

Intersex study: preliminary demographics and wellbeing data

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Reference Group/ Collaborators:

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Introduction

- 1.7-2% “born intersex” ([Carroll, 2005b, p. 441](#)); many known variations (chromosomal/ hormonal/ anatomical etc).
- **Current thinking** is that we all were intersex initially for first few weeks in the womb ([Ainsworth, 2015](#)), however clinical thinking changes often (e.g. 90s “female default”).
- **Why so invisible?** Stigma and silence based on conservative “sex norms”, sex testing of athletes, misunderstandings & misidentifications, and lack of consultation.
- **Increased advocacy:** 2013/5 UN Reports on torture/ the child condemned normalising treatment; 2013 Aus SDA amended.

Research Background

- **Shameful history** of de-humanising research.
- **Mainly medical/ clinical studies** of small samples (1-2 people, or up to 50 but including parents) using methods like buccal smears, measuring genitalia, photos etc.
- Small but important growth in **critical writing** by intersex people on their own experiences/ discussions (Georgiann Davis, Chris Somers xxy, and others – a thrill to read).
- **Some inclusion** within LGBTIQ & Queer studies.



Theory

- **Four main lenses** in intersex research: conservative, liberal, critical and post-modern. Researchers “create” (as a demographic) intersex people in pre-defined frames ([Jones, 2013](#)).
- Drawing on the latter two to facilitate self-representation and deconstruction of social concepts.
- **Sociological view** – self is socially influenced/ influences groups.



Aim & Questions

- **AIM:** Redress the research gap on the perspectives of intersex people on their personal and social experiences of being intersex.
- This project asked how intersex participants constructed *themselves* regarding the key constructions available to them (in medical discourses, activism discourses and other arenas) and their own experiences/ preferences?

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RESEARCH

Survey for Australians born with congenital variations in sex characteristics

University of New England researchers are conducting a survey of Australians born with congenital variations in sex characteristics (intersex/DSD/hormonal, chromosomal or other biological variations/conditions).

Some terms with which you might have heard used to describe these variations are: Intersex, DSD/Disorders of Sex Development, atypical reproductive or sex development condition or variation, whether hormonal, chromosomal, or otherwise biological (eg. CAH, Klinefelter, Turner, Klinefelter and many others).

This project has been developed in the context of a national, cross-institutional research project coordinated by the Australian Research Council (ARC).

Australian Genetic Panel of The Australian Intersex Health Support Group, Adelaide, and Dr. Gail Wilson at the Monash and ICH Health Alliance.

If you are interested in sharing your experiences of health, education and social support, please see the survey, a 15-20 page online questionnaire about the survey and what it involves, and how the data will be used.

www.surveymonkey.com/ausvariations

Call for adult participants – Genetic basis of stuttering project

The Murdoch Childrens Research Institute and The Royal Children's Hospital are conducting a project to help understand the relationship between genes and stuttering.

Who can take part?
We are looking for adults aged 18 years and above who have never stuttered. Stuttering is considered a complex trait that can be linked to the genetic language and who have not been diagnosed with a neurological disorder.

What is involved?
In order to participate, we will ask you to complete the following:

- Have a 15-minute conversation with one of our researchers.
- Provide a sample of your saliva so that we can do a genetic test to see whether there are common genetic factors linked to the disorder.
- Complete a short questionnaire about you.

OII Australia – Intersex Australia

Organisation Intersex International Australia Limited

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Survey of intersex Australians commences!

By Maggie on 8 May 2015

Folks at the University of New England, OII Australia, the AISSGA, and the National LGBTI Health Alliance have collaborated to create a detailed initial study of the circumstances, histories and needs of people born with atypical sex characteristics.

The project has a joint reference group with community involvement. We're sure that there are imperfections, but we're confident that it's the most appropriate and relevant study yet undertaken for our own community.

We're hoping for a broad level of participation by Australian resident people born with intersex variations. Please consider participating, and sharing with friends and other networks.

Thank you so much!

<https://www.surveymonkey.com/ausvariations>

More information

Research Design

- **Redressed gaps for:** collaboration, sociological approach, & large-scale quant/ qual work through co-designing **an anonymous SurveyMonkey survey** with intersex collaborators.
- Definition as title. Advertised networks/ FB.
- **10pgs, 61qs on:** congenital sex variation; sex allocated; feelings about body and gender; social and service treatment; health & wellbeing; sexuality & relationships; parenting; community & activism; research.

“I like that this study did not see me as a body first, but as someone with opinions and ideas on my body. Usually researchers are very curious about my body and want to see it (...) as if they forget I am in it” (Peter, male with an intersex variation / Leydig Cell Hypoplasia, 41yrs).

Findings

- 288 respondents, **272 people aged 16-85+ with intersex variations, 35+ known variations** (5-ARD, CAH, PAIS). 16 trans-only.
- **All Australian states proportionately represented**, 4% ATSI, 20% internationals.
- **73% had no religious affiliation.**
- **27% diagnosed with disabilities.**
- **6% homeless** (couch-surf/ street/ refuge).
- **22% had relatives with their variation**, usually more than one, most often siblings. Experiences of the variation varied for relatives. Inter-family secrecy.

“My little brother has KS, he has a better sense of taste” (Kyle, intersex male with Kallman’s, 28yrs).

“I assume this pattern continues back throughout my maternal ancestral line, however (...) all the people mentioned here have been extremely secretive” (Patti, intersex female with CAIS, 37yrs).

- **52% allocated F at birth**, 41% M, 2% X, 2% unsure, 4% another option.
- **52% were F now**, 23% M, 7% X, 6% unsure and the remainder another option.
- **Most (64%) learned about their variation at under 18yrs**, a third as adults.
- **Participants more commonly used the word intersex to discuss it** (48% used intersex, 20% intersex variation, 18% intersex condition) than other terms (25% diagnosis, 17% my chromosomes, 7% diff of sex dev, 3% DSD).
- **Some experienced treatments under 18yrs** (86 hormone treatment, 52 genital construction, 39 gonads removed).

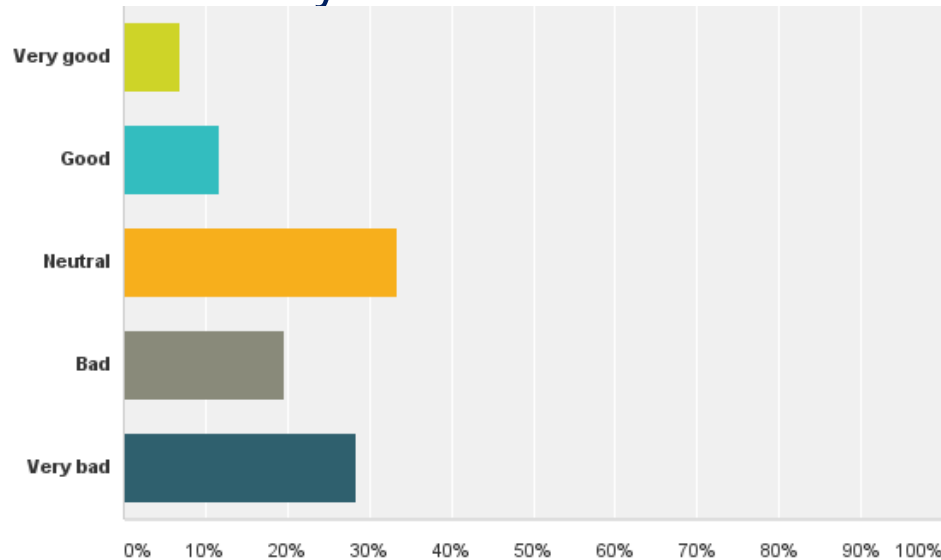
“I was initially raised as male despite having (...) XXY chromosomes, (...) since transitioned to female. After being forced to divorce, I lost my mortgaged home and have spent months being homeless. I am estranged from family”
 (Elaine, trans intersex woman with Klinefelter’s, 31yrs).

- **Many experienced negative impacts** from unnecessary treatments under 18 (trauma, scarring, poor sensitivity, 15% were sterilised).
- **One quarter were given no information** on treatments. Only 10% told they could defer.
- **Over 90% had attended schools with no inclusive sex ed/ puberty info** or supportive counsellors for intersex people.
- 41% being intersex **impacted work** experience.
- **42% had thought about self-harm** on the basis of being intersex, 26% engaged in it. **60% had thought about suicide** on the basis of being intersex, 19% attempted it.

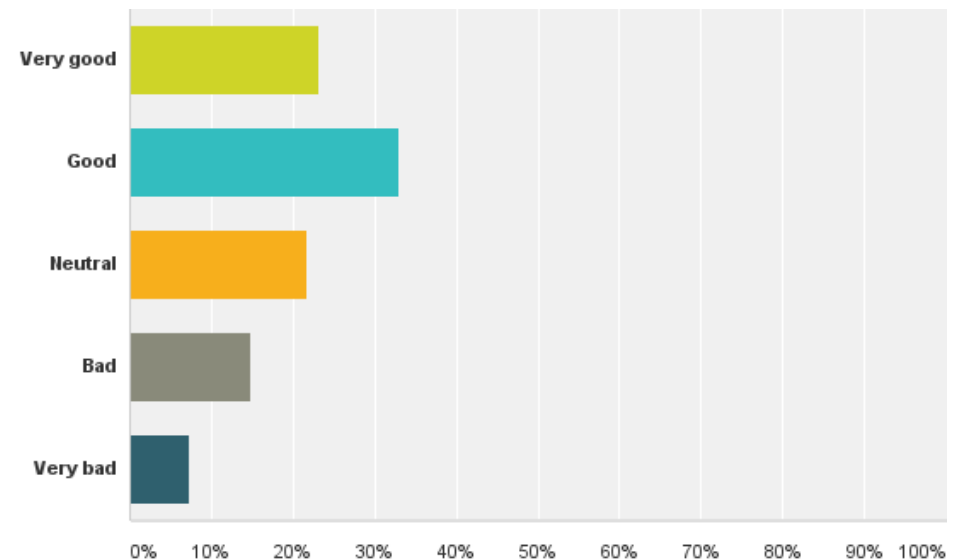
“I nearly died of septicaemia as a teenager, due to my genital surgery, I missed so much school I actually had to drop out entirely. It changed my whole life. Immense emotional impact to this day” (Sarah, woman with intersex condition PAIS, 44yrs).

- Participants usually felt from “neutral” to “very bad” about their variations when first told. They **felt better about it over time**; 56% now feel “good/very good”.

How they felt when first told.



How they feel now.



“Happier as I get older” (Marcia, intersex woman with Turner’s Syndrome, 27yrs).

“I was forced on Testosterone as a 15 yo. They tried to correct my body and my behavior. Now i'm embracing it” (Selma, intersex woman with 47XXY, 24yrs).

- 73% engaged in intersex community organisations/ social groups; **65% said engaging with others with their variation or similar improved their wellbeing.**

“It was hard to believe how things have changed for the better. There was nothing like that when I was going through it and I would have treasured that opportunity” (Anne, intersex woman with Ovo-testes and XXY/47 karyotype, 87yrs).

“That we're a tiny, tiny handful, one on a million - that's the most common myth” (Sarah, female with 3BHSD Late Onset Congenital Adrenal Hyperplasia, 40yrs).

“I cried when I saw the link to the (community group) website. I have yet to see how it goes” (Barry, intersex man with Klinefelter's, 25yrs).

- **16 “trans-only”** had no variation/s.
- **Various generations**, 16-66yrs.
- **Mainly MtF**, a few FtM and genderqueer.
- **Self-identification preceded diagnoses.** They “came out” as trans/ another sex, *then* received any Gender Dysphoria diagnoses.
- **None experienced childhood treatments/** interventions, some chose these as adults. Most left many questions blank. They **mainly used “DSD”** to explain being trans.

“I’m sick of other treating trans as anything other than a birth defect” (Hannah, MtF trans who sees trans as a DSD, 33yrs).

“My physical body has never matched what I know in my mind and heart.” (Jo, trans, 28yrs).

Conclusion

- Intersex people mainly learn about their variation and can start treatments under 18yrs, but can **later feel much more positively** about their variations (/bodies) and regret early interventions.
- Options of deferring/ no treatment are **inadequately promoted**, especially given the extremity of negative impacts experienced under 18.
- Many institutions (health, education, employment) must do **more to ensure inclusive treatment** and useful aid/ information provision.
- They should also **promote opportunities to engage socially with intersex people** to improve peoples' wellbeing.
- Researchers: trans(-only) people have **different experiences/ views**.