

**Supplementary materials: Lifespan healthcare transitions among individuals with intersex traits in Canada: a mixed methods
and qualitative study**

Table 1. Literature search methods for studies assessing healthcare transitions for individuals with intersex variations.			
Date	Bibliographic Database	Search String	Limiters
October 13, 2020	Medline	MeSH Search: ((MH "Transitional Care+") OR (MH "Stakeholder Participation") OR (MH "Patient Participation") OR (MH "Health Care Quality, Access, and Evaluation") OR (MH "Health Services Accessibility") OR (MH "Outcome Assessment, Health Care")) AND ((MH "Intersex Persons") OR (MH "Disorders of Sex Development")) Results: 20 General Search: (DSD OR "difference* sex development" OR "variation sex development" OR "disorder* sex development" OR intersex) AND (transition OR "life course" OR "long term outcome" OR "health care access" OR engagement) AND (program* OR service* OR access OR health OR care) Results: 55	Date: 2000-2020 Language: English (if applicable) Human studies only
October 13, 2020	CINAHL Complete	MeSH Search: ((MH "Transitional Care+") OR (MH "Stakeholder Participation") OR (MH "Patient Participation") OR (MH "Health Care Quality, Access, and Evaluation") OR (MH "Health Services Accessibility") OR (MH "Outcome Assessment, Health Care")) AND ((MH "Intersex Persons") OR (MH "Disorders of Sex Development")) Results: 1 General Search: (DSD OR "difference# sex development" OR "variation sex development" OR "disorder# sex development" OR intersex) AND (transition OR "life course" OR "long term outcome" OR "health care access" OR engagement) AND (program# OR service# OR access OR health OR care) Results: 18	Limiters: Date: 2000-2020 Language: English (if applicable) Human studies only
October 13, 2020	PsycINFO	APA Psych Index Term Search: ((DE "Life Changes") OR (DE "Psychological Engagement") OR (DE "Health Care Access") OR (DE "Treatment Outcomes") OR (DE "Life Span")) AND ((DE "Intersex Conditions") OR (DE "Genital Disorders") OR (DE "Sex Chromosome Disorders")) AND ((DE "Health Care Services") OR (DE "Health Care Access"))	Date: 2000-2020 Language: English Human studies only

		Results: 0	
		General Search: (DSD OR "difference# sex development" OR "variation sex development" OR "disorder# sex development" OR intersex) AND (transition OR "life course" OR "long term outcome" OR "health care access" OR engagement) AND (program# OR service# OR access OR health OR care)	
		Results: 27	
October 13, 2020	Web of Science	General Search: (DSD OR "difference* sex development" OR "variation sex development" OR "disorder* sex development" OR intersex) AND (transition OR "life course" OR "long term outcome" OR "health care access" OR engagement) AND (program* OR service* OR access OR health OR care)	Date: 2000-2020 Language: English
		Results: 65	
October 13, 2020	Journal of Pediatric and Adolescent Gynecology	General Search: ("DSD" OR "di! sex development" OR "variation sex development" OR "intersex") AND (transition OR "life course" OR "long term outcome" OR "engagement" OR "health care access")	Year(s): 2000-2020 In this journal or book title: Journal of Pediatric and Adolescent Gynecology
October 15, 2020 to February 19, 2021	Google Scholar & reference lists of included articles	Hand Search: Search terms varied Results: 29	N/a

Table 2. Survey responses from healthcare providers ($N = 3$) regarding the use of various resources and services in their practice with individuals with intersex variations.

Request	Results			Open-ended answers
	Yes	No/None	N/A	
What best describes your current healthcare situation?	--	--	--	Hospital-based adult provider setting, regulator, and pediatric endocrinologist
Guidelines and/or care-pathways used in practice settings	0/3	3/3	--	--
Local or provincial protocols and/or practice standards used	0/3	3/3	--	--
Screening tools (e.g., decision-support tools, mental health, and wellbeing measures) used at clinic visits	0/3	3/3	--	--
Specific transition materials for pediatric to adult care	1/3	2/3	--	--
Discharge summary resources for patients following health care visits	1/3	2/3	--	--
Support groups or sign posting information shared at health care visits	--	1/3	2/3	--
Use of telehealth to connect with this population	--	3/3	--	--
Specialists involved in working with this population	--	--	1/3	Endocrinology, Gynecology, Genetics, Psychology, Urology
ICD-10 codes used in practice?	--	--	1/3	2590, 758.8, 752, 255.2, 255.9, 752.4, 752.6, 752.7, 752.8, 752.9
Duration organization keeps medical records	--	--	1/3	10-20 years; >20 years
Ongoing/planned research in area of VSD within organization	--	1/3	1/3	In development (1/3)

Abbreviations: VSD= Variations in Sex Development

Table 3. Results from freedom of information requests (FOI's) submitted to 13 Canadian Children's hospitals

Request	Results
<ul style="list-style-type: none"> practice guidelines and policies surrounding the care of individuals with intersex differences in sex development (DSD). procedures regarding infants, children, or youth with intersex/DSD See https://doi.org/10.5281/zenodo.6092189 for complete costing and hospital sites 	<ul style="list-style-type: none"> 11/13 hospitals returned no guidelines, policies, nor procedures. <p><i>General policies/guidelines/standards followed by HCPs at two hospitals:</i></p> <ul style="list-style-type: none"> The World Professional Association for Transgender Health (WPATH) guidelines [1] Endocrine Treatment of Gender-Dysphoric/Gender-Incongruent Persons: An Endocrine Society Clinical Practice Guideline [2] The Ontario Human Rights Code [3] Consensus statement on management of intersex disorder [4] Clinical Guidelines for the Management of Disorders of Sex Development in Childhood [5] Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care [6] Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015) [7] Caring for individuals with a difference of sex development (DSD): a Consensus Statement [8] Pediatric Decision Making and Differences of Sex Development: A Societies for Pediatric Urology and American Urological Association Joint Position Statement [9] Monthly multidisciplinary meetings variable involving Medical Genetics, Cytogenetics, Laboratory Medicine, Pediatric Endocrinology, Pediatric Gynecology, Pediatric Urology, Social Work, Sexual Medicine, Nursing, and other interested parties Monthly Royal College-accredited review of topic of interest

References:

- World Professional Association for Transgender Health (WPATH). Standards of care for the health of transsexual, transgender, and gender-nonconforming people [7th Version]. 2012. Available: <https://www.wpath.org/publications/soc>. <https://www.wpath.org/> [Accessed 12 Mar 2021].
- Hembree WC, Cohen-Kettenis PT, Gooren L, *et al*. Endocrine treatment of gender-dysphoric/ gender-incongruent persons: An endocrine society clinical practice guideline. *J Clin Endocrinol Metab*. 2017;**102**:3869–903. doi:10.1210/jc.2017-01658
- Ontario Human Rights Commission. The Ontario Human Rights Code. 2021. Available: <http://www.ohrc.on.ca/en/ontario-human-rights->

- code [Accessed 12 Mar 2021].
- 4 Hughes IA, Houk CP, Ahmed SF, *et al.* Consensus statement on management of intersex disorders. *J Pediatr Urol.* 2006;**2**:148–62. doi:10.1542/peds.2006-0738
 - 5 Intersex Society of North America. Clinical guidelines for the management of disorders of sex development in childhood: Consortium on the management of disorders of sex development. *DSD Guidelines*. Available:<https://dsdguidelines.org/htdocs/clinical/> [Accessed 15 Mar 2021].
 - 6 Lee PA, Nordenström A, Houk CP, *et al.* Global disorders of sex development update since 2006: Perceptions, approach and care. *Horm Res Paediatr.* 2016;**85**:158–80. doi:10.1159/000442975
 - 7 Faisal Ahmed S, Achermann JC, Arlt W, *et al.* Society for Endocrinology UK guidance on the initial evaluation of an infant or an adolescent with a suspected disorder of sex development (Revised 2015). *Clin Endocrinol (Oxf).* 2015;**85**:771–88. doi:10.1111/cen.12857
 - 8 Cools M, Nordenström A, Robeva R, *et al.* Caring for individuals with a difference of sex development (DSD): A consensus statement. *Nat Rev Endocrinol.* 2018;**14**:415–29. doi:10.1038/s41574-018-0010-8
 - 9 Board of Directors. Pediatric decision making and differences of sex development: A Societies for Pediatric Urology and American Urological Association joint position statement. American Urological Association. 2019. Available:<https://spuonline.org/multimedia/files/SPU-AUA.pdf> and <https://www.auanet.org/guidelines/guidelines/joint-statement-on-dsd> [Accessed 05 Jul 2021].

Table 4. Interview questions posed to individuals with intersex variations in our engagement sessions and interviews, regarding healthcare transitions.

Interview Questions

- 1) What are ‘transition’ points in the life-cycle?
- 2) What expectations do you have at these transition points (from health care?), what does good transition care ‘look like’?
- 3) How has or will transition care support your health condition, functioning and well-being?
- 4) Which services have you engaged with to date OR you think you will involve with as you age?
- 5) Which services do you think we should provide at times of transition? – how would you want to / or do you access services?
- 6) How do you think we would know these are in place, are of good quality and use up-to-date information?
- 7) What are the differences between transition care (at any stage) for individuals living in urban and rural settings?
- 8) Are health care services that you access effective or efficient – how do you decide this?
- 9) At times of transition (meeting new providers, being referred to new services) how do you receive information about health protection, health promotion, disease prevention?
- 10) Where would you / who would you connect with if you believe that transition care is missing from your health care, or you would want to access services that meet your transition needs?
- 11) Is transition care about access to the right services and people?
- 12) How do you think we can in the future implement/ change transition care? Who needs to be involved?
- 13) In the future if you could design, plan or monitor transition care – what would it look like?

Table 5. Integrative literature review results (*N* = 8 studies).

Author, Year, Country	Study Design	Participant Characteristics				Key Methods and Findings
		N	Condition	Mean Age	Sex (F)	
Bachelot et al., 2017 Country: France	<ul style="list-style-type: none"> • Prospective • Cohort • Quantitative 	73	CAH (100%)	32.7y (<i>SD</i> = 5.7y; 24 – 44y)	66%	<p>Analysed effect of transition process and regular medical follow-up on health status and quality of life.</p> <ul style="list-style-type: none"> • 48/59 patients who were transferred to adult care had regular medical follow-up in adulthood. • 1/14 patients who were not transferred had a regular medical follow-up in adulthood • Patients with successful transition (regular follow-up in adult services) had better physical and psychological health, and quality of life. • Note: individuals with successful transition also had higher SES
Callens et al., 2020 Country: Netherlands	<ul style="list-style-type: none"> • Retrospective • Cohort • Mixed-methods 	18	TS (50%) KS (22%) CAH (11%) cAIS (11%) MRKHS (6%)	~19y (16-21y)	78%	<p>Used qualitative narrative analyses of interviews, and quantitative descriptive and questionnaire methods to determine information needs of adolescents in transition care.</p> <p><i>Interview:</i></p> <ul style="list-style-type: none"> • Adult hospital environment was more depersonalized – some wish they could have stayed with their pediatric team for longer • Psychological care was important for almost all participants, and HCPs should address psychological factors related to their feeling of being different, as well as shared decision making • Desire to receive person-centred care, while also having knowledge on the condition more broadly • Most participants would like a HCP who is, “... open, positive, and sensitive, and to provide reliable information in clear and uncomplicated language,” (p. 10) • Would like HCPs not to avoid topics such as sex/fertility <p><i>Questionnaire:</i></p> <p>Largest gap scores (ideal care minus current care) for:</p> <ul style="list-style-type: none"> • “Provides opportunities for me to meet other young people” (p. 11) • “Provides appointments that are convenient for me (and my family)” (p.11) • “Providers from child and adult care who arrange joint appointments/consulting hours for adolescents” (p. 11)

Gleeson et al., 2013 <i>Country: UK</i>	<ul style="list-style-type: none"> • Retrospective • Audit • Cohort • Quantitative 	53	CAH 21-OHD, SW (75%), SV (23%), 17-OHD (2%)	<i>Median</i> = 25.5y (18.4- 47.8y)	60%	<p>Evaluating successful transition from pediatric to adult care and effect of a Young Person Clinic (YPC) where a patient is appointed to an endocrinologist.</p> <ul style="list-style-type: none"> • 36/53 referred from pediatric to adult service, but 50% were lost to follow-up (two were never offered an appointment) • Only 19/34 attended their first new appointment and the subsequent appointment • No difference in engagement with adult services between those who attended YPC and those who did not. • Being offered more appointments during 2-3 years of pediatric service before transfer was associated with not being lost to follow-up for 3≤ years.
Godbout et al., 2012 <i>Country: France</i>	<ul style="list-style-type: none"> • Prospective • Cohort • Quantitative 	73	CAH (17%) HH/GHD (83%)	<i>M</i> = 24.7y (<i>SD</i> = 4.5y)	Total: 33%; CAH: 69%	<p>Assessing specific needs of young adults with CAH (among other endocrine conditions) to inform transition of care, reported on clinical discussions at adult clinic</p> <p><i>CAH-specific results:</i></p> <ul style="list-style-type: none"> • Discussions at initial visit to adult clinic for (percentage of) individuals included: height (92%), weight (77%), bone health (85%), patient relationships (69%), sexual activity (85%), menstruation with genital examination and breast examination (89% and 78% for female patients), reproduction/fertility (69%).
Lee et al., 2012 <i>Country: US</i>	<ul style="list-style-type: none"> • Retrospective • Case series • Qualitative 	6	<i>P5:</i> Gonadal DSD/ gonadal dysgenesis	Infancy to 32y	<i>P5: F</i>	<p>Study used six case studies to display factors related to problems in adulthood. However, healthcare transition was discussed explicitly for only one patient:</p> <ul style="list-style-type: none"> • <i>P5:</i> "She recognized an issue with transition of medical care from pediatrics since no doctor since has had a full picture of her situation or taken time to learn it. She has been unable to find a health care setting that provides the overall perspective for her diagnosis that she had as a child and teenager." (p. 146)
Liao et al., 2010 <i>Country: UK</i>	<ul style="list-style-type: none"> • Prospective • Audit • Cohort • Quantitative 	50	cAIS/pAIS (34%) CAH (32%) XY gonadal dysgenesis (18%)	17.8y (13-20y)	100%	<p>Clinicians assessed needs of patients at time of transition from pediatric to adult services using traffic light system.</p> <ul style="list-style-type: none"> • 15 (30%) categorized as green (low level of professional concern) • 21 (42%) categorized as amber (potential reason for concern) • 14 (28%) categorized as red (high/urgent level of clinical concern) • Of the clinical requirements (broadly, endocrine management, gynecological/urological requirements, and psychological support), 13/14

			Other (16%)*			individuals with red status had psychological issues (for 11/14 this was their only present issue).
Simoes et al., 2017	<ul style="list-style-type: none"> • Prospective • Cohort • Quantitative 	19	MRKHS (100%)	(10 - 19y)	100%	<p>To assess difference between healthcare preferences and current care for a range of health care services, including transitional programs.</p> <ul style="list-style-type: none"> • Though items from ‘transition programs’ had some of the lowest gap scores (i.e., difference between best practice/priority score and current care score on a scale of 7) compared to other elements of care; some of the highest gap scores within the ‘transition programs’ topic were: <ul style="list-style-type: none"> ○ ‘Assistance with search for psychological support’ (gap score = ~5/7), and ‘the hospital (center) has a dedicated space/room, in which MRKHS patients can get together’ (gap score = ~4.5/7).
Country: Germany						
Sutton et al., 2005	<ul style="list-style-type: none"> • Prospective • Cohort • Qualitative 	97	TS (100%)	(7 – 59y)	100%	<p>Interviewed individuals with TS across four age groups (childhood, adolescence, adulthood, mature adulthood), as well as their parents about their concerns related to TS, and strengths/weaknesses of healthcare.</p> <p><i>Individuals with TS: (N = 97)</i></p> <ul style="list-style-type: none"> • Infertility and stature were main concerns • Social aspects of sexual development and function, and health were secondary concerns <p><i>Parents: (N = 21)</i></p> <ul style="list-style-type: none"> • Concerns were primarily around health/healthcare (E.g., worried about making decisions around medication that could harmfully impact their child later) • Financial expense of condition was also a concern unique to parents <p><i>Recommendations for HCPs:</i></p> <ul style="list-style-type: none"> • Early diagnosis, offering hormonal interventions, increased education for all parties, strengthening physician-patient communications, increased sensitivity, compassion, and encouragement
Country: US						