WHO CARES? SCOTLAND

Annual Participation Programme

Theme 1

Sexual and Reproductive Health

August 2021

Contents

Summary

This year, 55 Care Experienced people shared their views with us on sexual and reproductive health as part of our Annual Participation Programme 2021-22. We found out about a range of experiences and views they have about sexual and reproductive health and we worked with members of our National Representative Body to develop recommendations for change.

Learning about sexual and reproductive health

- School was the main way Care Experienced people learnt about sexual and reproductive health. Low school attendance, problems at home and placement moves however, led to learning through older relatives, self-research, or through direct experience.
- Experiences of learning from other people – carers, family, and friends - was mixed. For those in kinship care, particularly those who lived with grandparents, their experience of learning about sexual health could be more challenging due to the older age of carers.
- Often members ended up learning about sexual and reproductive health by 'trial and error' through their own experiences. The most frequently mentioned learning experiences were pregnancy and parenthood, childhood trauma, or lack of understanding due to being a young age.

Feeling informed and making choices

- Many Care Experienced people told us they felt well-informed about sexual and reproductive health. However, when it came to making an active decision about their sexual and reproductive health, the picture was slightly less positive. They shared how decisions they made could seem like the right thing to do at the time but then later, this changed.
- An important theme in our evidence centred around either having or not having, a sense of control and autonomy in decision-making about sexual and reproductive health. Over half of those who answered the survey said they felt in complete control when making decisions about sexual and reproductive health, while others said they did not feel in control to some degree.
- This feeling of control was often because they had a trusted individual with them. Others explained that a sense of control was felt because their sexual and reproductive health was something they could decide on for themselves, even if other aspects of their lives felt out of control.
- Members also told us about how they could feel out of control when making choices, due to a lack of information and autonomy to make decisions. This could also be impacted by abusive relationships or because they did not feel listened to by adults and professionals in their lives.

Experience of services

- The most common service accessed was for contraceptives, while just under 1 in 5 had not accessed any of the services listed. Having choices available and being fully informed were seen to be the biggest factors which contributed to feeling supported when accessing services.

- For those who felt services were not helpful, we heard that this could be due to the awkwardness of professionals and carers, accessing services which were not trauma-informed, or who gave bad advice, and were not felt to be transparent enough.

- The biggest theme was the feeling of being judged, stigmatised or ‘othered’ by professionals and adults. Being care experienced could impact negatively on the way people felt they were treated when accessing services – over half of survey respondents believed that this has impacted their experience. Care Experienced people also shared issues about being stigmatised due to different parts of their identity, such as their young age or being part of the LGBTQ+ community.

What needs to happen now?

Care Experienced people told us about the changes they’d now like to see in sexual and reproductive health. We shared these views confidentially with members of our National Representative Body, who helped create different recommendations for change on 12 different areas of policy and practice. These will be shared with different organisations and policymakers, to make sure change happens, including the Scottish Government, Corporate Parents and with The Promise.

1. Empowerment through learning in schools
2. Upholding the right to inclusive education
3. Supporting carers and families
4. Bridging the generational gap in kinship care
5. Training the workforce
6. Honest and open conversations with carers and families
7. Access to period products
8. Questioning sexual experience as a learning method
9. Trauma-informed services
10. Accessibility of confidential resources and services
11. LGBTQ+ inclusivity
12. Understanding care experience and harmful prejudices

Why talk about sexual and reproductive health?

The topic of sexual and reproductive health was identified as a key theme in Who Cares? Scotland's Annual Participation Programme 2021-22. This programme creates different opportunities for Care Experienced members of Who Cares? Scotland to be involved in influencing work on areas we know are important to them and it allows members to choose what they get involved with and how they participate.

As a provider of professional, independent advocacy services, we support Care Experienced children, young people and adults to navigate different issues and challenges which they may be experiencing. From the data we collect about our advocacy work, we have evidence that Care Experienced young people often require advocacy support to access health professionals and services they need. However, we did not have the depth of data required to understand what those challenges look like in detail and particularly, the issues specific to sexual and reproductive health that Care Experienced people may need further support with.

Current available research also does not yet provide enough insight into the experiences of people with care experience in relation to sexual and reproductive health. Commonly accepted risk factors for poor sexual and reproductive health include suffering from mental ill health, substance misuse, being exposed to criminal activity, and having low educational attainment or being disengaged from school.[1] This indicates that some Care Experienced people may be significantly impacted by health inequalities due to existing statistics in Scotland on poorer outcomes across a range of areas such as education, health and employment.[2] We also know that sexual and reproductive health problems disproportionately affect people from more marginalised communities, for examples, pregnancies in under 18s are more common in areas of deprivation, which also have lower rates of abortion.[3]

Currently, we also know that Care Experienced children can have less access to consistent sources of sex and relationship education and advice.[4] This could be due to the fact Care Experienced children may have interrupted or low attendance at school, and many will have more than one placement with different carers.

By carrying out this work, we have gained further insight into the experiences of people who have been in care, particularly in relation to how they learn about sexual and reproductive health, and in how they have experienced and accessed a variety of specialist services. We also have 12 recommendations for change, which show how different areas of sexual and reproductive health can be improved. To create these, we shared the findings from our membership with members of Who Cares? Scotland's National Representative Body, who worked with us to create these clear calls to action.

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[1] https://www.isdscotland.org/health-topics/maternity-and-births/teenage-pregnancy/

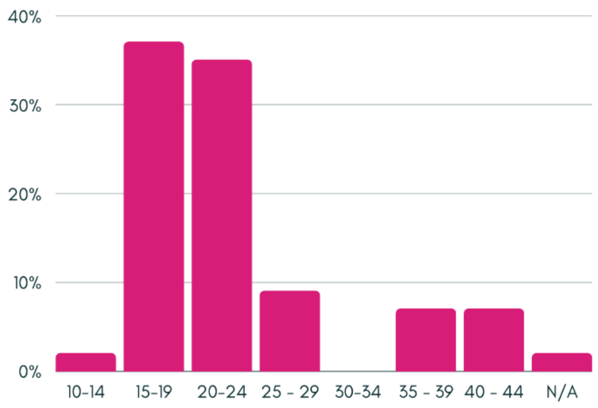
[2] https://www.whocaresscotland.org/who-we-are/media-centre/statistics/

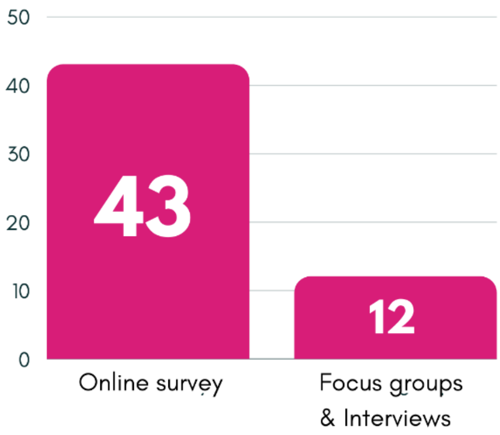
[3] *Ibid*.

[4] https://www.scie.org.uk/publications/briefings/briefing09/

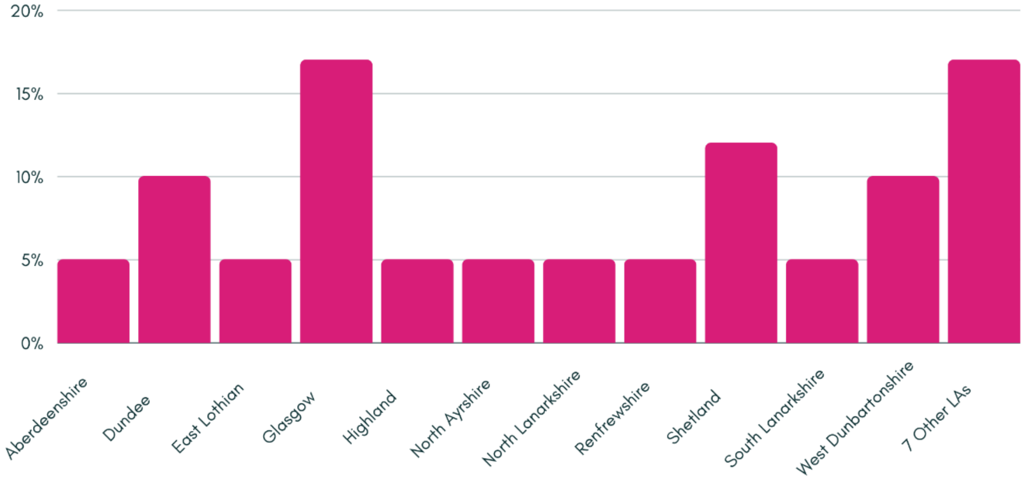
Who did we speak to?

A total of 55 responses were received, the majority (78%) of which came via online survey, with the remainder made up of focus group and interview participation. 43 Care Experienced people took part in the survey, of which 72% were aged between 15 and 24. Six people over the age of 35 took part in the survey.


Survey Responses by Age


How Participants Took Part

Responses to the survey were received from 18 of the 32 Local Authority areas in Scotland. Most responses were received from Glasgow (16%), Shetland (12%), Dundee and West Dunbartonshire (both 9%).


Survey Responses by Local Authority

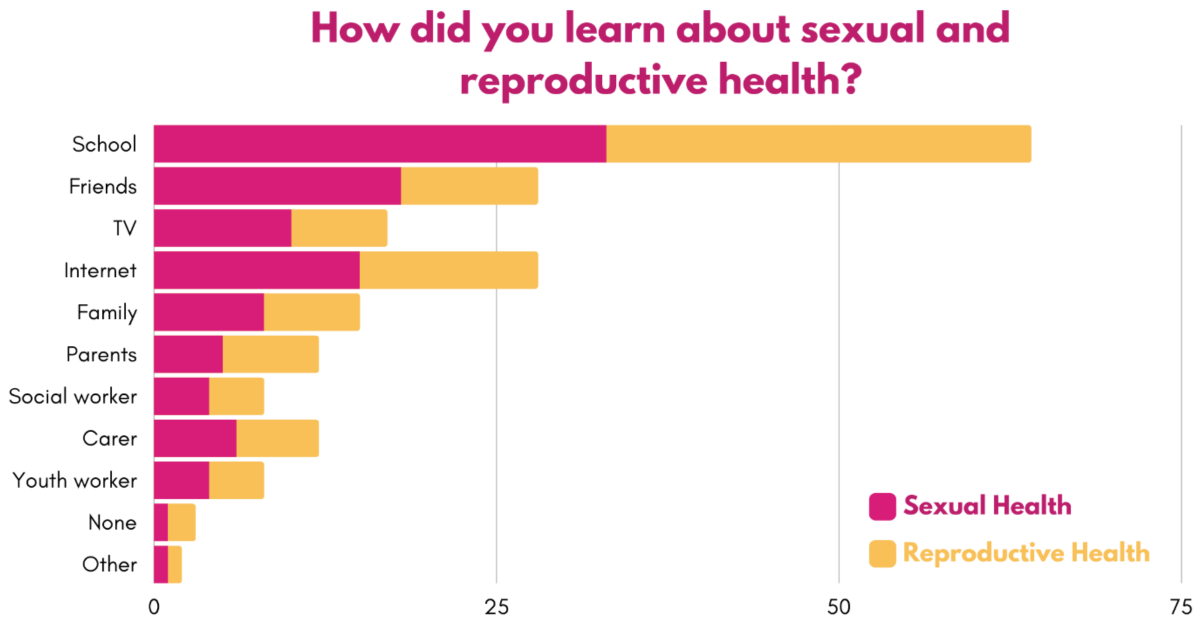
What did we find out?

Across surveys, focus groups and interviews, we heard about Care Experienced people's views and experience of sexual and reproductive health across three key themes:

1. **Learning about sexual and reproductive health**
2. **Making choices**
3. **Experience of services**

1. Learning about sexual and reproductive health

We asked our members questions about how they first learned about sexual and reproductive health, and how this has impacted them. Although school was identified as the main information source for Care Experienced people, many told us that low school attendance, problems at home and placement moves can lead to reliance on learning through older relatives, self-research, or through experience.


How did you learn about sexual and reproductive health?

In school

School was by far the most cited source of learning on sexual and reproductive health for participants, followed by friends and the internet. However, we heard evidence that learning in school could be inaccurate, vague and incomplete, leaving some to learn via other sources:

> *'I had a pretty bad experience with schools teaching reproductive health, I had an hour lesson in primary school which was filled with misconceptions.'*
>
> *'We learned about periods and stuff in primary school - but really vague, like a 15-minute discussion one time. [Learning about] sexual health was more like from my friends.'*
>
> *'[Learning in] school only focused on what not to do.'*

For Care Experienced people, placement moves and difficult circumstances at home can also mean they are more likely to miss school and miss out on any of this learning:

> *‘Because of my circumstances when I was young, I wasn’t able to go to school much, so I missed out on a lot of information about [sexual and reproductive health].’*
>
> *‘I think placement moves mean that people don’t know who to go to.’*
>
> *‘I didn't go to school long, and they didn't teach much apart from how to put a condom on.’*

Further, we heard evidence that teachers were at times not seen as the best people to be teaching this kind of subject matter:

> *‘Teachers just feel awkward, they don’t want to talk about it.’*

One participant shared that she felt there was too much emphasis in her school on personal responsibility and not enough on ‘rights education’. She explained that as a victim of abuse by a family member, she was not aware of what was happening until she was much older.

> *‘They only told us what we shouldn’t do… Nobody ever told me ‘If this happens, you should get help’…I didn’t know it was wrong until it exploded- everything came bad.’*

Family and carers

Evidence about learning from other people – carers, family and friends - was mixed. Many of the comments we received from people with experience of fostering or residential care were positive, where carers and staff would give helpful information and be at hand to answer questions:

> *‘Whenever I moved, every carer I had would give me the talk and explain everything to me and how to be safe so I knew.’*
>
> *‘Due to the care givers I had whilst in care, I was informed well enough with any questions I had.’*

However, one participant shared that they had found interactions with carers more difficult when accessing information and practical products too:

> *‘I wasn't given the resources to get help or information about other things. I only had staff to take me period shopping and this was uncomfortable. It would be better if there was an abundance of products in the bathroom so I didn't have to ask. Anything else I learned was online.’*

For those who experienced kinship care, particularly those who lived with grandparents, their experience of learning about sexual health was often more challenging:

> *‘[What I was told] wasnae accurate - I was raised by my grandmother...I grew up with really warped - not warped but not healthy views. So when I had sex, it led to underage pregnancy.’*
>
> *‘When you have kinship carers raising young people - when you have grandparents, older generations, there aren’t as many opportunities to have those discussions.’*
>
> *‘I lived with my grandparents and found it awkward to have those conversations with them.’*

Self-research and learning from experience

Many of the Care Experienced people we spoke to told us that, in the absence of any other quality or reliable information source, their main source of learning was either self-research on the internet or, in many cases, learning through their own experiences.

> *'I did have to find out a lot of things online but I think that meant I had access to more information than I would've been given at school.'*

> *'I looked at everything on the Internet and asked my resi workers anything I didn't understand after I was taken into care.'*

While internet self-research can be a first step, many explained the problems with this approach:

> *'Social media is a double-edged sword. It's really powerful tool for people to get information and learn. It shouldn't be the only source of information though.'*

Although our online survey did not specify it as a possible learning source, a frequently mentioned theme was that members ended up learning about sexual and reproductive health by 'trial and error' through their own experiences. The most frequently mentioned experiences here were pregnancy and parenthood, childhood trauma, or simply age:

> *'[Being a Care Experienced parent] You know from your own experiences what you didn't want to do. But not what you had to do.'*

> *'I'm a mother, so reproductive and sexual health I have had to learn through experiences.'*

> *'Fully versed [in sexual and reproductive health] due to childhood traumatic sexual experiences.'*

> *'Due to age and experiences now, I am more aware however I wish I had known what I know now when it was important.'*

2. Feeling informed and making choices

Linked to the process of learning about sexual and reproductive health is how that learning is put into action when making choices. We asked our membership how informed and in control they felt in relation to their sexual and reproductive health and found that although the evidence was mixed, control and bodily autonomy when making decisions is very important for Care Experienced people.

Informed decisions

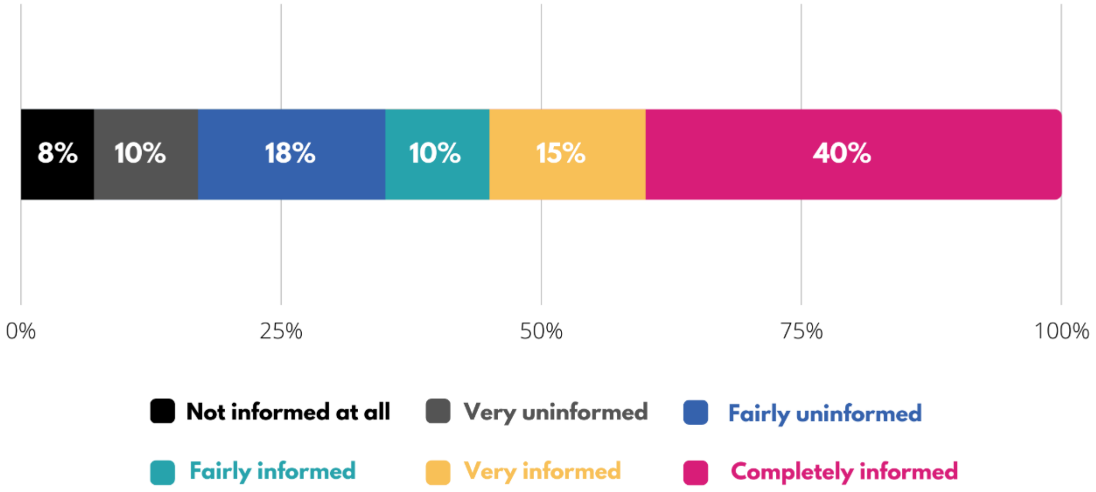
Many Care Experienced people told us they did feel well-informed about sexual and reproductive health, with 72% saying they felt either very informed or extremely informed in the survey. The reasons given for this ranged from good experiences of family conversations about sexual health and that being in care can lead to more access to information for some:

> *'Although I missed school sex ed, sexual health was a pretty open conversation in my family. I feel confident that I know my body and what is normal for me and what is something I should speak to a doctor about. I also feel confident in knowing my rights and responsibilities in regards to sex and relationships.'*

> *'[In care] people have a responsibility to make sure you are safe and so you are given lots of information that is useful. It has impacted on me positively.'*

However, when it came to making an active decision about their sexual and reproductive health, the picture was slightly less positive. Around two thirds (65%) told us they felt informed to make decisions to some degree, however 18% said that they felt either very uninformed or not informed at all.

How well informed did you feel you were when making decisions about your sexual and reproductive health?



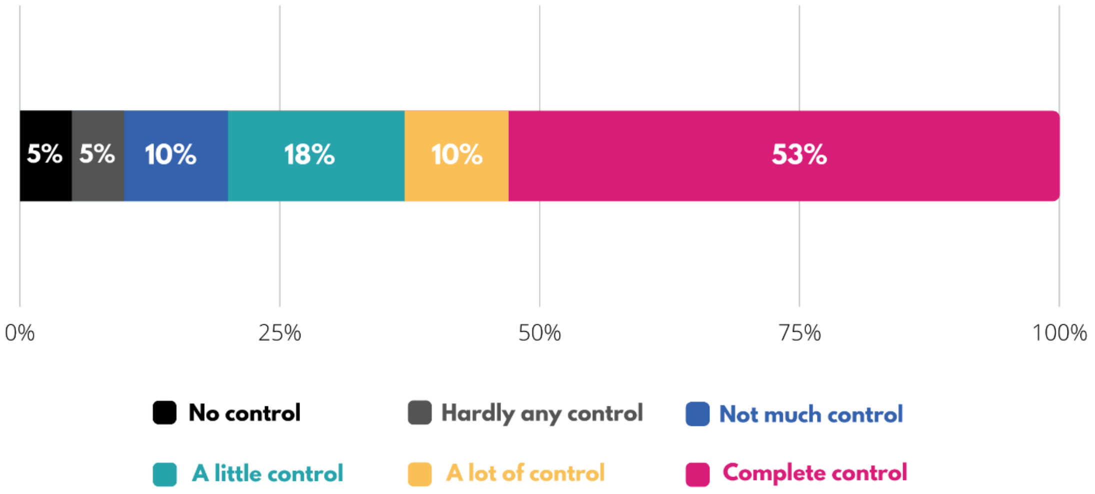
Care Experienced people shared how decisions they made could seem like the right thing to do at the time but then later, this changed:

> *'I thought I was well informed, but have recently discovered an abundance of awful side effects from the implant. I now need to decide whether or not to get it removed and it seems I will have bad side effects either way.'*
>
> *'I wish I was told more about the dangers of becoming sexually active.'*

Control and autonomy

An important theme in our evidence centred around either having or not having, a sense of control and autonomy in decision-making about sexual and reproductive health. Over half of those who answered the survey said they felt in complete control when making decisions about sexual and reproductive health, with one in five saying they did not feel in control to some degree.

How much control did you feel you had when making decisions about your sexual and reproductive health?



Care Experienced people explained that their feelings of control can come from a myriad of factors. Some of the most prominent ones we heard about were the ideas of free will, independence and bodily autonomy; being able to control something at a time when many other things felt out of control:

> *'I knew what I wanted, I knew what I needed. [My sexual health and identity] was the only thing I had any control over... [the same] with my body. It is all you've got - well, it isn't, but it carries you.'*
>
> *'[As a Care Experienced young person] you're subjected to a lot of things that might harm you, harm your body. So you have to take control over your body.'*
>
> *'If you don't have care-givers - or good relationships with them - you kind of become your own person, your own advocate - not necessarily always in a good way... People with Care Experience are so used to doing things for themselves.'*

Another important reason given for how Care Experienced people could feel in control was if they had the support of a trusted individual, be that a family member, carer, partner, or medical professional:

> *'I felt like I had a lot of control but I think that's because I had my aunty with me. She wouldn't take any shit.'*
>
> *'[My carers] took me along to the right places that I needed be to make informed/ confidential decisions and supported me on the decisions I made.'*
>
> *'Doctor talked me through [my choices] and I felt I had made the right decision.'*

However, participants also told us about how they could feel out of control when making choices, and this often manifested due to a lack of information and autonomy to make decisions:

> *'I wasn't given the necessary education to make an informed choice. I could only go on small pieces of information such as knowing that pads and tampons existed but I wasn't taught about alternatives.'*

> *‘I would've liked to have been given more information on my options, rather than feeling like I didn't have a choice what I did with my body.’*

> *‘I felt like I was slightly forced into being on birth control by my foster carer, felt like my relationships were constantly over scrutinised and expected to be perfect in the eyes of my social workers and foster carers.’*

In one instance, we learned that having no control over reproductive health at an early age had devasting and lasting repercussions in adulthood. One young woman explained that as a teenager *‘no one [teachers, carers, parents] wanted to sign the forms for my HPV vaccine’* resulting in her missing out. At the age of 21 she was diagnosed with cervical cancer. She recalls having to face her diagnosis face alone, during a global pandemic, often relying on foodbanks for support.

> *“Nobody asked- do you have a family. Nobody asked. They just assumed I’d get help.”*

Living alone on a 3rd floor flat, she only realised the day before her operation that she would likely be unable to make it up the stairs. It was only then that she called a colleague, explained her situation, and asked if she could stay with them.

She is now cancer-free but traces the probable chance of infertility to the lack of decisions made on her behalf when she was in care.

> *‘No one took an interest in me. Everyone was more concerned over who was the right person to sign the form rather than what was right for me.’*

Other participants shared more reasons for not feeling in control of decisions about sexual and reproductive health including circumstances related to abusive relationships or from not feeling listened to:

> *‘I ended up in an abusive relationship and I thought it was normal because no-one spoke about same sex relationships or abusive relationships and what to look for.’*

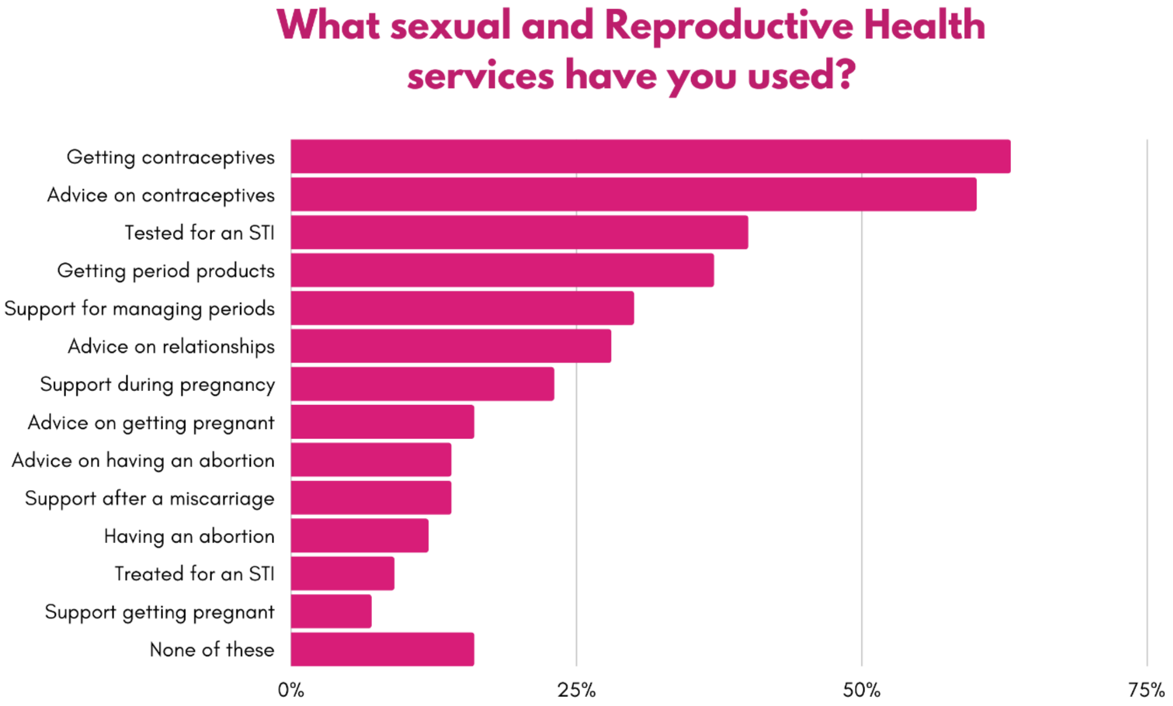
> *‘The support during miscarriage was awful. It was cold and felt like a production line. No choices and none of what I wanted was respected. When choosing contraception, I was often ridiculed for questioning because I was not qualified.’*

3. Experience of services

Care Experienced people also shared theirs views on sexual and reproductive health services. Our evidence suggests that services are seen helpful on the whole, however there are issues around awkwardness, not always being trauma-informed, and a lack of transparency. Care Experienced people also shared issues with being stigmatised due to different parts of their identity, such as their young age or being part of the LGBTQ+ community.

Access and provision

The most common service accessed was for contraceptives, while just under one in five had not accessed any of the main sexual or reproductive health services listed.


What sexual and Reproductive Health services have you used?

Of those who had accessed at least one, around three quarters (77%) found them to be helpful to some degree. Having choices available and being fully informed were seen to be the biggest factors which contributed to feeling supported when accessing services.

> *‘Having the support there was very helpful and services knew what to do.’*

> *‘Felt reasonably comfortable and happy enough with everything.’*

For those who felt services were not helpful, we heard evidence that suggested this was because of the awkwardness of professionals and carers, services which were not trauma-informed, gave bad advice, or were not transparent enough.

One participant explained that when she was going through a gynaecological exam, she asked to be ‘put under’ to avoid the trauma of remembering past abuse. The doctors thought she was worried about the pain and simply explained it would not hurt.

> *"They didn't ask if I had a history of sexual trauma".*

Similarly, another young woman shared her negative experience from services after being sexually assaulted. She explains that she had to wait two days before she could shower as, due to her history of abuse, she had requested a female doctor to conduct the exam. They were unable to find a female doctor qualified to conduct the exam for two days. When she did see a doctor, she explains that to avoid traumatic questions, she did not correct the doctor's assumption that the colleagues she was with were her parents.

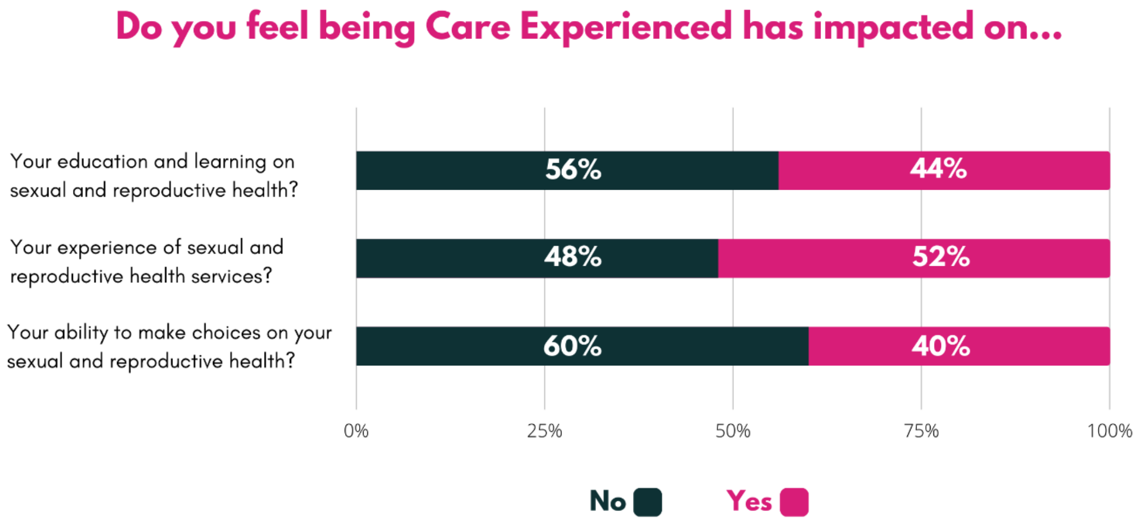
After the exam, she recalls being given a leaflet and asked by the nurse if she wanted follow-up therapy which she refused. *"It was a tick box."* She later struggled with severe mental health issues. She now reflects that she wished the nurse had been better trauma-informed.

Feeling judged and stigmatised

When it came to the negative experiences of services we heard about, there is one key theme above all others which was mentioned as a driver for this – the feeling of being stigmatised, 'othered' and judged by professionals and other adults.

> *'The overall feelings I get when I have accessed services - I have felt judged. I had to get a procedure done and I had it done quite a few times - and this woman was just looking at my notes, and she was just tutting. It's worse when you don't have parental figures there to make you feel better.'*
>
> *'After leaving care I would have been embarrassed and felt stigmatised accessing services due to being a care leaver.'*

We learnt that being Care Experienced could impact negatively on the way people felt they were treated when accessing services – over half of survey respondents believed that this has impacted their experience.



Experience of care was not the only demographic which was mentioned as a reason for othering and that a person's age also impacted how they were viewed:

> *'Young people aren't taken seriously.'*

> *‘I definitely feel when I was in hospital with my eldest - he was born at 27 weeks - I felt like I was treated a certain way ‘cause of my age. I had an emergency c-section and when my stitches burst – I kept telling them I was bleeding they just dismissed me. I had to wait for when my social worker came and she told them and they took me into theatre immediately.’*

Being part of the LGBTQ+ community was also identified as a way individuals experience discrimination. This could be when learning about sexual health as well as when accessing services and resources. More than half of our survey respondents identified as belonging to the LGBTQ+ community, and spoke about the impact this had on them:

> *‘I tried to get support for birth control but being a trans man no-one really knew what to do or say.’*
>
> *‘There's a big focus on [heterosexual] couples. There's not much information given to young people in how to stay safe when having sex with someone of the same gender. There's also no focus on being trans and the support available to trans young people.’*
>
> *‘[About the impact of identifying as LGBTQ+] Double labels, double scrutiny, double discrimination.’*

For many who we spoke to, they felt there were a combination of ways they were stigmatised in trying to access services resulting, in many instances, of avoiding them altogether:

> *‘I haven’t accessed services ‘cause of the stigma. I was so scared of what people would think.’*

What needs to happen now?

We worked with members of our National Representative Body to come up with a clear list of recommendations to improve the experiences of Care Experienced people in relation to sexual and reproductive health. These provide a call to action for different corporate parents, and other adults and professionals working to support Care Experienced people.

1. Empowerment through learning in schools

Sexual and reproductive health education needs to be taught by confident and understanding teachers, in an inclusive and empowering way. Members spoke about how education at school could be vague, patchy and awkward – with teachers potentially bringing their own views into how the subject is taught, especially on LGBTQ+ issues. School is a vital source of learning for Care Experienced children and young people, who may not always have family or support at home to learn about sexual and reproductive health.

2. Upholding the right to inclusive education

If a child in care is missing school or experiences disruption to their learning, pro-active efforts must be made to ensure they learn about sexual and reproductive health as an essential part of their right to education. It is also vital that sexual and reproductive health education is not overly gendered, and that all Care Experienced people learn about the full range of sexual and reproductive health information, regardless of gender identity.

3. Supporting carers and families

Carers and families must be equipped with the information and skills to support Care Experienced people to feel informed and confident about their choices in relation to sexual and reproductive health. This should be viewed as a fundamental part of a parental and caring role. Education and pro-active conversations should start at home, in a person-centred and non-judgemental way, meeting the individual where they are at in terms of knowledge and comfort.

4. Bridging the generational gap in kinship care

There must be better support for children and young people living in kinship care and further understanding of how to provide appropriate information and support to older kinship carers on sexual and reproductive health education. The older age of carers is an important factor in how children in care may feel able or not to discuss their sexual health at home.

5. Training the workforce

There must be robust training offers for the social care workforce on sexual and reproductive health and normalisation around leading out conversations about sexual health in a supportive and non-judgemental way. This is a specific skillset and needs support to get the right approach for Care Experienced people. This is especially important for carers.

6. Honest and open conversations with carers and families

Carers and families must understand the power they have to influence attitudes and behaviours of care experienced people’s sexual and reproductive health. Honesty and trust are extremely important in creating open conversations about sexual activity, rather than a solely disciplinary approach.

7. Access to period products

Every child in care must have access to the period products they need, in a way which suits them. Confidential advice and support should be available from carers and families alongside this on how to use these products and on wider questions about reproductive health.

8. Questioning sexual experience as a learning method

There must be a clearer understanding from all adults and professionals working with Care Experienced people, that sexual experience does not equate to someone having access to safe, positive sources of information about sexual and reproductive health. Many members told us how they learnt through experience, but that this could be negative or something that with hindsight they wish they had more information about first. There needs to be a supportive approach taken to understanding and exploring how an individual has learnt the behaviours they normalise when it comes to sexual activity and health.

9. All services must be trauma-informed

Trauma-informed practice must be essential and embedded in the way sexual and reproductive health education and services are designed and delivered. Conversations about sexual experience are essential for safety and information but may trigger trauma-responses for those who have had traumatic sexual experiences at any point in their life. Trauma-informed practice should also include the ability to choose a specific gender of doctor or professional when accessing services.

10. Accessibility of confidential resources and services

Information about sexual health services must be obvious and easy to find for all Care Experienced people. It was identified that secrecy, shame, and stigma could prevent understanding about which services are available and how to access these easily. This should include pro-active signposting to confidential, anonymous access to services where an individual can be honest about sexual activity they may have already engaged in.

11. LGBTQ+ inclusivity

LGBTQ+ inclusive sexual and reproductive health must be viewed as essential for all Care Experienced people, ensuring all information and education provided is sensitive to an individual’s sexuality and gender identity. There should be a diverse workforce delivering sexual health services who can understand and relate to LGBTQ+ experiences.

12. Understanding care experience and harmful prejudices

Professionals working across the health sector must have a better understanding of care experience and ensure they do not judge an individual’s ability to have a family or make other choices about their sexual and reproductive health due to being in or having been in care.