



Report on cervical screening and women's experiences in County Durham

March 2018





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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 to patients of health services and users of social care services, along with their family members or carers, to find out what they think of the services they receive.

We listen



We advise people how to get the best health and social care for themselves and their family. We provide help and information about all aspects of health and social care provided in County Durham.

We advise



We speak up

We make sure that consumers views are heard by those who provide health and social care. Wherever possible we try to work in partnership with providers to influence how they make improvements.



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 2016 it was reported by Public Health England that over the last 3 years in County Durham, 76.4% of eligible women invited to take part, had attended for screening. Whilst this figure is above the regional average there is still an opportunity to increase uptake.

Cervical Cancer Prevention Week 2018 took place at the end of January and HWCD took the opportunity to research the uptake of 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. In total 897 women shared their views in the County which is the highest completion rate for any survey carried out by HWCD in the last two years and it reflects the importance screening programmes have in the early detection of illnesses

Cervical cancer screening supports detection of symptoms that may become cancer and is estimated to save 4,500 lives in England each year. Improvements in coverage would mean more cervical cancer is prevented or detected at earlier, more treatable stages.

In our survey sample it was reassuring that the vast majority of women recognised the health benefits of cervical screening and did make timely appointments to attend. However there were barriers for some women, one of the greatest being fear and anxiety.



Observations and Recommendations

From the information provided in our surveys and our discussions with women we have made the following observations and recommendations for commissioners and service providers to consider,

Women told us they felt it was easier to delay or forget about the screening as they receive a letter to make an appointment, rather than an actual date to attend. We wondered if there could be a more effective follow-up procedure, for instance using texts or emails as well as letters. Suggesting times to attend or setting up on-line appointments systems for screening. We recognise there are some constraints on appointments due to the menstrual cycle, but still feel there is scope for improvement





- Nursing staff need to be mindful about the way in which they interact or talk to patients. Unintentional actions or comments can have an impact on women and can make them reluctant to have the procedure repeated
- There needs to be continued efforts to reinforce the importance of attending screening, including information about the HPV vaccination and how it ties in with the screening programme. Having read the leaflet that is sent out with the invitation letter we do not feel it gives enough clarity about the importance of still attending if you have been vaccinated

Some of the more general points raised or information we have gathered are listed below,

- 15 women told us in our survey that they believe the screening programme should start at an earlier age
- We also picked up that women do not always feel they get timely information about the screening, when they will be invited to attend and what to expect
- In Northumberland follow-up letters are sent out on pink paper, which seems to be having a positive impact in increasing uptake
- Of the women who had not accepted the invitation to be screened 25 women told us they were too frightened or embarrassed 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 CCGs.

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. Over the last 12 months HWCD has also conducted surveys on the uptake of Bowel Screening and Breast Cancer Screening.

DDES refreshed strategy

North Durham refreshed strategy

Cervical cancer prevention week 2018 took place at the end of January and Healthwatch County Durham (HWCD) took the opportunity to research the uptake of 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.

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Cancer is a major cause of death, accounting for around a quarter of deaths in England. More than 1 in 3 people will develop cancer at some point in their life. In January 2011 the Government published Improving Outcomes - a Strategy for Cancer. This document sets out how the Government plans to improve cancer outcomes, including improving survival rates through tackling late diagnosis of cancer. The cervical cancer screening programme plays an important part in preventing cervical cancer and reducing late diagnosis, and the strategy reaffirms this.

The graphs from Public Health England indicate the screening performance of County Durham in relation to other authorities in the north-east. It identifies the percentage of women in the resident population eligible for cervical screening who were screened adequately within the previous 3.5 years or 5.5 years, according to age (3.5 years for women aged 25-49 and 5.5 years for women aged 50-64)





2.20ii - Cancer screening coverage - cervical cancer 2017

Propor	tion -	4
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Area	Count	Value	95% Lower CI	95% Upper CI
England	10,569,154	72.0*	72.0	72.1
North East region	501,456	74.7*	74.5	74.8
County Durham	99,254	76.4	76.2	76.6
Darlington	20,460	75.5	75.0	76.0
Gateshead	38,308	74.3	73.9	74.7
Hartlepool	17,062	73.1	72.5	73.6
Middlesbrough	25,566	69.6	69.1	70.0
Newcastle upon Tyne	51,830	68.3	67.9	68.6
North Tyneside	41,880	76.6	76.3	77.0
Northumberland	60,558	78.1	77.8	78.4
Redcar and Cleveland	25,919	76.0	75.6	76.5
South Tyneside	28,502	74.1	73.6	74.5
Stockton-on-Tees	37,103	75.0	74.6	75.4
Sunderland	55,014	75.5	75.2	75.8
Source: Health and Social Care Informa	ation Centre (Open Exeter)/Public	: Health England		

Why this work was necessary?

This work was necessary as HWCD and the Clinical Commissioning Groups (CCGs) in County Durham are keen to increase the uptake of screening. To do this we need to understand why people do not access the service and what we can do to overcome the barriers. Cervical cancer can be prevented, we want to help ensure every woman knows how they can reduce their risk of the disease and the steps they can take to look after their health.

This means:

- Attending cervical screening when invited
- Knowing the symptoms of cervical cancer and seeking medical advice if experiencing any
- Taking up the HPV vaccination if aged 11-18
- Talking to friends and family to ensure they know how they can reduce their risk
- Knowing where to find support and further information





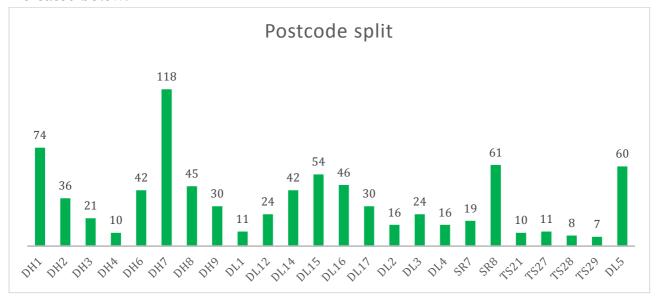


What we did

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

In total there were 897 responses, 765 on-line and the remaining 132 through face to face interviews. A range of venues were used which included GP surgeries, a women-only centre and a support group for adults with acquired hearing loss.

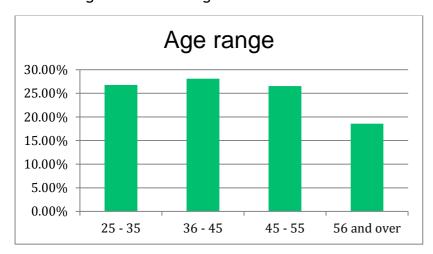
The responses were fairly well spread from across the county and the main postcodes areas are indicated below:





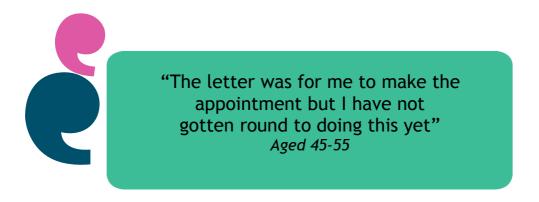


The graph below gives an indication of the age range of the women completing the survey, with most being between the ages of 25-55.



Of the women who completed the survey 95% had received an invitation to attend and 88% had made an appointment to be screened.

The vast majority of women (90%) told us it was easy to make an appointment, which was convenient to them.



Of the women who had not accepted the invitation to be screened **25 women** told us they were too frightened or embarrassed to attend. However many different reasons were given for not attending and some of the recurring themes were:





- Not being able to get an appointment time that suited them
- Forgetting or delaying making an appointment
- Finding previous cervical screening painful, so deciding not to attend in the future
- Finding that previous life experiences made them unhappy or too anxious to attend
- Cancelling because of menstrual cycle and then not making another appointment

"The nurse made derogatory comments about my weight affecting her ability to carry-out the procedure"

Aged 45-55

Observations and recommendations



Most women told us they recognised the importance of screening and made sure they did attend. However there were a number of women who had not followed up their invitation letter and made an appointment (18%).

From the comments made by women we have listed below some of the key points for consideration.

Women told us that it was easier to delay or forget about the screening as they receive a letter to make an appointment, rather than an actual date to attend. We wondered if there could be a more effective follow-up procedure, for instance using texts or emails as well as letters. Suggesting times to attend or setting up on-line appointments systems for screening. We recognise there are some constraints on appointments due to the menstrual cycle, but still feel there is scope for improvement





- Nursing staff need to be mindful about the way in which they interact or talk to patients. Unintentional actions or comments can have an impact on women and can make them reluctant to have the procedure repeated
- There needs to be continued efforts to reinforce the importance of attending screening, including information about the HPV vaccination and how it ties in with the screening programme. Having read the leaflet that is sent out with the invitation letter we do not feel it gives enough clarity about the importance of still attending if you have been vaccinated

Some of the more general points raised or information we have gathered are listed below,

- 15 women told us in our survey that they believe the screening programme should start at an earlier age
- We also picked up that women do not always feel they get timely information about the screening, when they will be invited to attend and what to expect
- In Northumberland follow up letters are sent out on pink paper, which seems to be having a positive impact in increasing uptake
- Of the women who had not accepted the invitation to be screened **25 women** told us they were too frightened or embarrassed to attend

We would like to thank everyone who took the time to complete our survey and the GP surgeries and the groups who allowed us to speak to patients and attendees including:

DDES & North Durham CCGs Area Action Partnerships Durham Voice Durham Community Action East Durham Trust Pioneering Care Partnership Advice in County Durham Network
Durham County Carers Support
Aspire
Durham Deafened Support
HWCD Volunteers who took the survey out to
their own friends/family/networks





Appendices

HWCD Cervical Screening Survey

Are you a woman aged 25 or over? We would like to hear from you about your experiences and thoughts on cervical screening. Cervical screening isn't a test for cancer, it's a test to check the health of the cells of the cervix.

1.	Are you?			
	□ 25 - 35			
	☐ 36 - 45			
	☐ 46 - 55			
	☐ 56 and over			
2.	Please provide us with the first part of y	your postcode eg DL17.		
3.	Have you been invited to attend a cervice	cal screening appointment? Y	ES NO	
4.	Did you attend? YES NO			
5.	If no, was this because:			
	I forgot to attend			
	I did not think it was important			
	County			D 40 645



	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			
	I did not receive a letter inviting me to attend Other (please specify)			
6.	Were you recalled at any time to have the screen	re done? YES NO		
7.	If YES did you attend? YES NO			
8.	If you didn't attend could you tell us why:			
9. If you made an appointment for your cervical screening test, did you find it easy to make an appointment that was convenient for you? YES NO10. What was your experience of your cervical screening test?				



13. Are you aware of the importance of your cervical screening test? YES NO

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.





