

Why don't women go?

Wessex Voices' findings about why women over 50 years old experience barriers to cervical and breast screening

Engagement activities in 2018/19

Introduction

Over the last year, Wessex Voices has engaged with women over the age of 50 years old, who live in more deprived areas of Dorset and Hampshire, to explore why they don't or have stopped going for NHS cervical and breast screening. Firstly, we organised focus groups, and then to engage with a wider group of women we ran a social media campaign linked to an online survey, which enabled us to learn more. Both sets of findings are being used inform Public Health colleagues, who manage screening programmes, and those they work with to improve screening uptake nationally and locally.

Why we did it

The NHS Cervical Screening Programme is world class and has the best recorded outcomes globally. However, the number of older women attending cervical screening appointments is at a 17-year low. In England, screening coverage in 2014 to 2015 was 81.6% for 50 to 54-year olds, falling to 74.8% of 55 to 59-year olds and 73.2% of 60 to 64 year olds. Breast or cervical cancer that is detected early is usually easier to treat, may need less treatment, and are more likely to be cured.

What did we do

Part 1: Focus groups and community outreach

Wessex Voices, with the NHS England Public Health Team and local GP practices, organised two focus groups in Bournemouth and Southampton, in areas of low take up of cervical screening. We wanted to have quality, face to face conversations with women aged over 50 about why they don't go or have stopped going to breast and cervical screening, and explore what improvements could be made.

We reached this group in a number of ways:

- Texting, via the GP surgery, women who had not attended screening
- Promoting via our networks and the Wessex Voices website, as well as targeted advertising through Facebook and twitter
- Putting up posters in community venues, such as libraries, churches, charity shops, supermarkets, dentists, pharmacies, doctor surgeries, gyms, etc

We spoke to 6 women via the focus groups but engaged with about 10 others through Facebook comments, emails and conversations in the community when promoting the work. Most women we spoke to had been to one or the other screening at some point but many had been put off by a bad experience.

By the very nature of who we were trying to reach and the personal nature of the conversation we knew we would not speak to large numbers of women. But we felt it was important to try to start a conversation about these sensitive topics.

Part 2: Social media campaign and online survey

To explore this further, we designed a two month social media campaign (December 2018 to February 2019) to encourage this group of women to complete an online survey.

For this, we:

- Developed a range of campaign materials
- Posted messages at least twice a week through the period, actively revising our messaging based on the engagement we were getting
- Encouraged Healthwatch and other partners, including some local GP surgeries, to get involved
- Used relevant awareness days/week, handles and hashtags
- Reviewed other social media interest to improve our own
- Paid (not much) to boost our Facebook and Twitter posts to the target group, during the general campaign and on the awareness raising week/day.

Find more details in Appendix 1.

What we heard

Part 1: from the focus groups and community outreach

1. Although the women know screening is important and they should go, some:
 - A) Might go for breast and not cervical screening, or vice versa (sometimes in the UK, sometimes abroad), or they may not go not at all now. Everyone had been to screening in the past but some ...
 - B) Had had a bad experience - either at a screening (extreme discomfort) or personally (examples were sexual violence and menopause)
 - C) Were just not motivated because they feel healthy.

2. How women are treated has put some off going. Having these personal examinations can make women feel tense and vulnerable. Simple things like a warm welcome and helping people to relax makes a real difference, but so too is responding sensitively when women express discomfort.

“... be more welcoming ... it’s a vulnerable place, situation to be in”

“... I hate having it done and I find it uncomfortable so that puts me off.”

“relaxation is key ...”

3. There are good practical reasons why appointments don’t work for women’s busy lives. Some didn’t find it easy to get to or find the venue. Others said where (e.g. near work) and when appointments (e.g. lunchtimes, evenings and weekends) were available could be more convenient.

“I’d have to get two buses and I wouldn’t have got back to work in time.”

“... They should put it (the mobile breast screening unit) somewhere where is it easily accessible ... it should be there ... it should be easy to find ”

“... If you can book it online that might be handy.”

“... if I could nip downstairs in my lunch hour to the van outside ...”

4. Whilst some of the women described how screening had ‘saved lives’ of family, friends, colleagues, some are not convinced of the evidence for screening.

“I found the cervical screening really difficult. It was only on the third appointment I managed to have the smear, after lots of relaxation and a student nurse holding my hand. I am pleased I went as it has picked up abnormalities and I will now have a colposcopy.”

“I will now tell you a bit about my journey. My last two mammograms were “dodgy” and each time I was told that it was a cyst. It was not when I found the lump and it was already stage 3 aggressive cancer. I had chemo and radiotherapy I also had a mastectomy, since I have had another mastectomy and a hysterectomy.”

5. There could be greater awareness of the screening programmes, particularly the age groups they apply to, so women can take more responsibility for making sure they are accessing screening in a timely way.
6. Taboos still exist about women's health issues. It is generally more acceptable to talk about breast cancer now but not other parts of their anatomy, periods or menopause etc.



Part 2: from the social media campaign and online survey

There were two elements to this engagement activity. Firstly, the social media campaign, and secondly, the engagement via our online survey. These are the results:

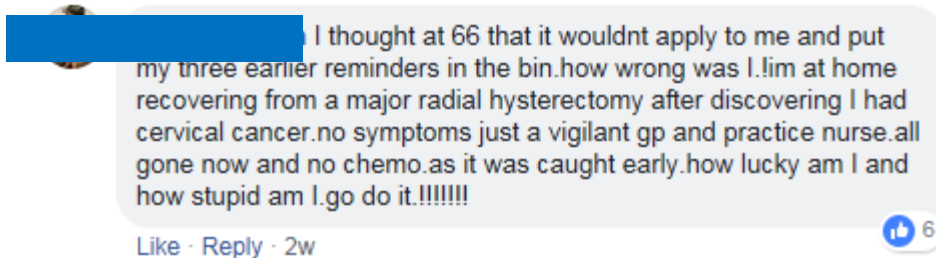
The social media campaign

In total, we reached 60,178 people via social media (Facebook, Twitter and LinkedIn). 2710 people engaged with our posts, including 460 likes, 285 shares, 35 comments, or 129 clicked through to our survey. The women were primarily over the age of 45 years old and from the South of England.

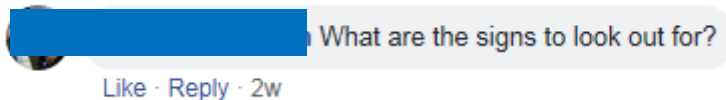
More information about the reach and channels used can be found in Appendix 2.

Social media comments show:

- Women encourage others to go for screening, and to check out concerns and ask questions of their GPs



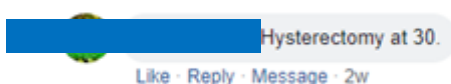
- Some women lack knowledge about the signs and symptoms of cervical cancer



- Women, particularly, at the upper age limit of the screening programmes, are confused about whether they are eligible



- Some of the reasons women no longer go for screening, e.g. having had a hysterectomy



Appendix 3 provides more examples of comments.

The screening survey

237 women responded to the survey. Of the 177 women who provided their age, 64 were between the ages of 50-70 years old. 27 were older but 86 were younger (i.e. not eligible for the breast screening). 23 women said they are disabled and 95% of those who gave their ethnicity were White British.

Because of our interest in the experiences and views of women who have never been or don't go for screening, we have shared these out first:

Responses from those who had never been	Number	Reasons, where given
Cervical screening	11	3 embarrassment 2 personal reasons (sexual violence survivor who has autism, and one from birth trauma) 1 had reviewed evidence for screening and saw no benefit
Breast screening	33	10 were ineligible (too young) 4 concerned it will be painful 2 didn't think they were at risk 2 embarrassment 2 poor previous experiences 2 other personal reasons 2 worried about risks of screening 2 not convinced of economic case of screening 2 not convinced of evidence base for screening 1 too lazy 1 worried about the result

Summary of general comments about screening

Just over 25% of the women who responded came from Dorset, Hampshire, Isle of Wight, Portsmouth and Southampton. Here is a flavour of the comments made.

Dorset

- Nurses are sometimes rough whilst doing smears
- Make appointments and booking process more convenient
- Smear cancelled twice due to lack of resources
- Mum not told about cervical screening till her 50s and at that point abnormal cells were found and she had to have treatment
- Question about whether gay women are attending screening
- Screening should be offered at all ages
- Important to educate people about early detection
- Would like screening at a sexual health clinic
- Make Jade Goody's story better known
- Don't know whether screening is needed if had a hysterectomy
- Would like sedation for a smear
- Find a less painful way, especially for those with a tilted cervix
- Learn from other countries
- Be sensitive and treat people with more dignity (including more than a paper covering)
- Don't question my husband being present
- Don't judge people who don't go, or are late booking appointments
- District nurse didn't want to go to her surgery because she knows the nurses there and it would be too embarrassing.

Hampshire	<p>Evening and local appointments would be more convenient - made online. Mobile and walk-in clinics highlighted as convenient</p> <p>Never take into account pain back and arthritis when doing a smear</p> <p>GP surgery down on nursing staff were cancelling appointments</p> <p>Lower the age eligibility for screening</p> <p>Nothing will persuade me.</p>
Isle of Wight	<p>Do at more venues. To have screening at the GP, woman said need to take half a day off work as too far away</p> <p>All health checks/smears are important</p> <p>Poorly trained nurses lead to painful screening. Use experienced nurses and monitor satisfaction</p> <p>Less embarrassing after having children</p> <p>Do it with calmness and it doesn't hurt.</p>
Portsmouth	<p>Make screening available to younger women</p> <p>Advising to take painkillers before screening to ease any pain.</p>
Southampton	<p>Like to talk to someone direct about convenient appointment rather than be sent a time (breast screening).</p>
All areas	<p>Examples were given of how screening has saved lives</p> <p>The thought of the test worse than the reality so do the smear and not the height, weight, other checks first</p> <p>Menopause can make smears more painful</p> <p>Don't judge overweight people</p> <p>Explain what screening involves and what outcomes may follow e.g. further tests but that not all referrals will lead to a cancer diagnosis</p> <p>Get people who have been through cancer to talk to others</p> <p>Text reminders when overdue</p> <p>Making the booking process more discreet</p> <p>Meet the nurse before screening to allay fears</p> <p>Those with poor previous experiences or other forms of trauma ask for specific help to be calm</p> <p>Offer help for those with children</p> <p>Take own lube that not allergic to</p> <p>Should be confident that those doing the smear will stop if asked to.</p>

Recommendations

For NHS England screening programmes and GP practices

- Explore how to make screening less uncomfortable and painful, and more dignified for women, both in terms of the process and improving staff training.
- Consider combining different screenings into a single overall health check.
- Create a searchable online tool for women to seek information anonymously according to individual needs¹ to see if they are eligible for screening. If they are, to book a convenient appointment at venue of choice.
- Consider how to make appointments more accessible to women in terms of times, places, booking methods, as well as offering double appointments for those who find screening distressing.
- Keep promoting the signs and symptoms of cervical and breast cancer, as well as the different screening programmes, particularly eligibility for women at the lower and upper age limits (and the reasons for the criteria).

“As a result of screening my breast cancer was picked up early and my dodgy cervical smear was dealt with quickly... probably both extended my life as a result”

For those carrying out the screening

- Recognise women feel vulnerable at this time so treat them as a person; not just another test to be carried out.
- Don't make assumptions about what might put women off. Gently encourage to take up screening, using the evidence as to why it is important, without making women feel guilty if they don't go.
- Provide a warm welcome and somewhere women can put personal items; and talk to them about what they can do to help themselves relax.

‘ ... why I don't go ...Have been but following birth trauma, cant bear the idea. try having people who care, who don't judge, who don't do procedures without consent, make it easier to make appointments. Stop making us feel like an inconvenience.

¹ age, disability (including learning disability), geography, whether had a hysterectomy and/or HPV vaccination, don't have cervix, Transgender status, sexual health, and other relevant fields

Our partners, Wessex Voices and women

- Start a conversation about women's health. We ask women to talk to their friends, siblings, mums, daughters, aunties, anyone about breast and cervical screening in particular. We will encourage everyone we work with to do the same.
- Use the learning from this social media campaign to inform future campaigns. (see Appendix 4).

"We should be having a campaign to talk more about our personal parts, advertising the services and what is 'normal', what's important and what's available. Have something on television again, on all media and encourage everyone to talk about it. Get more information out there, the more information the more people will know."

Conclusion

We knew it would be difficult to engage this demographic of women but we have been successful in hearing from local women about their experiences of cervical and breast screening. We found social media, with a relatively little resource, can be one way of doing this effectively.

Many women will have shared similar experiences, so endeavours must continue to improve the screening process at a national and local level. A focus should be given to continued awareness raising and making it easier for women to attend, specifically focussing on those who find it most difficult. This should ultimately benefit all women.

Appendix 1: More about the social media materials used

Here are some examples of the first multi-media images and text we used. We also produced a short video, social media banners (website, TV etc) and posters that could be displayed in GP practices and other community venues.

*According to #NHS, In 2017-2018:
 '25% of women did not attend their cervical #cancer screening'*

Please help us understand why, it could save a life: <http://bit.ly/wvscreeningsurvey>



'1 in 4 women skip cervical screenings, with the proportion increasing' - @NHSUK

*👉 Please help us understand why by completing our short survey:
<http://bit.ly/wvscreeningsurvey>*



Our World Cancer Day using Jade Goody's image

We found the 10th anniversary of Jade Goody's death was trending on social media during the campaign. The group of women we were targeting would potentially remember her so we successfully used her image to boost our engagement on an issue she had also campaigned about.

Whilst we had been getting good levels of response to the questionnaire, we felt we needed to review our messaging to encourage women over 50 specifically to fill in the questionnaires.

Relevant National Awareness days

Jo's Trust Cervical Cancer Prevention Week: 21st - 27th January 2019
 Hashtag and handles: #SmearForSmear @joscerivicalcancertrust #Smeartest

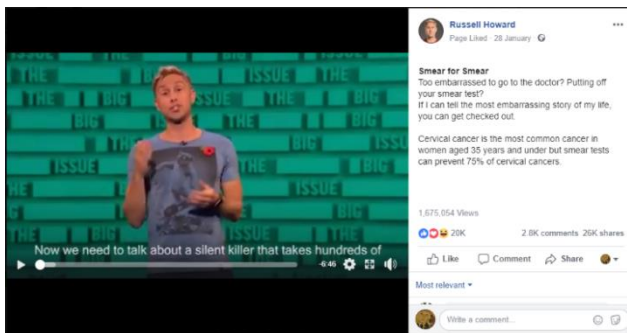
World Cancer Day: Monday 4th February 2019
 Hashtags and handles: #IAmAndIWill, WorldCancerDay, @worldcancerday

Main Twitter handles used	Main Twitter hashtags used
Healthwatch CCG NHS E	#Cancer #Cervical #NHS #Health

Other examples of popular social media coverage

We reviewed other popular social media to see how we could improve our messaging and extend our engagement reach. See examples below. Given the demographic we were trying to reach and the content of these posts we felt it would not be appropriate to link to these for our campaign. We may have done had we been trying to reach women who already go for screening.

1. Russell Howard Hour: Cervical Smears



2. BBC/ Jo's Trust² shares ladies smear test live on BBC



² For more examples of what women were saying during the Jo's Trust campaign look up their social media and #SmearforSmear2019 on Twitter.

Appendix 2: Summary of social media engagement


	Help and Care Facebook	H&C FB Cervical Cancer Week	H&C FB on World Cancer Day	H&C LinkedIn	H&C Twitter	Wessex Voices Twitter	WV Twitter on World Cancer Day	Total
Cost		£21.73	£27.50				£50	£99.23
Reach/ Impressions ³	2100	5364	5309	237	12,604	17,486	17,078	60,178
Engagements ⁴	94	656	274	46	141	222	1277	2710
Likes		233	37				190	460
Shares		101	31				153	285
Comments		22	7				6	35
Link click throughs		31	14				84	129


³ Where posts appear on people's time lines – they may or may see or engage with this


⁴ Engagements include likes, shares, comments, link clicks, picture clicks, and hashtag clicks


Appendix 3: Example comments from our social media campaign


Encouraging others to go for screening or to the GP if concerned



 I thought at 66 that it wouldnt apply to me and put my three earlier reminders in the bin.how wrong was I.lim at home recovering from a major radial hysterectomy after discovering I had cervical cancer.no symptoms just a vigilant gp and practice nurse.all gone now and no chemo.as it was caught early.how lucky am I and how stupid am I.go do it!!!!!!


Like · Reply · 2w  6



 Jade campaigned for the right for younger women to have tests under the NHS, I believe. A right that hasn't altered, as far as I'm aware (?) But, it is important for ladies to get checked, regardless.
 #dothesethings


Like · Reply · Message · 3w  8



 Any worries - GET IT CHECKED ASAP

Like · Reply · Message · 3w  3



 She was so honest about this .. tried to raise awareness before she left her family for good! It's such a quick check for a lifetime of avoiding this insidious illness ..

Like · Reply · Message · 3w  2


 I am 61 u
 Years Old, had some worrying Bleeding..... Went to see my Doctor
 🙌 Sadly she said that as I am on the Data Base to be sent an Appointment at the " Correct Time "..... That she didn't need to do a Smear Test?..... Hopefully she is right 🙌..... She did look, and said she couldn't see anything to be concerned about 😊🙌..... So it wasn't a waste of time going for a Smear 🙌 Even though I didn't get a Smear 😊

Like · Reply · 3w  1


Lack of knowledge about signs and symptoms


 What are the signs to look out for?


Like · Reply · 2w

Questions about age of screening

 Had one last year I'm 62 this year and was told I didn't need to go anymore.
Like · Reply · Message · 3w

 **Help & Care** According to NHS; women aged between 50-64 are required to go every 5 years. Here is a link to the NHS site which outlines how frequently cervical tests are carried out, Link: <https://www.nhs.uk/conditions/cervical-screening/>
Please do fill out the survey in the link: <http://bit.ly/wvscreeningsurvey...> See more

 Actually you can answer a question for me before your 50 you are meant to have a smear every 3 years after 50 its every 5 years, Why??
Like · Reply · Message · 3w


 No check after 65 ladies!!
Like · Reply · Message · 3w

 I'm 64 this year not had any notification of having anymore
Like · Reply · Message · 3w

 Had my last one at 62 was told nhs don't provide smear tests after this age!
Like · Reply · Message · 3w

There were lots more of these types of messages from women over 60

Reasons for no longer going

 Hysterectomy at 30.
Like · Reply · Message · 2w

Healthwatch Dorset podcast

Healthwatch Dorset recorded an interview with one of the women who took part in our focus groups. Nikki tells the story of how she perseveres to go for cervical screening, which results in her having abnormal cells being detected and removed. We think this would be a useful training tool as well as a story to make other women aware of. [Click here to listen.](#)

Appendix 4: Top Tips for running a social media campaign

Top Tips for running a social media campaign

1. Plan early and well - thinking about what channels might particularly work for your target audience
2. Brief our Healthwatch communications colleagues and other partners well in advance
3. Learn from and make use of other high-profile public figures, social media posts and trends
4. Proactively engage with social media handles, groups and hashtags more specifically aimed at your target audience
5. Review and adapt material and messaging as you go along - keep images, content and message fresh
6. Pay to boost posts to increase engagement with your target audience
7. Be prepared to respond to questions and comments promptly
8. Undertake sentiment analysis, using free tools, to review the opinions expressed during the engagement

Acknowledgements

Wessex Voices would like to thank all those who engaged with us during the focus groups, social media campaign, and completed a questionnaire to share your experiences and thoughts.

We would like to thank Sarah Ryan, Marketing and Communications Officer at Help and Care, for leading on the social media campaign and helping us learn from this approach. As well as Sarah Brown and Rosie Bird, who supported us with the focus groups, we would also like to thank our Healthwatch and other partners who supported the campaign.

For more information

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