

**Breast cancer information and support needs for women with intellectual disabilities : a scoping study**

COLLINS, Karen <<http://orcid.org/0000-0002-4317-142X>>, MCCLIMENS, Alex <<http://orcid.org/0000-0003-2859-910X>>, MEKONNEN, Stella and WYLD, Lynda

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**Submission to Psycho-Oncology**

**Full title:** Breast Cancer Information and Support Needs for Women with Intellectual Disabilities: A Scoping Study

**Short title:** Breast Cancer Support Needs for Women with Intellectual Disabilities

**Authors:**

Karen Collins-Reader in Health Care Research<sup>1</sup>

Alex McClimens-Senior Research Fellow<sup>1</sup>

Stella Mekonnen- Community Development and Health Improvement Practitioner<sup>1</sup>

Lynda Wyld-Senior Lecturer in Surgical Oncology and Honorary Consultant Surgeon<sup>2</sup>

**Affiliations**

1.Centre for Health and Social Care Research, Faculty of Health and Wellbeing, 32 Collegiate Crescent, Sheffield Hallam University, Sheffield, S10 2BP

2. Academic Unit of Surgical Oncology, University of Sheffield Medical School, E Floor, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2RX

**Correspondence to:** Dr Karen Collins (k.collins@shu.ac.uk)

Centre for Health and Social Care Research,  
Faculty of Health and Wellbeing,  
32 Collegiate Crescent,  
Sheffield Hallam University,  
Sheffield,  
UK.  
S10 2BP

Tel: 0114 2255732

Fax: 0114 2254377

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**Abstract**

**Objective:** To examine the compass and nature of relevant research and identify gaps in the current evidence in order to determine the priority of future research about breast cancer and ID.

**Methods:** A scoping study which comprised of a consultation exercise with a wide range of key stakeholders (n= 26) from one Northern City (Sheffield) within the UK.

**Results:** This study identified numerous gaps in the current evidence base. It highlighted a dearth of research that focuses specifically on the information and support needs of women with IDs (and their carers) across the breast cancer patient pathway. Within the interviews, whilst 'reasonable adjustments' were being made and there was evidence of good practice, they were neither strategic nor systematic. Participants suggested that future research should focus on devising protocols to advise on the legal, ethical and clinical imperatives so that clinical governance in this area is assured.

**Conclusions:** There remains a dearth of research or practice guidelines at every stage of the breast cancer care pathway for women with ID. This may arguably lead to late diagnosis, sub optimal treatment and management and overall survival rates for this group. Further research is needed to understand the specific information and support needs of both women with ID (and their formal and informal carers) through the breast care pathway and to identify appropriate protocols, strategies and interventions in order to address these.

**244 words**

**Keywords:** oncology, cancer, breast, intellectual disability, information.

## Introduction

There are approximately 1.6 million people living with an intellectual disability (ID) in England [1] with the incidence of cancer now rising to levels comparable with that of the general population [2, 3] and the health care needs of people with ID is a key priority for the UK Government [2-9]. The life expectancy of people with ID has increased significantly in recent years [1,2], with a mean life expectancy now being estimated to be 74, 67 and 58 for those with mild, moderate and severe ID respectively [10]. The World Health Organization uses intelligence quotient (IQ), social functioning and age of onset to determine ID with the IQ element being the conventional cut-off score of 70. Below this score there are four classifications of ID: mild (50–69), moderate (36–49), severe (21–34) and profound (20 or lower). However, in a primary care setting IQ score is not always readily available, making these distinctions more difficult to apply in practice [11].

People with ID are 2.5 times more likely to have complex health needs when compared to the rest of the population [12]. Communication difficulties and reduced health literacy also limit effective communication skills and reduce the capacity of people with IDs to convey health needs to others [13]. Deficiencies in access to and the quality of health care provision are other examples of health inequalities experienced by people with IDs. These include physical and informational barriers to access, inexperienced or discriminatory healthcare staff; failure of health care providers to make 'reasonable adjustments' and 'diagnostic overshadowing' (e.g. symptoms being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's IDs) [13-15]. A recent UK confidential inquiry into the premature deaths of people with IDs [16] concluded that the quality and effectiveness of health and social care given to people with IDs is deficient with 'many professionals are either not aware of, or do not include in their usual practice, approaches that adapt services to meet the needs of people with IDs...and there was considerable evidence of fragmented care ' [16:5]. Other measures taken in response to the inquiry's report included 'reasonable adjustments' to general health services primary care trusts (PCTs) [9, 17]. Mencap in their report 'Death by Indifference' [18] argued that the systemic failure of health care organisations to adjust their practices to take account of the particular needs and circumstances of people with ID should be considered as an example of institutional discrimination.

In the UK over 1 in 3 people will develop some form of cancer during their lifetime [19]. Due, in part, to increased longevity, the incidence and pattern of cancer amongst people with IDs is rapidly changing [1, 20]. Recent figures suggest that the incidence of cancer among people with ID is comparable with that of the general population [2, 3]. However, to date, there is contradictory evidence on incidence rates [21], treatment and survival outcomes for people with an ID [2]. The potential to delay diagnoses can then lead to poorer outcomes and higher cancer mortality in this group. [1, 2, 22-24]. Current advice from the Department of Health is that GPs should not carry out breast examinations, but that women should become more 'breast aware' [9]. This is likely to be an unrealistic goal for a woman with moderate or severe IDs. They are also less likely to have an awareness or appreciation of media-led breast awareness campaigns [25]. A recent UK report suggests that whilst people with ID can absorb health promotion information, they need on-going support from people other than health professionals, such as carers, families or community supports to maintain this learning [14]. Several studies have highlighted the challenges GPs face in identifying the people with ID on their lists in order to offer them services [26, 27]. Annual health checks for people with IDs typically lead to the detection of unmet need and unrecognised and potentially treatable conditions [13]. However, only half of the adults with ID who are eligible for health checks under an incentivised Directed Enhanced Service scheme receive them [28, 29]. Additionally, even when the patient with ID is successful in making an appointment to see their GP, many GPs lack confidence in treating them [30-32].

The NHS Cancer Screening Programmes published a good practice guidance 'Equal access to breast and cervical screening for disabled women' [33]. However, screening uptake rates among women with ID remain low [2, 8, 14, 34, 35]. There has also been some debate regarding the appropriateness and difficulties associated with screening in this group [25]. A recent inquiry found that people with IDs not responding to the invitation to participate because they did not understand the importance or implications of the screening and found the process difficult to follow [16]. They also found no evidence that people had received accessible information about the screening programme, and that there was little evidence that no 'reasonable adjustments' had been made to support their participation [16]. It has also been suggested that the reason for lower uptake may be due to GPs taking a unilateral decision that screening is inappropriate for some women and omitting them from the list of eligible patients [16, 25].

A recent National Cancer Survey [40 36] found that patients with an ID reported less positive experiences than other patients, however, there have been no detailed studies of the patient experience reported by cancer patients with IDs. GPs referrals often fail to mention a person had IDs when referring them to hospital services and hospitals do not 'routinely 'flag' people with IDs who might need reasonable adjustments made for them [16]. Additionally, appointment letters were usually sent in a standard format that was not easy to read for those with IDs. A review of the cancer information needs of people with ID reported that health care professionals lack guidance, expertise, training and knowledge of communicating and caring for people with ID [1, 16]. Similarly, health professionals working in the field of ID lack the specialist knowledge of cancer care management and need the guidance and support from oncology services [1]. There is also evidence to suggest that clinicians do not seek the consent of people with ID when providing tests and treatments and that they often base decision making on the assumption of incompetence and 'best interest' decisions [37].

Our research question was: What is known about the needs of people with IDs in order to promote early awareness and earlier presentation of breast cancer symptoms and ensure optimal breast cancer treatment and management? To address this, a scoping study was undertaken between April 2013 and August 2013. The aims were twofold: (i) to examine the compass and nature of research and identify gaps in the current evidence, and (ii) to determine priorities for future research with regard to the information and support needs of women with IDs. The methodological framework for undertaking the scoping exercise was guided by Arksey & O'Malley [38].

## **Methods**

Approval to undertake the scoping study was obtained from the Information Governance and Caldicott Support Department at Sheffield Teaching Hospitals NHS Foundation Trust and from Sheffield Hallam University Faculty Ethics Committee. A list of purposively selected key stakeholders (n=22) including those from national statutory and voluntary bodies; managers and practitioners from local organisations (n=21) and a local advocacy group for people with IDs and their carers (3 women with ID interviewed together) (within one Northern UK City (Sheffield) were identified by the study team and subsequently invited (by post or email) to take part in the scoping exercise. Information about the project and the proposed interview guide was also included with the invitation. All agreed to be interviewed. Four additional stakeholders were identified using snowball sampling (25 were interviewed

face to face and 1 via telephone). Recruitment ceased once data saturation had occurred. An interview schedule was developed from the literature and by the study team who all had expertise in the field of ID research or breast cancer research. The schedule focused on breast awareness, screening, diagnosis and treatment for people with IDs and perceived gaps in research and service provision. This guide was subsequently piloted on two professionals (1 GP and 1 Health Care Commissioner) and amended prior to the consultation period. Consent to interview the stakeholders was obtained prior to the interview commencing. The interviews were audio-recorded, transcribed by the two researchers undertaking the interviews (AMcC/SM). Analysis was undertaken using the framework approach [39].

## **Results**

Twenty six participants consented to be interviewed for this study. Interview duration ranged from 15 to 45 min. The thematic frame categorised the data into three main themes:

- roles and responsibilities
- inclusion - making 'reasonable' adjustments
- communication

The themes reported were identified by both the professional groups and the ID user/carer advocacy group with no themes unique to participants with ID, although the sample size is too small to draw any conclusions about this. See Table 1 for selected illustrative quotes to highlight the themes identified.

### **Theme 1: Roles and Responsibilities**

It was evident within the interviews undertaken that people with IDs can pose particular challenges for services. A key main theme to arise from the interviews, and one which was raised by most of the participants was the need for clear guidance on who is responsible for overseeing breast health and awareness for this cohort of women. There was acknowledgement that due to the range of cognitive ability and social function within the population made a one-stop solution difficult to achieve. There was a clear concern among the interviewees and no evident allocation of roles and responsibilities. There was also concern that some women with ID would be incapable of undertaking this role and participants were unaware of any formal guidelines that laid out the responsibilities for undertaking these activities.

One tailor-made training and awareness raising opportunity for women with ID to help them in examining their breasts and understanding breast awareness messages was identified within the interviews. This initiative was provided by local community nurses. These events were said to be well attended and useful to the target group of women. The interviewers prompted participants by asking if this initiative could be extended to giving carers some information to enable them to have a more proactive role and while the community nurses favoured the idea of establishing some variety of 'Train the Trainers' they cited lack of resources as a barrier to establishing this initiative.

The care home managers and the support worker interviewed viewed bathing as providing an ideal opportunity to perform some visual checks on their client's physical health and that through the act of washing a woman's body it might be possible to detect 'abnormalities' in the breast. They were equally clear, and the GPs supported this interpretation, that bathing should be primarily an exercise in assisting personal hygiene rather than specific breast examination. As one ID manager phrased it, 'We do personal care but we can't go groping their breasts'.

The need for leadership, guidance and protocols at a city level were echoed by many of the front line workers that were interviewed. The service managers interviewed were also aware of this issue and stated that they were actively considering options to address this.

Most participants felt that future research should focus on devising protocols to advise on the legal, ethical and clinical imperatives so that clinical governance in this specific area is assured.

## **Theme 2: Inclusion- Reasonable adjustments**

The second theme to emerge from the interviews was around the concept of inclusion. This is operationalized as making 'reasonable adjustments' to services in order to accommodate those patients whose disabilities and/or impairments mean that standard procedures might prevent their access to routine treatment and therapies.

Whilst within the interviews 'reasonable adjustments' were being made and there was evidence of good practice, they were neither strategic nor systematic. Where it happened, it happened largely due to the efforts of committed individuals or teams who took it on themselves to make the necessary provision to accommodate the ID clients they met professionally. Many participants identified the difficulties in identifying adjustments that will improve the experience of women with ID as they were viewed as being an heterogeneous group with complex and varied needs. This theme was not breast cancer

specific and was viewed as being applicable to other cancers and to people with IDs more widely.

Women with IDs received the same invitation letter as women without an identified ID. However, if the screening service were aware of the ID in advance women were given a longer appointment time and two staff were dedicated to this appointment. However for these reasonable adjustments to be made, it relied on GPs flagging up women with IDs and communicating these to the screening service.

Several participants spoke of a number of instances where women had attended but did not get screened. The reason most often being because the women became distressed or their physical condition meant that correct positioning necessary could not be achieved. The actual process of breast screening, for example, demands that the woman is cognitively aware of the procedure and physically able to comply with the intervention.

Participants suggested that future research efforts should be directed towards developing a pathway that contains step-off alternatives that can be deployed, with the full agreement of the individual and supported in the decision making by carers, so that optimum treatment is made available at each stage of the process from diagnosis to treatment.

### **Communication**

The third theme to emerge from the interviews, which was closely related to making reasonable adjustments, was the challenge of communicating effectively with the target population. Most participants stated that health promotion messages on breast health need to be communicated in a variety of media if they are to effectively reach this population. There was an overriding view that the challenge for the sector was how to communicate with those individuals who live with higher levels of impairment and disability. This was not viewed as being breast cancer specific but was viewed as being applicable to other cancers and to people with IDs more widely. For many women in the general population messages about breast awareness and treatment are delivered in print form on leaflets or posters and within healthcare settings. An example being from three women interviewed together and all living with varying degrees of mild ID. They spoke about their experiences of contact with the local screening service. All had varying degrees of difficulty with literacy and all needed help with understanding the referral letter they received asking them to attend for screening. One of the ladies, from previous experience and contact with the hospital, recognised that the letter she had received was from the hospital and she could make out the date and time. She surmised, correctly, that she was required to attend but for what exactly, she did not know. When she

arrived she showed the letter to reception staff who directed her to the appropriate area. It was only when she met the staff at the screening clinic that the purpose of the appointment became clear. The other two ladies were assisted in interpreting their letters by members of their family and carers respectively. The issue of 'easy read' is covered in more detail in the discussion. Tailored simple language was viewed by most participants as being needed. Several participants had devised their own 'breast awareness' training package and used a variety of tactile and visual materials to supplement the messages. There is readily available guidance on producing 'easy read' promotional literature ([www.bild.org.uk](http://www.bild.org.uk)) but this is only effective if the target audience can be assisted in their understanding of the materials.

## **Discussion**

This study has identified important issues in relation to breast awareness and behaviour, breast screening knowledge and uptake and views regarding current gaps in research and service provision. As indicated by the UK Department of Health [2] reducing cancer inequalities requires action to improve awareness and to promote earlier diagnosis, and ensure that all patients with ID are offered appropriate active treatment and have a positive experience of their care could make significant contributions towards securing greater cancer equality [2]. Undertaking a scoping study map has allowed the study team to summarise the compass and nature of research evidence currently available and to determine the value of undertaking future research in this area and the main sources and types of evidence available [10]. Specifically there is limited national information on variations in cancer incidence, treatment and outcomes for people with an ID, how people with IDs access cancer services and what is the role of carers/families in primary and secondary care. There is also a lack of research to guide women with ID and formal/informal carers and health care providers regarding breast awareness and breast (self) examination and with the added complication that women with IDs may have difficulty in communicating symptoms to their carers. There is also a general lack of research that seeks to understand the experience of people with ID diagnosed with (breast) cancer or on what interventions are effective in addressing the differing needs of this population.

Within the interviews it was evident that there was a lack of consensus over who should be responsible for directing self-examination when the woman was, for whatever reason, unable to perform this satisfactorily herself. In such a small sample it is unwise to suggest there is any pattern but the role of the GP and of the annual health check (AHC) were both mentioned as ways and means by which some advance could be made on establishing an accurate

assessment of the breast health of an individual. Against this it needs to be stated that the GPs interviewed were of the view that they had a limited role to play in terms of cancer awareness and education. Whilst they could see the potential benefits of the AHC for detecting unmet clinical need, the GPs were not convinced that it had any part to play in raising cancer awareness. They felt that this was a role for Public Health professionals. This professional boundary marking may have clinical justification but it is symptomatic of a wider, structural response that can put barriers in the way of access to healthcare.

### **Study limitations**

Despite recruiting a wide range of key stakeholders, the authors are aware that there are variations in service provision across the UK and therefore it would be inadvisable to suggest wider generalizability to other regions across the UK. However, a key strength of the scoping study has been that it has provided a review of available literature and identified numerous gaps in the current evidence base. It also increased the validation of the findings as both the literature and consultations elicited very similar gaps and priorities for future research. The purpose of the study was to map key issues, initiatives, gaps and priorities for future research within this field and arguably this has been achieved. It also provided the opportunity for participants to identify current issues facing them relating to the area that they viewed as being under researched. Based on the findings of this scoping study, it is recommended that future studies are undertaken to include a wider range of stakeholders including people with IDs and to establish, if, how and to what extent these locally based findings are generalizable to other cancer sites and settings and within other regions within the UK.

### **Conclusions**

There remains a dearth of research or practice guidelines at every stage of the breast cancer care pathway for women with ID. This may arguably lead to late diagnosis, sub optimal treatment and management and overall survival rates for this group. Further research is needed to understand the specific information and support needs of both women with ID (and their formal and informal carers) and to identify appropriate protocols, strategies and interventions in order to address these.

**3901 words (including abstract and Table 1)**

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**Table 1: Illustrative quotes from the themes identified**

Breast Awareness/behaviour/promoting early presentation of symptoms	Illustrative interview quotes
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Theme 1: roles and responsibilities	<p><i>'One day I noticed some discolouration on one lady's breast and she went to the GP to get it checked and it was benign. The qualified staff had seen this but not recognised it.'</i> Support Worker</p> <p><i>'When we bathe people we are in good position to check but we need guidelines. We need a consensus about the way forward'.</i></p> <p>Care Worker</p>
Theme 2: inclusion- reasonable adjustments	<p><i>'We have good engagement now from most GPs but the concept of 'reasonable adjustment' still defeats some of them'.</i></p> <p>Service Commissioner</p>
Theme 3: communication	<p><i>'One of the most important things is education of carers, so that they understand the actual examination. We don't mind if carers bring clients just for a look to get them used to the set up.'</i></p> <p>Screening Service</p>
Breast Screening-knowledge/uptake	Illustrative interview quotes
Theme 1: roles and responsibilities	<p><i>'A tumour/lump has to be 1cm before the patient can detect it so it's easy to imagine that someone with LD who has reasonable self-care skills (ie gets dressed/bathed independently) could miss signs until the later stages when the lump becomes big enough to be noticed'.</i> GP</p>
Theme 2: inclusion- reasonable adjustments	<p><i>'We support the women (going to screening) from making the appointment to going along with them and follow up'.</i></p> <p>Care Home Manager</p>
Theme 3: communication	<p><i>'The women don't want to go to screening because they don't understand'.</i></p> <p>Community Nurses</p>
Diagnosis/treatment/management of breast	

cancer	
Theme 1: roles and responsibilities	<i>'...for LD patients we need awareness for them <b>and</b> for carers/family and clear guidelines about how to self-examine and what to look for'. GP</i>
Theme 2: inclusion- reasonable adjustments	<i>'We have more engagement with GPs now but reasonable adjustments defeats some of them' Service Managers</i>
Theme 3: communication	<i>'We used pictures. We discussed how people might check. We had some training materials too. Three different sized breasts with lumps in. they had a feel with the support of trainers. That was good and generated discussion'. Community Nurse</i>

