

# The impact of Sexual Trauma on attendance for health appointments

July 2024



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## **Executive Summary**

## **Headline Findings**

This research shows that experiences of sexual trauma can significantly impact people's decisions about whether to attend cancer screenings and other health screenings and appointments.

Where people **do** decide to attend screenings/appointments, the attitude of staff, the level of trauma-informed training received by staff, and the information made available to patients – including the ways/formats in which information is made available – can make a significant difference to patients' experience. At worst, it can, in some cases, re-traumatise people and make them less likely to attend in future. At best, it can potentially save lives.

Our report focuses on people's experiences and their thoughts about what may help to make health screenings and intimate examinations feel safer and less traumatic.

This report sets out findings including:

- Feelings of anxiety are experienced by many survivors of sexual trauma before, during and after intimate health screenings and appointments.
- Many patients felt unable to take their time and have control over the pace of their appointment.
- Patients are not routinely offered adjustments or support.
- Many patients did not have confidence in asking for adjustments or support if they are not offered them.
- There are actions that healthcare practitioners could take to improve the experience of patients who are survivors of sexual trauma.

## **Key Recommendations**

Based on the report's findings, we set out the following recommendations for decision-makers, including primary and secondary health care providers, and integrated care systems (ICS):

- NHS Screening staff to work with diverse patients to co-produce invitation letters.
- GP practices to proactively call patients who don't respond to screening invitations, with an offer to answer their questions, and book them an appointment, with support to reschedule if required.
- Allow patients with digital access to book or re-schedule screenings (for instance if they
  are having a period) online or via an app. Include a range of language options and a BSL
  video option.
- NHS commissioners to consider providing alternative screening provision to allow patients a choice about whether to go to their GP practice or elsewhere.



- If the current national work on self-screening for cervical cancer proves it to be an effective method, seek to roll this out locally as quickly as possible to allow those who would prefer to self-administer the test to have this choice.
- Health passports and #CheckWithMeFirst cards to be available at GP practices, Walk-In Centres and hospital waiting rooms, accompanied by training for staff about their purpose and use.
- Encourage NHS staff to undertake existing NHS Learning Hub training on trauma informed care, e.g. 'Trauma-Informed Approaches to Healthcare' and to consider ways in which their patient care and clinical environments can be made more welcoming and safer for patients who have experienced sexual trauma.

#### Our full list of recommendations can be found on page 37 of this report.

We look forward to working with partners from across the health sector – including commissioners, providers and voluntary/community sector partners - to make these happen.



"The Survivors Trust is delighted to support Healthwatch Liverpool in publishing this crucial report, enabling a deeper understanding of the impact on survivors of sexual violence attending health appointments and the barriers this trauma presents. Through our programme #checkwithmefirst, we have solid research to demonstrate that the simple act of frontline staff attending a half-day workshop and raising awareness of how previous sexual trauma presents in healthcare appointments can dramatically reduce 'do not attend' rates, as well as improve staff well-being and retention. We hope to see this report used by other trusts throughout the country as a tool to help, not add to, existing workloads."

Lucy Duckworth, Policy Adviser, The Survivors Trust



The Survivor's Trust #CheckWithMeFirst cards which we hope to make widely available across Cheshire and Merseyside as one of the recommendations from this report.



## Introduction

One of Healthwatch Liverpool's key purposes is to gather feedback from people who use health services. Sometimes people contact us independently to tell us about their experiences, sometimes we reach out to ask community members questions to find out specific information. Often we run surveys based on feedback we have received from the public.

One issue that has been raised with us by patients and has also been discussed within NHS Cheshire & Merseyside, as well as nationally, is the impact that sexual trauma (which may be experienced when someone either touches another person in a sexual manner without consent or makes another person touch them in a sexual manner without consent) has on patients' attending for screening appointments for cancer, or other conditions, or feeling comfortable with health care professionals touching them in an intimate way in the course of legitimate/required treatment or clinical investigations.

The Survivors Trust<sup>1</sup> is a national membership organisation supporting specialist rape and sexual abuse services in the UK voluntary sector. They have developed a set of resources for sexual trauma survivors, called #CheckWithMeFirst<sup>2</sup> and have also developed survey questions for working with people who have experienced sexual trauma.

#### Survivors Trust information shows that:

- The Crime Survey for England and Wales 2020 (CSEW) estimated that 1.6 million people aged 16+ had experienced rape or sexual assault, but fewer than one in six reported this.
- The CSEW also estimated that 7.5% of all adults in England and Wales (3.1 million people) had experienced some form of childhood sexual abuse before the age of 16 years. In 2020, the police in England and Wales recorded 73,260 incidents against children.
- It is estimated that 1 in 6 people in the UK have experienced some form of sexual abuse or assault and these people are likely to have long-term effects and medical complications.
- Each survivor is affected differently, but the impact of trauma on the developing neural and immune system may mean a survivor of childhood sexual assault is up to 14 times more likely to attempt suicide, 3 times more likely to have heart disease, and 8 times more likely to get a cancer than other people.
- Survivors of rape and/or sexual assault are more likely than others to experience Post-Traumatic Stress Disorder (PTSD) resulting in flashbacks, panic attacks, nightmares and/or depression.
- Often when survivors of sexual assault visit a medical professional, memories can surface
  due to the type of examination and the lack of control the person might feel. This can be
  so difficult that many actively avoid seeking medical attention, putting their health at risk.
  Survivors often make a choice not to disclose their experience of sexual assault or abuse to
  medical professionals and may not want their medical records to contain this information.
- Many NHS professionals receive limited, or no, training about this. This training gap leaves healthcare professionals unaware of the prevalence of sexual abuse and the extent to which associated trauma can impact survivors and the way they access healthcare.



https://thesurvivorstrust.org

<sup>2</sup> https://thesurvivorstrust.org/training/healthcare-resources-for-survivors/

## What we did

We worked with the Survivors Trust to develop our own survey, based on theirs but adapted to gather our own local information.

We also worked with organisations including WHISC (Women's Health Information & Support Centre), RASA (Rape & Sexual Assault Centre), SLDAS (South Liverpool Domestic Abuse Services), Savera, Refugee Women Connect and Safe Place Manchester to develop the survey and check that it used suitable language, included relevant questions, and signposted people to appropriate support services.

We wanted to hear from survivors of sexual violence to:

- 1. Build a case for improvements in local healthcare.
- 2. Work with local services to help them understand how they can make their services more accessible and more supportive for survivors of sexual trauma.
- 3. Contribute to national work carried out by the Survivors Trust in association with NHS England (NHSE).

We circulated the survey via the organisations mentioned above, as well as sending it to Merseyside Polonia, Chinese Wellbeing, LCVS, Liverpool Public Health Department, Central Liverpool Primary Care Network (PCN), Mersey Care Talking Therapies, The University of Liverpool, The Maggie Oliver Foundation and Manchester NHS Foundation Trust for distribution.

The survey remained 'live' between November 2023 and February 2024. We offered to provide additional support to help people complete it if they required it – for instance translation/interpretation or Easy Read materials – including the option of a member of Healthwatch Staff helping people to complete the survey by telephone or video. One person requested this.

Data analysis and report writing took place during March and April 2024.

The majority of staff time was paid for through our core Liverpool City Council funding, with additional funding via:

- Liverpool Charity & Voluntary Services (LCVS), acting as community lead for Merseyside & Cheshire Cancer Alliance. This funding contribution was used to add a component about cervical screening to the survey, and for language support for survey respondents where required.
- 2. Healthwatch England (HWE), which funded an interview with a disabled woman about her experience of cervical screening. This was part of a wider piece of work involving 9 other Healthwatch organisations and also fed into a Healthwatch England report. A member of WHISC's staff was paid by us on a sessional basis to conduct this interview as the interviewee was known to the organisation and comfortable speaking to them. A former Healthwatch Liverpool employee was also paid on a sessional basis to transcribe the interview.



## Survey responses

Our online survey was engaged with by 66 people. These were overwhelmingly women but included one man and two non-binary people.

Not everyone answered all the questions but the information below summarises the information that was shared with us. Percentages have been rounded and may not always add up to precisely 100%.

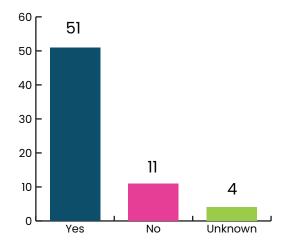
Fewer people answered the questions in the second half of the survey than the first – in many cases only about 50% chose to answer these questions. This may be because they felt uncomfortable with them, or because they had not realised the survey continued beyond the first section.

However, we have presented all available data below. Quotes have been edited, indicated by the (...) symbol, for clarity. Some specific references have been removed or replaced by wording in [brackets] to minimise potentially identifying information.

#### **Content Warning:**

Where people have shared additional information and examples of their personal experiences, we have included these in full as it is important that their voices are heard and their experiences 'seen'. Some of the information may be difficult to read or triggering. For readers who may find the section below or the Case Study on page 30 too difficult to read we suggest turning to the Recommendations on page 37 which are based on feedback but do not include examples of people's personal experiences.

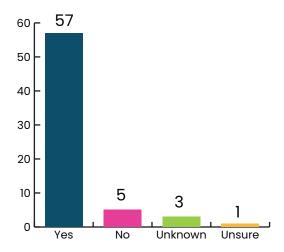
## 1. Have you used any NHS services in the past 12 months?



Over three-quarters of respondents (77%) had used at least one NHS service in the previous 12 months.

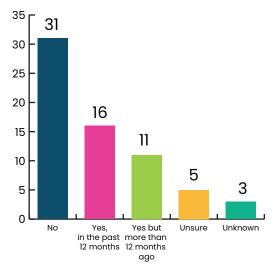


## 2. Are you a survivor of rape (including rape within marriage), sexual assault, sexual abuse or sexual exploitation?



86% of respondents told us they had experienced rape, sexual assault, sexual abuse or sexual exploitation. For the purposes of the survey we defined sexual assault as 'when someone either touches another person in a sexual manner without consent or makes another person touch them in a sexual manner without consent. It includes unwanted kissing and the touching of someone's genitals, breasts or bottom.'

# 3. Have you ever avoided booking or attending cancer screening (for example, cervical screening, breast screening, or bowel cancer screening) for reasons related to trauma?



Just under half (47%) had never avoided cancer screenings for trauma-related reasons. However, a relatively similar number of people had actively avoided cancer screenings because of previous or ongoing trauma (41%), with almost a quarter (24%) having avoided screening within the previous 12 months.

Where people answered 'yes', and if they felt comfortable doing so, we asked them to provide details about this. We received 23 responses. 21 were from people who answered 'yes', one was from someone who answered 'no' and one was from someone who answered 'unsure'.

"I have avoided attending cervical screenings as I have become distressed in the past."



"I attended but I delayed doing so. When the cervical screening invite first arrived I had some trauma memories quite active, and I knew that it would be difficult to attend until those had calmed down. When I'd tended to that and felt that attending for my smear would be possible I made the appointment with my GP practice. I then needed a follow up appointment at a colposcopy clinic. That then took a lot of time and chasing to make it happen because of hospital admin issues, and it was tempting knowing that I'd find the appointment difficult to give up and just not have the appointment. I preferred it when I could go to Abacus for my smear test not my GP. The staff felt more competent, and I never needed to have one of their smears redone for an insufficient sample, but I have with the nurse at the GP. Having to go back again doubles the stress and doubles the chance of me deciding I can't face it. If it wasn't because I am very aware of cancer risks I might easily have chosen not to go back. I would also feel more confident explaining my history in a sexual health specific service like Axess than in my GP practice. I'm not sure why that is the case, but it somehow feels easier. I'd also really appreciate it if home testing for cervical cancer could be rolled out. I think that would help many people. I don't have quite the same issues with breast screening (my abuse long predates having breasts, so they don't hold such traumatic memories) but I was very glad that all staff were women."

"I have a phobia after rape/sexual abuse of vaginal penetration with an object. I struggle to relax during a smear test so the speculum cannot be inserted."

"Used to avoid cervical cancer screening."

"First smear test was to be booked but I was putting it off due to the idea of having to go through an internal examination again like when reporting my assault."

"I would never attend an appointment on my own. Most hospitals will allow someone to attend with me when asked. Only one has not and unfortunately that was a male doctor who said no."

"Smear tests are routine for staff, but it can take more time. There's no point [at which] you can say why you might find it difficult. There's no box in the screening that asks if you have experienced sexual trauma so the person doing the test understands why it is harder."

"Because I had a traumatic experience with a NP [Nurse Practitioner] after I was raped, and it made my experience invalid. I didn't feel as though I would be properly listened to or respected at the hospitals/doctors. When I did eventually have a smear it was horrifically traumatic."

"Afraid of being triggered."

"It is extremely difficult to find trauma trained nurses. I find no one listens to me even if I have to go through the difficulty of explaining I've been raped and feel retraumatised by the dismissal. I also have been ignored and felt compelled to accept a male doctor even when I've specifically requested a female one. I get no extra care or patience when undergoing a smear, so I avoided it and still do."

"[I avoided a] Cervical smear."

"Can feel very invasive, brings back feelings of trauma."



"I have avoided attending cervical screenings. I find even the idea of the examination to be very triggering - lying down, half dressed, in a very vulnerable and powerless position with someone else having access to your genitals reminds me of memories of my own experiences of being raped and gives me strong flashbacks to some of my worst and most traumatic memories. I don't know how I would cope with the exam. I have only seen non-NHS organisations talk about sexual trauma and screening and I don't feel confident advocating for myself because I don't feel confident that I will be listened to or fully understood by NHS staff. Even in regular appointments, staff are often busy and rushed even though they're polite, but this wouldn't make me feel safe during a screening. When medical staff have talked to me about it (e.g. at in-person appointments when a screening is due), it feels very judgemental. Sometimes people might talk about it being embarrassing but going through the procedure would be so much more emotionally and physically intense for me, and I don't know what is reasonable to ask for in terms of support. Letters from my GP practice reminding me to attend are also very intimidating it's like TV Licence letters, they start off nice and then just get more demanding and threatening (stats about health risk, being instructed to contact the practice regardless even to tell them I won't attend) - it does not help me manage my feelings or get the confidence to enquire because the tone is so judgemental. I don't want to have to disclose my worst ever experience just to be treated with respect or to be given the time I need to make the decision on my own. NHS marketing makes the procedure seem like nothing, but I also have a number of friends who have had bad experiences with screening, either finding it painful or not being treated respectfully by staff, and this also does not help."

"A nurse that I kinda knew a bit asked me if I wanted to get it out of the way when I had an appt for something else."

"Because of the intimacy of examinations."

"I know I answered 'no' but I'm not old enough yet to need the cervical cancer screening. It is something that's really worrying me and will be avoiding when I'm old enough for it."

"It took me a long while to agree to my first cervical screening appointment (I had it about I year late) as I suffer from medical PTSD (gynaecological) and Sexual PTSD, and the thought of having to attend a medical setting to have such an intimate test performed caused severe flashbacks and depression."

"The previous time I had a cervical smear I asked the nurse to stop, and she didn't. For me that brought up a lot of feelings and I can't put myself through it again. I felt so alone in trying to deal with it."

"I'm overdue my next smear because my first smear was so traumatic. I have sexual assault trauma from when I was a teenager. My first smear was so painful I felt like I was being split in half, and the nurse doing it, who is still the main practice nurse at my GP, was very unfriendly and very abrupt and rude, and when I was shouting in pain, she ignored me and continued on. I felt retraumatised and have not been back for my now overdue smear."

"It's been longer than 12 months."

"I avoid these due to how traumatic any medical procedure is for me. I do not like things being inserted into my body (mouth in particular) due to the sexual abuse I experienced as a child in care."

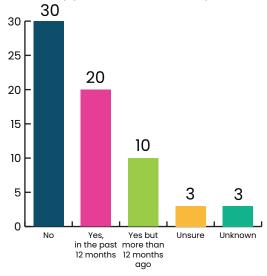


"It brings on a trauma Trigger for me and I do have PTSD. I don't like anyone that I don't know or trust to touch me."

"Difficult boundaries with physical touch."

## 4. Have you ever avoided other healthcare appointments in the past, for reasons related to trauma?

Equal amounts of respondents (45%) had, and hadn't, avoided other types of healthcare appointments, but 30% had avoided appointments in the previous 12 months.



Where people answered 'yes', and felt comfortable doing so, we asked them to provide details about this has impacted on their healthcare. For example, were there types of appointments they felt more comfortable attending than others?

20 people provided further information.

"I never really had good support for the trauma, and I have complex PTSD, if my appointment is with a male doctor and I have nobody to attend with me, I will either rearrange or not attend. I also believe that it is evident in my notes that I have experienced sexual trauma as when I have attended appointments with male doctors alone, they have excused themselves from the room and come back in with a female member of staff, even when the appointment is not related. This makes me extremely anxious about what is written in my medical records. I also find vaginal scans extremely triggering and have avoided gynae appointments if this is suggested as a procedure."

"Scared to go for vaginal based exams (e.g. checking for endometriosis)."

"I find it uncomfortable speaking to people in person sometimes. Would appreciate being able to get more advice using text-based services."

"Delaying appointments but having them in the end when I felt more prepared / my trauma felt most settled."

"Too embarrassed to get STD tested."

"I do not feel comfortable attending appointments where a male doctor is present. When talking about mental health and the impact my trauma has had they have been very submissive and lacked compassion."



"It's easier to have appointments with female doctors but that can often mean waiting for longer. I have found going to the GP scary and this redirects the appointment on to emotional reaction rather than the reason I wanted the appointment."

"In the moment when I eventually attended it was all I could focus on so answers to the questions asked did not fully reflect what I thought."

"I avoid healthcare appointments where the subject of a smear test is going to come up.".

"I avoided a trans nasal camera for as long as possible. I called to ask if I could be sedated due to my PTSD and was told no. I went along to see if I could cope and was so anxious my blood pressure reading meant I couldn't have the procedure. It wasted my time and the hospital's."

"I suffer with various things probably including PTSD (never diagnosed, always depression) but have never been able to discuss this with my GP. I was sexually abused as a child [by male family members] and I do have lasting effects from these physically and mentally but have never felt comfortable to ask."

"I generally tend not to seek out healthcare unless I can avoid it. Professionals can be very dismissive or judgemental and I find seeking healthcare to be very anxiety-inducing. I know many staff are respectful and kind, and I have had a number of good experiences, but I have also had some very horrible experiences of being judged, ignored, and treated poorly by medical staff which stick out in my memory, even in services where you would assume staff would be good. You never know if the person you see will be respectful or not. I know my trauma impacts my emotional and fight/flight response so advocating for myself during a negative encounter is often hard. I have been working on advocating for myself in personal therapy and think I am improving, but the power differential in healthcare settings between professional and patient often makes these situations more challenging and is an area where I have less confidence."

"It's more THAT THINGS ARE DELAYED UNTIL IT GETS QUITE BAD. An ex did something bad to me and it took a long time for me to get it checked out. I had a bad experience with a female GP, so I went to the WIC [Walk-In Centre] but was told I had to go to see a GP who was male but easier to talk to, he got a chaperone, he was amazing really, he set time aside. He made it not rushed, very nice, and I stayed with the practice because of him. I felt I could finally say things, took more than 2 years, but the practice changed, and that GP left. And I haven't been back to the practice since. Can't move because other services are linked to that practice."

"Any hospitals make me feel very triggered."

"I was anally raped but had not yet come to terms with it. When I started bleeding there when going to the toilet I got it checked but was just told it was a tear. When I finally came to terms with why it was and the memories returned I started to ignore other medical symptoms and avoided going to the doctor's in case it was something else related. I still regularly get it reopening but have not been to the doctor since because it will either be the same where I'm told it will heal eventually or I'll be questioned about something that happened years ago."

"Due to my complex PTSD (medical and sexual) I find attending any medical setting distressing, and always need a chaperone. I am also autistic, so I have severe



sensory processing issues with medical settings and this, altogether, creates a very large barrier I have to overcome for every single appointment."

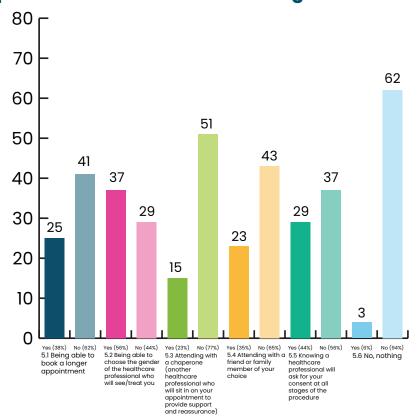
"It's been longer than 12 months."

"I have suffered with piles since I was a child. I was anxious petrified and wondering why I couldn't sit down without pain. About a year ago I finally got the treatment I needed with the support of my wife and a female GP who I trusted."

"I feel generally uncomfortable with the notion of being in a context that means I may have to undress/be left alone with somebody I don't really know."

"I was unsure if I had an STI and wanted to get tested but was afraid to go back to the same local clinic I went to initially after being sexually assaulted and given chlamydia. Free tests weren't on offer at the time in my town so I either had to go back to the place or purchase the tests which aren't cheap."

# 5. If you answered YES to either of the previous questions, is there anything that would make you feel more comfortable or able to access healthcare appointments or cancer screening?



Of the options provided, the most helpful was 'Being able to choose the gender of healthcare professional who will see/treat you' (56%), with 'Knowing a healthcare professional will ask for your consent at all stages of a procedure or examination' being helpful to 44% of people. Being able to book a longer appointment would be helpful to 38% of respondents and attending with a friend or family member would make things more comfortable for 35%. Having a healthcare professional act as a chaperone was the least popular option but would still improve the experience for almost a quarter (23%) of respondents.

It may well be that some of these options are sometimes already available to patients in some services but are not well-enough advertised or signposted. They may not be available in all services.



#### There were 14 additional comments:

"Knowing that I can choose when would work for me. My trauma is something I will be dealing with / tending to for the rest of my life but sometimes it feels more prominent than at others. Being a little bit in control of that helps rather than thinking that if I can't go at that time I have missed my chance. I have used the #CheckwithMe³ card to let the clinic know and that really helped. It felt I was taking charge and sharing what I felt comfortable to share and in doing so made the appointment more bearable."

"I was given speculums to take home and do exposure there with these prior to my appointment. The nurse said I can insert the speculum during my smear test to give me the control."

"Only once have I been asked for consent during a screening that involved an internal examination."

"For smears or personal examinations it would be easier if it was a standard question if you have experienced sexual abuse - it can be hard to bring up out of the blue and would easier if it was a standard screening question."

"Knowing that my feelings will be valid and if I ask for the procedure to be stopped, it will be."

"Being offered sedation or at least an empathetic ear regarding my anxieties."

"I would never think of feel comfortable asking GP or thinking they could even help me with this apart from giving me the number to Talk Liverpool which is absolutely useless or waiting 12 months to speak to someone else. Have paid for 2 years of private counselling and gone into debt to do this as otherwise I would have been depressed for a lot longer. Maybe a suggestion of mental health nurses in the community, actually stationed in doctor's practice that you can access straight away would be a good idea. I would feel comfortable doing that she/he would be my first point of contact."

"A safe and quiet space for after the appointment, I was very emotional after my smear, and I would've appreciated the opportunity to take 5/10 minutes before leaving the practice."

"I think meaningful consent is important, e.g. asking and waiting for someone to say they are ready rather than just 'informing' someone of an action and immediately doing it (which is still better than not communicating!) I appreciate this may be hard with NHS pressures, but it would be really reassuring to be able to ask for this for certain procedures. I think if these were offered pro-actively that would help. At the moment I don't know what I can ask for or what would be allowed to help during appointments."

"Longer appt: Depends on what I was going for, about MH [mental health] would be helpful. At the moment I don't know any of them, so longer appt would help me to get to know them. I have autism too. Other: have a couple of people that you see so you get to know them, to help me feel safe. If I don't feel safe or don't know them I won't go. I feel alien to my GP surgery, it feels quite scary now I don't have a clue about anyone, it's making me feel quite anxious."

<sup>3</sup> This is a reference to the Survivors Trust #CheckWithMeFirst campaign materials <a href="https://thesurvivorstrust.org/training/health-care-resources-for-survivors/">https://thesurvivorstrust.org/training/health-care-resources-for-survivors/</a>



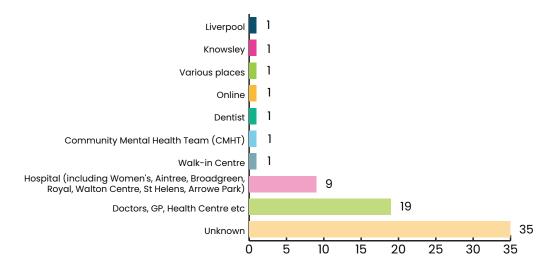
"Healthcare professionals need to be aware of past experiences and trauma informed."

"Maybe a more comprehensive assessment originally would have made me more comfortable coming back for a solution. I was originally just told it was a tear and will heal and now I dismiss it quite easily. If they had spent more time with me discussing what to do in future or asked more questions I might have reported it."

"Being able to book an appointment at the start of clinic to minimise the risk of prolonged waiting in the medical setting. Being able to request adjustments to make things better on a sensory level, such as no fluorescent lighting (they make a thrumming noise that is very distressing, and they are far too bright). I appreciate that sometimes the sensory trigger may be medically necessary (i.e. the clinician needs very bright lighting to allow them to do their job fully, but it would be nice to be offered the options for softer lighting or sensory safe waiting areas whenever possible."

"Ability/access to get my smear at a different service or by a different nurse - I do not want to have my smear done by the GP practice nurse I saw last time, but it seems the ability to specify who does it, doesn't exist at my practice."

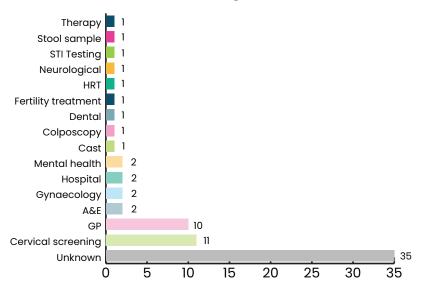
### 6. Where did your appointment take place?



From this point on, over half the respondents did not respond to the questions but of the 31 people (47%) who answered this question, several gave more than one answer. The majority of these had attended for screening appointments at a GP surgery/health centre, with hospitals being the next most frequent location.

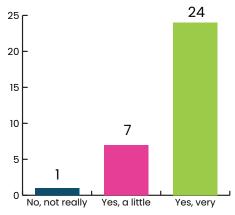


# 7. What kind of appointment or visit are you giving your feedback about (e.g. GP appointment, cervical screening, maternity services, dental check-up, A&E, mental health services)?



Again, 35 people (53%) did not answer this question and some of those who did respond provided more than one answer. The most common answer was 'cervical screening'.

## 8. Did you feel nervous or anxious in the waiting area before your appointment?



Of the 32 people who answered this question, only one person said they were not nervous or anxious in the waiting area before their appointment. The majority were very nervous/anxious.

#### 22 people provided further comments:

"Before any such appointment I have to do quite a lot of mental preparation. It's like there is a scared child part of me and I need to prepare and tend that part beforehand and throughout. I'm quite good at doing that now - I wasn't when I was younger. I took a calming book to read while I waited which was useful because there was a long wait due to appointments having been made for a doctor who wasn't rostered on so two lists had to be combined into one."

"Feel judged, rushed and not listened to."

"I don't know."

"I don't like being in a crowd of people. Especially around intoxicated people."



"I don't like to be in a crowded room with other people, nervous about the appointment and the psychologist was often late and kept me waiting."

"I find it difficult to be around males that I do not know and in crowded places."

"I have PTSD and was dreading the procedure."

"I knew my procedure would involve being touched in my genital area."

"I suffer with anxiety from what I have gone through over many years and get extremely nervous when attending all appointments."

"I was made to climb the stairs to the top floor even though I am disabled and struggle to use stairs (...), and I was unable to have a chaperone as [a female family member] was unavailable (...). I also received an erroneous reminder text which arrived with minutes to spare, so I had to dash to the appointment as fast as I could, which put me out of sorts (and it turns out I wasn't late after all!). The dentist clinic is very brightly lit with white walls which is a sensory issue for me. I also was aware I was about to allow someone to probe into my mouth and use needles and drills, which makes me feel very vulnerable (and reminds me a lot of when I was being swabbed by police after reporting my being sexually assaulted)."

"I was very nervous, but not really relating to past sexual trauma. I was discussing my mental health and was anxious about this."

"I was worried as it was a new doctor who would need to touch me to complete castings of my legs including upper thigh."

"I wasn't looking forward to it because of previous experiences with this person."

"It feels like everyone knows about your trauma/anxiety. I have left appointments before being seen because sitting in the waiting room is very hard."

"It is what it is."

"It makes me feel extremely uncomfortable and terrified for days before."

"Just a very awkward process, felt fine after but had repeated problems with faulty test results which meant I had to keep going back making my anxiety bad."

"My therapist has changed so I was worried about meeting my new one."

"The apprehension of the appointment being close."

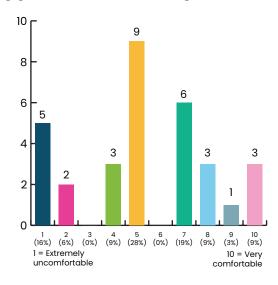
"The fear of reliving feelings or seeing equipment associated with the trauma. Having to admit to someone again that I am nervous because of what happened to me two years ago."

"The pain and discomfort I have felt at past appointments."

"The waiting is awful knowing what I'm going to have to go through on my own is such a reminder. I feel vulnerable and afraid."

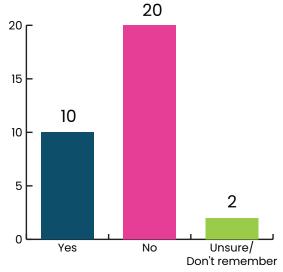


## 9. On a scale of 1-10, how comfortable did the healthcare professional(s) you saw during your appointment make your feel?



Although just over half (51%) of respondents did not answer this question, the answers we did receive were spread across the scale with the biggest group answering '5' (neither comfortable nor uncomfortable) but with slightly more people (13) on the 'comfortable' side of the scale than on the 'uncomfortable' side (10 people).

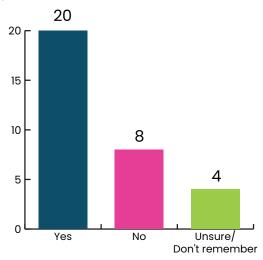
10. During the appointment, did you feel that you could take your time, and go at your own pace?



Twice as many of those who answered felt that they were not able to take the appointment at their own pace.

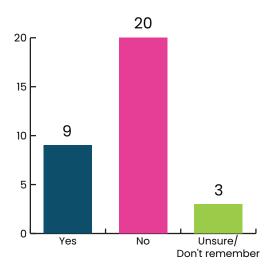


## 11. Did the healthcare professional(s) you saw give you the opportunity to ask questions during your appointment/procedure?



The majority of those who answered this question felt that they had been given the opportunity to ask questions. However, a quarter of people did not feel they'd been given the opportunity to ask questions.

## 12. Did the healthcare professional(s) you saw offer any adjustments to make your appointment easier for you?



In this instance, the majority of people who answered this question felt that they had not been offered any adjustments that might make the appointment easier. In the survey we gave examples of possible adjustments including "being given a clear explanation of what will happen, being offered more time for examinations, being given a choice of waiting space, being given a choice of position for any medical examination, being told that you can wear as much clothing as possible throughout the examination."

We asked if people would like to share any examples of adjustments which had been helpful. We had 9 responses. These mostly focused on positive experiences but there were also examples of where adjustments or supported opportunities to disclose trauma had not been offered.

"I had come prepared with one of the Survivors Trust #CheckWithMeFirst cards filled in with details on how I would be feeling and what might help. I gave it to one of the nurses before my appointment when they were updating on delays. They read it and thanked me for sharing it. They checked in with me about who would be in the



room (the doc and two nurses) and asked if that was too many - it's good that they asked but I actually find being alone with one person more difficult. They then came back to say that there was a GP who was shadowing but that they could ask them to leave if I wanted. After confirming it was a woman I agreed to her staying, but it was clear that it was my choice. They talked me through the process. They reminded me that I could stop if I wanted to and they followed all my requests on the form - this included little things like using soft tones of voice, making sure I could see their faces. They suggested I might want to leave my dress on under the hospital gown. Mainly it was their tone that helped and knowing that I'd been heard and respected. I've been to the same clinic before and they were nice but this time because I'd shared my needs it felt different, better. They didn't make me feel 10/10 at ease but no one could in that situation given my history, but they did everything they could have done and everything I asked."

"Longer appointment time."

"Fully explained the procedure and allowed me to take my time."

"Excellent care. My consultant let me leave my underwear on until I was put under GA [general anaesthetic] then she removed it herself. She stayed with me and held my hand whilst I went to sleep. She put ECG [electrocardiogram] monitoring on me so it would only be her who touched me. All the theatre staff knew my background as the consultant had told them beforehand like she had promised. I was given time to ask questions. Everything my consultant had promised would happen to help make my experience easier happened as she said it would, enabling me to put my trust in her."

"This was only a good experience because there is a particular doctor at my surgery who is very relatable and kind, but she has now left."

"Offered to reschedule appt."

"Positioning."

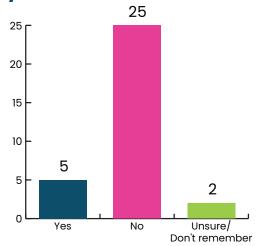
"I am just a person who fits in with their appointment slots. The tiny room was not adequately soundproofed, you could hear laughter outside, made me feel like they were laughing at me. I also wasn't able to stay in the room after the counselling sessions to ground myself before walking through a busy waiting room, feeling everyone was looking at me and could see my distress. I have had appointments at RASA [Rape and Sexual Abuse Support]<sup>4</sup>, and they really understand how important this is for survivors."

"The clinician told me that my baby would be taken away from me, based on wrong assumptions. I had to disclose that I had been pregnant through being raped. I had been in an abusive relationship and was in a refuge."



<sup>4</sup> www.rasamerseyside.org

## 13. Did you feel able to ask if any adjustments could be made to make the appointment easier for you?



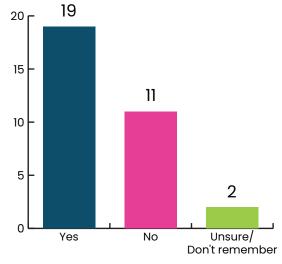
Since clinical staff do not always ask questions designed to create a safe environment for the disclosure of traumatic experiences, we asked how confident people felt about asking, unprompted, for adjustments to be made. The vast majority of those who answered did not feel able to request this.

Four people provided further information about this. Two of them referred back to their previous answers (about using the #CheckWithMeFirst card and about asking to leave their underwear on until asleep, and having the consultant stay with them while under anaesthetic). The other responses were:

"I wasn't offered the opportunity; he knew about my issues but I think he enjoyed watching me struggle."

"I spoke to them afterwards and was told there was another way of leaving the building that offered me more privacy and I should have asked. It didn't seem that the psychologist had even thought about this, or maybe was unaware too."

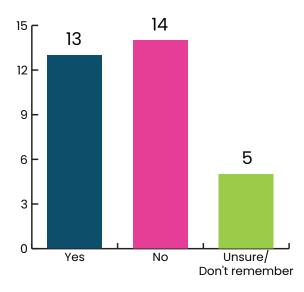
## 14. Did the healthcare professional(s) tell you what they were doing and why?



Whilst more professionals than not explained what the procedure entailed, there were still one in three who did not.

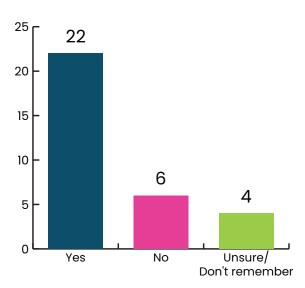


## 15. Did the healthcare professional(s) check that you were happy before proceeding with each step of the appointment/procedure?



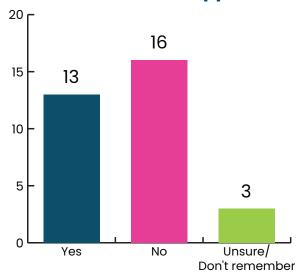
The figures were similar for professionals who did and did not check with the patient about each step of the procedure.

## 16. Did the healthcare professional(s) ask for your consent before any medical examination?



Over half of those who answered this question confirmed that healthcare professionals had sought their consent prior to beginning any medical examination but 10 people said they hadn't or were unsure.

### 17. Did you feel you had control of what happened in your appointment?



Half of those who answered this question felt that they were not in control of what happened in their appointment.

Of those who felt they had some control, one referred back to their use of the #CheckWithMeFirst card as having been very helpful. 12 other people gave us further information:

"I would have appreciated the opportunity to discuss procedures in more detail before proceeding, so I fully understood what was about to happen and why."

"Once my therapist changed to a different one, I got more uncomfortable because he was male (my previous one was female). He kept questioning why I preferred phone calls rather than video calls and kept pushing me to do video calls without my consent or considering how pressured I felt."

"No - I mentioned twice I was sexually assaulted and that I have had a speculum exam before but it was not even listened to and just simply shrugged off before asking me to get on the bed."

"I recently had an ultrasound examination on my [abdomen]. I had asked if my partner could be in the room with me during the procedure, to which I was told no. The doctor carrying out the procedure was male. I felt so uncomfortable during the procedure and really struggled to not get upset."

"My GP asks what I want to get out of each appointment at the beginning and focuses on that."

"Consultant had explained everything to me and was very empathetic about my worries. She did all she could to make me feel comfortable."

"Again this particular doctor was nice but she's not there anymore and wouldn't feel comfortable with any of the other 5 doctors on offer."

"Too many people were involved. Understand there are shift changes but there was inconsistency of care, explanations and lack of communication at times."

"I tried to ask the dentist to stop the scale and polish as it was causing sensory



distress but she continued insisting we were 'nearly there'. I also informed the dentist that the numbing hadn't worked and that I could feel her drilling and causing pain, but she continued despite knowing this!"

"I asked to stop as it was hurting and was told no as we are nearly there. I felt violated, out of control and like I was going through it all again. Now I can't contemplate going back for my next one and am putting my health at risk because of the reactions of that nurse. As if being sexually abused isn't bad enough but to be violated by a medical professional is deplorable."

"I have said no to some of the above, but it is more that it wasn't applicable - there was no examination etc, it was a discussion only, and there weren't really any adjustments required. The appointment didn't relate to my sexual assault history."

"It was a bit of a blur, the appointment, as I felt rushed and pressured, and unsettled in the room. I did not feel I had control of the surroundings, felt anyone could burst in, felt people could hear what I was saying. I needed more time to get used and settled into the room before going into deep stuff."

## 18. Was there anything that the healthcare professional(s) you saw did that improved your experience?

We received 20 responses to this question.

"Acted on the things she said would be put into place to help me. (Many times professionals say things will happen and then they don't)."

"Asking at the beginning what you want out of the appointment."

"Just being more respectful and aware of what having PTSD means for somebody and not treating it with "Oh you'll be okay I promise". That's not enough. Please ask questions. Have it on a pre-appointment check form maybe."

"Listening and understanding."

"Not this appointment, but some nurses have telephoned me after treatments or procedures to check in with me and see I'm ok, that's reassuring and helpful."

"One nurse was kind."

"She listened. Although she rushed she was very thorough."

"Spoke through each step – briefly, but still explaining."

"The GP was very empathetic and actually let me speak, and actually listened."

"The nurse was very friendly and caring and talked to me calmly and causally throughout."

"They allowed me to take my time and was very patient with me and tried their best to understand me creating a relationship of understanding between me and my previous therapist."

"They were supportive after the procedure, seeing how distressed I was but I feel the



distress could have been minimised with better procedures in place."

"They were very friendly, made me feel less nervous about it all."

"Took her time, was reassuring."

"Yes... Mainly the respect and care they showed."

"No, I left feeling super traumatised and upset."

A further 4 people answered "No."

# 19. Do you have any suggestions for ways that healthcare appointments could be improved for survivors of rape, sexual assault, sexual abuse or sexual exploitation in the future?

20 people answered this question.

"Ask us what we need to feel comfortable, let us know that we have choices."

"Be more willing to discuss this in a less formal way - it should be ok to talk openly about it."

"Be patient, understand and have empathy, not all trauma triggers are visible."

"Communication during appointments. The option to have female only appointments where possible. More training for staff on PTSD, mental health issues as a result of trauma, especially sexual trauma."

"Don't make us feel like what happened didn't happen. Don't write completely different notes to what I say. Don't roll your eyes at me when I tell you that I am too traumatised to do my own vaginal swabs. If you don't have the right information, speak to someone who does so that I can have the evidence on my body collected."

"Explain everything. Show equipment and check for consent for every aspect. Treat with respect and dignity."

"Have individual counsellors/mental health nurses working inside the doctor's surgery to make them more accessible as many doctors won't be experienced with mental health they are only trained for physical conditions."

"I believe that regardless of the reason you need it, clinicians should be explicit in obtaining consent, and should heed when a patient withdraws consent even part way through. (e.g., when I was making it clear I was in sensory agony, the dentist should have stopped the scale and polish) or should make adjustments as the need arises (such as when they find that their numbing injection hasn't worked, they should add additional anaesthetic, not just carry on causing immense pain)."

"I feel perhaps asking if the person has ever had an unwanted sexual encounter and if they need any extra support may have helped. This might have allowed for a discussion on options to help support me."

"I would like more patients and staff to be aware of the #CheckWithMeFirst cards. That made sharing my needs much easier than just starting a conversation would



have been. I'd like all NHS staff, including those less specialist than these, to be aware of the prevalence and impact of sexual trauma and the importance of making adjustments – sometimes it might only be little changes but they would help me. I'd feel more confident in future to ask but others might not. Visible posters up could make it feel more ok. Having better information at the point of invitation would also help."

"If there is something in your notes that they are aware of it, if it's delicate – asking the person what might help, or having an agreement to have the same staff, or having someone with you at the appointment, them being aware, and asking what would help. Also what the environment is like that the appointment is in, e.g. checking if there is anything that might be triggering and ask if someone has a particular worry having it in a more neutral place. And knowing what will happen, what to expect. Sometimes there is that power thing, it can make me shut down or help me speak – if they're abrupt I can go into that fear. It can be the difference between being able to get the help that you need."

"Listen to us, get trained in understanding trauma and how individuals may react or respond due to it. Be more reassuring."

"Maybe extra time be given for appointments. So survivors can explain their worries."

"Not related to the GP appointment I've just mentioned, but more generally - especially for any appointment that includes being examined etc - clearly explain what will happen BEFORE the examination begins and explain why it is being done. Sometimes, i.e. for personal examinations or anything that involved removing clothes - I don't know how to bring up my sexual assault history, and I have social anxiety, so the idea of just announcing that to a stranger fills me with dread if I have to initiate it. I wish there was a simple way to indicate this to the professional, or even a standard way that that is screened for at the start of the appointment, perhaps on any forms during check in. I know this wouldn't work for everyone and could be triggering, but I personally would find it useful, as I wouldn't have to initiate this topic."

"Offering the patient control over inserting the speculum."

"People just need to be aware and sensitive to other people's issues. There is not a right/wrong way to act around a person who's suffered sexual abuse, all we want is to feel heard and understood."

"Please just be more aware, "I promise it'll be okay" is not enough. Maybe put something on a pre-appointment questionnaire giving patients the opportunity to explain their difficulties."

"Please let us have it on our medical record so we don't have to explain, and we don't have to relive our traumas in an already emotional and sensitive situation."

"Staff to read my notes beforehand so know that I need a female member of staff to see/treat me. Instead it's often left up to me to explain this and I'm feeling distressed as it is. Then I have to wait longer to be seen by a female. It's not as 'accepted' for a male to request a female member of staff as it is a female as for a female and I feel it's often greeted with suspicion a times." (Male respondent)

"Take time, be courteous and kind - also making people feel comfortable."



20. Is there anything else that you would like to share about your experiences accessing healthcare services as someone who has experienced sexual trauma? You can use this space to tell us about anything else you think is relevant, including experiences of different appointments.

14 people answered this question:

"After being raped I was signed up for counselling with an organisation (...) at home. I told the people that I would prefer face-to-face counselling or at least Zoom instead of over the phone because it felt weird opening up about what had happened to me to someone I didn't even know or know what they looked like. Especially considering I had already had to speak to many people at my Uni/accommodation, who I didn't know either, about my situation. They didn't accommodate this for me and I had a phone call appointment. I found the woman to be fairly irrational, telling me that "it happens to men too" when I had never brought up the fact it didn't and also was not what I needed to hear, I just needed her to acknowledge it happened to me. At the end of our appointment she spoke about "setting boundaries" in my relationships in our next session, another weird choice of wording considering I had set my boundaries with my abuser when I told him I did not want to have sex with him. I'm not sure if I was extra sensitive at the time with how fresh it all was but I do think if you're in that line of work you should surely have more compassion and understanding for people that have been assaulted instead of objecting to everything they say."

"After my assault, I developed [an infection]. I attended the [a local hospital] who gave me medicine to cure heavy bleeding but nothing else. When I passed out in pain and an ambulance took me back to the [hospital] I was treated as a timewaster who wasn't worth helping (a massive complaint went ahead at the time). I then, days later, attended [another hospital] for a second opinion as I was in so much pain I was asking to die. The first doctor to examine me there immediately picked up that it was PID and had been all along. When we asked why the [first hospital] hadn't asked any questions about sexual history (surely relevant to gynaecological issues!) they said that it wasn't something the doctors are comfortable with!! I pointed out that I was distressed and not able to add any information beyond answering their direct questions (I was hardly about to declare unprompted that I was raped when I was still in the denial stage of processing the trauma). I pointed out that this specific line of questioning by the doctor at [the second hospital] got me diagnosed and treatment started immediately, and he was disgusted that I had been left in such a state. I am actually infertile now, as a result of the PID. Therefore I think it should be prudent that a doctor will enquire about sexual history whenever medically relevant (which is ALWAYS for gynaecology). I know some people may still not tell the truth, but it is providing the opportunity for them to do so. Maybe if my doctor at the [first hospital] had asked the right questions, I might not be infertile. Infertility seems a large price to pay to save the blushes of a doctor who is supposed to specialise in gynaecology!"

"I am not looking forward to my next appointment at [named mental health team] as it is with a male doctor, I have been told that I can bring my wife and there will be a female staff member there too but I would still prefer a male not to be there. I am told he's good but I'm still really anxious about it. Over the years at Moss House I have been often told that there are no female staff available and that I'd have to be seen by a male, in spite of what's been written in my notes about how triggering it is for me. My GP surgery are much better now and make adjustments as they know me, but I feel the rest of the system needs to change."

"I feel invisible."



"I find so many GP's (especially older males I'm afraid to say), are very unempathetic when it comes to abuse-related trauma. Domestic abuse seems a little more understood, but my experiences as a survivor of childhood and adult sexual abuse and the lifelong trauma and PTSD this can leave you with doesn't seem to have been considered. I have had the odd GP or consultant be amazing, but the majority are unaware and have a possibly unintentional attitude of ""Ohhh honestly, it'll be fine, just give it a go". I also have no faith in anyone passing messages on to consultants or other health professionals when I have contacted them beforehand to explain I struggle and to please be understanding as this has rarely happened. I understand it's because the NHS is overwhelmed and overstretched because the government are doing their darndest to break it to the point of having no choice but to privatise, but please, just be kind and sensitive!"

"I find that they always discuss weight and that when I needed anti-depressants they said that might not work as you will put weight on. They don't see my weight as an emotional issue caused by trauma and sexual abuse. I feel that they offer no help and that I tend to put off and avoid appointments as its traumatising and can make my mental health worse. No real solutions to problems unless its basic health. Would be good to see someone that has better approaches to mental health and the bigger effects of trauma and the lasting symptoms and health impacts."

"I have had several appointments relating to sexual trauma and long-term effects – often staff prioritise safeguarding over medical care. They told me what I "should" do (telling police etc) rather than focusing on my medical concerns. I made the decision not to report it and wanted doctors to respect that decision – some did, some definitely didn't. I feel that staff on gynae wards need more training – A&E staff and GP (more front line services) were brilliant!"

"I have rarely come across a medical professional who has asked questions about consent to aspects of procedures or given options/choices."

"I haven't accessed them at all only at breaking point when I have become clinically depressed. Anti-depressants are thrown at you and off you go. I have had to pay 2 years of counselling and got into debt, however not everyone has that luxury and I suppose then it becomes an alcohol and drug problem.

"I thankfully have a very understanding gynaecologist who listens to me and cares for me. I have had a bad experience of having a smear test at a different clinic when the nurse left the room for a long time and left me exposed."

"It feels like there is no support out there. I was struggling and so self-referred for specialist sexual abuse counselling for which I have been left alone on a waiting list with no support for a year. What is the point? You refer when you are in crisis and need help and it just goes to show how alone you are with this."

"It isn't just sexual health appointments that have been difficult for me. I know if I ever needed it other invasive procedures e.g. colonoscopy would also be difficult. In the past I've also even found dental and opticians appointments hard, someone being so close and in a closed room. I've not felt able in the past to ask for the optician's door to be left open because I've not felt that was allowed to ask or I've wondered if they would be offended (like I was assuming all men are potential offenders). If I knew people knew it wasn't personal I'd feel more able to ask."

"Soon I will be asked to attend a cervical screening. Whenever I think about this I have heightening anxiety and panic, and I am still a couple years away from that.



"My first smear was awful at my GP practice in Maghull (Sefton). I did not divulge my sexual assault history to the nurse. She was immediately not very friendly, so I didn't feel comfortable sharing. The smear itself left me feeling violated and it was extremely painful, and this was ignored. The nurse was aware this was my first smear. The nurse did not explain anything she was doing, although I had already looked it up in order to feel prepared. What I was unprepared for was the pain and the nurse's attitude. The nurse continued on throughout the smear, with me screaming in pain, and I felt gaslighted and violated. The speculum use was agonising, and I felt like I was being fully split in half. I have a connective tissue disorder, and this causes skin and joint fragility. I suffered microtears to my vagina following use of the speculum, which were painful for 2 or 3 weeks afterwards, and which bled for around a week. I believe the speculum used was too large (although size was never mentioned or discussed with me). Also, the position I had to be in for the smear, was made worse by the fact I was made to sit on my fists and push my bum up in the air, due to having a tilted cervix, and this positioning caused my hip and shoulder to subluxate (partially dislocate), and this was very painful. I wish different positioning was discussed to find a most suitable position for different needs. While I know that stirrups are not the preference for many people, for me, they would be A LOT more comfortable than the common 'butterfly' position. I wish I had asked her to stop, but I felt extremely vulnerable, and I also felt like maybe I was being a baby, because it was my first smear and everyone else I know who has had a smear, said it isn't painful. I felt very unprepared for the reality because of this. I wish more realistic stories of smear pain were shared - not everyone just finds it "a bit uncomfortable", and while I appreciate the NHS and fellow cervix owners don't want to scare people off having their smear, the lack of transparency around smear pain, left me very unprepared. I wish my cries about pain during the procedure would have been enough for that nurse to stop, but she was quite aggressive and had already got annoyed with me that I hadn't "warned" that I had a tilted cervix. Once the speculum was finally in, the nurse exclaimed "you have a very angry cervix", with no further explanation, which was terrifying. I was due to go back to work after my appointment and had to take time off because I was so traumatised and in so much pain. Following my smear, I received a referral to the Women's. It did not say what this was for. After phoning up, I found out this was for colposcopy. I assumed this meant my smear had come back with something showing, but I then got my smear results back and they showed no issue. Turned out the GP practice nurse had referred me to colposcopy anyway. I received absolutely no information about what colposcopy meant. I took my sister with me to this appointment, and I advised the health professionals at this appointment, about my awful smear experience. The staff at the Colposcopy clinic were lovely, and this was a much better experience, both with regards to pain, but also, staff attitudes and feeling safe. A small speculum was used, and this gave me no issue and was a lot more comfortable. Also, the position with stirrups was much more comfortable. There were 2 nurses in the room who were lovely, as was the doctor who did the colposcopy. She explained what she was doing at each stage and was overall a much more positive experience. "Cervical Ectropion" was found, which is benign and is where cells from inside the cervical canal grow on the outside of the cervix, and this didn't require any further treatment. I do not feel comfortable going back to my GP practice for my smear. I am now very overdue my next smear. That nurse is the only nurse who ever seems to be there, and I refuse to see her. I wish I could go back to the Colposcopy clinic for my smear, I wish that was an option. I don't know where else I can go for it, and online information, and even asking Jo's Trust<sup>5</sup>, has not given me any answers about where else I could access this."



<sup>5</sup> A cervical cancer support charity which has now closed.

# Cervical Screening Case Study

Whilst undertaking the research outlined in this report we were pleased to receive funding from Healthwatch England to interview one woman with disabilities as part of a qualitative research project they were conducing on cervical screening (for cancer and HPV<sup>6</sup>). Healthwatch Liverpool was one of 10 local Healthwatch organisations participating in this research. See page 6 for further details about how we worked with WHISC to conduct this interview.

The interviewee's personal experience is summarised below and also contributes to a Healthwatch England report<sup>7</sup>.

We have summarised the information using the following headings which match the 'coding' used by Healthwatch England in their research. Quotes have been edited, indicated by the (...) symbol, for clarity.

#### 1. Invitations and Appointment Booking

The interviewee (who was in the 30-49 age group) thought she had been invited for 6 or 7 screenings in her life and had attended all of them but said that Covid had impacted on the system and she thought she had not been invited for the most recent screening that was due. She intended to follow this up with her GP and also to ask whether her IUD could be removed at the same time.

The first time she received a cervical screening invitation she did not know what it was about and felt the invitation letter did not include enough clear information, particularly about potential pain and discomfort:

"When I got the letter (...) for the first time I was invited, I am wondering why, what it involved, and I had 101 questions, and that letter didn't (...) provide any explanation to it."

"I think that it needs to be clear that actually it might be painful."

She could not recall being given a patient information leaflet with any of her invitation letters, at the appointment or with the results letter.

#### 2. Hesitation

Despite the pain and discomfort involved, the interviewee had no hesitation about attending screening appointments as she was aware that they had the potential to be life-saving, and because she was used to pain.

"I mean I have given birth three times (laughs) you know like since [I was first invited to a screening], you realise that actually there are more traumatic things that will affect you, and more painful things [and] actually, out of all of these things, this is (...) the least invasive thing you really have to deal with."

<sup>7</sup> Further information and Healthwatch England's report will be available at <a href="https://www.healthwatch.co.uk/news-and-reports">www.healthwatch.co.uk/news-and-reports</a> soon



<sup>6</sup> Human Papilloma Virus www.nhs.uk/conditions/human-papilloma-virus-hpv/

#### 3. Family/friends

The interviewee thought there was not enough awareness that it's possible to bring a chaperone to a screening appointment. This was not something she'd ever been offered.

"there's no question of, would you like someone to come with you? And that's a possibility, you know, you could if you wanted to, you know if you had a close female friend or whoever you feel comfortable or safe with."

#### 4. Information

Generally, the interviewee did not feel the invitation, booking system or screening appointment took the opportunity to share useful, and potentially reassuring, information about support for patients who have experienced sexual trauma.

"there's never a question of have you had any sexual trauma (...) that doesn't come up in the letter, there's no mention of that (...), I mean I have a friend who suffers with (...) vaginismus okay, there's no question of – do you have any problems in that area? Okay. Quite frankly I don't think she can actually have them [screenings] because they can't actually fit the speculum up because of the bad uh, uh everything's too tight (...) and when something is insistent on pushing through it, it clamps up even more (...) and that's something else that isn't mentioned, okay, within it, you know, quite simply right what you need to do at this point is relax, okay, if you don't relax (...) we will find this process a lot harder."

#### 5. Knowledge

The interviewee felt that she had not initially had enough knowledge about the impact her health conditions may have on her pain threshold.

"I feel pain far more (...). Now, when I first started having the smears (...) there's no mention of any of these things or how it might impact you but I had got my diagnosis of fibromyalgia, I just didn't know about that link (...) between the two and in all honesty I suspect they did (...)they could have put those two things together and gone, actually, no, we need to go a bit easier on this one."

She also felt that clinical staff should have more knowledge of the possible impact of sexual trauma on patients and should be more relatable in their communication style and less procedural.

"I've started to get dissociative seizures (...) if I get overwhelmed by (...) the pain situation, by anything else, I just dissociate. And then they're back to square one okay (laughs) it's like... and the problem with people with trauma is often they get stuff like that (...) They get tics, they get tremors, they get all sorts of other inexplicable um, what d'you call them, symptoms that can impact the ability of someone to be able to actually continue to do the test itself."

"If you've never had a cervical smear and someone says "What reasonable adjustments can we make?", how can you possibly know what reasonable adjustments to make when you've never been in that situation?"

#### 6. Screening

The screening process itself was unpleasant and painful, because of the interviewee's health conditions, and experience of sexual trauma.



"I was surprised at how much it hurt actually (...) they used a metal speculum (laughs). And then, goddamn it, (laughs) it was like a cheese grater. I was just like what the hell, you know, you know, why aren't you telling me this before you put this inside me?"

She also said that specific consent to begin the procedure was not sought, leading to dissociation and negative feelings about her own body and sexuality:

"You don't get asked any permission (...) They just say "We're gonna do this, it might hurt a little bit". It's all very clinical (...). And there's not really much consideration for you as a person or your feelings or your emotions I don't think (...) as a consequence of me being in hospital so many times and all these different things (...) I think I've become a bit dissociated from my body overall and I feel a little bit like a chicken in a chicken factory, to a degree. So I find it quite hard to actually feel sexual about myself (...) and feel like a woman, you know?"

"and people inspecting your privates, I personally think (...) because you go, oh well, that's just, that's just that part of me but then you kind of subconsciously... you're negating that part of your body and you know, (so clinical staff) may as well have a look at it (...) And I mean does that consequently (...) have a knock-on effect to whether you enjoy sex or think about sex, and I can honestly say that because for the last couple of years I haven't really had any sex and I don't care (...) you kind of almost switch off to it. You go, right yeah, you do what you need to do (...) I think I'm almost indifferent. And that ain't right, is it really?"

The interviewee also speculated about the possible relationship between invasive procedures and her health condition, Functional Neurological Disorder.

"I wonder whether that has a link with my current FND."

She was not personally concerned about whether the procedure was conducted by a woman or a man, or whether a man was present in the room,

"No I mean it's like they've gotta do their job."

but having students present could be awkward.

"The only thing that sometimes bothers me is when they try and say (...) "We've got people training, is it alright if someone comes in?" (...) you feel compelled to agree. I don't think they should do that there and then. I think (...) they should ask you before you go (...) because then you're not being put under pressure whilst you're there to have to comply, to comply with something you're not actually happy with because I think (...) too many women will just go along with it and say yeah because um, just because, and then you go away and you think, well "Why did I say yeah?" I didn't really want that."

#### 7. HPV vaccines

The interviewee had never been offered an HPV vaccine and felt that it was not clear that the screening was for HPV as well as cervical cancer.

"If I didn't know what I know about cancer, HPV and the rest of it, if it hadn't been for the fact that when I got married the first time his wife had died because of cervical cancer (...) I probably wouldn't have gone again."

She had also not been offered an HPV test even when she attended a sexual health/GUM clinic due to concerns she had about a partner's previous sexual history.



#### 8. Self-screening

The interviewee had not heard of self-screening/home-screening but when informed about the pilot studies elsewhere she said she would not feel confident conducting one on herself.

"It's a little bit like doing me covid tests, you know, have you followed all the instructions, have you gone through it all and put things in there, that, the other? I prefer to get someone else to do it and know consciously that it's been done right."

However, she suggested that women who may find it difficult to attend screening appointments for cultural or other reasons – such as chronic fatigue or long working hours – might find self-testing very helpful. Although, other women with mobility issues, such as herself, may find it difficult to do on their own. She felt that a person-centred approach with a range of options offered would lead to a higher uptake of screening.

#### 9. Suggestions for improvement

The interviewee had a number of suggestions that might make the experience easier for herself and other women:

a) Focus on creating a relaxed and welcoming environment, where consent is sought throughout the procedure.

"They should be working harder to (...) create a relaxed environment and do it in a relaxed fashion so that the person is nice and relaxed and they feel happy with the situation before they do it (...) I think that's partly why my first experience was actually quite painful."

"No one ever says, are you okay? How do you feel about this? I mean, I mean, quite seriously."

b) Offer an opportunity to have a meeting (or call) with a professional between the invitation letter and the appointment, at which any issues of concern can be discussed safely.

"you shouldn't just be put straight into the, you know, you get the sent the letter and then you have the speculum put in you (...) Really there should be something in between like a buffer (...) particularly if they know you've got all these things, to have a discussion about how they can help you to do it to help you better, get you through it, get you through it a bit more easily. In my opinion."

#### c) Be honest about potential pain or discomfort.

"They never tell you that when they take the sample with the thing that they take the sample with, how painful that is and can be if you, if you've never had anything previously inserted or coming out of your vagina."

The interviewee contacted us following her interview to underline this point. Adding:

"I have just had a bunch more smear checks... and if I could reinforce any recommendation, it would be that the process can be extremely painful in many instances. I was crying in pain this time and the nurse didn't seem too bothered or recognise that it might be that way or offer any local analgesia... it's so frustrating not being listened to and being dismissed."



d) Make wider use of 'health passports' such as those used for neurodivergent patients or those with Learning Disabilities.

"I personally think things have changed in the last couple of years too (...) one of the things that seems to be in my favour which is a new scheme that the NHS has got okay, which is if you've got autism or you're neurodivergent okay they give you a, uh, it's like an autism thing to fill in (...) so that when you go into a hospital for whatever reason, A&E or gynae or whatever, you take it with you and say look, check that first, okay, uh, know what you're dealing with before you start dealing with me, okay, and I, I think that that is the way to go. Because then you have a piece of paper that follows you around, okay, and then other professionals can add things on as well, like I think she [the patient] probably needs a bit of this as well or don't do this because then... that! (...) I think this health passport is a great scheme (...) I think it could be utilised within the framework of you know, what Healthwatch are trying to look into."

"I do think that if people have had severe trauma and stuff they should have some, there should be some recognition of it on the system, okay, for the fact that this might impact... their capacity to be able to make rational decisions when they are in certain situations (...) I find that my trauma response affects my capacity to be able to verbalise things when I feel particularly stressed (...) and then I process it and I think about it afterwards and then about three weeks later I know what I would have said, if I was there (laughs)."

e) Never ask "Is there anything we can do to help?" without making suggestions about possible examples/reasonable adjustments and being honest about what can or can't be done. It can be hard for patients to think of their own suggestions or examples in the moment.

"Sometimes when people say, "Well what can we do to help?" I just go blank. Seriously, I'm like... "I don't know, what you offering?" And then they go, "We don't know what we're offering, we're asking you!" and I uh it, it, just for goodness sake can somebody just break this cycle of nobody knowing? They'll say to you "What is it we can do, what do you think would help?" and it rather presumes that you have any answers or solutions doesn't it really? (...) if they haven't got any solutions okay, and I haven't, someone needs to go away and darn well think of some okay, because I believe there's always a solution to different problems okay, but sometimes the person who's in the situation is just so far up in the situation that they're not able to be in a position to figure out what the solutions are okay, and the people in the jobs (...) they've got the theory, they've got the time, they're the ones being paid. I'm sorry, I'm not being paid to be a patient and fix all my problems."

f) Be aware of physical disabilities and offer reasonable adjustments without expecting the patient to ask.

"I mean the number of the number of professionals who just go, "Oh, hop up here!" I'm going, "I'm terribly sorry but I can't hop anywhere, good luck with that!" But in the back of your head you're thinking you should be able to, so you try, and then (...) you go "Actually, no, I probably shouldn't've done that!" (laughs). And, and then you go, "Actually, excuse me, could you lower it or..." When actually, they should be ahead of you."

g) Use cervical screenings as an 'Every Contact Counts' opportunity to offer information and signposting about sexual trauma support.

"A cervical screen, okay, part of the deal is that they're, they're being, uh, they're having their personal, um, they're being invaded to a large extent and I personally think that it is a perfect opportunity for health professionals to gauge whether that person has had



a traumatic experience, particularly in terms of rape and sexual abuse, and they can easily use that opportunity to actually be able to maybe find some of the people who slip through the gap because they're too scared to say anything."

"No one is using that as an opportunity to find these women who've been, um, sexually abused and stuff, or raped, you know, um, no one asks the question, "Oh well, this person hasn't come to have a, a, uh, their cancer screening for the last ten opportunities. No one asks "Why?" okay, no one ever gets in contact and asks "Is there a particular reason? Are you alright?"

## h) The results letters should be clearer to understand – perhaps using bold font for key information.

"maybe if there's anything to say, you know the sentence where it says the outcome, maybe they could put that in bold (...) so you know what you're looking for because it's just text (...) and you have to read it all through to get to the point (...) where it says actually there isn't a problem or (...) you need to go to your GP and there's a follow up (...) it doesn't bounce out at you (...) easy to read and clear but more specifically (...) there's a sentence in it where it just tells you whether you're clear or not. If they put that as a separate paragraph and put it in bold (...) people with a second language as well (...) everyone would go, oh alright, that's the bit that I need to know, okay, bounces out and you know whether you need to do something or not."

## Other Feedback

While we were conducting our research we also received feedback from members of the public which was not part of our survey but concerned similar themes. We have included the anonymous information below as an additional example of cervical screening feedback, and the differences between a poor experience and a good one.

This patient tried to get their first smear test with a nurse at their GP surgery. This was delayed due to Covid and was then rescheduled several times due to them being on their period on the dates offered.

"I was made to feel ashamed for having to reschedule, like I was deliberately being difficult, and being told I should "plan better" when I was having irregular, long, heavy periods (which I had been to my GP repeatedly about)."

The patient felt uninformed by the nurse about what would happen during the appointment and was upset by the nurse's attitude and lack of empathy.

"When I eventually went in for the test, the nurse didn't really inform me of what was going on, it basically felt like she just suddenly started ramming something cold and hard at my vagina without any warning of when to expect it. She struggled to insert the speculum, and when I asked her to stop, her response was to tell me to relax while she just forced it harder. I was crying from pain and kept begging her to stop, but she didn't. I ended up having to force her to stop by pulling away, sitting upright and closing my legs. She told me it wasn't worth crying over, we hadn't even got to the difficult bit, and that I should let her try again otherwise I'd have to be referred as a difficult patient, "And you wouldn't want that, would you?".



Unsurprisingly, the second attempt was no better and I got referred to the hospital. I had two days of bleeding after and it was really quite a traumatic experience."

The trauma experienced by the patient at the appointment was still very present when the hospital appointment finally took place, as well as throughout the months of waiting. However, the difference in staff attitude and willingness to listen to and be guided by the patient, ensured that a potentially difficult experience became a relatively easy one, and further trauma was avoided.

"It took nearly a year before I managed to get to the hospital appointment (again due to periods, and also nurses' strikes), and I felt extremely stressed and anxious about it throughout the time it was hanging over me. But when I eventually went it was such a huge contrast and a massive relief. The set-up was slightly different, being in a seat with stirrups and having a private room to get ready in, but the main difference was the attitude of the staff. They were reassuring, informative, and, most importantly, they listened to me. In the end the procedure wasn't really painful, and my results came back quickly."



## Recommendations

We have divided this section into 2 parts. The first list focusses on recommendations to make NHS screening programmes for e.g. cervical cancer, HPV or prostate cancer more trauma informed. The second list applies more widely across all health services.

#### a) Recommendations for Screening Programmes

The recommendations in this list draw both on responses to our survey and on cervical screening interviews conducted by Healthwatch colleagues in other parts of the country as part of a wider Healthwatch England project referred to elsewhere in this report.

- NHS Screening staff to work with diverse patients to co-produce invitation letters including, e.g.
  - a. Commitment to trauma-informed practice
  - b. Information about chaperones
  - c. Clarity about cervical screening being for all women, not just those who are sexually active
  - d. Accessible/Easy Read versions, and versions in a range of community languages
  - e. Information about reasonable adjustments and how to request them
  - f. Honest information about the possible levels of discomfort/pain that some patients may experience during screenings
  - g. Clear information about how to delay/re-book screening appointments after giving birth or if having a period
  - h. Information about whether the screening may be conducted by a man and/or how to request female staff
  - i. A recognition that men, and non-binary people may have experienced sexual trauma, and this may impact on them attending for cancer screenings. Trans men and women may also have experienced sexual trauma and may need to attend screenings that do not appear to 'match' their gender e.g. trans men attending cervical screenings. Staff may require additional training about this.
  - j. Clear information about what positive or negative results mean, and how to follow them up
- 2. GP practices to proactively call patients who don't respond to screening invitations, with an offer to answer their questions, and book them an appointment, with support to re-schedule if required.
- 3. Allow patients with digital access to book or re-schedule screenings (for instance if they are having a period) online or via an app. Include a range of language options and a BSL video option.
- 4. NHS commissioners to consider providing alternative screening provision to allow patients a choice about whether to go to their GP practice or elsewhere.
- 5. If the current national work on self-screening for cervical cancer proves it to be an effective method, seek to roll this out locally as quickly as possible to allow those who would prefer to self-administer the test to have this choice.



#### b) Recommendations for wider health care

- 1. Health passports and #CheckWithMeFirst cards to be available as a matter of course at e.g. GP practices, Walk-In Centres and hospital waiting rooms, accompanied by briefings/training for staff about their purpose and use<sup>8</sup>. This would make it easier for a range of patients to discreetly let health practitioners know that certain procedures may be difficult or re-traumatising for them. This is something to consider beyond screening programmes, and may also be helpful to e.g. neurodivergent patients, patients with learning disabilities and trans or non-binary patients.
- 2. Encourage NHS staff (clinical and non-clinical) to undertake existing NHS Learning Hub training on trauma informed care, e.g. 'Trauma-Informed Approaches to Healthcare' and to consider ways in which their patient care and clinical environments can be made more welcoming and safer for patients who have experienced sexual (or other) trauma.

We hope that the information shared by contributors to this report will contribute to positive outcomes, and influence local practice in a number of ways, including:

We are seeking funding to allow us to continue our work on this subject and would be interested in speaking to potential partners who could support us.

Outcome and influence		How will we know if we have achieved this?		
1.	NHS services are more aware of the experiences of survivors of sexual trauma and what measures they can put in place to meet survivors' needs.	<ul> <li>Feedback from services</li> <li>Inclusion in their meeting agendas and workplans</li> </ul>		
2.	Survivors are more empowered to request adjustments and feel more comfortable to access services.	<ul> <li>Feedback from future survey responses</li> <li>Feedback from service users</li> <li>Feedback from support organisations</li> <li>Feedback from services</li> <li>Views of Healthwatch Liverpool 'Asking for Reasonable Adjustments When Going for a Health Screening' FAQ on website<sup>10</sup></li> <li>Take up of the #CheckWithMeFirst cards locally</li> </ul>		
3.	Take up of screening services by survivors is increased	Anecdotal feedback from professionals and patients that e.g.  #CheckWithMeFirst cards are being used more frequently to inform staff		
4.	Survivors' experiences of NHS services improve.	<ul> <li>Feedback from future survey responses</li> <li>Feedback from service users</li> <li>Feedback from support organisations</li> <li>Feedback from services</li> </ul>		

<sup>8</sup> The Survivors Trust can provide training, including webinar options. Information videos are also available.

 $<sup>10 \ \</sup>underline{\text{https://healthwatchliverpool.co.uk/asking-for-reasonable-adjustments-when-going-for-a-health-screening-FAQ} \\$ 



<sup>9</sup> https://learninghub.nhs.uk/Resource/39776/Item

# **Useful References**

- The Survivors Trust #CheckWithMeFirst campaign materials <a href="https://thesurvivorstrust.org/">https://thesurvivorstrust.org/</a> training/healthcare-resources-for-survivors/
- NHS Cervical Screening Programme statistical report for England, 2022–2023 https:// digital.nhs.uk/data-and-information/publications/statistical/cervical-screening-annual/ england-2022-2023
- NHS Digital, 'Health and Care of People with Learning Disabilities, Experimental Statistics 2021 to 2022' https://digital.nhs.uk/data-and-information/publications/statistical/health-andcare-of-people-with-learning-disabilities/experimental-statistics-2021-to-2022
- Jo's Cervical Cancer Trust, 'What is HPV self-sampling?' <a href="www.jostrust.org.uk/about-us/news-">www.jostrust.org.uk/about-us/news-</a> and-blog/blog/what-hpv-self-sampling
- Health Equity Evidence Centre, 'What works: Addressing inequalities in the uptake of cervical screening' www.heec.co.uk/wp-content/uploads/2023/10/What-works-Addressinginequalities-in-the-uptake-of-cervical-screening.pdf

# Acknowledgements

Thanks to everyone who took the time to share their stories, experiences, and information with us. Their contributions were anonymous, but very much appreciated.

Thanks to WHISC and all the organisations who helped us to circulate survey information as widely as possible.



Thanks to the Survivors Trust for their support and for the use of their graphics on the cover of this report.

### **About Healthwatch**

Healthwatch is the independent champion for people who use health and social care services. We're here to make sure that those running services put people at the heart of care. One of our main purposes is to understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf.

As part of a national network made up of local Healthwatch organisations in every local authority area of England (and Healthwatch England, the national body) our work contributes to a nationwide perspective on health and social care services.

At Healthwatch we also provide an information and signposting service which helps to put people in touch with services and activities that can help maintain and improve their health and wellbeing.

If you require a copy of this report in another format or language, please contact us and we will provide it.

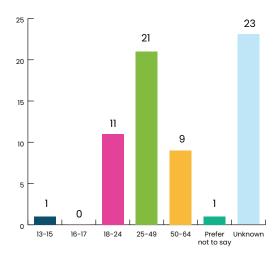
July 2024



# Appendix A: Equality, Diversity & Inclusion

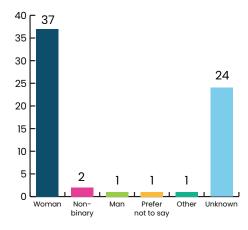
The following questions are based on Equality, Diversity and Inclusion (EDI) questions developed by Healthwatch England and designed to help us to monitor any evidence of health inequalities in treatment or outcomes. As with the questions above they are entirely voluntary, and patients may choose not to share this data with us.

#### 21. Please tell us your age



Approximately two thirds of respondents told us their current age. Approximately one third were aged between 25 and 49 years old. However, 17% were aged 18 – 24 and 14% were 50+. One person was under 16. The survey response did not indicate when they had experienced sexual trauma and/or whether this situation was still ongoing. All responses were anonymous.

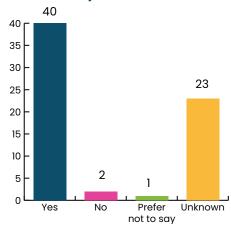
#### 22. Please tell us your gender



Where we know the respondent's gender, the vast majority of people are women, with 2 non-binary people and one man.

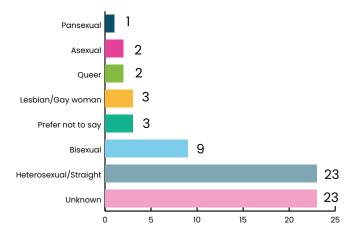


#### 23. Is your gender identity the same as your sex recorded at birth?



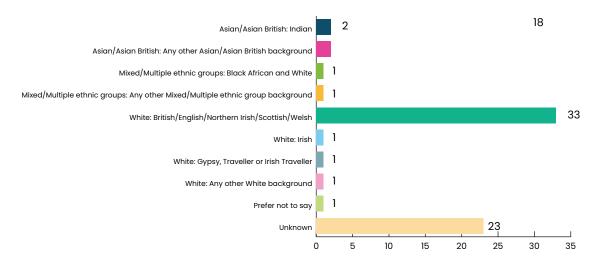
These figures were reflected in the data on gender identity.

#### 24. Please tell us which sexual orientation you identify with



Just over half of those who provided this data (23 people, 35%) identified as heterosexual/straight. However, a quarter (17 people, 25%) identified as LGBTQIA+ (lesbian, gay, bisexual, trans, queer/questioning, intersex, asexual and other non-heterosexual identities).

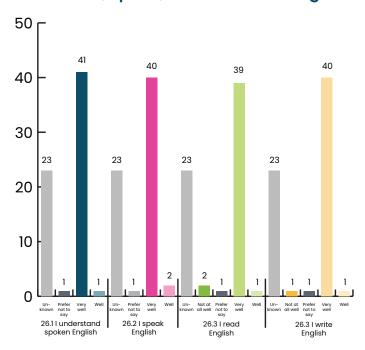
#### 25. Please select your ethnicity



We know that at 50% of respondents were 'White: British/English/Northern Irish/Scottish/ Welsh' and that 15% were from other ethnic groups. However, 35% of people did not share this information.

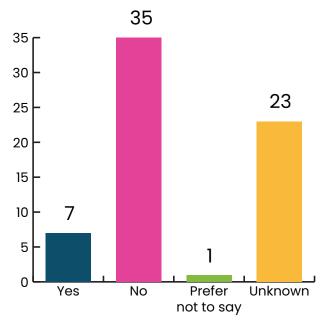


#### 26. How well can you understand, speak, read and write English?



We included this question as we sometimes receive feedback from people who find it difficult to access health or social care services for language-related reasons. In this case, respondents generally had very good English language skills. However, it may well be that we did not reach people from groups who are already excluded.

#### 27. Do you consider yourself to be a carer?

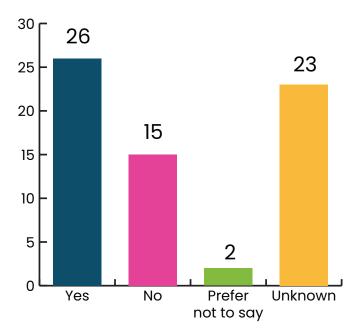


The majority of respondents did not see themselves as carers but 11% did have caring responsibilities.



#### 28. Do you have a disability or long term health condition?

Almost two-fifths (39%) of respondents said that they had (at least one) disability or long-term health condition.



# **Appendix B: Survey**

# Trauma informed healthcare survey

#### 1. Trauma informed healthcare survey

We know that experiencing trauma can have a big impact on many different parts of a person's life. This can include how comfortable they feel accessing healthcare. There are many different kinds of trauma people can experience. This survey focuses on sexual trauma. If you have experienced sexual trauma, we would like to know if this has impacted your experiences of accessing care and treatment when using NHS services, and your experiences of accessing cancer screening.

Your responses to this survey are anonymous. We will use your feedback to work with the local NHS to improve how people who have experienced trauma are supported when visiting healthcare settings. The survey should take 10 - 15 minutes to complete.

If you prefer to complete the survey by speaking to someone by phone or in person we can arrange an appointment; please email engagement@healthwatchliverpool.co.uk or phone us on 0300 77 77 007.

We understand this is a sensitive and upsetting topic. If you need any support after completing this survey, the following services are available:

- Rape Crisis England and Wales 24/7 Rape and Sexual Abuse Support Line
- Galop <u>National Helpline for LGBT+ Victims and Survivors of Abuse or Violence</u>
- RASA Merseyside
- Survivor's UK National Male Survivors Online Helpline
- The Maggie Oliver Foundation: <a href="https://www.themaggieoliverfoundation.com">https://www.themaggieoliverfoundation.com</a>

We would like to thank the Survivors Trust for their support. For more information about the 'Check with me First' campaign, please check their website: <a href="https://www.thesurvivorstrust.org/">https://www.thesurvivorstrust.org/</a>



2.			
1. Have you used any NHS services in the last 12 months?			
Yes			
□ No			
2. Are you a survivor of rape (including rape within marriage), sexual assault, sexual abuse or sexual exploitation?			
Sexual assault is when someone either touches another person in a sexual manner without consent or makes another person touch them in a sexual manner without consent. It includes unwanted kissing and the touching of someone's genitals, breasts or bottom.			
Yes			
☐ No			
Unsure			
3. Have you ever avoided booking or attending cancer screening (for example, cervical screening, breast screening, or bowel cancer screening) for reasons related to trauma?			
Yes, in the past 12 months			
Yes, but more than 12 months ago			
☐ No			
Unsure			
If you answered 'yes', and if you feel comfortable doing so, please provide details about this?			

4. Have you ever avoided other healthcare appointments in the past, for reasons related to trauma?			
Yes, in the past 12 months			
Yes, but more than 12 months ago			
No			
Unsure			
If you answered 'yes', and if you feel comfortable doing so, please provide details on how you feel this has impacted your healthcare. For example, are there types of appointment you are more comfortable attending than others?			
5. If you answered YES to either of the previous questions, is there anything that would make you feel more comfortable or able to access healthcare appointments or cancer screening?			
Being able to book a longer appointment			
Being able to choose the gender of healthcare professional who will see/treat you			
Attending with a chaperone (another healthcare professional who will sit in on your appointment to provide support and reassurance)			
Attending with a friend or family member of your choice			
Knowing a healthcare professional will ask for your consent at all stages of a procedure or examination			
No, nothing			
Other (please give us more information in the comment box below)			
Comments:			



3.

We are asking you these questions because you told us you have used an NHS service in the past 12 months. These questions will ask how you felt about the appointment, as a victim/survivor of sexual assault, abuse, or exploitation. We would like you to think about one specific appointment or visit when answering these questions.

There is a text box at the end where you can provide comments on other appointments, if you wish.

6. Where did your appointment take place?				
7. What kind of appointment or visit are you giving your feedback about (e.g. GP appointment, cervical screening, maternity services, dental check-up, A&E, mental health services)?				
8. Did you feel nervous or anxious in the waiting area before your appointment?				
Yes, very				
Yes, a little				
No, not really				
No, not at all				
Unsure / Don't remember				
If you feel comfortable doing so, please tell us more about why you felt this way:				

professional(s) you saw during your appointme	nt make you feel?
1 - Extremely uncomfortable	
2	
3	
4	
<u> </u>	
<u> </u>	
7	
8	
9	
10 - Very comfortable	
10. During the appointment, did you feel that yo time, and go at your own pace?	u could take your
Yes	
☐ No	
Unsure / Don't remember	
11. Did the healthcare professional(s) you saw opportunity to ask questions during your appoi	
Yes	
☐ No	
Unsure / Don't remember	

9. On a scale of 1-10, how comfortable did the healthcare

### 12. Did the healthcare professional(s) you saw offer any adjustments to make your appointment easier for you?

(For example, adjustments might include being given a clear explanation of what will happen, being offered more time for examinations, being given a choice of waiting space, being given a choice of

position for any medical examination, being told that you can wear as much clothing as possible throughout the examination) Yes No Unsure / Don't remember If you answered 'yes', please let us know what adjustments were made? 13. Did you feel able to ask if any adjustments could be made to make the appointment easier for you? (For example, adjustments might include being given a clear explanation of what will happen, being offered more time for examinations, being given a choice of waiting space, being given a choice of position for any medical examination, being told that you can wear as much clothing as possible throughout the examination) Yes No Unsure / Don't remember If you answered 'yes', what adjustments did you ask for? Were these adjustments made?



14. Did the healthcare professional(s) tell you what they were doing and why?
Yes
□ No
Unsure / Don't remember
15. Did the healthcare professional(s) check that you were happy before proceeding with each step of the appointment/procedure?
Yes
□ No
Unsure / Don't remember
16. Did the healthcare professional(s) ask for your consent before any medical examination?
Yes
□ No
Unsure / Don't remember
17. Did you feel you had control of what happened in your appointment?
Yes
□ No
Unsure / Don't remember
If you feel comfortable doing so, please give details:

18. Was there anything that the healthcare prodict that improved your experience?	ofessional(s) you saw
19. Do you have any suggestions for ways that appointments could be improved for survivors	
sexual abuse or sexual exploitation in the futu	• •
20. Is there anything else that you would like to experiences accessing healthcare services as experienced sexual trauma?	
You can use this space to tell us about anything else you think is rel different appointments.	evant, including experiences of

### 4. Demographic Questions

21. Please tell us your age	
13 to 15 years	
16 - 17 years	
18 - 24 years	
25 - 49 years	
50 - 64 years	
65 to 79 years	
80+ years	
Prefer not to say	
Not known	
22. Please tell us your gender	
Woman	
Man	
Non-binary	
Prefer not to say	
Prefer to self describe:	
23. Is your gender identity the same as your sex recorde	d at birth?
Yes	
☐ No	
Prefer not to say	

24.	Please tell us which sexual orientation you identify with
	Asexual
	Bisexual
	Gay man
	Heterosexual/straight
	Lesbian/Gay woman
	Pansexual
	Prefer not to say
	Prefer to self describe:
25.	Please select your ethnicity
	Arab
	Asian/Asian British: Bangladeshi
	Asian/Asian British: Chinese
	Asian/Asian British: Indian
	Asian/Asian British: Pakistani
	Asian/Asian British: Any other Asian/Asian British background
	Black/Black British: African
	Black/Black British: Caribbean
	Black/Black British: Any other Black/Black British background
	Mixed/multiple ethnic groups: Asian and White
	Mixed/multiple ethnic groups: Black African and White
	Mixed/multiple ethnic groups: Black Caribbean and White
	Mixed/multiple ethnic groups: Any other Mixed/Multiple ethnic group background
	White: British/English/Northern Irish/Scottish/Welsh
	White: Irish
	White: Gypsy, Traveller or Irish Traveller
	White: Roma



White: Any other White background						
Prefer not to say						
Other (please specify):						
26. How well can you understand, speak, read and write English?						
	Not at all well	Not well	Well	Very well	Unsure or don't know	Prefer not to say
l understand spoken English						
l speak English						
I read English						
I write English						
27. Do you consider yourself to be a carer?						
Yes						
No						
Prefer not to say						
28. Do you have a disability or long term health condition?						
Yes						
☐ No						
Prefer not to	say					



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