Jo's cervical cancer trust

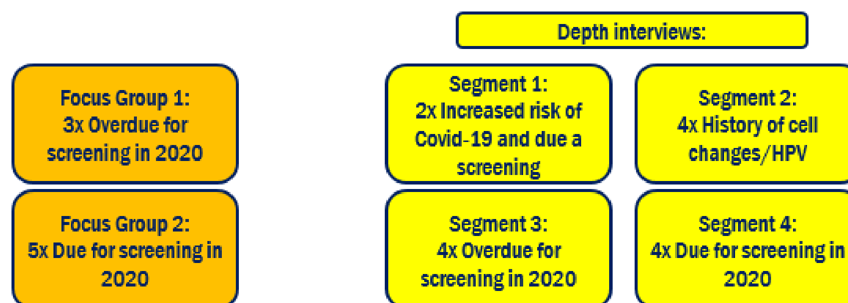
Research to understand attitudes to participation in cervical screening during the pandemic

Objectives

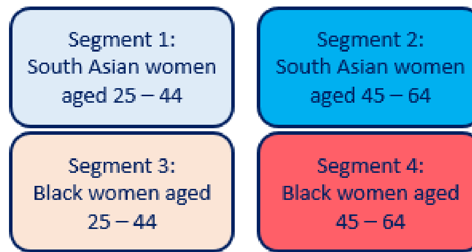
- To better understand attitudes towards cervical screening during the Covid-19 pandemic and perceptions of risk associated with attendance
- To gather insights from audience research to inform messaging, communications and support services for women affected.
- (Phase 2) Focus on women from South Asian and Black backgrounds who were identified in phase 1 as having greater anxieties and barriers

Method

- Phase 1:
  - Online survey of 2,000 women aged 25-64 living in England between 17-25 June
  - 2x 90 minute online focus groups + 14 x 45 minute video-conference interviews held during the fortnight commencing 29 June 2020
    - Participants were from a range of locations, ethnicities and background and aged between 25-58 years.



- Phase 2:
  - Online survey of 1,000 women aged 25-64 living in England between 15-22 September
    - Sample includes 200 women from a Black ethnic background and 200 women from a South Asian ethnic background
  - 4x 90-minute online focus groups of 4 participants + 12 x 45-minute video-conference interviews held between 18 September and 2 October 2020.
    - Participants were South Asian or Black women from a range of locations and backgrounds, and aged between 25-61 years. All participants were either due or overdue their cervical screening



Note: We are in a rapidly changing and uncertain situation in which opinions and views can and will change quickly. In the first wave less anxiety was reported in the qual research than was suggested by the quant research – this may be explained by the easing of lockdown measures. The second phase was conducted at a time when a 2nd wave of Covid-19 was looking increasingly likely.

Similarities in findings between both phases

1. Pre-pandemic barriers and motivators to attendance, such as fear, embarrassment, pain or discomfort, inconvenience have not gone away
2. Many have concerns over availability/capacity of the NHS
3. Assumption screening is not currently happening
4. Fear of coming into contact with general public (e.g. in waiting rooms).
5. Covid-19 is a barrier to attendance, but does not supersede pre-existing barriers for the majority
6. Overall positive reception to idea of self-sampling, some concerns raised over efficacy of test.

Impact of the pandemic on lives

In the first wave there was a wide spectrum of concern about catching Covid-19, but generally less anxious than at start of lockdown. Higher concern was among Black, Asian and minority ethnic participants, especially in light of evidence indicating higher risk. Concern about passing Covid-19 to loved ones greater than getting virus themselves. Those who had attended medical settings were surprised by how positive their experiences have been. Reported settings as feeling safe, hygienic, efficient and quiet.

> *"I went to a hospital appointment last week. It felt different due to masks and hand sanitiser, but I felt safe and it was friendly enough."*
>
> (White, 25, High-risk CV19)

In the second wave a rise in cases has led to increased caution, particularly among South Asian women. There is a general lack of trust in guidelines (potentially due to confusion) and most women report deciding for themselves what is 'safe'. Most have done some but not all activities permitted within guidelines. Black women more likely to report being less anxious about risks, however still exhibit behaviour that adheres to guidelines.

"I won't take public transport. I did the Eat Out to Help Out scheme."
(Indian, 46)

- 42% of women either know/think they have had coronavirus or know somebody else who thinks they have had coronavirus. This figure is noticeably higher for South Asian women (62%) and those living in London (56%).
- 81% are a little (51%) or very (30%) worried about their own risk of getting coronavirus, with only 16% of the sample not worried at all. South Asian women were the most worried (90%) while Black women were the least worried (73%).
- 88% are very (49%) or a little (39%) worried about the risk of coronavirus to loved ones, with only 10% of the sample not worried at all. South Asian women are the most worried (93%), with 60% very worried about the risk of coronavirus to loved ones.
- 52% felt more worried than they did before as a result of recent news coverage (66% of South Asian women).
- 48% of women are confused about latest government guidance and not sure how to protect themselves, up significantly from 31% in the first wave. Women aged 30-34 (62%), South Asian women (57%) and women from London (59%) are all more likely to agree with this statement
- 45% are worried about getting coronavirus and hardly ever (or never) leave home at the moment, which is unchanged from the first wave. South Asian women and women at higher risk (or living with someone at higher risk) are significantly more likely to agree with this statement (62% and 67% respectively).
- Most have rationalised risk – BAME people more likely to work on frontline, in manual jobs, so don't necessarily perceive there to be a greater threat on them as individuals. Multi-generational households also mentioned as possible cause.
- Concern is highest amongst younger South Asian women – more likely to be worried about their families. Older South Asian women say they feel they are more cautious than non-BAME colleagues/friends.

"I've been really affected by these reports. Massively impacted. It's factors beyond our control - socio-economic, frontline jobs etc - I'm really frustrated by it."
(Indian, 26)

Visiting a GP practice

There are still significant levels of concern about attending a GP practice, however most of those who have visited a medical setting report a positive experience with 84% saying they felt safe and 85% felt reassured staff were taking safety measures seriously. 78% felt confident about returning to a medical setting if they needed to.

- 20% still don't think it is safe to visit a GP surgery at the moment, however this is down from 29% in the first wave
- Concerns are higher among Black women (26%) and South Asian (31%) women, although both are much lower than the 40% of BAME women who reported feeling it was not safe in the first wave
- 23% say they would be anxious about their safety (or safety of someone they live with) and only visit a GP surgery if it were serious/important, down from 36% in the first wave.
- 39% of women trust their local GP surgery to keep them safe (33% among Black women).
- Of the 45% of women who had not visited a medical setting during lockdown, 31% needed an appointment and did not make one in person

"My GP I'm very comfortable with – I've been with him for 45 years. When I think of NHS I think hospital - we have a hospital we call a slaughterhouse - everyone that seems to have gone to that hospital has come out in a body bag."
(Caribbean, 51)

"Anything I might need to do differently to prepare. In the practice I'd want to know where I can sit - which seats are clean. Have other people sat in them?"
(Indian, 47)

General screening barriers

Across both phases a sense of screening being an unpopular but necessary test prevailed with a wide range of barriers including pain, discomfort, embarrassment, inconvenience, lack of relevance.

In the first wave 64% reported being up to date with their cervical screening, 53% book a test as soon as they receive their invitation, 29% normally put it off for a while, while 18% rarely or never book a test or have opted out.

59% don't like cervical screening but see it as a necessary test. 29% say it makes them anxious, 27% find it embarrassing and 21% find it painful. Among the qualitative most had attended / intended to attend screening, however almost all considered it to be an unpleasant experience.

"I've never had one done. Been chased up about it quite a lot. They offer to do it straight away when I go to the doctor, but I'm not mentally prepared for it and I just cant bring myself to do it."
(Pakistani, 35)

"I know I should go but I still don't go. It's just uncomfortable, and you're lying there on the bed legs akimbo, the nurse is popping her head up between your legs to ask how the weather is. I just don't like it."
(White, 49, High-risk CV19)

In the second wave, younger South Asian women were most likely to report never having been, reporting having heard horror stories, being put off by not knowing what will happen and feeling the need to mentally prepare.

Most women said there are no specific cultural/religious influences on them personally however South Asian women were more likely to report knowing of issues in their communities such as pressure not to go before marriage, concerns over having a male doctor, lack of education/knowledge.

"I don't really know what the process is. If I did I might be more likely to go if I had more of an idea about what happens during screening."
(Indian, 26)

"Nobody talks about it. I don't think most of my friends have been. My sister is 36 and I don't think she's ever been."
(Indian, 26)

"South Asian people don't tend to talk about intimate areas or reproductive issues so it's just not talked about. They don't really talk about screening or HPV. My white friends talk about it though."
(Pakistani, 27)

"I'm originally from Kenya and I know people don't go until they're very seriously sick - they wont go every year just for a check."
(African, 55)

Impact of the pandemic on screening

High numbers report their feelings being unchanged by the pandemic, however BAME women in the first wave and those at higher risk of COVID-19 were less inclined to attend. Overall, Black women appear more pragmatic about screening, talk more openly and rationalise the process. South Asian women seem to be more powerfully affected by hearsay and more likely to be fearful of the idea of screening. In the second wave most South Asian women in the qualitative, and significant numbers in the quantitative said they wouldn't go at the moment. Black women were more split in likelihood of attendance, however Covid-19 is not the main barrier for those who say they won't go. All audiences admit to using Covid-19 as an excuse not to attend, rather than citing fear of catching/spreading the virus.

> *"Not very high on my list of priorities. I'm due one but putting off going, I feel funny about attending during pandemic."*
> (Indian, 46)

> *"I'm also aware of capacity and wouldn't want to put extra pressure on NHS."*
> (Pakistani, 27)

> *"I've got in the back of my mind that I'll just sort it when this whole Covid thing has gone. But I need to stop using it as an excuse."*
> (Caribbean, 35)

Black women had more strongly held opinions and were more vocal about trust issues, and are more cynical about health services (potentially fuelled for at least some by perceived institutional racism).

In the first wave anxieties over delayed appointments were felt by many and in the second wave there were greater themes of concern that appointments wouldn't be available, or that screening is a waste of resources at this time.

- 48% said coronavirus had not affected how they would feel about attending cervical screening in the near future, remains unchanged across both waves. This drops to 26% for South Asian women
- In the first wave 9% definitely wouldn't attend because of coronavirus, 22% are less likely and 12% are more likely to attend.
- Women from BAME backgrounds (43%) and women who are overdue (47%) were much more likely to say they definitely wouldn't attend or would be less likely to attend in the first wave.
- 44% do not think delaying screening is the safest thing to do because of coronavirus, but BAME women, women overdue screening, younger women and women who are shielding were more likely to agree with this statement.
- 39% agree that people at higher risk from coronavirus are better off delaying screening for now (30% disagree). This rises to 62% of South Asian women.
- Of those who are overdue, 30% were delaying prior to coronavirus, while 30% have received an invitation but are delaying booking due to coronavirus (up from 23% in the first wave).
- 28% say they have more important / urgent things to worry about than cervical screening so it is not high on the to-do list at the moment (37% disagree). However South Asian women are far more likely to agree (51%).

In both waves there was a high level of trust in GP practices to have effective safety measures in place to protect those attending screening. However this varies dependent on personal experience and was high among those who have closer relationships with healthcare staff. Sympathy and compassion for NHS staff was also expressed.

> *"I trust them in the hospital - I see the same people all the time. I don't have the same level of trust with my GP because i see someone different every time."*
> (Black, 52)

> *"I trust that the NHS and our practice are making an effort. But I'm not sure how well they enforce it. I'd want to know how staff are making other staff abide by the rules."*
> (Indian, 35)

While fear of catching COVID-19 was not a significant barrier for most, especially in the first wave, additional associated potential included uncertainty about if/when screening will be available, expectation of backlog / long waiting list for appointment; fewer appointments, not being able to make appointments online and male practitioner doing procedure due to staff shortages.

> ***"I usually book online but that's currently suspended, so it feels less convenient."***
> (White, 25, High-risk CV19)

Those needing reassurance want very detailed information about exactly what to expect when they go to their appointment.

- 51% need more information about what would happen at cervical screening now / what safety measures would be in place (69% of BAME women) but 44% don't want to think about cervical screening at the moment (58% of those overdue).
- 37% are worried they could get coronavirus at a cervical screening appointment, especially BAME and shielding women.
- 43% say more information / reassurance about safety measures at their GP surgery would make them more likely to have a cervical screening test if they were due / invited now, and 36% would be more likely if they knew the nurse would definitely be wearing a mask.
- The measures that would make people feel most reassured / safe are if the doctor / nurse was wearing protective equipment such as gloves and a mask (57%), other safety measures being in place such as hand gel being available or social distancing in the waiting area (47%) and more information about what changes have been made to make the test safer (44%).
- Women would most welcome information or support online (47%), through their GP (30%) or by email (28%).

Self sampling

Almost all were enthusiastic about idea, but some concerns raised about not taking sample correctly. Convenience, ease and privacy were motivations but concerns including not correctly taking sample, greater confidence in trained professional and risk of procrastination – making appointment for screening is making commitment to it happening.

- Women were split on their preferences between being sent a kit to take a sample at home using a vaginal swab (32%) compared to the usual cervical screening (smear test) with a doctor or nurse (31%). 30% said it depends what's involved with taking a sample / how easy or reliable this is.
- Women who rarely or never book a test or have opted out of screening in the past are far more likely to prefer self-testing (47%) than clinician-led screening (9%). The same is true for women who are overdue, with 50% preferring a self-test and 18% preferring clinician-led screening.
- Women from BAME backgrounds have a higher preference for self-testing (34%) than clinician-led screening (26%).
- However, women whose test results are not always clear prefer clinician-led screening (38%) over self-testing (25%), although 33% answered 'it depends'.
- Middle-aged women appeared to have a slightly higher preference for clinician-led screening (35% aged 40-44, 39% aged 45-49 and 36% aged 50-54), while younger women and older women appear slightly more open to the idea of self-testing. 64% aged 25-29, 66% aged 30-34, 64% aged 55-59 and 62% aged 60-64 either prefer this option or answered 'not sure – it depends'.

Addressing concerns through communications

Four main groups were identified:

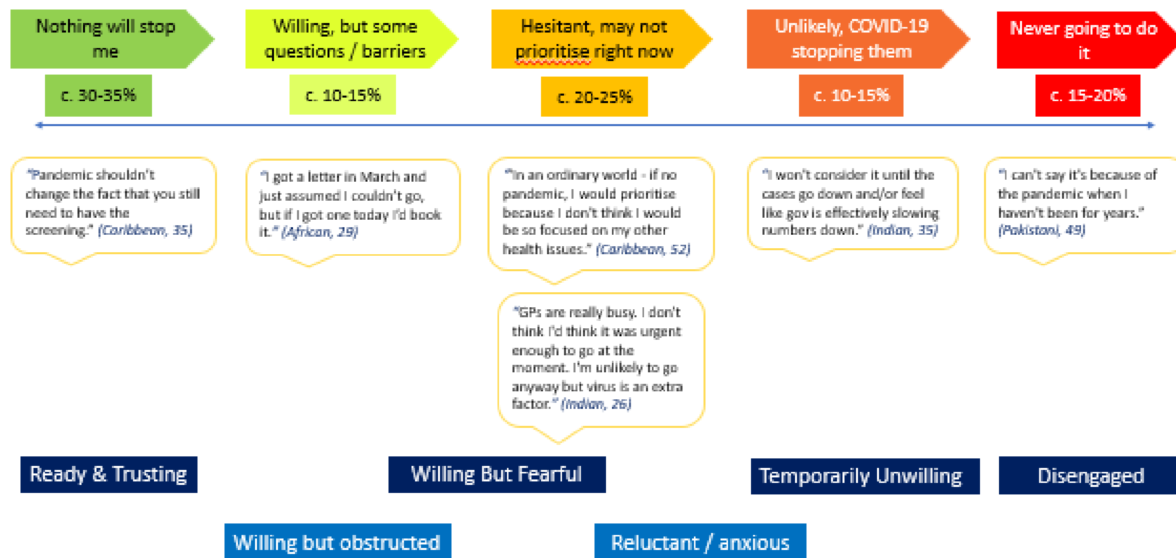
1. **Keen but fearful:**
   Want to attend cervical screening, but are experiencing fear about mixing with others, travelling, and attending at a medical setting during the pandemic – even as restrictions ease. This group includes people who would attend screening but are feeling anxious due to Covid-19 as well as those who might feel too afraid to attend.

2. **Ready and trusting:**
   Trust the NHS implicitly – they assume they wouldn't be invited unless it was safe to attend, and that all relevant precautions will be taken. Especially true for white and younger participants. This group are most likely to attend if invited.

3. **Resolutely unwilling:**
   Most fearful group about COVID-19. Most people in this category are already overdue on cervical screening due to other pre-existing barriers and are extremely unlikely to attend.

4. **Disengaged:**
   Not overly concerned about Covid-19 but also are not very motivated to attend cervical screening. It's a low priority for them.

Would they go spectrum



For many the pre-existing barriers to attendance are still most powerful with the additional challenges presenting by the pandemic and inconvenience of making appointment loaded on top. COVID-19 has given those more inclined to delay another barrier and a swing towards non attendance, communications are needed to tip the balance back.

Key messages:

1. Screening is happening and you can book an appointment
2. Benefits of screening
3. Medical settings are following guidelines to keep everyone safe
4. Explain / show what will usually happen when people arrive for appointments
5. Explain what they can do themselves- offer sense of agency / control

Communications addressing group 1 will satisfy those who just need confirmation it's safe, and may potentially start to reassure some of those who are more fearful. This is particularly important for South Asian women and groups at higher COVID-19 risk.

Identifying how to deliver the above messages to patients in important for practices and local teams. Interventions such as training reception staff, calling non attenders, use of text messaging, local campaigns and using local influencers or community ambassadors to deliver them are just some of activities that could be employed.

Tips for communicating with patients about cervical screening during the pandemic: https://www.jostrust.org.uk/about-us/news-and-blog/blog/tips-communicating-patients-about-cervical-screening

Thanks to Claremont https://claremontcomms.com/ for their support with this research