

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



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### Executive summary

This research was conducted as part of the Reprofutures project, a co-produced and collaborative study involving people with variations in sex characteristics, support and community group facilitators, activists, and campaigners. The work addresses the **psychosocial support needed with reproduction, fertility, relationships and parenting** for people with variations in sex characteristics (VSCs).

The following recommendations highlight the need for people with VSCs to act as partners in their healthcare decisions, and for medical practitioners to be given more consistent, up-to-date training and awareness of VSC referrals and support; for practitioners to provide clearer communication and reassurance in consultations and give more attention to psychosocial and holistic wellbeing; for practitioners to take a careful and transparent approach to the interaction between fertility and medical interventions; for more inclusive educational VSC resources and cultural awareness; and for fertility clinics to provide more consistent specialist services for people with VSCs.

The conclusions from this work have been developed into a support guidance pamphlet and research report (see further resources).

#### Our research project

Our practice is rooted in a commitment to co-create our work with the people whose lives are affected by our research and its outcomes. Together 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.

- **Stage one:** seven community members of the research team participated in a series of written activities and discussion sessions about how support provisions could be improved for people with VSCs in the UK, exploring their understanding of quality reproductive information and care.
- **Stage two:** we used the outcomes from these activities to develop questions and co-facilitate a series of consultation workshops with 21 members of VSC support/social groups.
- People with a variety of VSCs were involved, including:
  - Mayer-Rokitansky-Küster-Hauser syndrome (MRKH)
  - Classical congenital adrenal hyperplasia (CAH)
  - XXY/Klinefelter's syndrome
  - Androgen insensitivity syndrome (AIS)
  - 17β-Hydroxysteroid dehydrogenase III deficiency
  - Hypospadias

#### What are VSCs?

VSCs are variations in sex characteristics, 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.

## Policy and practice recommendations

### General medical support

A more person-centred approach is needed in clinical care. People with VSCs should be invited to actively participate as partners in their own reproductive, parenting, and healthcare decisions and given greater control. This means the reproductive options, information, and referrals available to people with VSCs need to be offered proactively and transparently, at different intervals, 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.

### Medical and awareness training:

- Healthcare practitioners (including GPs) need to be given **more consistent and up-to-date training and awareness of VSCs, the specialist care available, and relevant reproductive pathways**. This should include an awareness of the different local specialist support channels that people with VSCs can be directed to, and the practicalities and pathways available for people with VSCs interested in parenthood, including adoption, surrogacy, and assisted reproductive treatments. They should provide this information to all adults, irrespective of gender, age, wealth, ethnicity and sexual orientation.

“Information isn’t always made clear to patients. If you happen to be seen by a doctor who doesn’t have very good familiarity with MRKH – which is quite likely – then you may not know that support exists and that there is specialist professional care.”  
- MRKH consultation

### Diagnosis and referrals:

- Practitioners should have an established procedure for checking the fertility status of people with VSCs at the point of diagnosis, where applicable.** Early diagnosis of VSCs and early assessment of fertility and reproductive options can sometimes open up more opportunities and choices for fertility preservation.
- Referrals to VSC specialist support need to be provided more urgently and consistently following a diagnosis.** This support should be made available to all people with VSCs, regardless of where they are based. **Specialist VSC/DSD multi-disciplinary clinics need to be provided more comprehensively across the UK, not only London.**
- Continued support needs to be offered after people with VSCs are no longer eligible for paediatric care.** Medical support should not be terminated after young adulthood; different kinds of guidance and treatment may be desired at different stages and ages.

“All of a sudden it all stops. You get to puberty and then you stop because it’s like, oh, you’re responsible for yourself now. And if you don’t have that psychological support and that comfort about your own body up to that point, it then becomes an incredibly daunting prospect that you are now responsible for yourself.”  
– CAH consultation

**Communication:**

- **Practitioners should reassure people with VSCs and their families that their circumstances and bodies are normal, natural, and unexceptional, and there are many people in similar circumstances who lead fulfilling lives.** They should also be told it is possible for them to be sexually intimate, have relationships, and have children if they would like to, and that none of these are contingent on medical treatments.
- **Practitioners should pay attention to how they approach conversations about fertility and parenting with people with VSCs.** They should be open and honest and manage expectations, but also discuss how potential issues can be overcome, and endorse the diversity of pathways to parenthood. Dismissive or discouraging comments about infertility can be stigmatising and negatively shape or restrict future life goals and priorities.
- **Conversations about VSCs in healthcare settings should not only be about medical interventions.** From young adulthood, consultations should also address approaches to feeling confident about sex, pleasure, intimacy, and parenting.
- **Practitioners should always provide people with VSCs the full title of their diagnosis** (and/or their parents, depending on age) and write this down so that they can do their own research after the consultation.

“Right up until mid-teens, late teens, early twenties, I didn’t fully understand the condition. Because nobody had ever sat down with me and said, “This is what you’ve got.” So of course there was me merrily popping away these tablets, having to go to the hospital, not having a full grasp of what the condition was.”  
– CAH consultation

**Psychosocial support**

Healthcare practitioners should give more attention to psychological wellbeing and holistic support with reproductive decisions, and ensure people with VSCs are given opportunities to privately explore their feelings about parenting with a third-party professional before making any decisions.

- **Healthcare professionals should be briefed on the professional one-to-one, psychosexual, and relationship counselling available for referral,** including specialist practitioners with an in-depth understanding of VSCs who can support people with VSCs, their family members, and partners. Where possible, this should be provided free of charge. **They should also be familiar with peer support and community groups provided for people with VSCs and their families.** Psychological and peer support should be offered proactively and signposted to people with VSCs by healthcare staff at regular intervals.

“I was just basically in shock [after my diagnosis] and people would tell me things and I wouldn’t really be processing them. And actually, it made me a little bit scared to ask questions sometimes, out of embarrassment. So I feel like if there was that emotional support, you could really break it down.”  
– Klinefelter’s Syndrome/XXY consultation

- **On-site psychologists and clinical counsellors should be included in all VSC/DSD multi-disciplinary teams and specialist VSC clinics.** If these roles are unavailable due to budget limitations or resourcing, healthcare assistants should be trained in counselling skills, and invited to diagnostic consultations (at the discretion of the person with a VSC).
- **Sex, sexual health, and relationship support should be provided** consistently at all VSC/DSD specialist clinics, alongside reproductive health.
- **The partners and families of people with VSCs need to be directed to educational resources, emotional support, and settings which offer them the opportunity to ask questions about VSCs, and to learn and reflect privately** (see further resources).

### Pharmaceutical and surgical approaches

- **Before any medical treatments take place, people with VSCs should be given information about potential future fertility and preservation options** (if applicable) and given time to learn about their circumstances and the option to discuss their thoughts with a professional therapist.
- **Before starting hormone therapies, practitioners should provide guidance on the impact these treatments may have on libido and intimate relationships** and offer people with VSCs the option of sexual and relationship support.
- **If genital surgeries are offered to or asked for by an adult with VSCs, practitioners should provide information about the potential negative as well as positive consequences, such as scarring and a possible lasting impact on sensitivity, intimacy, and pleasure.**  
Practitioners should take an open approach to individual differences and preferences.
- **Practitioners should approach conversations about sex and intimacy with openness and flexibility, and avoid heteronormative assumptions about sexual behaviour.** People with VSCs may find sexual pleasure in a range of ways, not only through penetration. This diversity should be foregrounded in conversations about surgery and dilation to support people with VSCs making the right decision for them.

“If someone had said to me “Oh, before you have them [gonads] removed, shall we have it tested to see if there’s any viable sperm in case you want to have kids in the future and stuff like that?” that would have been really, really helpful. But I think it just seems to be a surgical kind of “Let’s get you operated on, let’s get you fixed.”  
- VSC/I consultation

### Accessibility and information

#### Resources:

- **A centralised and unified support hub or online information point should be created,** collating all specialist consultants, clinics and multi-disciplinary teams working on VSCs.
- **Medical literature and clinical website content should be up-to-date and considerate of tone.** There needs to be more recognition and acceptance of the diversity of sex, bodies, relationships, and families. Heteronormative assumptions about the relationships and sexual behaviours of people with VSCs and the medicalisation of their experiences should be avoided.

- **Resources to support communication should be provided to help people with VSCs share information with others and respond 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.

**Language and cultural differences:**

- **Practitioners should pay attention to language barriers in consultations and written resources.** People with VSCs and families whose first/main language is not English need to be supported with interpreters and clear explanations.
- **Medical and psychological support needs be provided by practitioners who are culturally sensitive and aware.** The reproductive and parenting options available to a person with a VSC will be contingent on culture, faith, and upbringing. Conventions of privacy may also vary, and this needs to be respected and negotiated with relevant experience.

“I’m Bangladeshi but I’ve grown up in the UK and for me language was a bit of a barrier and I found that very hard, so I could not translate and explain to my parents about what I was told. [...] I didn’t get the name MRKH, so for me that’s a big issue.” – MRKH consultation

**Fertility clinics**

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

“We went through the NHS system and got referred where we are to a hospital for IVF. But they couldn’t do anything for male factor infertility, so we reached this brick wall. And they said under special circumstances you can be referred onwards but apparently being male, having azoospermia, and not being able to get pregnant naturally isn’t a special circumstance.”  
– Klinefelter’s syndrome/XXY consultation

**Further resources**

Our project report and support guide are available here: <https://sites.exeter.ac.uk/reprofutures/>

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