Supporting the reproductive and psychosocial needs of people with variations in sex characteristics

Reprofutures final project report. 2022

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REPROFUTURES

Reprofutures project

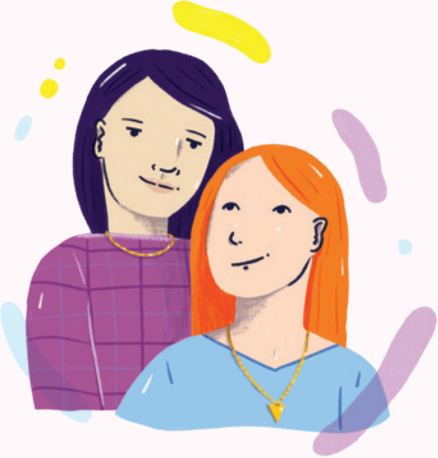
Despite the prevalence and significance of infertility and subfertility in the lives of many people with variations in sex characteristics (VSCs) in the UK, their experiences are rarely acknowledged in fertility and reproduction literature. Similarly, whilst public interest in the wellbeing of people with VSCs has grown, reproductive concerns for this population are also largely omitted from the policy agenda. The social, emotional and psychological consequences of fertility challenges are especially overlooked.

Reprofutures is a co-created research project which took place from 2019-2022. Our objective was to understand what kinds of support that adults with VSCs would like to receive with issues relating to reproduction, fertility, relationships, intimacy, and parenting (biological and non-biological). In particular, we aimed to consider how to improve the support provided in healthcare settings and social circles – from families, friends, partners – and to develop guidance to assist with these improvements.

Our understanding of reproductive support was broad and included the freedom not to become a parent, as well as the potential to become a parent, and in either case for the environment to be safe, healthy, approving, non-judgemental and non-intrusive. This report draws on qualitative workshops, written activities, and consultation sessions with people with VSCs across the UK. The project has also produced support materials and policy recommendations.

What are VSCs?

Variations in sex characteristics are also referred to as disorders or differences of sex development (DSDs) or intersex traits. These terms describe



sex characteristics which are different to traditional expectations of development, affecting chromosomes, genetics, hormones, secondary sex characteristics, reproductive organs/gonads, or genitals. We have chosen to use variations in sex characteristics as an umbrella term to include people with a range of experiences as this term is becoming widely used and has been adopted in UK government documentation. We understand how complex language can be, and respect everyone's right to use the terminology they are happy with, for example some may prefer the name of their diagnosis or variation.

Contents

Summary

In this report we focus on three key themes which highlight the experiences of people with VSCs and their perspectives on the support they would like to receive with issues relating to reproduction, parenting, and relationships.

Independence, control and agency

- Participants wanted greater control and understanding of their options for support. They discussed the significant inconsistencies in the healthcare support they had received and the lack of clarity and transparency about what psychological support, referrals, and fertility treatments were available or applicable to them.

- Many participants also wanted more control over how their VSCs and fertility challenges were acknowledged in social settings. Some participants were excluded from social events focusing on children or pregnancy; some had dealt with issues around unwanted disclosures and insensitive comments; and some struggled to value their own bodies and sexual pleasure.

Beliefs, advocacy and understanding

- Due to a lack of reliable resources or formal support pathways, participants often felt responsible for educating others about their VSCs and related fertility challenges, and providing them emotional and psychological support. This was taxing, and some participants did not feel best placed to provide what was needed.

- Open-minded, affirmative and accepting responses from family, friends and partners were important to participants as they established their own life plans. Discovering VSC community and peer support was also transformative for many. This was commonly found in diagnosis-specific support or VSC discussion groups, but also in friendships with others affected by infertility, or with people with VSCs who were part of the same minority ethnic group.

Barriers to choice, access and transparency

- Participants described restricted access to reproductive choices, and their decisions about parenting were often shaped by their VSCs, medical histories, and social inequalities. Some participants had been told their VSC would be a barrier to parenting and felt compelled to avoid all pathways to parenting; others described the impact of an upbringing which encouraged acute caution; some experienced sexual and romantic partnerships as uncomfortable or unwanted; and some found that many fertility clinics did not have the treatment provisions required for their VSC.

- Participants suggested that an over-medicalised approach by practitioners led to their emotional and psychological needs being neglected, including their plans around parenting and sexual and romantic partnerships. Some participants who received diagnoses later (30s-40s) felt their potential to have children had been discounted due to their age. Male participants also noted that assumptions about gender meant that their female partners received greater pressures about parenting, and their partners were also assumed to be the only ones in need of emotional support.

Our healthcare recommendations and support guide are available here: https://sites.exeter.ac.uk/reprofutures/

Our collaboration

Reprofutures is an engaged, co-created research project. Alongside university researchers, our project team is composed of seven community collaborators with VSCs. This includes individuals working in a personal capacity, as well as support and social group facilitators, activists, and campaigners. The collaborators are diverse in their backgrounds, identities, and expertise, and each brings a different perspective to our work and a dedication to forming a respectful and ethical coalition. The team formed in late 2019 with two initial meetings in person, followed by regular gatherings over the next two and a half years, held online due to the COVID-19 outbreak. Our work has been shaped by the context of the pandemic, as one of the most challenging times faced by many of the communities involved in this project, both personally and collectively. Our regular online meetings have been important to us during a stressful and isolating time and – despite the drawbacks of remote research – moving our work online has given us more time together and created different opportunities and routes for involvement.

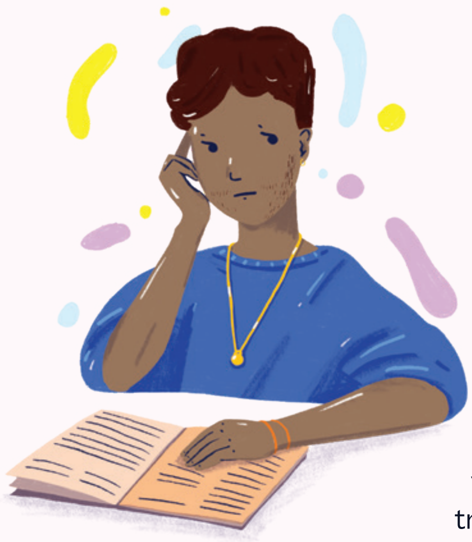
Our practice is rooted in a commitment to meaningfully engage and co-create our work with the people whose lives are affected by our research and its outcomes, and have first-hand experience and expertise. As a team, we developed the focus of our work and identified our research questions, prepared a plan of collaborative research, carried out the research, and delivered its outcomes. We also responded to emergent needs by including skills training and reflecting on the work's emotional impact. We placed a focus on the wellbeing of collaborators and participants and aimed to share control and ownership over the project.

In addition to this report, we have produced a support pamphlet for the partners, families and friends of people with VSCs as we want this work to be useful to the people involved, and to support the changes that are urgently needed. At times this work has been challenging and complex, requiring reflection, changes in perspective and direction, and compromise. Nevertheless, we hope our approach will support the transformative potential of the research, providing reciprocal benefits for all collaborators and participants, and ensuring its impact on the health and wellbeing of people with VSCs, with a legacy beyond the project's duration.

What did we do?

This project emerged from meetings beginning in late 2019. At the start of our data collection in the summer of 2020, the seven community members of our team participated in a series of co-written activities and discussion sessions about how support provisions could be improved for people with VSCs in the UK, exploring their own understandings of quality reproductive information and care. They were asked what kinds of supportive actions and attitudes they would choose to receive from a partner and a family member. They were also asked how someone supporting them could avoid causing pressures or expectations about reproduction. Finally, they were asked if fertility and reproductive issues can have an impact on sex, intimacy and pleasure, and who could offer support with this.

We used the outcomes from these activities to develop questions on the same themes for a series of consultations with 21 members of four VSC support/social groups for further input. We selected these groups based on the VSCs and existing affiliations of our team members. Each of the four online sessions took place between April - June 2021. They lasted two hours and were co-facilitated by two community members of our team, one of whom had an existing connection with the relevant support organisation and helped to recruit the participants for their session. These were small groups and were intended to expand and develop conversations which had been happening within the team. We also hoped they would be supportive, beneficial, and interesting collective spaces for those participating and sharing their perspectives.



Who did we speak to?

Three of the four consultation sessions focused on specific variations and were connected to UK support groups, and the fourth was connected to a social group who were meeting through Interconnected UK, an organisation for all people with VSCs or intersex traits (I/VSCs):

- **XXY/Klinefelter's syndrome** - 6 participants
- **Classical congenital adrenal hyperplasia (CAH)** - 4 participants
- **Mayer-Rokitansky-Küster-Hauser syndrome (MRKH)** - 6 participants
- **A range of I/VSCs, including androgen insensitivity syndrome (AIS), 17β-Hydroxysteroid dehydrogenase III deficiency (17βhsd3), MRKH, hypospadias** - 5 participants

An effort was made to collect diverse views and experiences but, as a small-scale qualitative study, our research does not aim to provide a statistically representative overview. Whilst not everyone in the sessions knew each other, recruiting within established groups and communities meant that facilitators had already formed trusting relationships. However, this method of recruitment also meant that people with VSCs who were not already linked to VSC groups – and may face additional barriers to support – were not involved. From a total of 21 participants in the consultations, 17 provided demographic information. A third of these were men, almost two thirds women, and one felt unsure of their gender. Two thirds who responded were heterosexual, one was bisexual, one was gay, and one was queer. A third of participants were aged between 25 to 34, almost a third 35 to 44, and just over a third 45 to 54. One participant was 18 to 24 and one 55 to 64. Of those who responded, 12 were White British, three White Other, one was Bangladeshi, and one was British Pakistani. Six participants identified as disabled or as having a long-term condition.

What did we find out?

Theme 1: Independence, control and agency

Inconsistent and unclear support pathways

Across all sessions, participants discussed the significant inconsistencies in the healthcare support they had received; even those of a similar age with the same diagnosis said they had received different options. They also described a lack of transparency whereby they were unsure of the psychological and reproductive referral pathways and treatment choices available to them.

This meant they did not know what they could ask for and – without examples of potential routes – they often felt unable to imagine what might help. Participants agreed that they would prefer more understanding of and control over their available support options, but this required being more proactively offered referral pathways.

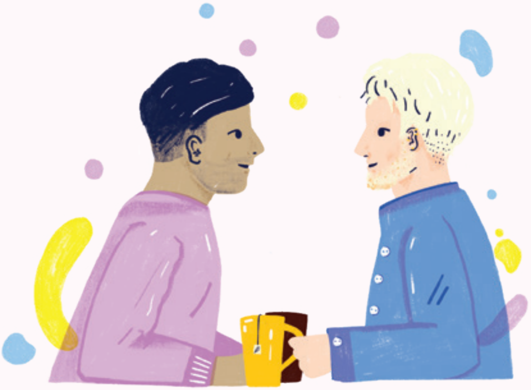
"Trying to go through your GP, it often feels like a battle to try and talk to mental health people. And you think, well, if I knew it was there and I could access it through my endocrinology consultant, then I think that might be a bit better." **(CAH consultation)**

Exclusions

Some participants experienced exclusion, both as a result of not having children, and due to the assumed sensitivity around their infertility. They said they would not always be invited to family or children-centred events, such as baby showers or family picnics, which were viewed as potentially upsetting. One participant commented that it felt like she was being excluded due to her MRKH. Participants emphasised that they wanted the control to make decisions for themselves.

Privacy and communication

Participants had differing attitudes to privacy and sharing details of their VSC. For some, telling close friends, family, or partners about their VSC and any fertility challenges felt important, became easier over time, and led to further support. Some also shared their experience on public platforms, whilst others kept it more private. Some participants said they had experienced negative or judgemental comments from more peripheral family and friends, outside of their immediate circle, who did not know about the VSC. These were described as hurtful and especially difficult to manage. Whilst participants felt it was crucial to stay in control of who was told, how, and when, some said they would



appreciate assistance from family or partners when dealing with these difficult questions or comments.

Sexual intimacy and self-worth

Some participants said that their VSC or associated medical experiences had an impact on their confidence and feelings about sexual intimacy and their body. Some recalled being told by clinicians at an early stage that sexual intimacy would be difficult or impractical, and were left feeling reluctant or hesitant as a result. Some struggled to value their own sexual pleasure and felt like their bodies – and in some instances, their surgeries – were intended only for the enjoyment of others. In some cases, insecurities had been exploited by abusive sexual partners.

These challenges had improved over time for some participants. One woman with MRKH described a long, difficult process with a supportive partner, who helped her to communicate openly and feel more positive about intimacy. Many participants were disappointed in the lack of affirmative conversations or resources about sex for people with VSCs. Participants often underlined the importance of guidance which was not heteronormative or focusing only on vaginal penetration, but instead encouraged people to find pleasure in a range of ways and to value their own enjoyment.

> *"I wish that I'd known all of this that I am now learning about sexual pleasure, about the fact that the vulva is made specifically for pleasure. All these little things I wish I'd known all those years ago, and it wouldn't be about someone else's pleasure, it would be about me as well."* **(MRKH consultation)**

Theme 2: Beliefs, advocacy and understanding

Independent learning and adequate resources

Some participants described the importance of people in their immediate social circles being well informed about VSCs and fertility. They believed this often led to better communication and understanding. However, many participants felt there was a lack of reliable resources tailored for people who are close to adults and young people with VSCs. This meant that participants often felt solely responsible for educating others. For some, this was an uncomfortable and exhausting task, which also meant that people they knew did not get the opportunity to learn privately or the space to reflect and digest independently.

"In order for those closest to us to support us, they need support or education about the thing we're asking them to support us on." **(Klinefelter's syndrome/XXY consultation)**

Emotional and peer support for family, friends and partners

Participants reported a lack of emotional and psychological support pathways available for people close to them, which meant that the responsibility to provide this support was left with them.

Some participants felt that they were not always the best people to support others, as they were sometimes still processing their own feelings. It was suggested that confidential support from a counsellor or other third party may also help the people close to them to provide effective support. Many participants also spoke positively about the potential for VSC support or community groups to benefit their family and partners. They underlined the importance of separate communities tailored for this purpose, to allow them to hear from others with shared roles and experiences.

> *"My partner says that he's got no one to talk to because he can't go down the pub and chat to his friends or brother about the problems he's having because it's private with me and him, I don't talk about it publicly. We need to make sure that they're supported."* **(I/VSC consultation)**

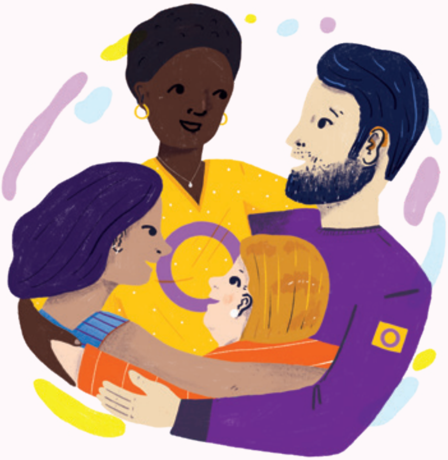
Re-evaluating beliefs

Many participants spoke of the happiness they had found by taking a flexible and pragmatic approach to life and finding their own pathway. To support this, some emphasised the importance of receiving affirmative and accepting responses from people close to them about their VSC and parenting decisions, allowing them to feel valued and celebrated. Negative and unsupportive responses made some participants feel like they were inadequate and their lives were not valued. External pressures to become a parent and seemingly small, critical comments made in passing were sometimes remembered years later, influencing future decisions and self-esteem. Instead, they appreciated being listened to without judgement and were comforted when others were willing to re-evaluate their preconceptions about what kinds of lives were good and fulfilling. One participant in the I/VSC group recalled that her friends made her a cake in the colours of the intersex flag – a community she felt a part of – in response to her becoming more open about her VSC. Others spoke of the pride they felt in family roles that involved caregiving (e.g. sibling, cousin, aunt) and felt validated by others acknowledging their value in these relationships.

> *"The kind of sadness or shock at finding out that your child won't have children, I think, comes at the price of maybe not seeing all the other great things they do or could be. There are so many wonderful ways of living a good life, and having kids is one way. In my ideal world there would just be a very different idea about what a good life is."* **(I/VSC consultation)**

Finding a community

VSC community and peer support was described as vital by most people involved in this research, and many wished they had been directed to communities earlier. This was often found in diagnosis-specific support groups, but other coalitions were also celebrated, particularly across different VSCs. One community collaborator with CAH commented on how much she had learned from facilitating a session focusing on MRKH and discovering the similarities between their stories and her own. Some participants also spoke positively about friendships they had formed with people who were affected by infertility but did not have a VSC. Some reflected on intersecting oppressions, and the importance of opportunities to meet people with VSCs from the same minority ethnic group, for example. One Pakistani participant in the I/VSC session said that she was especially in need of a community who understood her specific cultural experience and her family's approach to privacy.



Theme 3: Barriers to choice, access and transparency

Acknowledging pathways to parenting

In some sessions, participants discussed the pressure they felt to avoid all parenting options due to a perception that this was either impossible, dangerous, or irrelevant to their situation. Some participants with classical CAH and MRKH described how their variations were represented by clinicians and family from the earliest stage as negative and as a barrier to reproductive freedom. This shaped their understanding of the parenting options available to them and what kind of futures felt possible.

One Asian participant described the cultural significance of motherhood in her family, and noted that her parents were left without hope because the clinician said that she would be unable to have children, and gave no suggestions for available routes to parenthood. This put considerable strain on their relationship.

Many participants noted that clinicians' focus on medical interventions and monitoring seemed to come at the expense of addressing social, emotional and psychological needs. This emphasis on a medical 'fix' was stigmatising, and made some participants feel like their sexual and romantic desires – or their interest in parenting – were not recognised.

> *"I would have liked some support, as in these options should have been given out, 'Yes, you can do surrogacy, you can go through adoption', but because it was said right at the beginning that 'No, you can't ever have children', I internalised that."* **(MRKH consultation)**

Avoiding risk

Some participants who attended our classical CAH discussion shared their experience of over-protective parenting, which they described as limiting and overwhelming. They felt this may have been partly due to their parents' concerns about causing an adrenal crisis which, despite being very rare, can be life-threatening. Participants said they wished they had been allowed to experience more situations with the potential to be stressful as an important part of their development. The lesson to avoid all risks and uncertainties at a young age had a lasting impact for some adults, who felt they missed out on good opportunities later on, such as careers and parenting options. Participants in the Klinefelter's syndrome/XXY session also described feeling vulnerable and acting cautiously and defensively, often as a result of bullying in their youth, which led to low confidence.

> *"I think there needs to be almost a recognition on the side of the parents that your kid's alright. They can do all these things that kids do and they'll injure themselves and they'll eat worms and all of these things. And it's okay."* **(CAH consultation)**

Barriers to relationships

Many participants' partners were an important part of their support community. However, others described romantic partnerships as uncomfortable or unwanted. For some, this was partly due to their fertility challenges and the fear of encountering complex and potentially stigmatising conversations about parenting. They also felt anxious about explaining their VSC diagnosis to a future partner, and described issues with self-esteem. These concerns created a distance from reproductive choices. Without a relationship, some participants felt like parenting options were not directly relevant to their circumstances.

"If I did get into a relationship now, I would have to sit down with a partner and give them, basically, a mini medical lecture. And that is going to be a difficult one to tackle. How do you go about it? But there you go, it's just been a 'don't go there' issue." **(CAH consultation)**

Judgements and assumptions

Two participants in our Klinefelter's syndrome/XXY session explained how they felt clinicians had discounted their capacity for parenting due to their age. After receiving a diagnosis in their 30s and 40s, they recalled they were immediately prescribed testosterone and there was no discussion about fertility or children. Family members also made assumptions about them being too old for parenting. In both instances, it felt like reproductive options were withdrawn from them. Gender also played a role in others' expectations. Some male participants noted that their female partners were subject to heightened pressures about parenting and disappointment from family. One participant explained that when he received his diagnosis of Klinefelter's syndrome/XXY, it was only his wife who was understood to require any emotional support. Some male participants felt that counsellors and health professionals had wrongly assumed that they were seeking to distance themselves emotionally from their circumstances and find a quick solution.

"When you're coming as a man, they distance themselves from you because they think that you're asking the way you come to a mechanic: 'fix this car'. Whereas what you want is the opposite; you want to agree on a position together."
(Klinefelter's syndrome/XXY consultation)

Inconsistent fertility provisions

Some participants who had attended fertility clinics found that their needs were not always supported, and noticed significant variations and inequalities across regions. One participant with Klinefelter's syndrome/XXY said that one of the hospitals he was referred to for IVF did not have the provisions to support azoospermia. Participants who had received quality specialist fertility support often felt that this had occurred through coincidence or luck, and would not be reliable for others in the same or more disadvantaged circumstances.

Recommendations

- A more person-centred approach is needed in clinical care. People with VSCs should be actively invited to participate and act as partners in their own parenting and healthcare decisions, and given greater control. This means reproductive options, information, and referrals need to be offered proactively and transparently, at different intervals, with time to process, and in response to the individual's specific requirements and feelings. Clinical approaches should be guided by an understanding that people with VSCs will have different perspectives and priorities to each other, which may also change over time.

- Healthcare practitioners providing an initial diagnosis to an adult with a VSC should reassure them at this stage that it is possible for them to be sexually intimate, have relationships, and have children if they would like to. They should be able to explain in detail the practicalities and options available for people with VSCs interested in parenthood, including adoption, surrogacy, and assisted reproductive treatments (as applicable), and signpost to relevant resources for those interested in finding out more. They should provide this information to all adults, irrespective of their gender, age, wealth, ethnicity and sexual orientation.

- More emotional and psychological support and resources need to be available for people with VSCs and their friends, families, and partners, including therapists with an in-depth understanding of VSCs. Clinicians should be briefed on the professional one-to-one, psychosexual, and relationship counselling available for referral, and on the peer support and community groups provided for people with VSCs and their families. These should be offered proactively and signposted to people with VSCs by practitioners at regular intervals. Psychologists and clinical counsellors should also be included in VSC/DSD multi-disciplinary teams and specialist clinics.

- Fertility clinics should be provided with up-to-date information about VSCs and the resources to support a full range of specialist treatments. Support needs to be more consistent across clinics and regions, and should not depend on gender and the treatment required, the postcode of GPs, or the financial status of the person with a VSC.

- Communication resources should be provided to support people with VSCs sharing information with others and responding to difficult conversations. This could include information cards to educate others, with small amounts of non-stigmatising and easily digested details about the VSC, and suggested scripts and conversation starters.

- Positive and open representations of VSCs, fertility issues, and diverse bodies and development are needed in the mainstream media and in Relationships and Sex Education (RSE) in schools to ensure public visibility, understanding, and awareness. This should be informed by people with lived experience, and needs to move away from a medicalised perspective, instead celebrating the diversity of bodies, relationships, sex, and families.

A full list of our healthcare recommendations and our support guide can be found here: https://sites.exeter.ac.uk/reprofutures/

Future directions

- Further research on VSCs is needed in the following avenues: the differing cultural and religious contexts of VSCs and reproductive decisions, and how these intersect with treatments, beliefs, and options; healthcare referrals to psychological support; the experiences and role of families in providing support to people with VSCs; the mental health impact of stigma, prejudice and marginalisation for people with VSCs; and experiences of sexual intimacy, relationships, and dating.

- Research is also needed to better understand the different reproductive experiences and perspectives of people with VSCs who are underrepresented in research, particularly Black people, children and young people, LGBT+ people, older people, and those who are not involved in I/VSC communities or support groups. We also recommend further research supporting collaborations and knowledge exchange between and across different variation or diagnosis-specific support/social groups.

- We recommend further VSC research focusing on positive change. Whilst there is clear value in research on past experiences and harms, this work can also be exhausting and re-traumatising for those involved. We believe this work needs to be complemented and expanded with forward-looking research, imagining different futures and the potential for transformation.

- This report draws on co-produced research with people with VSCs. We recommend further research should involve co-production and engaged approaches, working alongside people with VSCs from the earliest stages of the research and throughout the process, and providing payment for their participation. We note our gratitude to the Wellcome Centre and University of Exeter for funding a project which will have a significant impact and legacy, and hope further funding will be available to support similar future research.

Reprofutures project team

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https://sites.exeter.ac.uk/reprofutures/