



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Family of people with innate variations of sex characteristics

A qualitative study to understand the health and well-being needs (including unmet needs) and experiences of adolescents and adults with innate variations of sex characteristics, and their families

Chief Investigator: Associate Professor Bridget Haire

1. What is the research study about?

You are invited to take part in this research study. The research study aims to improve understanding of the health and well-being needs (including unmet needs) and experiences of adolescents and adults with innate variations of sex characteristics, and their families.

2. Who is conducting this research?

The study is being carried out by the following researchers:

- Associate Professor Bridget Haire, University of New South Wales
- Dr Kate Burry, University of New South Wales
- Associate Professor Morgan Carpenter, University of Sydney
- Professor Adam Bourne, La Trobe University
- Ms Katie Gabriel, University of Sydney
- Ms Bonnie Hart, University of Southern Queensland
- Professor Martin Holt, University of New South Wales
- Professor Ashleigh Lin, University of Western Australia
- Associate Professor Julie Mooney-Somers, University of Sydney
- Professor Christy Newman, University of New South Wales
- Dr Ingrid Rowlands, QIMR Berghofer Medical Research Institute
- Dr Penelope Strauss, The Kids Research Institute Australia
- Dr Alana Papageorgiou, University of Western Australia

Research Funder: This research is being funded by the Medical Research Future Fund.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- Are 20 years and older.
- Are the parent or legal guardian of someone with innate variations of sex characteristics.
- Are confident and comfortable communicating in English.

Participants who meet the following criteria will be excluded from the study:

- Are 19 years old or younger.
- Are not the parent or legal guardian of someone with innate variations of sex characteristics.
- Are not confident communicating in English.

4. Do I have to take part in this research study?

Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study, or provide verbal consent when you meet with the interviewer;
- Take a copy of this form with you to keep.

5. What does participation in this research require, and are there any risks involved?



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If you agree to participate you will be asked to complete the following research procedures.

Interview: An interview, either over the phone, online video, or face-to-face (if requested and close to one of the participating universities), and you will be asked questions about your health and wellbeing experiences and needs as a family member of someone with innate variations of sex characteristics. The interview will take place over the phone, Microsoft Teams, or in a private location at the university campus, and will take approximately one to one-and-a-half hours. With your permission, the research team would like to audio record the interview. If you do not wish to be recorded but you would like to participate you advise the research team and written notes will be taken.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you be paid. However, you will receive a \$90 GiftPay e-gift card as compensation for your time while completing the interview.

Psychological Distress: You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a number of free contactable support services are included at section 10, after the research team's contact details. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

6. What will happen to information about me?

By signing the consent form or providing your verbal consent when you meet with the interviewer, you consent to the research team collecting and using information about you for the research study.

The research team will store the data collected from you for this research project for a minimum of 5 years after the publication of the research results.

The information about you will be stored in a re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that:

- Will be specific to the aims of this research;
- Will be an extension of, or closely related to, the original project, i.e. relate to the larger project of which this study is a part and involving the same researchers.

Your information will only be shared in a format that will not identify you. You can withdraw your consent by sending the 'Withdrawal of Participation' form at the end of this document to the Chief Investigator. Audio recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators. Audio recordings will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.



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The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

7. How and when will I find out what the results of the research study are?

The research team intend to publish and report the results of the research. All Information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by inserting your email or mailing address in the consent form or giving your email address to the interviewer. We will only use these details to send you the results of the research.

8. What if I want to withdraw from the research study?

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney, the University of Sydney, La Trobe University, University of Southern Queensland, University of Western Australia, QIMR Berghofer Medical Research Institute, The Kids Research Institute Australia, or InterAction. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

9. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	iRECS8349

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details

Name	Dr Kate Burry
Position	Postdoctoral Research Fellow
Telephone	+61 2 93482401



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Chief Investigator: Associate Professor Bridget Haire

Email	k.burphy@unsw.edu.au
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Chief Investigator

Name	Associate Professor Bridget Haire
Position	Associate Professor
Telephone	+61 2 9385 1227
Email	b.haire@unsw.edu.au

Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Organisation	InterLink
Organisation details	InterLink provides mental health and wellbeing services to people with innate variations of sex characteristics and their family members located anywhere in Australia.
Telephone	+61 7 3017 1724
Email	Use chat box at the bottom of this webpage: www.ilink.net.au

Organisation	(for those in ACT) Variations in Sex Characteristics Psychosocial Service
Organisation details	They work with children, young people and their families to understand all aspects of their variation and support them throughout their journey.
Telephone	(02) 5124 7834
Email	CHS.WYC-VSCPpsychosocial@act.gov.au

Organisation	LifeLine
Organisation details	LifeLine is available to all Australians experiencing emotional distress with access to 24-hour crisis support and suicide prevention services.
Telephone	13 11 14
Email	Chat or text online at this website: www.lifeline.org.au

Organisation	Beyond Blue
Organisation details	Beyond Blue provide support programs to address issues related to depression, suicide, anxiety disorders and other mental health concerns.
Telephone	1300 22 46 36
Email	For webchat support service, visit: www.beyondblue.org.au/get-support/talk-to-a-counsellor

Organisation	Kids Helpline
Organisation details	Kids Helpline is a free (even from a mobile), confidential 24/7 online and phone counselling service for young people aged 5 to 25.
Telephone	1800 55 1800
Email	For webchat support service, visit: www.kidshelpline.com.au/about/contact-us



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Organisation	MensLine
Organisation details	MensLine Australia offers free professional 24/7 telephone counselling support for men with concerns about mental health, anger management, family violence (using and experiencing), addiction, relationship, stress and wellbeing.
Telephone	1300 78 99 78
Email	For webchat support service, visit: www.mensline.org.au/phone-and-online-counselling/

Organisation	QLife
Organisation details	QLife provides anonymous and free LGBTIQ+ peer support and referral for people in Australia wanting to talk about sexuality, gender, bodies, feelings or relationships.
Telephone	1800 184 527
Email	For webchat support service, visit: www.qlife.org.au



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Consent Form – Participant providing own consent

Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate in this research study;
- ☐ I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- ☐ I understand the purposes, study tasks and risks of the research described in the study;
- ☐ Recordings: I understand that the research team will audio record the interview; I agree to be recorded for this purpose.
- ☐ I provide my consent for the information collected about me to be used for the purpose of this research study only.
- ☐ I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- ☐ I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;
- ☐ I understand that I will be given a signed copy of this document to keep.
- ☐ I understand that the results of the research will be made available on the InterConnect website: <https://interconnect.org.au>
- ☐ I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

Optional Consent for reuse of data and future research:

- ☐ I provide my consent for the information collected about me to be made available for research that relates to the larger project of which this study is a part and involving the same researchers, as described at section 6 of this document.
- ☐ I provide my consent for my name and contact details to be retained in a register until December 31, 2030, so I can be contacted about other research pertaining to people with innate variations of sex characteristics.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

- ☐ I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	
Date	

***An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

Note: All parties signing the consent section must date their own signature.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, UNSW Sydney, the University of Sydney, La Trobe University, University of Southern Queensland, University of Western Australia, QIMR Berghofer Medical Research Institute, The Kids Research Institute Australia, or InterAction.

- ☐ I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
- ☐ I am withdrawing my consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.
- ☐ I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Associate Professor Bridget Haire
Email:	b.haire@unsw.edu.au
Phone:	+61 2 9385 1227