PSII: Quarterly Research Update: January 2026

Purpose

Here is the first Psychosocial Studies of Intersex International (PSII) quarterly research update. We aimed to quickly and briefly describe new research of relevance to the PSII network; summarizing recent research literature conducted with and about people with variations, their family members, and healthcare professionals. We are publishing quickly on our own website to create a quick feedback loop between researchers, those they research, and the users of academic research. Mindful that replicating existing findings can have little benefit for communities **(**Mestre-Martínez, 2025), we aimed to focus on what seemed to most update our understanding here. We currently aim to repeat this review in the first half of 2026, and so we would welcome your input as to whether this was or was not helpful to you (and why!). Our methods and conclusions are a work in progress and we value your input; you are the peer reviewers.

Methodology

This review cannot scope all relevant under-researched areas. In October and November 2025, Annette Smith conducted Google Scholar searches, and she exported the first 100 outputs published in 2025 revealed by several search terms. She next excluded citations, theses and dissertations, unpublished article pre-prints, books, book chapters, and articles published before 2025, searches on, using multiple search terms. Peter Hegarty and Annette Smith independently read the abstracts of 387 outputs generated by this search and assessed their possible relevance for PSII.

We ruled out studies on non-human animals, medical case histories, medical reviews of particular variations written for practitioners, and biomedical research that did not discuss psychosocial issues. We ruled out papers that examined cultural and legal phenomena in depth but which didn't clearly concern those with psychosocial interests. We also excluded several articles including intersex under LGBTQIA+ umbrellas, which did not clearly conceptualize or sample intersex people distinctly. We included a small number of papers with 2024 publication dates and book chapters following suggestions from the PSII steering group.

This review describes 66 new publications The search terms that yielded each publication are shown in the reference section below. We recognize that any method for searching Google Scholar would have shortcomings, and that many, if not most, of the people diagnosed with some conditions that we used as search terms would not identify with any of the umbrella categories that we used as search terms. As one wise recent commentary notes, researchers should engage new forms of language, particularly those suggested by communities, even if "[a]cceptance of any single term by 100% of community members on applicability in all situations in unlikely" (Whitehead et al., 2025).

Mental Health and Quality of Life Differences and Inequalities.

A key question in psychosocial studies of intersex concerns the mental health and wellbeing of people with variations and their causes. People with VSC are ill-served if research either over-estimates their psychological distress, or under-estimates it. There is no consensus about the single best way for researchers to ask people with VSC to identify themselves. Population statistics are lacking; a recent systematic review concluded that no population health studies routinely collect VSC or intersex status, and that there is little research on how best to do so (Rich et al., 2025). In this context, researchers ought to clarify carefully how and where they collected their samples, so that readers can draw reasonable conclusions about the generalizability of results. For example, one recent USA study identified community resources, “race” and health insurance status as determinants of which patients in a hospital were and were not lost to its own follow-up study on hypospadias surgeries (Beland et al., 2025).

Recent studies suggest heightened levels of psychosocial distress among people with KS in general, that parents may not always perceive accurately (Jünger et al., 2025), and in particular domains such as sleep health (Paparella et al., 2025). A retrospective cohort study of USA health insurance customers found that women with either AIS or Mullerian duct aplasia/agenesis were statistically more likely to register one or more mental health diagnosis (Sorouri Khorashad et al., 2025). A meta-analysis found that men who underwent hypospadias surgery had lower satisfaction with penile appearance, but similar overall Quality of Life to other men (Gunawan et al., 2025).

Three recent studies of well-being stand out by virtue of their sampling. First, a Mexican household survey found that rates of bullying and harassment were far greater among self-identified intersex individuals, and rates of completion of post-secondary education much lower. Such disparities were largest among women and girls, and were not particular to intersex-identified people who were also sexual and gender minorities (Muñoz et al., 2025). The second study, exploited the UK’s biobank database to compare the cognitive function and mental health off 333 intersex people to over 400,000 other (endosex) biobank participants. Differences in mental health outcomes emerged, but those differences were fully statistically explained by differences in cognitive functioning (Reineberg et al., 2025). Finally, a large multi-sited clinical study in the USA found that patients with Turner’s Syndrome were more likely to be neurodivergent, but no more likely to have a mental health diagnosis than a control sample (Hutaff-Lee et al., 2025).

On the whole, these recent studies suggest that statistical differences in psychological distress, quality of life and well-being are not global or inevitable and should be understood as contextually determined, as argued by several authors, such as Anand (2024). Such studies could be in dialogue with moves to reject deficit model of difference such as recent calls for an understanding of “intersex joy” (Orr & Burkholder, 2025). Indeed, this dialogue seems particularly necessary when VSC are associated with particularly happy outcomes, as in a recent Dutch study which found higher than average relationship satisfaction among male partners of women with MRKH (Bleijenberg et al., 2025).

Experiences and Advocacy in Healthcare

Whilst healthcare should alleviate and offset psychological distress that may come with VSC, research has long suggested that healthcare may be structured and delivered in ways that cause distress. There are ample calls for attention to the gap between the psychological services needed and those available, in general (Davoudian & Hills, 2025, Mehmet et al., 2025), in specific areas such as speech and language therapy (Laing et al., 2025), and at particular transitions such as that between paediatric and adult healthcare services (Nahata et al., 2025). The research literature continues to document structural barriers within healthcare such as variability in practices within the DSD teams in a single country (Schnoor et al., 2024). There is also new critical attention to how healthcare practices are currently problematic and might do better in recognizing people with VSC in areas such as organ donation (Moseson et al., 2025), language use in genetic testing (Dusic et al., 2025), translating laboratory findings into surgical practice (Wilczek et al., 2025), and in making fertility treatments more consistently available to women with MRKH (Milford et al., 2025).

Qualitative interview studies of small groups of individuals continue to show the necessity for self-advocacy in such health care environments. One Canadian study which drew on interviews with both adults with VSC and healthcare providers concluded that a lack of medical education creates confusing healthcare environments where patient self-advocacy is essential (Knoppers et al., 2025). Such in-depth qualitative research has the advantage of challenging assumptions that people who share a medical diagnosis have the same needs and experiences. As one participant in this study put it; "If you have met one intersex person, you have met one intersex person" (Knoppers et al., 2025). Nonetheless, similar themes about (a) being made to feel different in confusing healthcare environments, (b) the resulting need for self-advocacy, and (c) calls for better-informed healthcare free of structural barriers are evident in qualitative interviews studies of the healthcare experiences of individuals with MRKH (Marshall et al., 2025) and parent's encounters with genetic counsellors (Horowitz et al., 2025). In one UK clinic, the most common outcomes of psychological input reported by young people were increased access to resources, and confidence regarding their variation and how to talk about it with others (Lee et al., 2024). However, attention to the possibility of self-advocacy was notably lacking in a Turkish interview study focused on individuals' with MRKH experiences of *disease* rather than *healthcare* (Güner et al., 2025).

Several new studies centred on the experiences of people with Klinefelter's Syndrome. In the USA, qualitative studies have explored how individuals render their KS more talkable and build support systems (Tubman et al., 2025a) and diverse experiences of available fertility treatments (Tubman et al., 2025b). In the UK, a qualitative study shows that available testosterone treatments points are helpful to many but can become problematic for some when they prescribe masculine sex development (Harkin & Elander, 2025). Relatedly, a UK survey found that only 53% of 139 people with KS identified as male - 19% identified as non-binary or intersex, and 12% as female (Clark et al., 2024).

Caretakers' Experiences and Advocacy

Consistent with this landscape of healthcare environments, new perspectives from clinical social work in the USA describe parents as subject to "hermeneutical marginalization," when those parents are not systematically taught the knowledge, support and skills needed to act in the best interests of their children with VSC (Scranton & Doherty, 2025). Relatedly, even among adults and caretakers of children in Germany who were mostly satisfied with their DSD teams, psychological counselling, contact to self-advocacy groups, and help with coordination were commonly reported unmet needs (Schnoor et al., 2025). Both young people and caretakers in a German psycho-educational program most frequently mentioned "the feeling of no longer being alone" as its best outcome (Wiegmann et al., 2024). The clinical literature now includes guides for caretakers and others with responsibility for children on how to talk about specific variations such as Turner's Syndrome (Norman et al., 2025) and Congenital Adrenal Hyperplasia (Nokoff et al., 2025).

Caretakers, such as parents, must make sense of available care pathways, often without access to these psychosocial resources that enable them to talk about variations with others. Creative self-empowerment strategies are also needed, and achieved, by caretakers bridging the gap between their obligation to communicate about a young person's diagnosis and the capacity to do so (Kimball et al., 2025). Caretakers' priorities may be different from those of their children, as shown in a recent study about preferences for fertility options (Dowlut-McElroy et al., 2025). A new systematic review of 27 previous studies on parent's decisions following pre-natal diagnosis found that ultrasound-detected variations, karyotype variations, and counselling were all key factors influencing parental decisions (Dorf et al., 2025). After one German psychological intervention, parents consistently rated trust in their DSD providers as its most positive outcome (Wechsung et al., 2025). Parents in China reported less conflict about hypospadias surgery decisions when they experienced more social support, because that support was associated with greater hope and resilience (Liu et al., 2025).

Surgical Interventions and their Consequences.

Decisions about care pathways might be less psychologically stressful for people with VSC and their parents if the psychological consequences of controversial care pathways were better research. Variability in expertise among those professionals who carry out controversial health interventions complicates this landscape. Over the past twenty years, surveys have repeatedly documented that many endocrinologists and urologists with specialist expertise in VSC do not think that genital reconstructive surgery is always being done in centres of excellence (Khorashad et al., 2025).

Most recent studies examining the effectiveness of surgical interventions were generated by our search for "hypospadias." Researchers currently debate how common hypospadias are and if they are becoming more common. One study estimated the rate is 0.33% of all male births globally (Liu et al., 2025), whilst a Danish study estimated that rate to be 0.8% (Leunbach et al., 2025). A scoping review concluded that mild hypospadias often go undetected and have no clear functional effects, leading its authors to argue for postponement of this controversial, but common, infant genital surgery in these cases (Bohane et al., 2025). Both a systematic review pooling outcomes from 13 precious studies (Effendi et al., 2025), and a new study of almost 1000 parents in the USA (Beland et al., 2025) suggest that complications come around for about 12-16% of boys following hypospadias surgeries. These findings are relevant to the first PSII podcast, *Hypospadias surgeries: Emotion, talking and timing*.

Other recent studies addressed other specific interventions. A systematic review of 12 studies conducted in diverse countries concluded that growth hormone interventions to address short stature had no consistent positive effect on quality of life of people with Turner's Syndrome, whilst neurodevelopmental disorders were more common among those treated with growth hormone or estrogen (Stoynova et al, 2025). A single-centre questionnaire study found rates of sexual dissatisfaction to be high among women with Complete Androgen Insensitivity Syndrome, irrespective of whether those women had or had not received either vaginal dilation treatments or hormone replacement treatments following gonadectomy (Mangone et al., 2025). In contrast, a Brazilian study found a majority of 60 women with various VSC who had experienced genitoplasty agreed that the genitoplasty should be performed in childhood (Bag et al., 2025).

What Might the Law Deliver?

In the last two decades, International Treaty Bodies have spoken out with firm language and increasing frequency against *intersex genital mutilation* (IGM) but these statements have not translated into changes within nation states (Ravesloot, 2025). Western bioethicists have recently argued for ethical frameworks, grounded in *all* children's rights to privacy, bodily integrity, sexual boundaries, and future genital autonomy, that would also address genital surgeries on minors with VSC in medical contexts (Brussels Collaboration on Bodily Integrity, 2025). New US laws banning gender affirmative care for transgender youth typically allow interventions on minors with VSC as exceptions (Mar et al., 2025). Legal and cultural analysis of these laws have concluded that these "intersex exceptions" demonstrate that bans on transgender healthcare are not grounded in moral concerns about harm to minors, but in fear and loathing of transgender people (Lau & Fedders, 2025) and a fascist logic about disability (Orsak, 2025).

2025 began with the publication of the first report on intersex health equality from the US department of health and human services (Sharpe et al., 2025). It was quickly superseded by President Trump's Executive Order titled *Defending Women from Gender Ideology Extremism and Restoring Biological Truth to the Federal Government* which has received ample criticism for its negation of the existence of people with VSC (Becker & Ahmed, 2025). These events were the subject of the PSII podcast *Executive orders.*

These recent events worsen longer-standing concerns that failing to imagine gender-diverse futures as positive outcomes of healthcare generate the apparent need for medical interventions to normalize the appearance of VSC in the first place (Kamoun & Dalke, 2025), or to ensure that people with variations are not born at all (Meoded Danon et al., 2025). In surveys conducted over the last 20 years, endocrinologists and urologists with specialist expertise in VSC consistently ranked "gender identity consistent with assigned sex" as the most important factor affecting their patients' life satisfaction, ahead of family and community context, clinical presentation, aspects of treatment and individual characteristics of the child, and a significant minority of clinicians agreed that sexual orientation should factor into gender identity decisions (Khorashad et al., 2024).

Laws and policies that do not recognize the social existence of people with VSC marginalize and harm. For example, recent research points to the lack of guidelines for how to recognize and accommodate people with variations in a hospital emergency room (Kruse et al., 2025), a prison (Brömdal et al., 2025), or a physical education classroom (Haase et al., 2025). This last venue is particularly poignant given the highly visible attempts to use scientific research to create a rationale to exclude women with variations from elite sporting competitions (Gollish et al., 2025), the subject of a PSII webinar earlier in 2025 (see PSII Podcast 3, *On what basis is elite sports fair?*). A recent qualitative study describes how intersex traits may make people particularly vulnerable to sexual abuse (Yuodsnukis et al., 2025). Intersex studies scholars are increasingly expanding awareness of how harm can be done through exploitation in medical research and practice to social science research and practice (Munro, 2025). In Pakistan, intersex persons have no legal basis to protect them from social and economic marginalization, denial of access to healthcare and religious worship, or protection from organized crime (Naseer et al, 2025). This situation stands in contrast to long-standing recognition within Islamic jurisprudence of people with VSC (Alipour, 2025) and recent calls for bioethics that is integrated with Islamic thought and tradition (Woodman, 2025).

Take Home Conclusions

- Studies reporting mental health outcomes are unlikely to be statistically representative. Variability in quality of life and psychological distress, and withdrawal from studies, may be effects of psychosocial variables which quantitative researchers should anticipate and measure.
- Qualitative researchers describe practices and discourses in healthcare and the agency and self-advocacy that those environments require of individuals. Quantitative studies predicting health outcomes as dependent variables do not yet address these forms of agency.
- Peer support, when it can be accessed, is experienced as empowering. This is particularly important given the context of hermeneutic injustice.
- Controversial surgeries are believed, even by medical experts in DSD, to be taking place under conditions that are not optimal, risking considerable long-term harm.
- The recent positioning of irreversible surgical interventions on VSC as "exceptional" within recent laws against transgender healthcare raise principal ethical concerns about what is practiced as healthcare in the USA.

Closing Comments

We hope this brief review has helped you to make sense of the very many psychosocial conversations that were – and were not – happening in the published research literature in 2025. PSI-I is comprised of enthusiastic volunteers who share a drive to create a more open society which values bodily autonomy and human rights for all and we strive to communicate about research in ways that work towards those goals. We hope to hit the mark, and whether we do or do not, we value your feedback at any time, so please feel free to tell us how we did on this occasion at PSI_International@yahoo.com.

Links to Related PSII Podcasts

1. Hegarty, P. (Host). (2024a, April 30). Hypospadias surgeries: Emotion, talking and timing. [Audio podcast episode]. In *Podcasts*. Psychological Studies Intersex International. https://psiinternational.wixsite.com/home/episode-1
2. Hegarty, P. (Host). (2025b, July 21). Executive orders [Audio podcast episode]. In *Podcasts*. Psychological Studies Intersex International. https://psiinternational.wixsite.com/home/episode-2
3. Hegarty, P. (Host). (2025c, September 22). On what basis is elite sports fair? [Audio podcast episode]. In *Podcasts*. Psychological Studies Intersex International. https://psiinternational.wixsite.com/home/episode-3

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9. Brussels Collaboration on Bodily Integrity. (2025). Genital modifications in prepubescent minors: When may clinicians ethically proceed? *The American Journal of Bioethics, 25*(7), 53-102. **(VSC)**
10. Clark, D., Kago, T., Sahota, K., Rashid, T., & Yap, T. (2024). Gender identity in Klinefelter Syndrome: a patient-centered approach to treatment. *Annals of Medicine, 56*(1), 2406447. **(KLINEFELTER SYNDROME)**
11. Davoudian, T., & Hills, E. (2025). The need to integrate mental health treatment into the care of Mayer—Rokitansky—Küster—Hauser. *F&S Reports*. **(MRKH)**
12. Dorf, I. L. H., Lou, S., & Skakkebæk, A. (2025, April). Parental decision-making following a prenatal diagnosis of Turner Syndrome: A systematic review. In *American Journal of Medical Genetics Part C: Seminars in Medical Genetics* (p. e32140). **(TURNER'S SYNDROME)**
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