the USA (Wilkinson *et al.* 2011). Barriers to breast screening which relate to the woman's disability are frequently cited within the literature. Individuals with higher support needs, physical difficulties (Taggart *et al.* 2010) and poor communication are associated with lower rates of screening (Horner-Johnson *et al.* 2013). Family carers and support staff reported discrimination from medical staff towards women with ID surrounding breast screening, especially in cases of severe ID (Willis *et al.*, 2015). However, there are also reports of family members who requested that their relative did not engage in breast screening due to the complex decisions which could result from a possible cancer diagnosis (Greenwood *et al.* 2014).

Some women with ID report feeling too scared, embarrassed and anxious to participate in breast screening (Taggart *et al.* 2010; Truesdale-Kennedy *et al.* 2010). Those who were unprepared or did not understand its purpose had the poorest experiences (Wilkinson *et al.* 2011). The lack of accessible information was reported to be a barrier to screening (Taggart *et al.* 2010; Truesdale-Kennedy *et al.* 2010) along with poor support or a lack of importance afforded to screening by members of staff (Taggart *et al.* 2010). Reasonable adjustments, such as 'easy read' information (Taggart *et al.* 2010), longer appointment times and having support from a trusted staff/ family member (Greenwood *et al.* 2014), was shown to assist in facilitating screening for women with ID.

Several risk factors have been associated with contracting breast cancer; such as a pre-existing family history of the disease (McPherson *et al.* 2000), alcohol consumption (Shield *et al.* 2016), use of tobacco (Parkin, 2011), high fat diet (Blackburn *et al.* 2004), a sedentary lifestyle and obesity (McTiernan, 2003). Many of these risk factors are associated with having an ID which could potentially place women with ID at an increased risk of contracting the disease. People with ID experience higher levels of obesity, with fewer than 10% of individuals residing in supported accommodation, eating a balanced diet, and less than 20% meeting the UK government guidance level for physical activity (Emerson *et al.* 2012). A French study also showed that women with ID who developed breast cancer were twice as likely to be obese than those who had not contracted the disease (Trétarre *et al.* 2017). However, fewer people with ID smoke or drink alcohol than the general population (Emerson *et al.* 2012). Even though support staff are the main facilitators for many women with ID towards leading healthy lifestyles, a survey study indicated that few members of staff received training in cancer prevention and substantial gaps were identified in their knowledge of the risk factors and symptoms associated with breast cancer (Hanna *et al.* 2011).

In the UK, breast screening is widely considered as positive and remains largely uncriticised; however, there are still some associated risks, such as a possible false positive result and subsequent unnecessary treatment (Hersch *et al.* 2011). In 2010, a screening leaflet produced by the NHS for the general population was criticised for failing to highlight the risks of breast screening to enable women to make an informed decision (Mayor, 2010). Whelehan *et al.*'s (2015) study emphasised how Mammographers encounter individuals who present for breast screening under coercion and referred to cases where it was difficult to establish informed consent. However, it was unclear if any participants in this study had ID. In 2005, the MCA enshrined in UK law an individual's right to make decisions over their care

and treatment. It states that If a person (“D”) does an act in connection with the care or treatment of another person (“P”), the act is one to which this section applies if—

- before doing the act, D takes reasonable steps to establish whether P lacks capacity in relation to the matter in question, and
- when doing the act, D reasonably believes—
  - (i) that P lacks capacity in relation to the matter, and
  - (ii) that it will be in P’s best interests for the act to be done

(MCA, 2005, p.4)

The first principle of the MCA is a presumption of capacity. Only if this is in doubt should capacity be assessed. If a person is found to lack capacity after all reasonable steps have been taken to facilitate their understanding, should a best interest decision be made on their behalf. NHS guidance on consent to treatment also states that assessing capacity should be done by “an appropriately trained and experienced health professional who is either recommending the treatment or investigation or is involved in carrying it out” (NHS, 2016).

Research indicates that some health and social care professionals working with people with learning disabilities experience difficulties when applying the MCA principles in practice. Willner et al (2012) reported that even after receiving training, professionals still showed limited knowledge on the subject. They also identified that some (predominantly senior) care staff experienced issues surrounding the capacity assessment itself, in terms of understanding when one is required, determining who is responsible for conducting it and the actual process. Willner et al (2012) argued that decision-making process was followed most effectively in relation to large decisions. However, it is unknown if staff would consider undertaking breast screening as a ‘large’ decision, which could determine how rigorously the process is followed. Ratcliff and Chapman (2016) highlighted several challenges around the issue of capacity assessment, which impact on community learning disability teams. A lack of time and resources were the main challenges highlighted, as assessments need sufficient planning and good information gathering. Additional challenges centred on working with staff and families who have a poor understanding of capacity. Ratcliff and Chapman (2016) acknowledged that specific characteristics of the individual can also pose challenges especially if their capacity is considered to be ‘borderline’ or if the individual is overtly influenced by external factors, including support staff. In such cases, there can be indecision or confusion over who is responsible to make the ‘decision’ for the individual. In best interest decisions this issue is reduced with joint decision making (Willner et al, 2011; Willner et al, 2012; Ratcliff and Chapman, 2016).

NHS guidance for breast screening and capacity states that lack of capacity to consent should not result in an automatic removal from the screening register. 'If an individual permanently lacks the mental capacity to consent to screening, a decision may be made on his or her behalf in that person's best interests' (NHS, 2009, p.13). A review of the UK literature from 2000 - 2016 identified 26 articles which focused on breast screening and women with ID; however, no research primarily explored the possible impact of capacity on breast screening. Only two articles discussed capacity to consent in their findings. Mcilfatick *et al.* (2011) interviewed NHS staff looking at the barriers to breast screening for women with ID and consent was considered a barrier. In particular, who provides the consent and the necessity for the process to be followed correctly was discussed. However, this point was not expanded upon. Willis *et al's* (2015) study on paid and family carers' views, on supporting women with ID through breast screening, included one reference to capacity, where a staff member stated that they would get support from the Community Learning Disability Team if they felt a person lacked capacity for screening. It was unclear from the study how many participants shared this view. There is no data available which identifies whether women with ID who lack the capacity to consent participate in breast screening, how the decision-making process is undertaken, what information is considered and who typically makes the final decision.

The main aims of the proposed research are:

- To explore the impact of capacity in relation to breast screening for women with ID.
- To identify the percentage of women with ID that undergo breast screening and also identify the percentage that undergo the procedure but also lack capacity.
- To explore the decision-making process including who is involved and who makes the final decision.
- To examine the decision regarding screening for women who lack capacity in relation to the associated risk factors of developing the disease (e.g. smoking) or factors associated with low screening uptake (e.g. having high support needs).

## Method

### Participants

Participants were recruited via eight charity organisations that provide social care to adults with ID in England and Wales. Adverts were placed in online social care newsletters and organisations contacted the researchers directly to express their interest. No organisation who contacted the researchers was excluded from participating. All organisations that responded, excluding one in Kent, were national charities. The study included two groups of participants; women with ID and proxy informants, who were staff members that supported

women with ID who lacked capacity to take part in the research. Therefore, the proxy informants filled in the questionnaire on their behalf. Women with ID who had the capacity to complete a questionnaire were given an accessible version. However, this contained words, so it was advised that participants who were unable to read could dictate their answers to a person of their choosing. If the women with ID lacked capacity to complete the questionnaire, a support worker who knew them well could complete this on their behalf. For women with ID, the inclusion criteria included being aged between 50 to 70 years and having an ID. The exclusion criteria included being over 70 or under 50 years old as only women in this age range are invited for breast screening. Males were excluded from the current study as only females are invited to breast screening. For the support staff, the sole inclusion criteria was that they supported a woman with ID aged between 50 to 70 years who was unable to complete the questionnaire themselves.

### Survey Design

As no previously validated questionnaire that captured data surrounding breast screening and the decision-making process was available, two questionnaires were designed by the authors: an easy-read version for the women with ID and a staff questionnaire. Both questionnaires were anonymous and were partially informed by the findings of McIlpatrick *et al.* (2011) and Willis *et al.* (2015), exploring in more depth the possible impact of capacity and the decision making process regarding screening. The questionnaires contained questions focussing on the risk factors associated with breast cancer which were identified in the research literature. A group of women with ID, who did not participate in the research, provided feedback on its design and content. Both questionnaires were available online and as a paper version. Surveys predominantly consisted of tick boxes, with some sections of narrative text and took an estimated 10-15 minutes to complete. No incentives were offered to participants for completion of the survey. The key survey areas included:

- Risk factors associated with breast screening including BMI, family history of breast cancer, alcohol consumption, smoking and level of physical activity.
- Barriers to screening such as limited mobility or lack of verbal speech.
- Participation in breast screening – reasons why it may not have taken place.
- Capacity to engage in breast screening and if they lacked capacity who was involved in determining this (e.g. family, staff, GP).
- Best Interest Meeting (BIM) - who took part (e.g. family, staff, GP) if this was required, how was it held, what information was used, who made the decision, what was the decision and reasoning behind it.

Almost all questions included in the staff version questionnaire were also included on the easy read version but with simpler language and pictures. Women with ID were not asked if they had a capacity assessment, but were asked if they were able to decide themselves whether to be screened or if they needed help with this; and if the latter was the case, who helped them. If they had not been screened, they were asked to state why.

#### Data Collection

The data was collected as the first phase of an exploratory study between January 2017 and July 2017. A national cross-sectional survey was conducted. Organisations were responsible for identifying and recruiting appropriate participants. The study information (i.e. participant information leaflets, what participation would entail etc.) was sent to a member of the senior management team within each organisation. For the online survey, the management team distributed a hyperlink to the web-based electronic version of the survey using *Qualtrics*® online survey software. The management team disseminated, collected and returned the paper versions by mail to the researchers. As the survey was anonymous, it was unknown to the researchers how many individuals received copies of the research information/ survey and what percentage of potential participants went on to take part in the study. It was unknown to the researchers where the questionnaires had been distributed once they were sent to the organisation's head office.

#### Data Analysis

Descriptive statistics were used to describe the sample of women with ID and the impact of mental capacity on breast screening. Chi Squared Tests ( $\chi^2$ ) were conducted to test for relationships between different categorical variables relating to breast screening and mental capacity. A significance level of 0.05 was adopted for all Chi Squared tests and data was analysed using IBM SPSS 24. As there is no previous information available in relation to the primary outcome measure employed, a more generic approach was used to determine effect size. According to Clark- Carter (1997), to obtain a medium effect size ( $d=0.50$ ) in a Chi Squared test with  $df=1$ , power at 0.99 and alpha at 0.05, 75 participants would be needed. With a total of 131 participants, it can be argued that the current study has comfortably sufficient number to detect effects of medium effect size.

#### Ethical Considerations

Questionnaires were anonymous and a formal consent process would have breached anonymity. Completion of the questionnaire was taken to imply the respondent's consent. Women with ID who completed their own questionnaires were unable to return them independently, as organisations had to check them to ensure they remained anonymous to researchers. No consent is lawfully required to involve participants if the research is

considered 'non-intrusive' in that it has been "anonymised and cannot be traced back to individuals" (Department for Constitutional Affairs, 2005, p.205), as a result family members were not consulted. The data collected by the survey was predominantly descriptive. Ethical approval was obtained from The University of Kent's Research Ethics Committee.

## Results

### **Participants**

The sample comprised of 131 women with ID, 42% were able to complete their own questionnaire and 58% required a staff member to complete this on their behalf. The mean age of participants was 58.3 years old (age range was 50 to 70 years old). 61% of the women with ID had mobility issues, ranging from a slight limp to being unable to weight bear. 42% of the women with ID used no (or limited) verbal communication.

### **Invitation to screening**

All British women aged between 50-70 years old are entitled and invited to participate in breast screening. The results reflected this, with only 7% of participants not receiving an invitation for breast screening. Only two women were removed from the screening register, the justification for removal noted was 'osteoporosis combined with postural complications' and 'lack of capacity and a dislike of intrusive body contact'.

### **Assessing Capacity**

The MCA (2005) states that there should always be an assumption that the person has capacity to make the decision in question (to take part in breast screening). Under the MCA, practitioners are required to assess capacity before carrying out any care or treatment. If there are concerns about a woman's ability to consent, a two-stage functional test of capacity should be completed to assess if the person can make the decision. Approximately half of women (49.6%) had capacity to consent to breast screening. The results indicate that not all organisations were assessing capacity regarding breast screening, in line with the MCA process, as 10% (n=6) of participants who possibly lacked capacity had not received a two-stage functional test of capacity. Capacity was unknown for 2.4% (n=3) of participants which is concerning, suggesting that staff had not conducted an assessment if they had concerns regarding capacity and possibly did not consider this to be important in relation to participation in breast screening. Where capacity was being assessed, those involved in deciding if the women lacked capacity, varied substantially (see Table 1). Support staff and GPs were most likely to be involved in the decision-making process. The Act also states that if a person is assessed to lack capacity to make a decision, any action taken, or any decision made for, or on behalf of that person, must be made in his or her best interests. According to the results, 28% of women who lacked capacity did not have a BIM (n=22). Individuals who



were involved in the decision-making process regarding breast screening at BIMs mirrored that of capacity assessments, with a slight increase in the percentage of support staff and mammographers included. However, women with ID were routinely excluded from the decision-making process.

### **Decision Makers**

The results indicate that 32% (n=6) of best interest decisions regarding breast screening were made by groups or individuals from an exclusively non-medical background such as social workers, staff or family members. Mammographers were rarely included in BIMs and there was only one instance of them being involved in making the final decision. Most BIMs took place via face to face discussions (61%), however some took place by conference call (16%) and via email (23%). Therefore, almost a quarter of professionals conducted BIMs in a format which almost definitely would exclude women with ID from participating (or even being present), which contradicts a key principle of the MCA of involving the individual as much as possible.

[Insert Table 1 here]

### **Risk Factors**

47% of the participants displayed two or more risk factors associated with developing breast cancer; including being overweight with a BMI over 25 (n=71) and living a sedentary lifestyle (n=83). A chi-square test was performed and a significant relationship was found between participation in breast screening and displaying two or more risk factors associated with contracting breast cancer,  $\chi^2 = 3.93$ ,  $df=1$ ,  $n= 131$ ,  $p = .047 < 0.05$ . Women who displayed two or more risk factors associated with the disease were more likely to have attended breast screening. However, when asked what information was utilised to inform the best interest decision surrounding breast screening, lifestyle was only considered by the decision makers in 4% (n=2) of cases, despite evidence directly linking lifestyle factors to the development of breast cancer. Risk was only considered by the decision makers in 2% (n=1) of cases; however, it was unclear if the 'risks' were those associated with the person or associated with breast screening (such as false positive results).

### **Potential barriers to breast screening**

Decisions made following a BIM around breast screening were divided, 49% (n=16) of the decision makers decided not to proceed with the screening, 42% (n=14) decided in favour of breast screening and the final decision was unknown in 8% of cases (n=3). The reasons

behind the decision not to screen a women with ID are shown in Figure 1, with the most common reason being the decision makers “felt that the procedure would be too disctressing”.

[Insert Figure 1 here]

49.2% of women with ID (n=62) lacked capacity for breast screening, however only 61.5% (n=48) had a BIM. For the 62 women who lacked capacity, it was decided by health professionals and/or social care staff, either via a BIM or not, that 27 women would participate in breast screening. Of the 62 women, 12 were sucessfully screened and 15 attempted screening but were unsuccessfull for completing the procedure. The results did not include information on who made the decision to abort 15 unsuccessfull screening attempts, making it unclear if this was the health or social care professional or if the women herself refused to cooperate in the procedure. A chi-square test was performed and a significant relationship was identified between lack of capacity to consent and non-participation in breast screening,  $\chi^2 = 5.08$ ,  $df = 1$ ,  $n = 131$ ,  $p = .024 < 0.05$ . Less than half of the participants who lacked capacity had attempted to engage in breast screening.

[Insert Table 2 here]

Participation in breast screening was also examined in relation to women who did not use speech to communicate. A chi-square test was performed and a significant relationship was identified between not being able to verbally communicate and non-participation in breast screening,  $\chi^2 = 8.07$ ,  $df = 1$ ,  $n = 131$ ,  $p = .004 < 0.05$ . Even though mobility was cited as a reason for not attempting breast screening, a chi-square test demonstrated no evidence of a relationship between poor mobility and non-participation in breast screening,  $\chi^2 = 1.05$ ,  $df = 1$ ,  $n = 131$ ,  $p = .304 > 0.05$ .

## Discussion

The current research offers some useful insights into the impact of mental capacity on participation in breast screening for women with ID and provides a starting point for discussions surrounding the impact of mental capacity on screening and its implications for practice.

This study provides evidence to suggest that lack of mental capacity is a barrier to accessing breast screening among women with ID, supporting Mcilfatick *et al's* (2011) study who suggested that GPs considered “lack of consent” to be a barrier to breast screening. Mcilfatick *et al.* (2011) attributed the barriers to confusion regarding who provides the

consent and the necessity for the process to be followed correctly. This study raised a few concerns as not all professionals were following the processes outlined in the MCA (2005) surrounding breast screening. There were various instances of two-stage functional tests of capacity not being completed when concerns existed regarding a person's decision-making ability and best interests meeting did not happen routinely if a person lacked capacity to decide to engage in breast screening. Women with ID are typically invited to participate in breast screening via letter, therefore the decision-making process typically begins with the social care staff, which could be problematic considering Willner et al (2012) concerns regarding the capability of residential care staff to apply the principles outlined in the MCA. Unfortunately, without discussing this with the support staff, it was not possible to ascertain the reasons as to why such processes were not followed consistently.

Marshall and Sprung's (2017) systematic review concluded that the MCA is not sufficiently embedded within practice. This was attributed to a lack of knowledge, awareness and understanding, especially regarding how to conduct mental capacity assessments (Heslop *et al.* 2014; Marshall and Sprung, 2016). Willner *et al.* (2011) argued that despite training, gaps persist in knowledge amongst health and social care professionals. It was possible that many of the staff supporting the women in this study did not understand the formal requirements of the MCA and that capacity to engage in breast screening needed to be assessed. Dunn *et al.*'s (2010) results support this by identifying that in practice there was a 'clear disjuncture between this formalised, detached and procedural approach to the regulation of substitute decision-making under the MCA, and support workers' accounts of making substitute decisions' (Dunn *et al.* 2010, p. 155). The most commonly stated reason as to why women in the current study had not been screened was that it would be too distressing, but as only 10% of best interests meetings involved the woman herself in the decision making process, this was typically a judgement made by professionals on her behalf. A possible explanation for the observed findings might be the lack of resources; also highlighted by Ratcliff and Chapman (2016). Time constraints and lack of appropriately trained staff might be one of the reasons women with ID were not involved in the decision-making process. Dunn *et al.* (2010) also claimed that support staff made best interests decisions by drawing on their own values and life experiences, a negative view of breast screening could possibly impact their decision making. The MCA states that the person should be involved wherever possible in best interest decisions. However, the results indicate that just 10% of women with ID were involved in this, as not all methods were inclusive to women with ID such as conducting meetings by conference call or emails.

The results highlighted how a lack of verbal communication was a barrier to participation in breast screening. This resonates with the results of Wilkinson *et al.* (2011) and Horner-

Johnson *et al.* (2013), who found that women with higher support needs are frequently excluded from breast screening. Due to limitations regarding the method used, it was not possible to know how/ if staff had attempted to involve women who do not use speech in the decision-making process. Jingree (2014) argued that when making decisions for people with ID, support staff favoured repertoires relating to normalisation (making choices based on what is socially acceptable) or around their duty of care. Participation in breast screening is 'normal' in the UK and if staff are making decisions based on normalisation and duty of care (early detection of cancer) it would be expected that they would favour breast screening. Arguably, 29% of UK women do not attend breast screening (IPPR, 2018) which perhaps impacts on whether they advocate this to the women they support.

The results highlighted the different combinations of professionals involved in the decision-making process surrounding breast screening. This reflected Mcilfatick *et al's* (2011) concerns regarding confusion over who provides the consent, if the woman is unable to. Support staff in Willis *et al's* (2015) study reported that they would contact their Community Learning Disability Team if they felt a person lacked capacity for screening. What was unclear was who in this team they would request support from, as the "team" can involve community nurses and social workers. In terms of assessing capacity, as opposed to making a best interest decision, arguably this may be best undertaken by those who know the woman well and can best communicate information in a way she understands, such as a support worker or social worker. However, within the MCA, the 'decision maker' should be the person best placed to make the decision, who is responsible for the action being considered. As breast screening is a medical process, this would suggest that a GP, nurse or mammographer might be best placed to make such decision. In this study, 37% of all decisions were made without the involvement of any medical professionals. A degree of professional role conflict has been identified among health and social care practitioners regarding who is best placed to the conduct assessments and who has the availability, as resources are often stretched (Ratcliff and Chapman 2016). This indicates that the process of assessing capacity varies substantially, with no standardised format for assessment in terms of who leads the process.

A limitation to the current study was the sample size as this was smaller than anticipated; despite recruiting eight social care organisations, participation was challenging. As the survey was anonymous it was not possible to follow up with organisations regarding non-responders. Due to the study being unfunded, it was not within our means to be able to travel to organisations to discuss the project with staff directly or to pay participants for their time, which may have increased uptake. However, as this was the first stage of an

exploratory study to determine if there was a relationship between mental capacity and breast screening participation, the sample was sufficient to suggest there was a relationship and identified the professionals involved in the decision-making process. The second phase of the research will be to conduct interviews with decision makers, including women with ID, to gain further insight into the assessing capacity/ best interests' process, how decisions are reached and what information is used.

## Conclusion

Women with ID who lack mental capacity and do not use speech to communicate are frequently not participating in breast screening, despite many displaying risks associated with developing breast cancer. The results suggest a lack of consistency among health and social care professionals regarding who assesses capacity or if this even takes place. There needs to be greater consistency among health and social care professionals in this area. This will ensure support staff are not left to make such an important decision without the appropriate support. The study illustrates the need to increase awareness among support staff regarding the importance of breast screening as they are often the first ones involved when appointment letters arrive. Further training is required to also ensure a full understanding of the decision-making process.

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## List of Tables

Table 1: Individuals who were involved in the decision making process at capacity assessments and best interests meetings regarding breast screening

Role	Capacity Assessment	Best Interests Meeting
Support Staff	23% (n=39)	25% (n=37)
GP	21%(n=37)	19%(n=28)
Social Worker	15%(n=26)	14%(n=21)
Family	12%(n=21)	14%(n=21)
Women with ID	10%(n=16)	10%(n=16)
Practice Nurse	10%(n=17)	6%(n=10)
Mammographer	2%(n=4)	7%(n=9)
Psychologist	7%(n=11)	5%(n=7)

Table 2: Mammograms and Capacity

	Screened	Not Screened	Attempted	Not invited
Women with ID who have capacity	73.3% (n=44)	20.0% (n=12)	5.0% (n=3)	1.7% (n=1)
Women with ID who lacked capacity	20.0% (n=12)	48.3% (n=29)	25.0% (n=15)	6.7% (n=4)
Cases where capacity was unknown	0%	75% (n=3)	0%	25% (n=1)

Missing data regarding screening or capacity (n=7)

List of Figures

Figure 1- Reasons for Non-Engagement in Breast Screening

