

Press release: Government calls for evidence on people who have Variations in Sex Characteristics

Variations in sex characteristics (VSC), sometimes referred to as 'intersex' or 'differences in sex development', is an umbrella term used to describe physical sex development which differs from what is generally expected of males or females. These variations are present from birth and may be chromosomal, gonadal, anatomical or hormonal.

Depending on the individual case, these differences may be visible at birth or untraceable until puberty, or even later in life. Research from clinical experts suggests the 'number of people born with atypical genitalia may be as high as 1 in 300 births, but the birth prevalence of a condition that may lead to true genital ambiguity on expert examination may be as low as 1 in 5000 births.'

The [call for evidence](#) is designed for VSC individuals, their parents, carers, and legal guardians, and professionals and service providers to share their views and experiences on:

- Terminology – the terms people prefer using to describe having variations in sex characteristics
- Healthcare – how decisions are made around medical interventions and how healthcare services could be improved
- Education – how people with variations in sex characteristics experience school and how the education system could be improved
- Support services – what support, if any, affected individuals and their families receive and how support services could be improved
- Issues faced in day to day life – people's experiences of being in the workplace, of claiming benefits and using sport and leisure services
- Sex assignment, birth registration and correcting birth certificates – whether people have changed their birth certificate if the sex was incorrectly assigned at birth and parent's experiences of registering a child's birth
- Any other issues they have faced and want to raise

The Government Equalities Office has heard from people who had poor experiences when using the healthcare system 20-40 years ago. This included people who struggled to access their medical records and people who did not have access to a psychologist. Reflecting on their experiences, they reported that a psychologist could have helped them make informed decisions about the medical interventions they had undergone at the time.

Some young people have also had to take regular time off from school to attend medical appointments, are unable to fully participate in school activities and require psychosocial support to understand how and why their bodies develop differently to their peers.

Minister for Equalities Baroness Williams said:

“It is concerning to think that people in the UK may be afraid to visit the doctor or feel unable to take part at school because they are not receiving the support they need or deserve.

“Everyone in this country has a right to an education, healthcare and to go about their daily life without intrusion or fear of humiliation.

“This call for evidence is a chance for us to learn more about people’s everyday lives, and I look forward to hearing more about their experiences.”

Kaz Williams, adult support co-ordinator at UK Congenital Adrenal Hyperplasia Support Group, said:

“The UK CAH Support Group is happy to be working with the Government Equalities Office on the Variations in Sex Characteristics call for evidence. We believe this is a positive step forward towards the Government gaining greater understanding and insight into the experiences and needs of children, young people and adults living with a variation in sex characteristics and their families.”

Ellie Magritte, founder of dsdfamilies:

“We at dsdfamilies are delighted that the GEO want to hear directly from young people (aged 16+) and their families about the impact of having different sex development. We are impressed and encouraged by the breadth of topics covered in this call for evidence. Our recent consultations with children and families highlighted their needs relating to support and information, as well as for improvements in levels of understanding throughout health care and wider society. As this is the first time the Government has looked at these issues, we hope this call for evidence will lead to actual changes for children and families and we encourage people to respond.”

Valentino Vecchietti, academic and campaigner:

“As a leading figure in the UK intersex movement, I welcome the UK Government’s call for evidence. It is much needed, and I fully support their intention to seek a greater understanding of the experiences and needs of our varied community.”

The call for evidence will run for 10 weeks from 17 Jan to 28 March 2019 and is open to anyone to respond. The government is working closely with support and advocacy organisations, campaigners, academics and clinicians to raise awareness and understand people’s experiences.

Notes to editors:

The call for evidence can be found [here](#).

Anyone can respond to the call for evidence.

Population stats – Ahmed, S. F. et al. (2016) Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development. Ahmed, S.F., Dobbie, R., Finlayson, A.R. et al. (2004) Regional & temporal variation in the occurrence of genital anomalies amongst singleton births, 1988–1997 Scotland. Archives of Disease Childhood, 89, F149–F151. Thyen, U., Lanz, K., Holterhus, P.M. et al. (2006) Epidemiology and initial management of ambiguous genitalia at birth in Germany. Hormone Research, 66, 195–203.