

The background of the cover features a stylized profile of a human head facing right. The head is composed of two overlapping shapes: a purple one on the left and an orange one on the right. The text is overlaid on the purple portion of the head.

Towards Affirmative Intersex Health Communication in Canada

**An Introductory Guide
for Healthcare Providers**

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Themes and topics in this guide are connected to original interviews with individuals with VSC and healthcare providers from diverse areas of care. The content was primarily shaped by the areas and issues interviewees found most salient as well as from the results from a comprehensive literature review. It is specifically written for the Canadian context. The quotes contained in this document are anonymized from participant interviews and use pseudonyms.

This guide is the final component of a SSHRC-funded initiative aimed at improving health communication practices with intersex people in Canada. The project was centrally carried out by past and present members of Professor Yann Joly's team at the Centre of Genomics and Policy at McGill University's Faculty of Medicine including Terese Knoppers, Kaleb Saulnier, Nicole Palmour, Jess Baptista, Marilou Charron, Sasha Faraji, Hortense Gallois, Narges Jamali, Kacey San Diego and Angelica Voutsinas.

This guide has also two companion articles: a qualitative paper centered on interviewee insights, perspectives, and experiences (DOI: 10.3389/fpubh.2024.1436354), and a comparative legal paper arguing for a more proactive approach to legal and medical reforms and protections in Canada (CanLII Docs: 2842).

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McGill



Introduction

- Health communication is the exchange of health information between healthcare providers and patients. It includes:
 - the verbal and nonverbal interaction between patients and providers – i.e. what is communicated and how
 - how health information is transmitted administratively within a healthcare clinic/organization
 - what the healthcare environment set up and decor communicates to patients

Health communication forms a crucial component of positive physical and mental health outcomes.

- While practices and medical norms are shifting towards affirmative intersex care, there is still much progress to be made and community members are still reporting adverse experiences. Intersex individuals and organizations continue to ask for improved health communication practices from healthcare providers. At the same time, healthcare providers in most specialties repeatedly point to gaps in their training regarding intersex care and the need to pursue independent supplementary training to familiarize themselves with the needs and background of this population. This guide is a primer for healthcare providers interested in bridging those gaps and helping to make healthcare communication more accessible, effective, relevant, and responsive. Ultimately, the pathologization of intersex traits is a systemic issue. Shifts in healthcare communication practices can also make broader contributions to society by increasing awareness and decreasing stigma around intersex variations.

Purpose of this guide

- To help work towards health communication practices that best support and advance the wellbeing and quality of life for adults with intersex variations in Canada.
- It was created for the Canadian context as no such guidance document currently exists.
- It is meant to start a conversation and facilitate change at this specific point in time, recognizing that knowledge and standards around language and affirmative practice evolve quickly.

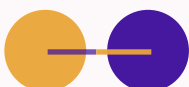
Terms & Concepts



Intersex (adj.)

Intersex is an umbrella term for innate variations in the spectrum of physical sex characteristics that fall outside of binary norms for human sexual development. Sex characteristics include chromosomes, genitals, internal sex organs, hormone production and responses, and the secondary features that develop during puberty. There are over 40 medical terms for specific combinations of intersex traits. Intersex variations may be identified at various periods in personal development, most commonly prenatally, at birth, at puberty or when trying to conceive. Some variations involve specific medical needs and complications, but many do not. For a variety of reasons, many people go their whole lives without knowing they were born with an intersex variation.

While intersex is a description for a group of variations, every intersex person is unique and will have a unique relationship to their body, experiences, and needs. Learning about a patient's specific intersex trait(s) and individual context is essential to effective health communication.



Endosex, perisex, dyadic (adj.)

Terms used to describe people who are not intersex, i.e. whose physical sex characteristics conform to binary norms for human sexual development.



Sex is a spectrum

The term intersex encompasses the concept that rather than a binary, there is a spectrum of natural variation in physical human sex characteristics.

A note on terminology

We have opted to use the term intersex, as it is the umbrella term most often used by the stakeholders informing this guide as well as organizations, advocates, and support groups. It is generally asked by intersex organizations for medical professionals to avoid using the term “disorders of sexual development”, as the language of disorder contributes to the stigmatization and pathologization of intersex embodiment. In contexts where DSD must be defined, “differences in” or “diverse” sexual development is preferable. Some medical providers have also started using variations of sexual characteristics (VSC).

At the individual level, there is no universally preferred term. When meeting with patients it is important to ask about and use preferred terminology. People may use a variety of language to describe themselves including their variation or diagnosis. Some people relate to intersex as an identity category - such as the way people have identities around gender or sexuality - while others do not.

The difference between sex characteristics, sex, gender, and sexual orientation

Sex, gender, and sexual orientation are distinct concepts from sex characteristics. Gender identity is a person’s internal or felt sense of being or not being a particular gender; the external or public-facing component of gender is called gender expression. Sexual orientation refers to the gender(s) that a person is attracted to, and sex is a categorization based on a collection of physical/biological characteristics. Contrary to popular misconception, there is no inherent association between being intersex and having a minority gender (nonbinary, transgender) or sexual orientation (bisexual, pansexual, queer). Just like endosex people, intersex people can have any gender and sexual orientation and are legally assigned a sex at birth with which they may or may not identify. Further, assigned legal sex being incongruent with physical sex/sex characteristics and gender identity in intersex people is a specific life experience with distinct care needs and is not synonymous with being transgender; some people who have this life experience consider themselves transgender and some do not.



Affirmative Health Communication

The following are four key aspects of affirmative intersex health communication between patients and providers.

Patient-centered care

“ I was lucky, I have a family doctor who has been following me since I was pretty young. I have complete trust in the doctor. My family doctor didn't treat me differently, even though I was a pretty rare case; they just treated me like me. And it was hard to accept [when I found out about my variation], because that means there were implications- about reproduction, about how my life would be changed in the future. But they took it step by step, and helped guide me through the process.

Miles, intersex person

”

- Affirmative health communication puts the person at the heart of care. Each patient is approached with warmth, compassion, respect, and as a unique individual with unique care needs
- Individualize care to the patient's wishes, needs, values, sociocultural context, personal history, experiential knowledge, and general level of health literacy
- Have a baseline knowledge regarding affirmative intersex care that is kept up to date, including about the most common intersex variations. Learn more on a patient-by-patient basis. Put the person first, before any diagnosis
- Cater health information to the individual- in form and delivery (e.g. some people will want a large volume of information, others will appreciate learning one thing at a time, some people are more verbal, others more visual, etc.) Allow time to process information, as well as for follow-up questions
- Identify and address any gaps or misinformation from past medical experiences
- Ask about and respect the patient's language for self, VSC, body parts etc. (while still being accurate- see bullet above)
- Follow up on how the patient is doing, especially during pivotal moments in care (e.g. after initial discovery of variation)
- Ensure care plans are holistic and interdisciplinary, attending to both physical and psychosocial wellbeing
- Provide long-term care if possible. Otherwise facilitate the transition to a new affirmative provider

Shared decision-making

“ I think it's really important -and we do that these days- to make sure that the family and the patient really are full members of the medical team and that decisions are made with the parents and the young...to really include them as much as possible in the decision-making process, to help them understand that they really are full team members.

- Dr. Lee, pediatric endocrinologist

”

- While increasingly a general standard of care, it is very important when working with adults from the intersex community that they be active participants in their care, and involved in all decisions regarding their health, including surgical decisions and medical interventions
- The shared decision-making process promotes patient bodily autonomy, self-determination, and informed consent
- Questions and discussions are integrated into medical visits. Younger patients are given space to speak to medical providers independently from parents where appropriate
- Do not pressure patients to undergo nonessential medical interventions. Risks should be framed realistically, avoid “urgency” outside of genuine medical emergencies.
- For surgeries outside of an emergency context, wait until the patient is old enough to provide full informed consent to surgery
- Obtaining free and informed consent:
 - Use lay language and validate understanding
 - Share what is known about variation and what is uncertain. Do not be afraid to share if you do not know something or if the literature or best care are contested
 - Provide information and options regarding all care paths
 - Include accurate and complete information about any medical interventions: desired outcomes, possible complications, long-term effects, etc.
 - Give time to digest and process information and options

Culturally-responsive trauma-informed care

“

I've been left with a massive distrust of anything medical, even to the point where we are now going to discuss my parents' care, and I distrust the people who I have to get involved with. I'm gearing up, so what's been fostered in me is to fight. Fight or flight, and that's PTSD in my opinion.

- Callie, intersex person

”

- Many intersex individuals carry past adverse medical experiences that continue to impact their lives and/or hold intercommunity knowledge from their peers that will make them understandably wary of medical encounters. It is helpful for providers to be aware that people may bring this into the room and that they may anticipate stigma and pathologization
- Culturally-responsive trauma-informed care meets patients 'where they are at' in their relationship to and needs regarding medical care and services. It is attuned to impacts of medical trauma, physically and emotionally
- Providers can help by:
 - Vocally expressing support and intention to provide affirmative care
 - Listening, demonstrating empathy and humility
 - Reading medical charts before the first appointment, both to be informed and to avoid medically unnecessary questions
 - Consistently communicating in an affirming and normalizing way
 - Forefronting informed consent, personal agency, and bodily integrity in all medical decision-making and acts, e.g. by explaining procedures or why certain questions are medically relevant, and by giving options
 - Staying attuned to the emotional state and nonverbal communication of the patient
 - Respecting that the person may not want to share certain information right away, giving time for the doctor-patient working relationship to develop

- After delivery of particularly emotionally impactful information (initial diagnosis, fertility options), following up at a later appointment both to see what was understood, to answer new questions, and to see what types of additional supports might be needed
- Asking about ideal care paths and outcomes, physically but also psychosocially, and helping scaffold actionable goals including via referrals to other healthcare practitioners
- Checking in near the end of appointments about remaining questions or concerns
- Providing information about peer support resources



Accessible and relevant medical information

- Age appropriate
- Clear
- Comprehensive
- Current
- Defines any complicated/medical terms and limits their use overall
- Delivered with emotional impact in mind
- Good, thoughtful, interesting design
- Honest
- Non-pathologizing (naturalizes and normalizes intersex variations)
- On topic, relates directly to patient's presenting concern, context and variation
- Uses multiple mediums (e.g. in person discussion, physical handouts, web resources)
- Well-paced, avoids information overwhelm

Needs across the lifespan

The following chart discusses various challenges that may occur for intersex people and their families at different stages of life as well as suggestions for how healthcare practitioners can be helpful. It assumes that the four key aspects of effective health communication will be used throughout. As always, care and information should be adapted to the person and context. These suggestions encompass both general healthcare provider and specialist domains.

Possible challenges

Helpful communication

Birth/Infancy

- Family reactions
- Care path decisions
- Infant's inability to consent
- Social pressure and announcement of sex

- Provide clear, thorough, non-pathologizing information regarding the specific variation and possible care paths/any medical decisions
- Normalize intersex variations and challenge related assumptions, such as those around quality of life
- If there are accompanying health concerns, give all options and realistic, clinically proven presentation of risks
- Give time to process information and for decision-making
- Assist in connecting to healthcare specialists for the infant as is relevant
- Plan for continuation of medical history across the lifespan
- Assist in finding psychosocial support for the parents - counselling, peer support groups

Childhood

- Giving child relevant and age-appropriate information
- Development of gender identity
- Social adjustment when entering school
- Decisions regarding medical interventions/treatment
- Child's inability to consent to any medical interventions

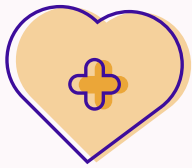
- For parents, same recommendations as above
- Encourage parent-to-child discussion/normalization of the subject
- Provide child with age-appropriate, affirming information about variation, including basic background knowledge of sex, sex characteristics, and gender
- Facilitate age-appropriate involvement in care: child's assent
- Preserve right to an open future: possibility to wait until individual can actively participate in their own care before going forward with irreversible procedures
- Make referrals to help with applicable peer skills as relevant - e.g. communication skills around bodily difference, decisions around privacy, managing bullying
- Facilitate connection to peers with intersex variations

Teenage Years

- In some cases, puberty will be different from peers and/or not as anticipated
 - Identity questions and challenges, especially if VSC found at that age
 - Emerging sexuality, communication around relationships and intimacy
 - Peer stigma/discrimination
 - Distrust and/or avoidance of healthcare providers
 - Decisions regarding medical interventions/treatment
 - Parental adjustment process and anxieties
 - Family conflicts
- Give relevant medical information: affirming, up-to-date, variation-specific, engaging for a teenager
 - Facilitate or refer to a health professional who will provide affirmative comprehensive understanding of body, sexuality, and sexual health, including different ways to be intimate
 - Nonjudgmentally acknowledge and address medical distrust/avoidance/anxiety if present
 - Meaningfully include teen in informed consent process and decision-making, in accordance with local provincial/territorial law. Explain confidentiality and its limits
 - For any care path/medical intervention decisions, provide multiple clear thorough options with evidence-based information on possible complications and risks
 - Assist in finding mental health, peer, and family support as applicable
 - Encourage open communication within the family
 - Facilitate transition from pediatric to adult services, continued support when patient 'ages out' of youth services

Adulthood

- Reproductive complications (e.g. infertility)
 - If variation found at that age: distress and identity challenges
 - Stigma
 - Decisions regarding medical interventions/treatment
 - Distrust and/or avoidance of healthcare providers
 - Long-term effects of earlier medical interventions or treatment (e.g. pain, discomfort)
 - Additional health complications and needs with age
- Give relevant medical information: up to date, variation-specific, and evidence-based for maintenance of health and any decision-making
 - Nonjudgmentally acknowledge and address medical distrust/avoidance/anxiety if present
 - Check in about mental health status and needs
 - If applicable and requested, provide or make referrals for affirmative support in areas of adult health needs such as:
 - Information for sexual health, intimacy, and fulfillment
 - Available/applicable family building options: fertility counselling, adoption, surrogacy
 - Open communication within the family such as discussing variations of sex characteristics with children
 - Peer support
 - Mental health support
 - Reparations or revisions of prior treatments
 - Attend to additional health needs and complications that occur with age, make referrals to older adult care providers and support programs as needed



Communicating a Welcoming Healthcare Environment

Reception and Intake

- Because reception is the first point of contact in a health setting and considering patients often arrive wary or nervous due to past experiences, general friendliness from reception staff is important
- Physically set up the office environment to promote privacy when talking to reception
- Review patient forms and materials in general for sensitivity and inclusivity

Physical space

“

There's some clinics where they put up stickers saying -"all people welcome"- and that kind of thing. I look for those, because I know I'll likely have a better experience.

- Sacha, intersex person

”

- Signalling from decor and materials and physical space (posters, brochures, magazines, patient education materials), should reflect the diversity of your patients and be generally inclusive, e.g. have an all-gender bathroom option
- Have a system for confidential patient comments/suggestions
- The physical layout of furniture and including plants etc. can reduce busyness/anxiety

Organizational culture

- Employee and staff non-discrimination policy should include sex characteristics
- Training for all staff in basic medical and cultural competence in working with intersex patients

Website

- As many people find their providers online, it is useful to reference being intersex affirmative on organizational/practitioner websites

Structural Access Factors



Structural factors are important to take into account as they affect people's access to healthcare in the first place. While they impact all people in Canada (and addressing them could be helpful for everyone), they are included in this guide because they are compounded for and thus disproportionately impact intersex individuals. These factors are also further mutually compounding with each other. For instance, if you are intersex, older and live rurally, it will be even harder to find good care. Finally, it is important to note this list of structural access factors is not exhaustive. In this guide, we discuss some ways healthcare providers can mitigate the impacts of systemic inequities in their practice. Ultimately, resolving structural access inequities will require structural solutions - including around resource allocation and legal/policy reform.

Geographic location

“ When I called them, they were like, ‘we have no hits for anybody within 400 kilometres of you, have fun on your own’... There isn't really a central space where you can be like, ‘I'm going to start there!’; you have to think about where you are and what's around you and start in the easiest place. For me it was like okay, I want to try and find someone locally, and then if I can't do that, I'll go to the next town over...then keep branching out as I can. That took a lot of trial and error.

- Noah, intersex person ”

Intersex specific health resources are largely concentrated where the population is concentrated in Canada, particularly Toronto, Vancouver, and Montreal, yet many people live far from these cities. There are also geographical inequities in healthcare due to the fact that it is organized and resourced differently by province/territory. Features of underserved areas include:

- Fewer medical specialists and fewer specialty health services available locally
- Potential challenges in access to appropriate medication
- Added cost of travelling to meet with specialists/access needed healthcare (requires time, money, energy, travel resources)
- Fewer community resources and 2SLGBTQIA+ friendly clinics

To help overcome structural barriers to comprehensive quality care for people with intersex variations in underserved areas, healthcare providers can:

- Offer telehealth services as permitted by profession
- Advertise your affirmative practice online so people can find you
- Reach out to community organizations (such as Intersex Canada) to let them know you are interested in learning more about inclusive and affirmative practice or are an ally providing services
- In provinces with long waiting lists for general practitioners, provide a periodic drop in service
- Have added flexibility/accommodations for patients travelling from out of town
- Have information to provide on hand regarding online resources and peer support groups
- General practitioners in underserved areas can provide certain relevant services associated with specialists such as hormone-replacement therapy

Age

“

I was seeing the same healthcare practitioner for a very long time. Until I turned 18, then I had to stop seeing them. Since then, I have not had regular visits with a healthcare practitioner... that's something that I've heard echoed back to me; that it's really easy to get consistent care with the same doctor until you are an adult. It's a lot more challenging when you are an adult.

- Regan, intersex person

”

Another structural trend is that children's services are better resourced and more comprehensive than adult services. Transitions from youth to adult services and then from adult to older adult services can be difficult or disjointed and people cannot always find the care providers they need. Individual healthcare providers can help by:

- Facilitating any necessary transitions between HCPs where possible. For example, by helping youth aging out of pediatric services to find their new HCPs, a follow-up appointment post-transition, and back-up referrals if the first new HCP is not a good fit
- For HCPs that work with adults, following patients long-term where possible, and helping to find additional services for older adult care as relevant

Socioeconomic circumstances

The systemic stigma and discrimination intersex people face, as well as the physical and emotional impacts of adverse medical experiences can render intersex people susceptible to socioeconomic disadvantage. This can impact the time, energy, and resources they have to access medical services, especially those not covered under Canada's healthcare system. Individual healthcare providers and organizations can help by:

- Having referrals on-hand for lower-barrier healthcare providers and services not covered by the public health system (such as many mental health care services)
- If in private practice, by offering sliding scale services or lower fees for low-income clients
- Providing travel accommodations where applicable, such as travel vouchers or tickets for public transportation

Race and ethnicity

Intersex people who are racialized and/or from ethnic minority groups face additional barriers to accessing sensitive, responsive and affirmative health communication due to systemic biases in healthcare, language differences, historical and ongoing discrimination, and under-resourcing of cultural competency training within healthcare systems. Racialized populations have also been seen as masculinized or feminized compared to white individuals in a way that can impact clinical interactions for racialized intersex people. Individual healthcare providers can help by being sensitive to and proactive regarding this additional structural layer including:

- Actively listening to patient concerns, asking open-ended questions about cultural practices, family expectations, and other factors that might influence the patient's health goals
- Where possible, supporting patients in connecting with social supports specifically addressing both VSC and their racial, ethnic and/or cultural identities
- Offering interpretation services and multilingual health materials

2SLGBTQIA+ health services and organizations

“

We are a minority community, in the LGBTQ long list, we are a minority of the minority. So if we could have more representation there, and then be involved in the education of healthcare practitioners as well.

- Sacha, intersex person

”

There are historic and cultural parallels between communities harmed by dominant paradigms around sex, gender, sexual orientation, and sex characteristics as they intersect and overlap. Hence the 2SLGBTQIA+ acronym and the tendency of health and peer organizations centered around the wellbeing of minority gender and/or sexual identities to include an 'I' in their service umbrella. Some intersex people do actively seek out healthcare providers through 2SLGBTQIA+ organizations because of the 'I', because their sexual and/or gender identities fall within the umbrella, and/or because they anticipate these providers will be more affirmative overall. However, it is important to note that not everyone who is intersex will identify with the larger umbrella and not to conflate being intersex with any given gender identity or sexual orientation. There is a range of opinions among the intersex community about the inclusion of the 'I' in the umbrella in the first place, and about how well intersex-specific issues have been and can be represented and resourced within. It is essential for 2SLGBTQIA+ organizations and healthcare providers who have included the 'I' in their service mandate:

- To provide a welcoming space for people with intersex variations while acknowledging that not everyone who is intersex will identify or associate with the umbrella
- To make sure to meaningfully integrate the needs and experiences of intersex people in their services (i.e. do not just merely fold intersex people into existing practice, learn about the specific situation/history/medical needs of the intersex population and what they are asking for from healthcare providers)
- To not operationalize intersex experience to make points around gender and sexuality

Medical provider education

“ *Just working in a healthcare setting myself, we've had a few presentations on gender, sexuality and the nomenclature behind everything...Unfortunately, there hasn't been that much there for intersex.*

- Riley, intersex person

”

While certain professions, such as endocrinology and genetic counselling, are more likely to provide education and training on working with intersex patients, overall preclinical and clinical coverage of the subject is lacking. Individual healthcare providers who are in a position to contribute to curriculum, influence continuing education opportunities, invite guest speakers and/or who are educators themselves can make a significant difference towards inclusive and affirmative care.



Conclusion

Thank you for reading this introductory guide. We hope that it has helped you feel better equipped to care for intersex patients. Building the background knowledge and skills to become an affirmative provider is an ongoing journey and we have included additional resources in the following pages. We also encourage you to mobilize the resources and networks available to you towards implementing intersex affirming health communication in Canada.

“ *Being intersex is very central to me as a person. I think that it has kind of shaped me, made me who I am today. I'll always be grateful for what it has brought me, growing up with that lens on the world, being able to see, not only black and white, but also those colors of grey, in between. It sounds cliché, but I genuinely think I wouldn't change anything and I'm grateful for that.*

- Regan, intersex person

”

Additional Resources

International Resources for Affirmative Care

Affirming Primary Care for Intersex People

National LGBTQIA+ Health Education Center-The Fenway Institute (U.S.A.)

lgbtqiahealtheducation.org/publication/affirming-primary-care-for-intersex-people-2020/

Intersex Health and Wellbeing: Healthcare and Service Map, Psychosocial Impact Map, Best Practice Indicator Checklist

Intersex Human Rights Australia and Intersex Peer Support Australia, together with Queensland Council for LGBTI Health

ihra.org.au/pathways/

Lend a Helping Hand: A Resource Guide for DSD Care

Accord Alliance (U.S.A.)

accordalliance.org/wp-content/uploads/2021/09/e-RR_v2.0_September-2021.pdf

Providing Ethical and Compassionate Health Care to Intersex Patients: Intersex-Affirming Hospital Policies

InterACT and Lambda Legal (U.S.A.)

lambdalegal.org/publications/intersex-affirming

Support Guide, Research Report, Healthcare Policy and Practice Recommendations

Reprofutures (UK) - covers support relating to reproduction, fertility, relationships, intimacy, and parenting

sites.exeter.ac.uk/reprofutures/

TRN Publications

Frequently updated list of curated publications regarding best practices and new evidence regarding intersex/DSD care for a healthcare practitioner audience (U.S.A.)

dsdtrn.org/resources/trn-publications/

What We Wish Our Doctors Knew

InterACT. (U.S.A.)

interactadvocates.org/resources/intersex-brochures

Pour une pleine reconnaissance des réalités des personnes intersexes :

Conseil Québécois LGBT

<https://conseil-lgbt.ca/wp-content/uploads/2023/05/GIX-CQLGBT-2023-fr.pdf>

Canadian Intersex Peer Support and Advocacy Organizations

Congenital Adrenal Hyperplasia Canada provides information and resources towards health and wellness for people with CAH.

cahcanada.ca/

Egale Canada is a national 2SLGBTQIA+ human rights organization that advocates for intersex rights and awareness on an ongoing basis. They have several active campaigns.

egale.ca/

Groupe de soutien intersexe Montréal (francophone) aims to create links between intersex people in Quebec and elsewhere and they post information about local, national, and international events, campaigns, cultural production etc. They run a peer support group.

intersexe@genderadvocacy.org

facebook.com/Groupe-de-soutien-intersexe-158839041229160/

Intersex Canada pioneers efforts to advance the rights, dignity, and inclusion of intersex individuals in Canada through education, awareness, community building, and collaborative initiatives. Our work includes providing resources, hosting community gatherings, fostering collective networks, and advocating for policy changes to ensure equal rights and opportunities for intersex people nationwide.

intersexcanada.org/

facebook.com/intersexcanada

Intersex Community Hub is a project that aims to improve the quality of life for intersex people in Canada via creating an online support space for intersex people as well as parents and guardians of intersex children to interact, create community, and support one another. It is run by Egale and Intersex Canada.

egale.ca/awareness/intersexhub/

Apply to the hub via: app.smartsheet.com/b/form/fa17664e8f5f44fe9a3298cab6e4322d

MRKH Canada is a Facebook page aimed at providing support, empowerment and information to those born with or affected by Mayer-Rokitansky-Küster-Hauser (MRKH). They hold activities and workshops for people with MRKH.

facebook.com/mrkhcanada

Syndrome de Turner (francophone) is a public Facebook group for people affected by Turner syndrome and their families. They also provide information to the general public.

facebook.com/groups/276753213037124

The Turner Syndrome Society of Canada provides resources and support for people with Turner syndrome and their families including online and regional chapters as well as events. Their mission is to provide advice and share stories in order to help families going through similar journeys.

info@turnersyndrome.ca

turnersyndrome.ca/

facebook.com/groups/1662593047295553

The Klinefelter Syndrome Association of Canada (KSAC) is a voluntary, non-profit, self-help organization that was established in 1987. It provides support to affected individuals and family members, promotes professional and public awareness, and functions as a resource service on Klinefelter syndrome.

rarediseases.org/organizations/klinefelter-syndrome-association-of-canada

