

The information and support needs of survivors of sexual violence around cervical screening

A survey by Jo's Cervical Cancer Trust and Rape Crisis England and Wales

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1. Background

1.1 Cervical screening in the UK

Around 3,200 women are diagnosed with cervical cancer every year. The NHS Cervical Screening Programme saves 5,000 lives each year in the UK, but over the past five years one in four (3.7 million) women have not attended cervical screening – attendance of cervical screening in England is the lowest for two decades.

1.2 Sexual violence in the UK

- Nearly half a million adults are sexually assaulted in England and Wales each year, with almost 2,000 cases of rape (including attempted rape) in Scotland¹.
- One in five women aged 16 to 59 has experienced some form of sexual violence.
- Only around 15% of those who experience sexual violence choose to report to the police².

1.3 The relationship between cervical screening and sexual violence

A gynaecological exam may be uncomfortable or embarrassing for anyone³. But for someone who has experienced sexual violence, a test like cervical screening could force disclosure of their experience, trigger flashbacks and physical responses, plus introduce many more challenges.

Without the right self-management or healthcare professional support, these challenges could deter survivors from attending screening after their initial appointment or at all. Cervical screening is the best protection against developing cervical cancer, so it is reasonable to assume that survivors of sexual violence are at a higher risk.

¹ Scottish Government, Crime and Justice – Recorded Crime in Scotland, 2016-17.

² Ministry of Justice (MoJ), Office for National Statistics (ONS) and Home Office, An Overview of Sexual Offending in England and Wales, 2013.

³ Jo's Cervical Cancer Trust, Barriers to cervical screening among 25-29 year olds, 2017.

2. Aims

Jo's Cervical Cancer Trust conducted a survey to find out about the experience of cervical screening for survivors of sexual violence, in partnership with Rape Crisis and with the support of My Body Back.

With this research, we aimed to:

- Understand what support is currently offered to survivors of sexual violence around cervical screening.
- Identify information and support gaps and what is needed to bridge those.
- Identify how survivors would like to be communicated with.
- Understand whether healthcare professionals need further training specifically around sexual violence.
- Produce a list of recommendations for future work.

“It needs to be widely known how distressing it is for us. There's a stigma that you're being over dramatic or performing for attention... but that's not what it's about and nurses need to understand as well as the public. Women shouldn't feel so alone.”

- A survivor

2.1 Terminology

We define sexual violence as 'any unwanted sexual act or activity'.

We use the term 'survivor' to describe someone who has experienced sexual violence, following the example of leading sexual violence charities like Rape Crisis England and Wales and My Body Back.

3. Methodology

3.1 Online survey

We used an online survey to gather data, asking both quantitative and qualitative questions to allow for a true account of a survivor's experience of cervical screening. The survey launched on Monday 22 January 2018 and closed on Friday 13 April 2018.

Due to the sensitive nature of the survey, we signposted to support services for respondents.

3.2 Ethical considerations

Respondents were under no obligation to participate and made a voluntary decision to take part. Information requested about the following was on an optional basis:

- Age range
- Ethnicity
- Smoker / Non-smoker
- Disability / No disability.

We put ethically based data collection procedures into place. All respondents were informed of the purpose of the survey, the benefits of participation, and all data collected was anonymised.

4. Results

4.1 Demographics

In total, 143 people took the survey, of which:

- 136 (95.1%) identified themselves as survivors of sexual violence
- 5 (3.5%) are a friend, partner or family member of a survivor
- 1 (0.7%) is a healthcare professional
- 1 (0.7%) opted for an 'Other' answer and identified as 'a woman'.

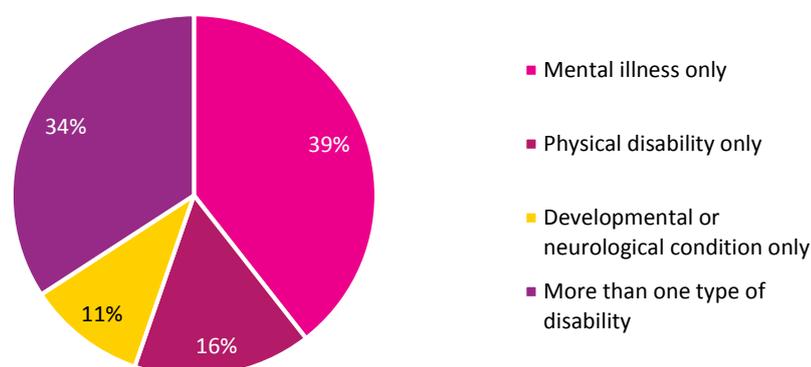
141 people gave their age, with 114 (80.6%) between the ages of 25 to 49, 12 (8.5%) between the ages of 50 and 64, 14 (9.9%) under 25 years old, and 1 (0.71%) over the age of 65.

142 people gave their ethnicity:

- 120 (85.1%) are English, Welsh, Scottish, Northern Irish or British
- 3 (2.1%) are Irish
- 11 (7.8%) identified as Other white background⁴
- 1 (0.71%) is Polish
- 1 (0.71%) is Mixed or Multiple ethnicities
- 1 (0.71%) is Indian
- 1 (0.71%) is African
- 1 (0.71%) identified as Other Asian background – Sri Lankan.

Of the 142 people who answered whether they smoke, 14 (9.86%) do smoke, 14 (9.86%) used to smoke but have now quit, and 114 (80.28%) do not smoke.

38 (26.8%) people described themselves as having a disability – higher than the national average⁵. That broke down into the following:



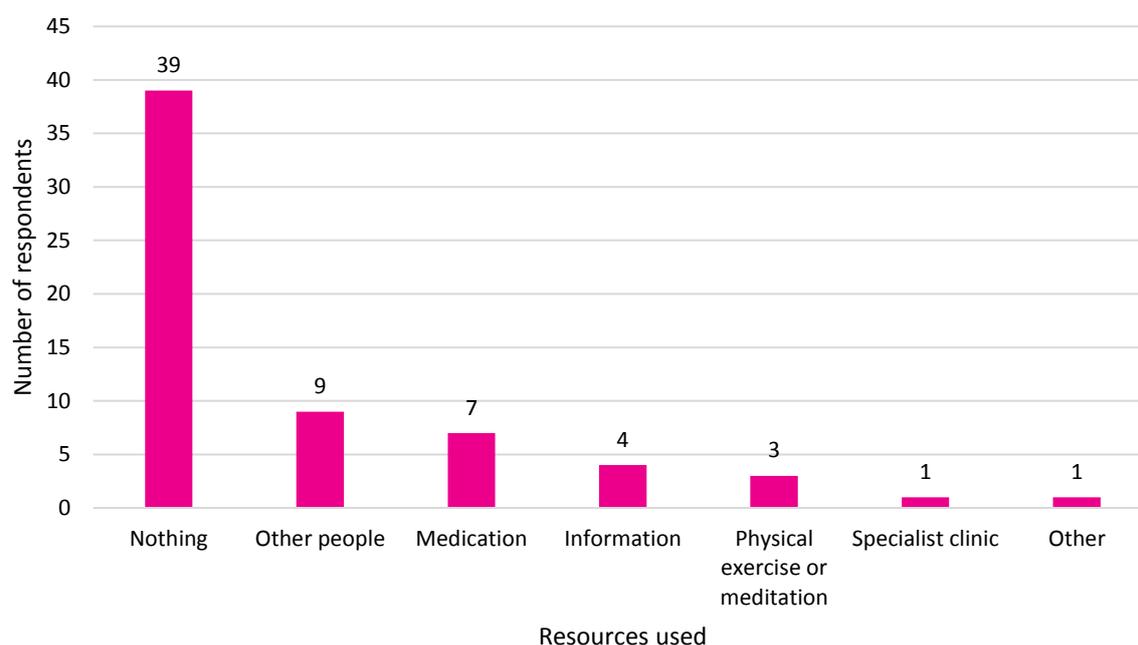
⁴ The respondents identified as Finnish; Caucasian; French; Mixed; Scottish; Mixed East European, Jewish and Roma; European; Slavic heritage, Welsh-born and Spanish-raised; and Northern European.

⁵ <https://www.gov.uk/government/publications/disability-facts-and-figures/disability-facts-and-figures> [last accessed April 2018].

4.2 Experience of cervical screening

131 people answered our question ‘Have you not attended cervical screening due to your experience of sexual violence?’ Almost half (63 or 48.1%) said they have not attended directly because of their experience of sexual violence, with a further 31 (23.7%) saying they have delayed the test in the past for the same reason. Just 19 (14.5%) respondents said they attended when invited and 18 (13.7%) gave reasons for not attending, ranging from being under 25 to fear to other gynaecological conditions.

63 people answered our question ‘Are there any resources you currently use to help you prepare for or support you during the test?’



For over half of respondents (60.9%), nothing helped prepare for or offered support during cervical screening. When respondents expanded on their answers, most of the time this was because of the link between screening and sexual violence.

“There aren't any resources! I'm too scared to ask family or friends – they wouldn't be able to cope with me if I have a flashback, intrusive memories or dissociate.”
- A survivor

However, rarely, it was because they do not link the two experiences, so did not need support.

“I do not connect my sexual violence with the test at all.”
- A survivor

Support or resources that respondents did use included:

- other people⁶ (9 or 14.1%)
- medication⁷ (7 people or 10.9%)
- information (4 people or 6.3%)
- physical exercise or meditation (3 people or 4.7%)
- a specialist clinic (1 person or 1.6%).

“I use my own resources. I have a printed timeline of photos of me up to the present, and I tell the nurse or doctor that if she loses contact with adult me, she needs to tell me it's 2018, that I survived and I am an adult now – and give me the photo line to remind me who I am. I also have a bag of items that will connect to each of my senses. These help me to anchor back in reality after dissociative episodes.”

- A survivor

4.3 Information needs of survivors

131 people answered our question ‘Do you think information about cervical screening (smear tests) specifically for women who have experienced sexual violence would be helpful?’ Of those:

- 113 (86.3%) said yes
- 4 (3.05%) said no
- 14 (10.7%) were unsure.

For those who expanded on their answer, the general feeling was that the practicalities of the test (what will happen) did not need more information, but signposting to support may help.

“The issue is not always with the unknown of the procedure – that can be explained. How do people get support during or after the smear?”

- A survivor

“I believe the information would be helpful but should be delivered to everyone - women should not have to signal they're a survivor to get it.”

- A survivor

⁶ Other people included healthcare professionals, family, friends or a partner. It involved getting information or support from them, or having them present during cervical screening.

⁷ Medication included any kind of drug (including alcohol).

However, for some respondents no information or support would help.

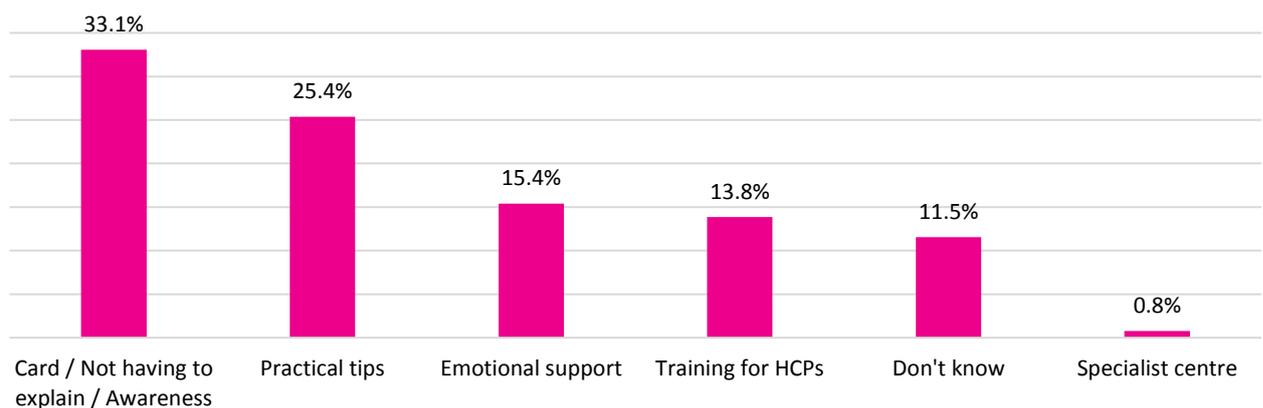
“Women know about smear tests. I know what will happen. I do not want one. There is nothing that you can tell me that will change my mind.”

- A survivor

“It's not my job as a survivor to make medical staff comfortable – it's their job to make me comfortable.”

- A survivor

113 people answered our question ‘We know from previous research that survivors have different information needs. Some people want a card to show a doctor or nurse without needing to talk about their experience, while others would benefit from information around emotional support and practical tips. What would you want this information to be about?’



“I don't want to have to keep telling my story, but at this point I have it down by rote.”

- A survivor

“A card might help. Also total choice about position, maybe music, no stirrups, a longer appointment – but to be honest I'd rather not go at all. I would rather do a urine test or have a session where my partner could learn to do it instead.”

- A survivor

5. Information needs of healthcare professionals

113 people answered our question 'As well as information for survivors, we are thinking of creating information to help healthcare professionals make cervical screening (smear tests) better. In your experience, would this be useful?'



“The procedure may be 'routine' for them, but for some people it is anything but routine and can be terrifying, no matter what happens.”

- A survivor

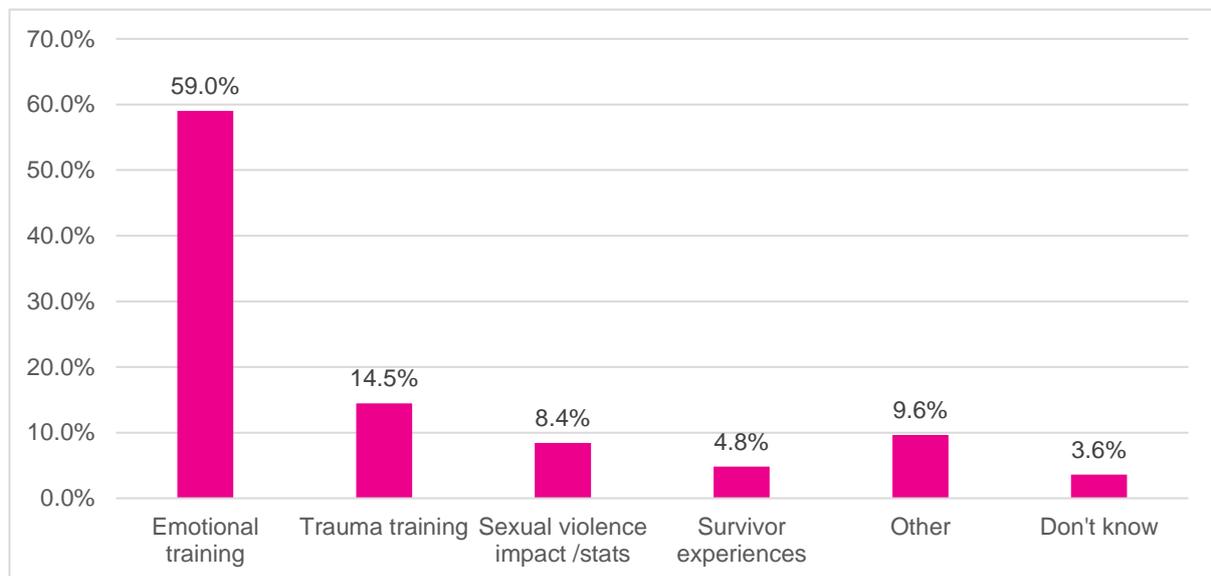
“The healthcare professional I spoke to was not at all understanding. Whereas my dentist was amazing! So I've had wisdom teeth removed, but haven't had a smear test.”

- A survivor

“Telling me to relax is one of the worst parts about a smear. It never helps and, in fact, every time it happens makes it more difficult.”

- A survivor

87 people answered our question 'If we create information for healthcare professionals, what would you want to see included?'



Over half (59%) said more emotional training was needed, while less than 15% said specialised trauma training was needed. From this we can infer that a positive emotional response – empathy, sensitivity, listening – is most important to survivors and currently lacking.

“I imagine the things that can be triggering may be some of the last they'd think of. They need to understand that even the very minor elements of it can be awful – the feel of cold lube on your genitals or the sound the speculum can make as they screw it open.”

- A survivor

6. Conclusions and recommendations

6.1 Training for healthcare professionals

Our survey showed 91.2% of survivors felt healthcare professionals need more information to better support survivors, mostly around emotional training (59%). While Jo's Cervical Cancer Trust and Rape Crisis England and Wales can provide written online information/training, there is a need for a bigger conversation around this at a national level, especially when considering 1 in 5 cervical screening attendees may be a survivor of sexual violence. There was a consensus among our survey respondents that healthcare professionals do not understand how and why cervical screening can be such a difficult experience, an underlying issue that must be addressed so survivors get the right support.

“They need to understand that having this test is traumatic for us. The way they are with us makes all the difference.”

- A survivor

6.2 Information for survivors

Our survey data showed over 86% of survivors want information specifically for them about cervical screening, with a message on informed choice, practical things they can ask for before and during the test, and further support. Jo's Cervical Cancer Trust and Rape Crisis England and Wales can develop some user-led online information for survivors.

While over 33% of survivors said that a non-verbal disclosure card would be a useful resource, more research is needed to find out how this would work – for example, whether healthcare professionals would recognise it, and whether it would solely be for cervical screening or for other health tests.

6.3 Specialist support for survivors

More options are needed for the vast group of people who make up survivors of sexual violence. While specialist centres for cervical screening, like the ones run by My Body Back in London and Glasgow, are available, they are few and are severely underfunded and oversubscribed.

Self-sampling may also give survivors control over their test, a significant theme in our survey, and make them feel able to have cervical screening. As highlighted in our 2018 **Computer says no** report, more work is needed to make self-sampling a viable choice. Read the full report: jostrust.org.uk/access

“Sexual assault or rape is about lack of control. The smear needs to be the opposite – the woman in full control.”

- A survivor