healthwatch County Durham



Breast cancer screening in County Durham

Research into the uptake of screening and

the experiences of women





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Healthwatch County Durham

Healthwatch County Durham is the county's consumer champion for health and social care, representing the voices of current and future users to decision makers.

We listen, we advise and we speak up

We listen to people's experiences and use the evidence we gather to influence those who provide health and social care services. We provide a single point of contact to help signpost people to the right health and social care services at the right time.











We advise We speak up





Executive summary

Healthwatch County Durham (HWCD) and the Clinical Commissioning Groups (CCGs) in County Durham are committed to improving the health of residents in the county. Health screening helps with early diagnosis and treatment for a number of illnesses. In County Durham the uptake of breast screening percentage is higher than the average for England and the north-east region, however 22% of women invited to take part in 2016 (Health and Social Care Information Centre (Open Exeter) Public Health England) did not attend.

To increase the number of women attending we want to understand why some people do not access the service and if there is anything we can do to overcome the barriers. This survey was aligned with Breast Cancer awareness month to capture the views of some women in the county.

To carry out the survey staff and volunteers attended venues throughout the county to gather the views and experiences of local people. A wide range of venues were utilised. The questionnaire was also placed on survey monkey and promoted through social media. In total, there were 478 responses, 332 online and the remaining 146 through face to face interviews.



Recommendations

From the views of the women who completed the survey we have identified some recommendations, listed below.

- If it does not already happen, ask women to confirm that they will be attending the appointment, this may reduce the number of DNA's and also simplify the process for making an alternative appointment.
- The process for making an alternative appointment needs to be simple with checks incorporated to ensure new appointments are sent out to patients.
- When inviting first time patients for screening, information should be provided on what to expect. This could include comments from users of the service, offering some reassurance.
- Radiographers and support staff need to understand the anxiety and discomfort the procedure can cause for some women, therefore making sure they offer support, empathy and a friendly encouraging approach.





- Commissioners of the service need to ensure it is an accessible service for all eligible women, including women with disabilities.
- There generally seems to be some confusion about the age ranges for invitation to attend and the service providers should ensure women reaching the age of 70 are given information about being eligible to self-refer directly to a local breast screening unit once they stop getting automatic invitations to attend.







Background to this work

The Healthwatch County Durham work plan for 2016/17 included research into the barriers to health screening programmes. This is linked to the refreshed Primary Care Strategies of the North Durham and Durham, Dales Sedgefield and Easington CCG's. The work plan specifically required HWCD to research screening programmes which have the poorest uptake, plan appropriate engagement activities and collate data to produce reports.

DDES refreshed strategy

North Durham refreshed strategy

Healthwatch County Durham (HWCD) and the CCGs in County Durham are committed to improving the health of residents in the county. Health screening helps with early diagnosis and treatment for a number of illnesses.

October 2017 was Breast Cancer awareness month and HWCD took the opportunity to research the uptake of breast cancer screening in the county to see why some eligible people were not taking part in the screening programme and if there was anything that could be done to encourage more people to participate.

The graph below from Public Health England shows the screening performance of County Durham in relation to other authorities in the north-east. It identifies that at 78% the uptake percentage is higher than the average for England and the north-east region, however 22% of women invited to take part do not attend

Area	Count	Value		95% Lower CI	95% Upper CI
England	4,399,968	75.5		75.4	75.5
North East region	237,038	77.3		77.1	77.4
Northumberland	34,532	80.1		79.7	80.
Gateshead	17,572	78.9		78.3	79.4
Sunderland	26,086	78.9		78.4	79.
County Durham	48,340	78.1		77.7	78.4
Redcar and Cleveland	13,183	77.6	H	77.0	78.
North Tyneside	18,846	77.0		76.5	77.
South Tyneside	13,802	76.8		76.2	77.4
Stockton-on-Tees	16,829	76.3	H	75.7	76.9
Darlington	9,354	76.1	Н	75.3	76.8
Hartlepool	7,961	74.0		73.1	74.8
Newcastle upon Tyne	19,661	73.3		72.8	73.9
Middlesbrough	10,872	72.2		71.5	72.5







What we did, who we listened to and what they said

A survey was created and staff and volunteers attended venues throughout the county to gather the views and experiences of local people. The questionnaire was also placed on survey monkey and promoted through social media.

In total there were 478 responses, 332 online and the remaining 146 through face-to-face interviews. A wide range of venues were used, which included the Fulfilling Lives event, East Durham Trusts' Annual Event, Shotton Health Awareness Day, North Durham Patient Congress and Durham Dales, Easington and Sedgefield CCG Commissioning Event.

There was a mixture of face to face interviews and surveys collected as part of focus groups and surveys left and collected at one site.

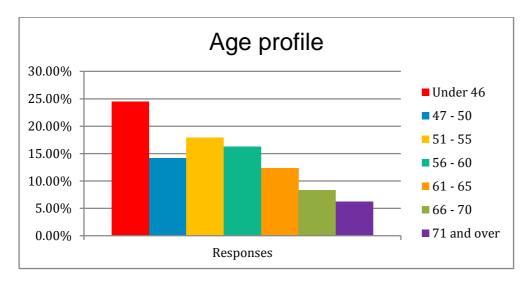
Respondents were asked to provide the first half of their postcode to enable us to identify which locales were represented. Unfortunately not all respondents carried out this request. Postcode areas that were identified are listed below and illustrated a good geographical spread of responses across the county:

DH1	DH7	DH8	DH9	DL12	DL13	DL14	DL15	DL16	DL17
61	81	20	14	10	25	10	19	20	8
DL5	DH2	DH3	DL3	DH6	DL2	DH4			
27	23	17	8	23	8	7			
TS21	TS28	SR7	SR8						
4	5	10	13						



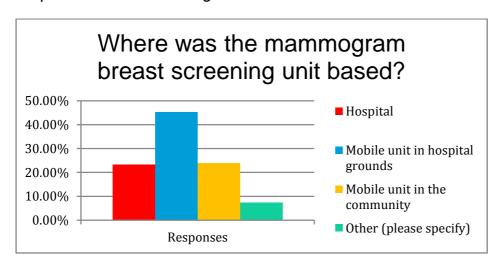


Of the women who took part in the survey, 331 were aged between 47-70 yrs. Thirty women who responded were aged 71+. Of these 361 women, 312 had attended a breast cancer screening appointment in the last 3 years.



Twenty six women aged 71+ still attend breast screening appointments, with 32 women stating they no longer attended. Interestingly, 27 women said they were given information about self-referral at their last routine mammogram, with 24 women stating they weren't provided with this.

The majority of women, 157, attended a mobile screening unit in hospital grounds, with 83 women attending a mobile unit in the community and 81 women visiting a hospital for their screening.



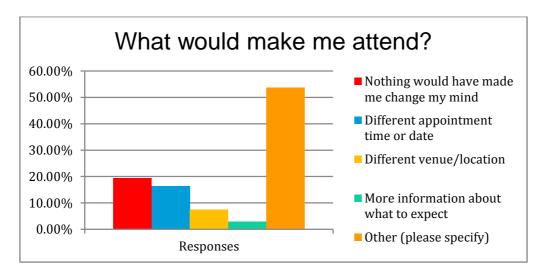




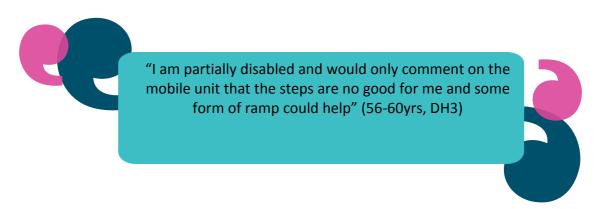
The main reason why women didn't attend their breast cancer screening appointment was because they did not receive an appointment letter. Thirty seven women stated this as the reason why. Other reasons for non-attendance included:

- The appointment time or date was inconvenient (5 women)
- The venue was inconvenient (2)
- I was embarrassed/frightened (2)
- I forgot (2)
- I did not think it was important (1)
- Inaccessibility for a wheelchair user (1)
- The experience was too painful (1)

Those women who didn't attend their appointment said that they may have attended if they'd been given:



- A different appointment time or date (11)
- A different venue/location (5)
- More information about what to expect (2)
- A wheelchair accessible service (1)







We asked women to tell us about their experience of breast cancer screening and we received 214 comments.

Eighty-four women were extremely positive about both the service and the staff, using phrases such as 'very efficient and helpful; staff are always friendly, courteous and very efficient; excellent service; a good, valuable and important service; very professional and friendly.

Fifteen women commented on the age range for breast cancer screening, with 2 women stating that the age should be lowered and 14 stating that the upper age limit should be increased, with women being called without the need for self-referral. From the comments made by women regarding the age limits, there is a sense of confusion and a lack of awareness about who will be called for screening and when.



"The screening detected my cancer very early and was dealt with incredibly well. It could have been so much worse had I not attended the screening. Can't understand why women don't, it's so important and free in this country. It's a wonderful service with wonderful tactful, staff. Hard to better" (66-70yrs DH2).

There were some recurring themes in the comments made by the women:

Impairment:

- "I am a disabled person. On my last screening the pictures collected were not as good as they could have been. I found it difficult to position myself at the correct angle. I don't know if there is an alternative way to do the screening."
- "I have been denied breast screening simply because of my mobility impairment."
- "Hard to do sitting in a wheelchair not sure if I got comprehensive scan."
- "I used to go until they modernised the equipment which does not allow for me to use my electric chair during the procedure as the old one did. I have





now been excluded through no fault of my own. As I have had cancer extensively in 2005 I am annoyed about this exclusion but I cannot transfer into another chair for physical reasons."

Perceptions and experiences:

- "It was a bit daunting facing three staff members as I walked into the mobile unit."
- "I think it is ideal when you are given a mobile unit appointment. Hospital appointments alone can make some women very nervous and they have to travel there whereas in the community you can arrange shopping etc. on the same day."
- "I was told it was painful but this is not the case, mildly uncomfortable if anything."
- "I felt it was efficient, professional, 'conveyer belt fashion' and not a very empathetic experience. Not a criticism as they have a large number to get through but just a note as many may require more reassurance, and if their previous experience was not reassuring they may not return again."
- "I think that the staff can underestimate the level of pain or discomfort and be rather unsympathetic. It might be a daily routine to them but is more important to each and every patient."
- "There needs to be more information available to the public and possibly even from a younger age so that people are made more aware of the issues and possibilities out there."
- "I haven't had a screening yet so would find it useful to have extra info for the first appointment to know what to expect."

Changing Appointment:

- "Called to move date none available. Said they would send another the following month. Didn't happen"
- "Not easy to reorganise appointment when needed to."







Recommendations

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- Radiographers and support staff need to understand the anxiety and discomfort the procedure can cause for some women, therefore making sure they offer support, empathy and a friendly encouraging approach.
- Commissioners of the service need to ensure it is an accessible service for all eligible women, including women with disabilities.
- There generally seems to be some confusion about the age ranges for invitation to attend and the service providers should ensure women reaching the age of 70 are given information about being eligible to self-refer directly to a local breast screening unit once they stop getting automatic invitations to attend.







Thank You...

Healthwatch County Durham would like to thank everyone who has contributed to this piece of work:

Age UK Durham County
County Durham Carers Support
Durham Community Action
Board members
Durham Voice
DDES & ND Clinical Commissioning Group's
Advice in County Durham Network
PCP newsletter
Durham County Council
Area Action Partnerships
The Medical Group GP Practices x 5
St. Andrew's Medical Practice, Spennymoor

Engagement Activity

People's Parliament/Fulfilling Lives East Durham Trust Annual Event Shotton Health Awareness Day North Durham Patient Congress DDES Commissioning Event





Appendices

Breast Cancer Screening Survey

We listen to the views of the public and their experiences of health and social care services. We would like to learn more about your experience of breast cancer screening services. We will use this information to make recommendations to improve future services.

1. Please tell us your age Under 46 47 - 50 51 - 55 55 56 - 60 56 - 65 56 - 65 56 - 70 57 58 59 59 59 59 59 59 59 59 59 59
2. Have you attended a breast screening appointment in the last 3 years? Yes $\hfill\Box$ No $\hfill\Box$
3. If you are over 70 years do you still attend breast screening? Yes 🗆 No 🗆
4. If you are over 70 were you given information about self-referral for screening at your last routine mammogram? Yes No No Not applicable Description:
5. Where was the mammogram breast screening unit based? Hospital Mobile unit in hospital grounds Mobile unit in the community Other (please specify)
6. If you received an appointment to attend screening but did not attend, can you tell us why? I forgot to attend I did not think it was important I did not think that it was relevant to me The appointment time or date was inconvenient The venue was inconvenient I was embarrassed or frightened was embarrassed was inconveniend was embarrassed was emb





I did not receive a letter inviting me to attend \Box Other (please specify) 7. If you decided not to attend, is there anything which might have made you change vour mind? Nothing would have made me change my mind \square Different appointment time or date \square More information about what to expect \Box Other (please specify) 8. Are you a person who: Smokes currently □ Is an ex-smoker Has never smoked 9. Have you participated in the bowel cancer screening programme? Yes □ No □ 10. Have you attended the cervical cancer screening programme? Yes No □ 11. Could you please provide the first part of your postcode (eg DL17) 12. Are you currently? In voluntary employment \Box Not working □ Retired

13. We would like to know about your experience of breast cancer screening to make recommendations to improve the service in the future. Please give details of anything you think we should know in the box below.

Thank you for taking the time to complete the survey, if you would like to know more about Healthwatch County Durham or sign up to receive our e bulletin please contact us on 0800 3047039 or provide you email address below.

