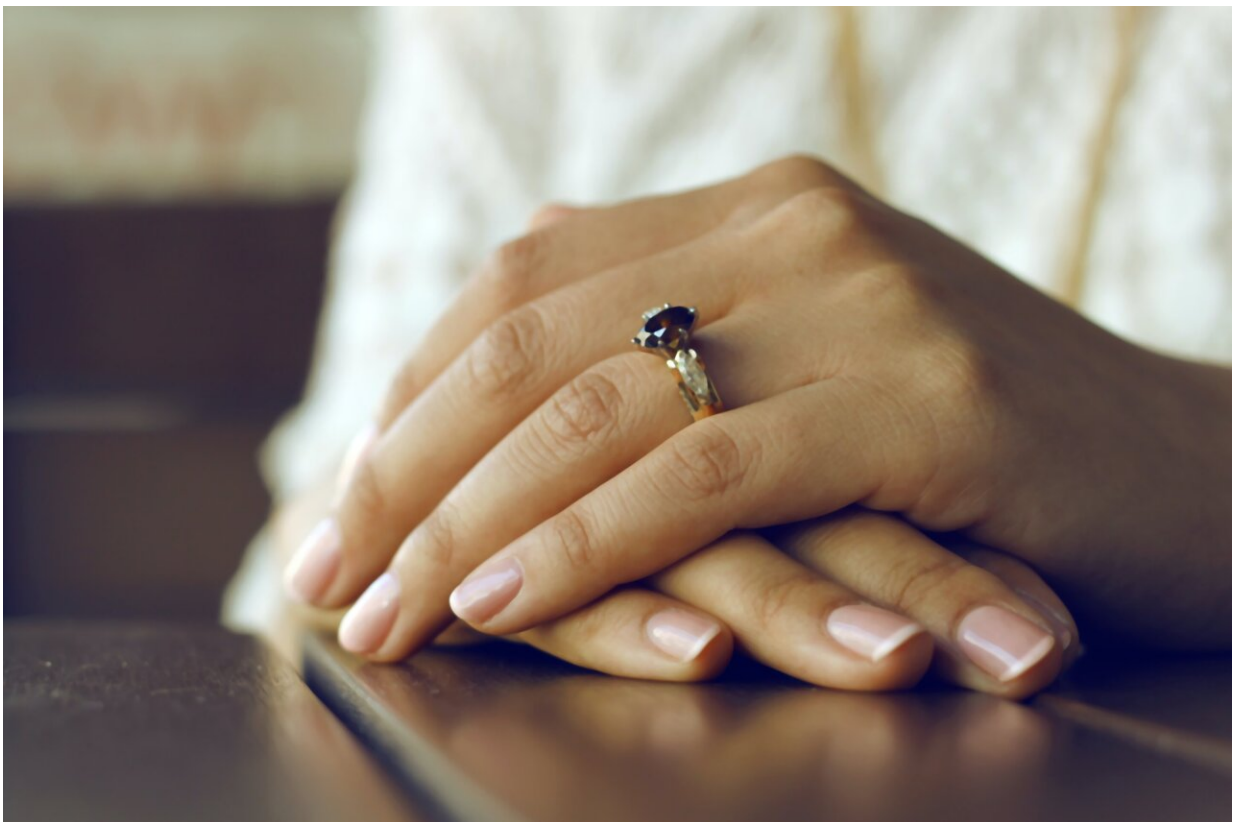


Fertility support for people with variations in sex characteristics overlooked by medics, report shows

April 21 2022



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An over-medicalized approach to support for adults with variations in sex characteristics means their emotional and psychological needs are

being overlooked, a new report shows.

Variations in sex characteristics (VSCs) are also referred to as differences of sex development (DSDs) or intersex traits. These terms describe sex characteristics which are different to traditional expectations of development, including chromosomes, genetics, hormones, secondary sex characteristics, [reproductive organs](#), or genitals. This includes diagnoses such as Klinefelter's syndrome, [congenital adrenal hyperplasia](#) (CAH), and Mayer-Rokitansky-Küster-Hauser syndrome (MRKH).

The new report publishes findings from a co-produced study involving focus groups with people with VSCs across the UK. The report identifies their restricted access to reproductive choices and their wish for greater control and understanding of their options for support.

Participants also raised concerns about significant inconsistencies in the healthcare they had received and the lack of clarity and transparency about what psychological support, referrals, and fertility treatments were available or applicable to them. Some noted that fertility clinics did not have the treatment provisions required for their VSC.

The experiences of people with variations in sex characteristics are rarely acknowledged in fertility and reproduction research, despite the prevalence and significance of infertility and subfertility in the lives of people with VSCs. Reproductive concerns for this population are also often neglected by policymakers. The social, emotional and psychological consequences of fertility challenges are especially overlooked.

The report recommends:

- People with VSCs should be actively invited to participate and

act as partners in their own parenting and healthcare decisions and given greater control. 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.
- 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.
- 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 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.
- 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. This should be informed by people with lived experience, and should celebrate the diversity of bodies, relationships, sex, and families.

The research team, led by Dr. Charlotte Jones from the University of

Exeter, included seven people with VSCs, who participated in a series of co-written activities and discussion sessions about how support could be improved for people with VSCs in the UK. The project team used this evidence to develop questions for a series of consultations with 21 members of four VSC groups, which were led by community collaborators.

Project lead, Dr. Jones, says that "many participants wanted more control over how their VSC and any 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."

"Some participants had been told by clinicians that their VSC would be a barrier to parenting and felt compelled to avoid all pathways to parenting; others experienced sexual and romantic partnerships as uncomfortable or unwanted, in part due to fertility challenges."

"This research shows that people with VSCs sometimes have different access to different reproductive choices, and highlights the importance of a supportive social environment when making decisions about parenting. In addition to our report, we 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."

Research collaborator, Magda Rakita (Interconnected UK), says that "this research is exciting for numerous reasons. It was created as a collaboration between people and groups of people with different experiences of living with VSCs and it shows how a less medicalized and more holistic approach to VSCs is needed. Many of us—intersex people/people with VSCs and our loved ones—did not have access to

this sort of support and information, and this informed our process of working on this research."

"It allowed our voices to be heard, leading the process and then creating resources which may be particularly helpful for those with lived experiences of VSCs and our loved ones. I also hope it will help medical professionals to inform their practice."

Research collaborator, Tabitha Taya (Founder of Living MRKH), says that "often diagnosis can be very clinical, many people experience a lack of compassion during appointments with no onward support. This project allowed us to identify the affect this has for the person with a VSC for understanding diagnosis, healing, traumatic response and living each day after diagnosis."

"This led us to pinpoint areas of progression for everyone supporting to do better: for clinicians to understand the impact their role has on this journey for the individual, for the support network of the individual to have support themselves, as well as provide necessary support, and for the individual with a VSC to understand what they require and their pathways to live a fulfilling life, however that may look for them."

"It is our hope this project highlights a more comprehensive view on aspects of a life with a VSC to allow for a more inclusive, supportive, thoughtful world with less trauma."

More information: Project report, healthcare recommendations, and support guide: sites.exeter.ac.uk/reprofutures/

Provided by University of Exeter

Citation: Fertility support for people with variations in sex characteristics overlooked by medics, report shows (2022, April 21) retrieved 4 May 2024 from

<https://medicalxpress.com/news/2022-04-fertility-people-variations-sex-characteristics.html>

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