



Becoming a Consumer Representative

Who are we?

The Rio Tinto Children's Diabetes Centre (the Centre) is a JDRF Global Centre of Excellence; the first in Australia, part of the Children's Diabetes Centre at Telethon Kids Institute and integrated with the Diabetes Clinic at Perth Children's Hospital. The Centre's vision is to *"Reduce the morbidity and mortality of Type 1 diabetes and its burden on children, their families, the health service and the community"*. A research and clinical integrated hub where collaboration between researchers across the globe, those living with type 1 diabetes and the Australian type 1 diabetes community have come together to develop new models of care to achieve the Centre's vision.

The real-life experiences of those living with type 1 diabetes, and the communities that support them, will ensure that the Centre's research is meaningful and valuable. This unique knowledge will:


- Help find new and better ways of managing type 1 diabetes;
- Contribute to the improvement of health policies; and
- Put research findings into clinical practice where children and young people will benefit faster than before.

Our Key Stakeholders and Partners

JDRF Australia are our funding providers. This partnership along with Rio Tinto, Telethon Kids Institute and Perth Children's Hospital places the Centre in a unique position to access world-leading collaborators. The Centre has established relationships with a range of national and international stakeholders; Macquarie University, Monash University, Queensland Children's Hospital, Adelaide Women's and Children's Hospital and Harvard University, who will support, assist and guide the Centre to achieve its goals. They will collaborate, inform and partner with Centre researchers, those living with type 1 diabetes and the Australian type 1 diabetes community in specific research programs. In particular, government and policy makers are vital to ensuring that our research outcomes are reflected in policy and practice so we can make a real difference.

Community Involvement – Our Promise

The Centre is committed to involving those living with type 1 diabetes and the type 1 diabetes community in its research. Community involvement is about conducting research with or by consumers and the community, rather than for or about them. We have pledged a promise to provide opportunities for the type 1 diabetes community to lead, partner, advise and consult on research projects undertaken by the Centre and to keep you informed along the way. By involving the type 1 diabetes community from not just the metropolitan areas, but from rural, regional and remote areas of Australia, as well as all walks of life, our involvement processes will be inclusive. We strongly encourage the voices of those who are



living with or supporting someone who is living with type 1 diabetes from every community to be heard, including:

- Aboriginal communities;
- Other culturally and linguistically diverse communities;
- Disability communities; and
- LGBTIQ+ communities.

We want to make a difference for you, your child, your family and your community and we would like you to join us as a Consumer Representative on this journey.

Who is a Consumer?

A consumer is a child or young person living with type 1 diabetes or a parent or family member who cares for a child or young person living with type 1 diabetes who accesses health care services and products.

Who is a Consumer Representative?

A Consumer Representative is an individual person who voices consumer perspectives and takes part in the decision-making process on behalf of other consumers.

What is a Community?

A community is a group of people sharing common interests such as cultural, religious, language, beliefs, values and traditions. They may share social, political, health, economic and technological interests, but are not necessarily limited to geographical location and includes parents, family/friends or other people who support someone living with type 1 diabetes.

The Centre recognises that consumers are those individuals living with type 1 diabetes and the community are those that surround and support them. For the purposes of a holistic approach, the Centre refers to both groups as “the type 1 diabetes community”.

What we aim to do

- Develop strategies that enhance and improve type 1 diabetes community involvement in the Centre's research.
- Serve as a capacity building tool to ensure children and young people living with type 1 diabetes in Australia have a voice in their own health care.
- Recognise the real-life experiences of children, young people, parents, family, friends and the wider community in the planning, delivery, monitoring and evaluation of type 1 diabetes research.
- Foster better relationships so that facilitation of research findings are translated quickly into clinical practice so children and young people benefit sooner.

Our programs of work

Programs of work will change as the Centre evolves and new programs of work will be supported by the Centre as projects are completed and move to different phases. In the first few years, the Centre will have the following programs of work:

- Type 1 diabetes new models of care implementation;
- Diabetes technology-based treatments and devices, including dashboards and technology in a clinic setting;
- Improving the volume and safety of physical activity;
- Translation of nutrition research into knowledge and behaviour change.
- Australian-focused economics.
- Type 2 diabetes models of care also form parts of the Centre's programs of work.

These represent national and international groups undertaking research projects. The programs are responsible for the planning, implementation, execution and reporting to a relevant Working Group on scientific investigations within the Centre.

Where relevant, programs of work will integrate with JDRF initiatives, including Population Screening Initiative, Immunotherapy Collaborative and Australasian Diabetes Data Network.

The general responsibilities of the programs of work include:

- Managing day-to-day aspects of research projects;
- Developing new research ideas and preparing grant applications;
- Coordinating sample/data access applications for projects;
- Reporting progress to the relevant Working Group; and
- Collaborating with other programs of work.

We are here to support you

So that you can gain an understanding of research and feel confident in your role as a Consumer Representative, the Telethon Kids Institute has developed online training for consumers and community members. Once your application has been received and processed, we will send you the training link. It is preferable that you complete this training prior to attending your first meeting, but you can do it at your own pace and it is free to complete.

Will you be paid?

Being a Consumer Representative is not a paid position, however you will receive an Honorarium payment that will be deposited into your nominated bank account to reimburse you for any expenses that you may occur to attend meetings, review documents, parking if applicable etc. Honorarium payments will only be made after each meeting or event where you have contributed.

Our Community Involvement Coordinator will be your first point of contact should you have any questions or concerns in your role as a Consumer Representative.

Our path from here

Factsheets have been developed to give you an overview of what the Community and Consumer Involvement Committee and other governance committees, subcommittees and working groups are about. You will have an opportunity to join one of these committees too, however only two positions can be held by a Consumer Representative (i.e. Community and Consumer Involvement Committee and Health Economics Working Group). Any opportunity to join another committee will be shared at Community and Consumer Involvement Committee meetings when they become available and a nomination process will take place. Once you have decided which committee you would like to be a Consumer Representative on, we will ask you to complete a Consumer Representative Application form. Your personal information will be stored confidentially and only used within the Centre and the Telethon Kids Institute. Once your application has been processed, we will notify you. Before attending the first meeting, all Consumer Representatives will need to read and sign the Telethon Kids Institute Confidentiality Policy and Agreement.

For more information about the Children's Diabetes Centre or becoming a Consumer Representative, please contact our Community Involvement Coordinator via email at community@childrensdiabetesresearch.org.au.

Thank you for your interest in joining our Centre as a Consumer Representative. Your voice and real-life experiences are very important to us and the research we undertake so that research findings are meaningful, valuable and can be translated into clinical practice where children and young people living with type 1 diabetes will benefit the most.