

Short study into women's views on breast screening' in Limerick city.

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Involving service users - questions

- How do we know we provide the health and social care services that people feel they can engage in?
- How do we strengthen partnership between service users and service providers?
- How do we empower service users?
- How to we engage with service users in shaping health and social care services?



BreastCheck – what is it?

- Government funded free breast screening service (x-ray)
- National remit for all women
- To offer all women aged 50-66 a mammogram every 2 years (24-27 months), extension by 2021, 50-69
- Goal of reducing the number of mortalities from breast cancer in the population if at least 70 per cent of eligible women attend their screenings
- From Feb 2000, 9800 breast cancer have been detected by BreastCheck



2015-2016 in numbers (1st Jan-31st Dec 2015)

- 198,986 women were invited by BreastCheck for screening.
- 145,822 women attended for a mammogram.
- The eligible uptake rate at 74.7 per cent surpassed the programme standard of 70 per cent.
- 986 cancers were detected. This represents the highest number of both total cases and invasive cases diagnosed in any year.
- 399 small invasive cancers (<15mm) were detected and treated surgically.
 This is the highest number in any single year since BreastCheck began screening.
- The programme was extended to the 65 year old age group for the first time with high uptake and over 950 women screened.



Structure

- Run nationally by the Screening Service in NCCP
- 4 stative units Galway, Cork, Merrion, Eccles
- 18 mobile units
- Country divided in 4 areas by numbers and screen approximately 14,400 women per month
- Programme standards, against which performance is measured, are based on the 'European Guidelines for Quality Assurance in Breast Cancer Screening and Diagnosis' (4th edition), as well as the BreastCheck 'Guidelines for Quality Assurance in Mammography Screening' (4th edition).



However

- Screening can cause confusion and concern for some women
- Screening can pick up small non invasive breast cancers
- New women to the programme aged 50 or 51, uptake is poor
- Screening is hard to understand and explain harm versus benefit
- QA standards are tight and lead to a numbers game
- Repetitive strain and burnout in our radiographers
- Staff retention in radiographers
- Service design and delivery efficiencies, mobiles and DNA's



Why we wanted to talk to women?

- In limerick city the uptake in certain areas has at one time been as high as 80% among the eligible population and as low as 28%.
- The uptake in general was good once the service launched and is now poor below 50% in all areas.
- National initial women uptake 56% Dec 2016, target 70%
- In limerick we did a small database analysis and identified 192 women in limerick city who had attended for CervicalCheck but not for BreastCheck – why was that??



Study Aim

To understand why some women attend some screening services and not others, specifially targeted were those who attended cervical screening but not BreastCheck



Methodology

- 2 focus groups limerick city, evening time
- Incentive offered and refreshments provided
- Wrote to the 192 women and asked them to bring a friend
- Advertised for non attenders (specific age) on social media
- Advertised to local women's groups for non attenders (specific age)
 Topic guide:
- Awareness and understanding of cancer
- Awareness of and attitudes towards breast screening.
- Reasons for not taking part in screening.
- Exploring strategies to encourage uptake



Findings

- 24 women attended –
- 8 women were non attenders,
- 15 women had experience of mammography either through screening or the symptomatic service,
- 2 women were underage and had no experience of mammography

Confusion between screening and mammography received in other clinics



Findings

- General views on breast screening women questioning the pain and discomfort associated with mammography and benefit to themselves
- View of the mammogram reassurance, someone looking out for me, pain, stretching of skin, pressure from machine
- Radiographer be gentle and kind, talk the woman through the process, focus on the woman not the machine, introduce yourself, explain the possible pain
- Reasons for non participation pain, fear of result, appointment time doesn't suit,
- Encouraging uptake look at issues on the mobile unit, ask women to mind themselves, women telling their cancer stories, address the pain issue as its not painful for everyone



Conclusions

- The <u>radiographer</u> and the actual <u>environment</u> plays a huge part in the woman's experience of breast screening, particularly on the first occassion.
- Women are <u>fearful and nervous</u> and for many the clinic or mobile environment is a very new experience.
- Women have fears about getting the results, possible treatments to follow, telling family members and the mammogram procedure itself.
- In a couple of cases, women wondered if the mammogram is more damaging than good and if radiographers were more interested in the machine than the woman.
- More time is required at an individual personal level prior to and during the first screening appointment explaining the procedure, the benefits of screening and reassuring the woman about the procedure.



Recommendations

Radiographers

- Talk to radiographers about this study
- Provide training to radiographers
- Review pain reduction methods for mammography
- Develop a feedback system to radiographers
- Consult with radiographers about how to improve the screening experience for women



Screening logistics and environment

- Allow for longer appointment slots for initial women
- Communicate widely with women on the flexibility of the service
- Direct women to video of mammograms
- Encourage women to ring re: concerns and questions about mammography
- Consider out of hours appointments
- Ensure comfort and confidentiality on the mobile units
- Use of multi-task attendants for women before mammogram at unit level



Involving Service Users

- Establish a number of local consumer panel for BreastCheck made up of service users to advise the screening service in local delivery
- Develop a work-plan to engage service users more in promoting and improving the screening experience
- Engage with a number of breast screening champions locally to represent the service and share their stories. These women could be used in a number of different ways and in different parts of the work.



Awareness Raising

- Roll out more educational materials/video on the mobile/clinic and what is involved in a mammogram – across all media platforms. This should include further outreach sessions in communities, aimed at women and families, etc.
- Develop "minding women" concept "let us look after you"



More research

- Given the limited data available in this study, in-depth interviews with other PNA's could reveal greater insight into reasons for non attending and potential responses to encourage attending.
- Research with women and radioraphers on pain reducing interventions should be considered.
- Women who have ceased breast screening should be followed up as to the reasons why, similarly women who have returned to breast screening should be given the opportunity to explain their motivation to return – this information is useful to target similar sub populations.



What we have done to date

- Feedback to radiographers on this study results
- Training for radiographers for empathy (NHS expert)
- Changes to letters recommended for when review is due
- Campaign idea around the 'Mind Me' discussion with communications
- Progression of PPI training complete by staff, discussion of development of area
- Saturday screening piloted in 2 units
- Recommendations for changes to mobile units sent to BC national manager



Women

UsersThank you for asking us

Providers......We need to ask more often