

RIO TINTO CHILDREN'S DIABETES CENTRE

A JDRF Global Centre of Excellence

RioTinto

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COMMUNITY INVOLVEMENT

GUIDELINES

ACKNOWLEDGEMENT OF COUNTRY

The Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land and waters of Australia. We also acknowledge the Nyoongar Whadjuk Elders, Peoples and their lands and waters upon which the Centre is located. We pay our respects to Elders past, present and emerging and to all first nations people in the lands of our global collaborators. We seek their wisdom in our work to improve the health and development of all children.

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1.0 Executive summary

These Community Involvement Guidelines provide a best practice model to consumer and community involvement in type 1 diabetes (T1D) research. The Principles and Standards have been developed alongside the National Health and Medical Research Council's *Statement on Consumer and Community Involvement in Health and Medical Research*¹ and has drawn on several similar frameworks from around the world so that a true global collaboration can occur. It provides a clear strategy for the Centre's partners, collaborators, researchers and clinicians to use when conducting their work. We also conducted our own consumer research to ensure we had a deep understanding of T1D consumers and their communities.

Those living with T1D and the T1D community have a right to be involved in their own healthcare or the health care of their child. Their real-life experiences and knowledge contributes to the improvement of clinical practice. Their involvement adds value to the shared decision-making processes. Involving those living with T1D and the T1D community in research provides opportunities to ensure the research conducted and the outcomes achieved are meaningful, so that new models of care can be implemented and the benefits can make a difference to the lives of children and young people.

The Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence (the Centre) has the vision to *"Reduce the morbidity and mortality of type 1 diabetes and its burden on children, their families, the health service and the community"*. It aims to be a world-class research hub where the collaboration between researchers across the globe, those living with T1D and the T1D community in Australia provides an opportunity to develop new models of care that achieves better life outcomes for children and young people living with T1D quicker than ever before.

To achieve a strong global collaboration, the Centre is a network of:

FUNDERS

- JDRF Australia
- Rio Tinto

PARTNERSHIPS

- Telethon Kids Institute, Perth, Western Australia;
- Perth Children's Hospital, Perth Western Australia;
- Monash University, Melbourne, Victoria;
- Macquarie University, Sydney, New South Wales;
- Women's and Children's Hospital, Adelaide, South Australia;
- Queensland Children's Hospital, Brisbane, Queensland;
- Harvard University, Boston, Massachusetts.

¹ National Health and Medical Research Council. NHMRC Statement on Consumer and Community Involvement in Health and Medical Research. Commonwealth of Australia [Internet]. 2016 September [cited 2021 October]; Page 2. Available from <Statement on consumer and community involvement in health and medical research | NHMRC>.

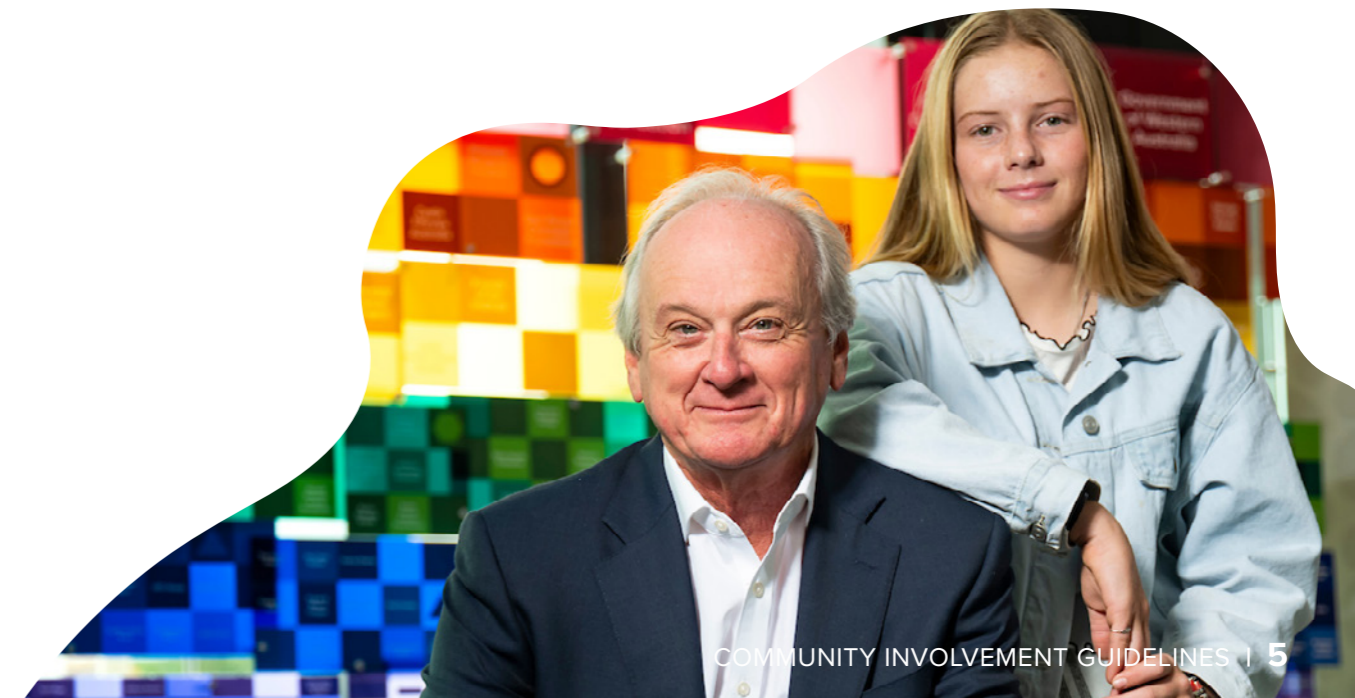
WHAT IS COMMUNITY INVOLVEMENT?

Community involvement in research is about ensuring research is conducted with or by communities, rather than for or about them. The real-life experiences of the T1D community adds value to health and medical research. Through their vested interest in their own health care, or their child's health care, their genuine involvement will ensure that new models of care are translated into clinical practice that benefits children and young people living with T1D.

WHAT IS THE COMMUNITY INVOLVEMENT GUIDELINES?

These Guidelines supplement the Community Involvement Framework and the Stakeholder and Community Involvement Plan as a pathway for involving the T1D community in the Centre's research programs. It will ensure that the voices of those children and young people living with T1D in Australia and their parents and families who help with day-to-day management of their condition, are heard, acknowledged and valued and the research the Centre conducts is meaningful and can be translated into clinical practice faster than ever before.

Setting clear principles and standards for community involvement, these Guidelines establish a common understanding of and commitment to community involvement in research. It sets the expectation that the Centre's partners, stakeholders and clinicians will involve those living with T1D and the T1D community in the planning, delivery, monitoring, evaluation and translation of the Centre's research programs. This will be done by building strong relationships and partnerships with the T1D community. It provides guidelines to navigate barriers and risks to involving consumers by understanding who consumers are, where to find them in the community, how to engage with them and addresses the importance of recognising the ethical issues to involving children in research. When implemented, the extended framework will add value, inform decisions and benefit the advancement of personalised healthcare.



2.0 Acknowledgements

Consultation and feedback on these Guidelines was sought from consumers, partnering researchers, JDRF Global Centre of Excellence stakeholders and staff members of the Telethon Kids Institute Kulunga Aboriginal and Community Engagement teams. We would like to thank everyone who was involved in developing these Guidelines, in particular:

- Leanne Cromb – Community Involvement Coordinator, Rio Tinto Children’s Diabetes Centre; a JDRF Global Centre of Excellence (Community Involvement Guidelines Author), Perth Western Australia
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- Belinda Frank – Community Engagement Manager, Telethon Kids Institute, Perth Western Australia
- Mitch Messer – Community Involvement Coordinator, Telethon Kids Institute, Perth Western Australia
- Tanyana Jackiewicz – Senior Program Manager, Children’s Diabetes Centre, Telethon Kids Institute, Perth Western Australia
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- Julie Dart – Clinical Research Nurse, Perth Children’s Hospital, Perth Western Australia
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- Mara West – Operations Manager, Kulunga Aboriginal Unit, Telethon Kids Institute, Perth Western Australia
- Jake O’Brien – Consumer Representative for the JDRF Global Centre of Excellence, Telethon Kids Institute, Perth Western Australia
- Yvonne Zurynski – Associate Professor of Health System Sustainability, NHMRC Partnership Centre in Health System Sustainability, Australian Institute of Health Innovation, Macquarie University, Sydney New South Wales
- Ann Carrigan – Research Fellow, Centre for Healthcare Resilience and Implementation Science, Macquarie University, Sydney New South Wales
- Rebecca Lake – Macquarie University, Sydney New South Wales



3.0 Introduction

ABOUT THE RIO TINTO CHILDREN'S DIABETES CENTRE: A JDRF GLOBAL CENTRE OF EXCELLENCE

T1D is a life-threatening, life-long auto-immune disease that has immediate and long-term implications for children and young people who have been diagnosed with the condition across the world. It requires management and decision-making 24 hours a day, seven days a week. It affects the child, young person, their parents, extended family, friends, health systems and the wider community physically, emotionally and financially.

The Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence (the Centre) has the vision to *"Reduce the morbidity and mortality of type 1 diabetes and its burden on children, their families, the health service and the community"*. It aims to be a world-class research hub where the collaboration between researchers across the globe, those living with T1D and the T1D community in Australia provides an opportunity to develop new models of care that achieves better life outcomes for children and young people living with T1D quicker than ever before.

"To reduce the morbidity and mortality of type 1 diabetes and its burden on children, their families, the health service and the community"

The Centre aims to be a hub where collaboration between researchers across the globe, children and young people living with T1D, their families and the Australian T1D community come together to identify new knowledge and technologies that can be implemented and integrated into effective models of care. Research findings will be translated into clinical practice to ensure children and young people living with the condition can access the right treatment, at the right time, that is right for them. Through this collaboration, the Centre will work towards achieving a better life course with improved health outcomes and reduce the mortality gap for children and young people living with T1D.

To achieve a strong global collaboration, the Centre is a network of partnerships between:

- Telethon Kids Institute, Perth, Western Australia;
- Perth Children's Hospital, Perth Western Australia;
- Monash University, Melbourne, Victoria;
- Macquarie University, Sydney, New South Wales;
- Women's and Children's Hospital, Adelaide, South Australia;
- Queensland Children's Hospital, Brisbane, Queensland;
- Harvard University, Boston, Massachusetts.

The development of these Guidelines drew on several similar documents from around the world so that a true global collaboration can occur. In particular, the foundation of these Guidelines has been built around the *NHMRC Statement on Consumer and Community Involvement in Health and Medical Research*. We also conducted our own consumer research to ensure we had a deep understanding of T1D consumers and their communities.

The *NHMRC Statement on Consumer Involvement in Health and Medical Research (2016)* states, "Effective consumer and community involvement benefits many stakeholders including the public and researchers".² It adds value, informs decisions and benefits the advancement of personalised health care. The T1D community has a vested interest in being involved in research, where the translation of research findings is used to improve policies and clinical practice through new models of care. The only way that true quality research outcomes can be achieved is to ensure that the T1D community have a voice in the overarching strategy of the Centre, as well as the planning, delivery, monitoring and evaluation of research programs and projects. The involvement of children, young people, parents, families and the wider T1D community is imperative. Their unique real-life personal experiences provide a holistic perspective that ensures research programs are considered, relevant, valuable and can be translated into policy and clinical practice. The Centre has an opportunity to embed the T1D community into its governance structure and research programs and be richly involved in the Centre's activities.

² National Health and Medical Research Council. *NHMRC Statement on Consumer and Community Involvement in Health and Medical Research*. Commonwealth of Australia [Internet]. 2016 September [cited 2021 October]; Page 2. Available from <Statement on consumer and community involvement in health and medical research | NHMRC>.



4.0 Definitions

The following words are used throughout these Guidelines and definitions are taken from the *NHMRC Statement on Consumer and Community Involvement in Health and Medical Research* (2016)³.

Carers (Family/Friends) A carer is a family member, a friend of the family or someone who provides support to family or friends who have a disability, mental illness, terminal illness or have a chronic condition such as T1D. Carers provide this support as an ongoing basis and are unpaid in their role. According to the *Carers Recognition Act 2010*, carers must be included in the assessment, planning, delivery and review of services that impact their role⁴. Whilst this Act applies to public service care agencies and the Centre is a private organisation, it still stands to reason that those who care for children and young people living with T1D should be included in this extended framework and fall within the “Community” category. For the purposes of this document, *Carers* will be referred to as *family/friends* out of respect for the T1D community’s preferred language.⁵

Clinicians (Healthcare Professionals) Healthcare professionals such as Endocrinologists, Diabetes Educators, Dieticians, Social Workers, Psychologists and General Practitioners (GPs) who provide direct patient care. Clinical engagement is crucial in the translation of research into clinical practice, but in also building trusting relationships with children, young people, parents and family/friends to encourage acceptance of new practices, involvement and engagement in research studies. For the purposes of this document, *Clinicians* will be referred to as *healthcare professionals* out of respect for the T1D community’s preferred language.⁶

Community 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 interests² but are not necessarily limited to geographical location. The Centre notes the importance of understanding that different communities are likely to have different approaches to involvement in research⁷. This group would include parents, family/friends and other support people including GPs and other health care practitioners.

Community Member An individual person who identifies as being a part of a community.

Consumers Parents, children and young people living with T1D and access health care services⁸.

Consumer Representative An individual person who voices consumer perspectives and takes part in the decision-making process as part of a governance structure on behalf of other consumers. The Centre notes that a Consumer Representative may have a narrower point of view and not necessarily be that of the wider community.

Engagement The relationships, communication practices and interactions between the T1D community and the Centre that works collaboratively to reach an outcome.

Involvement A partnership where those living with T1D, the T1D community and researchers work together to shape decisions about research priorities, policies and practices.

Participant An individual who takes part in a clinical trial or activity for research purposes.

Research Buddy A Consumer Representative who provides advice and links between the researcher, other consumers and community members, organisations and/or the research funder⁷ on a project level.

² National Health and Medical Research Council. NHMRC Statement on Consumer and Community Involvement in Health and Medical Research. Commonwealth of Australia [Internet]. 2016 September [cited 2021 October]; Page 2. Available from <Statement on consumer and community involvement in health and medical research | NHMRC>.

³ National Health and Medical Research Council. NHMRC Statement on Consumer and Community Involvement in Health and Medical Research. Commonwealth of Australia [Internet]. 2016 September [cited 2021 August]; Page 6. Available from <Statement on consumer and community involvement in health and medical research | NHMRC>.

⁴ Australian Government. Carer Recognition Act 2010. Federal Register of Legislation [Internet]. 2010 October 25. [cited 2021 October]. Available from <Carer Recognition Act 2010 (legislation.gov.au)>.

⁵ Diabetes Australia. Language Matters Position Statement. [Internet]. 2021. [cited 2021 October 21]. Available from <https://urldefense.com/v3/_https://www.diabetesaustralia.com.au/research-advocacy/position-statements/_;!!Lav448XFWxY!qsWWI9xuzu0VX5TsA-WO_SVCeXrM8X5_UICvHvBBNzKuH3s-SCbirXIJC2LiIR6uR2v5I0\$>

⁶ Diabetes Australia. Language Matters Position Statement. [Internet]. 2021. [cited 2021 October 21]. Available from <https://urldefense.com/v3/_https://www.diabetesaustralia.com.au/research-advocacy/position-statements/_;!!Lav448XFWxY!qsWWI9xuzu0VX5TsA-WO_SVCeXrM8X5_UICvHvBBNzKuH3s-SCbirXIJC2LiIR6uR2v5I0\$>

⁷ McKenzie, A and Hanley, B. Consumer and Community Participation in Health and Medical Research. Perth: The University of Western Australia and Telethon Institute for Child Health Research. 2008 [cited 2021 August]. Available from <www.ichr.uwa.edu.au>.

⁸ McKenzie A, Hanley B. Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers. Australia: UWA TKI. 2014 [cited 2021 August]. Page 76. Available from <Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers — the UWA Profiles and Research Repository>

5.0 Purpose

The Centre brings world-leading expertise from across the globe together to collaborate on the very best T1D research programs. The purpose of these Guidelines is to foster better partnerships and relationships through a robust governance structure and involvement activities where best practice communication strategies between the Centre and the Australian T1D community can be achieved. These Guidelines recognise the importance of involving parents, family/friends, children and young people across Australia, from all cultural backgrounds in rural, regional and remote areas.

These Guidelines provide a pathway for the Centre to build T1D community capacity, help make research decisions and inform how the Centre will engage and involve those living with T1D and the T1D community in all aspects of its research. It will challenge the Centre to be more inclusive, strategic and considered in their approach to T1D community involvement. To be effective, it needs to be applied to all Centre activities so that better life outcomes for children and young people living with T1D can be achieved.

A TWO-WAY COMMUNICATION PROCESS

Grunig (2009) describes two-way communication practices as symmetrical and a process of research and listening that “facilitates dialogue before and after decisions are made”⁹. Utilising this two-way communication best practice ensures that the voices of those living with T1D and the T1D community are heard, their views, beliefs and values are considered and real-life experiences are acknowledged¹⁰. It provides an opportunity for them to feel valued by making a difference to the lives of children and young people living with T1D. These Guidelines will facilitate a two-way communication process via a bottom-up, top-down approach between the T1D community, researchers, health care professionals and broader stakeholder groups.

⁹ Grunig, J.E. Paradigms of global public relations in an age of digitalization. University of Maryland in Prism (Issue 6). [Internet]. 2009 [cited 2021 October]; Page 2. Available from <<https://www.prismjournal.org/uploads/1/2/5/6/125661607/v6-no2-a1.pdf>>.

¹⁰ National Health and Medical Research Council. NHMRC Statement on Consumer and Community Involvement in Health and Medical Research. Commonwealth of Australia [Internet]. 2016 September [cited 2021 August]; Page 2. Available from <Statement on consumer and community involvement in health and medical research | NHMRC>

Our aims for community involvement





6.0 The Principles: our commitment to community involvement

The commitment of the Centre to genuine T1D community involvement will be bound by the following principles. It is our promise to meaningful T1D community involvement:

| | |
|---------------------------------|--|
| BEING INCLUSIVE | Ensure access to being involved in T1D research at the Centre is flexible to meet the needs of the T1D community. We will enable a diverse range of communities to be fully involved in the planning, decision-making, implementation and evaluation that allows all voices to be heard. We will use a variety of involvement techniques to remove inclusivity barriers and recognise the need to use different communication practices to meet the needs of the T1D community. |
| WORKING TOGETHER | Develop and nurture relationships, partnerships, connections, capacity and trust through open and honest conversations, sharing ideas, knowledge and resources. We will respect individual expertise and encourage ownership over processes and decision making. We will involve the T1D community from the beginning and agree on where, when and how to engage. We will build trust and compassion through interactions that are open, transparent and have integrity. We will acknowledge mistakes and be open to identifying the unknown. We will ensure any level of influence is disclosed and decisions are fair and shared, equitable and ethical. |
| LEARNING AND DEVELOPMENT | Provide opportunities for learning to build T1D community confidence and capacity through best practice involvement. |
| COMMUNICATION | Facilitate a two-way communication process that promotes open dialogue. We will ensure communication is timely and messages are clear, concise and free from ambiguity, including the negotiation of timeframes whenever possible. The Centre will use plain language in all communications with the T1D community. The Centre will take a holistic information sharing approach, including the communication of research outcomes. |
| EVALUATION AND IMPACT | Regularly evaluate the Community Involvement Framework, the Community Involvement Guidelines and Stakeholder and Community Involvement Plan, learning from past and current involvement activities. We will ensure that any learning is used to inform future involvement plans so that continuous improvement in the Centre is supported. We will commit to publishing the impact of our community involvement activities so that others can learn too. |
| GOVERNANCE | Facilitate involvement in all aspects of T1D research through committed leaders, excellent research management and inclusive decision-making. We will develop ethical processes to ensure research priorities, policies and clinical practices are cohesive so that the Centre's vision can be achieved. |

7.0 The Standards: our levels of involvement

There are many ways the T1D community can be involved in research projects. The following Levels of Involvement diagram has been adapted from The University of Western Australia and Telethon Kids Institute's *Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers*¹¹. Involving the T1D community at all levels of the Centre's governance structure is an important part in ensuring their voices are heard and considered throughout every research activity. Where involvement in the governance structure is not appropriate, the Centre still has an obligation to keep the T1D community informed of research involvement opportunities and research outcomes.

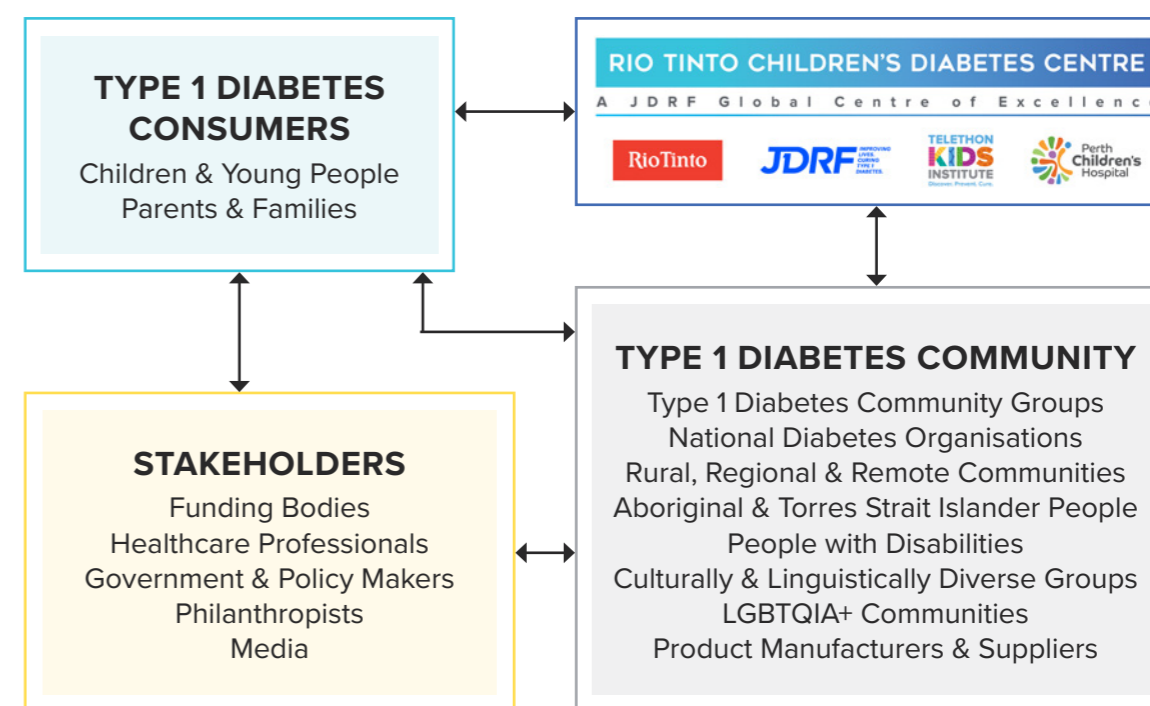


8.0 Knowing who to involve

Having a deep understanding of who the T1D community are will lead to knowing where to find them and how best to involve them. Along with the Principles and Standards identified in the Community Involvement Framework, this understanding will facilitate strong relationships and form longer-term productive partnerships that will build a solid foundation for the Centre.

These Guidelines acknowledge the diversity in the T1D community, including culturally and linguistically diverse communities and the unique needs of regional, rural and remote areas of Australia. The Centre has an obligation to keep the T1D community informed of research opportunities and outcomes that will be translated into clinical practice through a variety of communication strategies.

The following diagram shows the T1D community groups and broader stakeholders who have been considered when developing the Centre's Stakeholder and Community Involvement Plan.



¹¹ Mckenzie A, Hanley B. Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers. Australia: UWA TKI. 2014 [cited 2021 August]. Page 76. Available from <Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers — the UWA Profiles and Research Repository>

9.0 Potential barriers, risks and mitigations/opportunities

Several potential barriers and risks exist when involving the T1D community in health research. By understanding the challenges those living with T1D and the T1D community experience helps to inform a Stakeholder and Community Involvement Plan and to mitigate these risks and barriers so that the Centre's vision can be achieved.

9.1 ETHICAL ISSUES TO INVOLVING CHILDREN AND YOUNG PEOPLE IN RESEARCH

Whilst it is important to understand the potential barriers and risks for the T1D community in not wanting to be involved in the Centre's research, and what can be done to change their decision, it is also essential to understand the ethical issues that exist when involving children and young people safely in health research and acknowledge this as a barrier. The UN Conventions for the Rights of the Child (the Convention)¹² states that children and young people have the right to be active participants in their own lives. They are not just subjects of research, but should be a part of the planning, delivery, monitoring and evaluation of research programs that relate to their own health.

Embedded in the Convention, as discussed in Powell and Colleagues (2012)¹³, are four (4) types of rights that are recognised as best practice when involving children and young people to safeguard them:

- 1. Welfare:** Research should directly or indirectly impact the child or young person's wellbeing.
- 2. Protection:** Contingencies should be made to support a child or young person who, during the research process, are identified as being at risk of harm.
- 3. Provision:** Children and young people should feel a sense of pride in the contribution they make towards informing society, policy and practice and other individuals through their research involvement.
- 4. Choice and Participation:** Opportunities to make informed choices about consent, opting out, confidentiality boundaries and contributing to research agendas and processes should be given to children and young people.

¹² UNICEF. United Nations Convention on the Rights of the Child. New York City, United States of America. 1990. [cited 2021 September]. Available at <[unicef-simplified-convention-child-rights.pdf](#)>

¹³ Powell MA, Fitzgerald R, Taylor NJ and Graham A. International Literature Review: Ethical Issues in Undertaking Research with Children and Young People (Literature review for the Childwatch International Research Network). Lismore: Southern Cross University, Centre for Children and Young People / Dunedin: University of Otago, Centre for Research on Children and Families. 2012. [cited 2021 September].

Alderson and Morrow (2011)¹⁴ suggest that ethical safeguards need to be put in place to address issues around power, authority, accountability and responsibility when children and young people are involved in research. These issues include those that surround the recruitment and selection process, appropriate training and support, how payments and rewards will be administered and the expectations that are raised about the need for research to be taken seriously.

As recommended by Radford and Ellis (2012)¹⁵, and in line with the *National Principles for Child Safe Organisations*¹⁶, the Centre will put in place the following safeguards for children and young people involved in its research activities:

- 1.** Provide clear, concise and age appropriate communication so children and young people understand how they will be involved, what is expected of them, what they will need to do, how much time they will need to commit, the limits of their influence and the payments and rewards offered for their involvement.
- 2.** Committee Chairs and other adult members of committees shall demonstrate a knowledge of what to do if a child or young person is at risk of harm. This includes the necessity to breach confidentiality if the child or young person is in immediate danger and agreed protocols for named persons for making referrals should a child or young person be identified as at risk of harm.
- 3.** Appropriate levels of training and support will be given to children and young people throughout their involvement in research programs and activities.
- 4.** Children and young people will be given opportunities to withdraw their consent to be involved that will be implemented safely and confidentially and without impact on their healthcare.
- 5.** Conduct ongoing critical evaluation of ethical behaviours and policies.
- 6.** Ensure children and young people be included in ethical decision-making.

The Centre will therefore work hard to ensure that it operates and involves children and young people in an ethical manner, including involving parents if children are not old enough to represent themselves.

¹⁴ Alderson P and Morrow V. Ethics of Research with Children and Young People. SAGE Publications Ltd, London. 2011. Cited 2021 September.

¹⁵ Radford L and Ellis J. Offering Children Confidentiality in Research: What are the limits in Fleming J and Boeck T (eds) Involving Children and Young People in Health and Social Care Research, Routledge, London. Pages 118-126. 2012. [cited 2021 September].

¹⁶ Australian Human Rights Commission. National Principles for Child Safe Organisations. Sydney, NSW. 2018. [cited 2021 September]. Available at <[National Principles for Child Safe Organisations \(humanrights.gov.au\)](#)>

10.0 How do we reach those living with T1D and the T1D community?

10.1 THE STAKEHOLDER AND COMMUNITY INVOLVEMENT PLAN

A Stakeholder and Community Involvement Plan provides a pathway for the Centre to reach the T1D community across Australia. The Plan aims to involve Consumer Representatives, from all diverse walks of life across regional, rural and remote areas of Australia on Centre committees, sub-committees and working groups, consult through events, distribute research findings and build awareness of the programs of work being undertaken by the Centre. It outlines the ways that the Centre’s research partners, researchers themselves and health professionals can assist Consumer Representatives in their roles, provide information about specific research projects and share research findings with the T1D community ensuring a two-way communication process is achieved. They will help translate research outcomes into clinical practice so that these new models of care can benefit all children, young people and their families living with T1D quicker, thereby fulfilling the Centre’s vision.

Involvement activities such as community conversations, focus groups, conferences and online webinars also play an important part in the Stakeholder and Community Involvement Plan. These give the broader T1D community an opportunity to also have an opportunity to be involved in the Centre’s work.

The role of the Community Involvement Coordinator is crucial in implementing, monitoring and evaluating the Stakeholder and Community Involvement Plan, ensuring the Principles and Standards are put into practice and the voices of those living with T1D and the T1D community are heard, considered and valued in the Centre’s work. They will ensure that the partners, collaborators, researchers and clinicians embed community involvement into their work in a meaningful way.

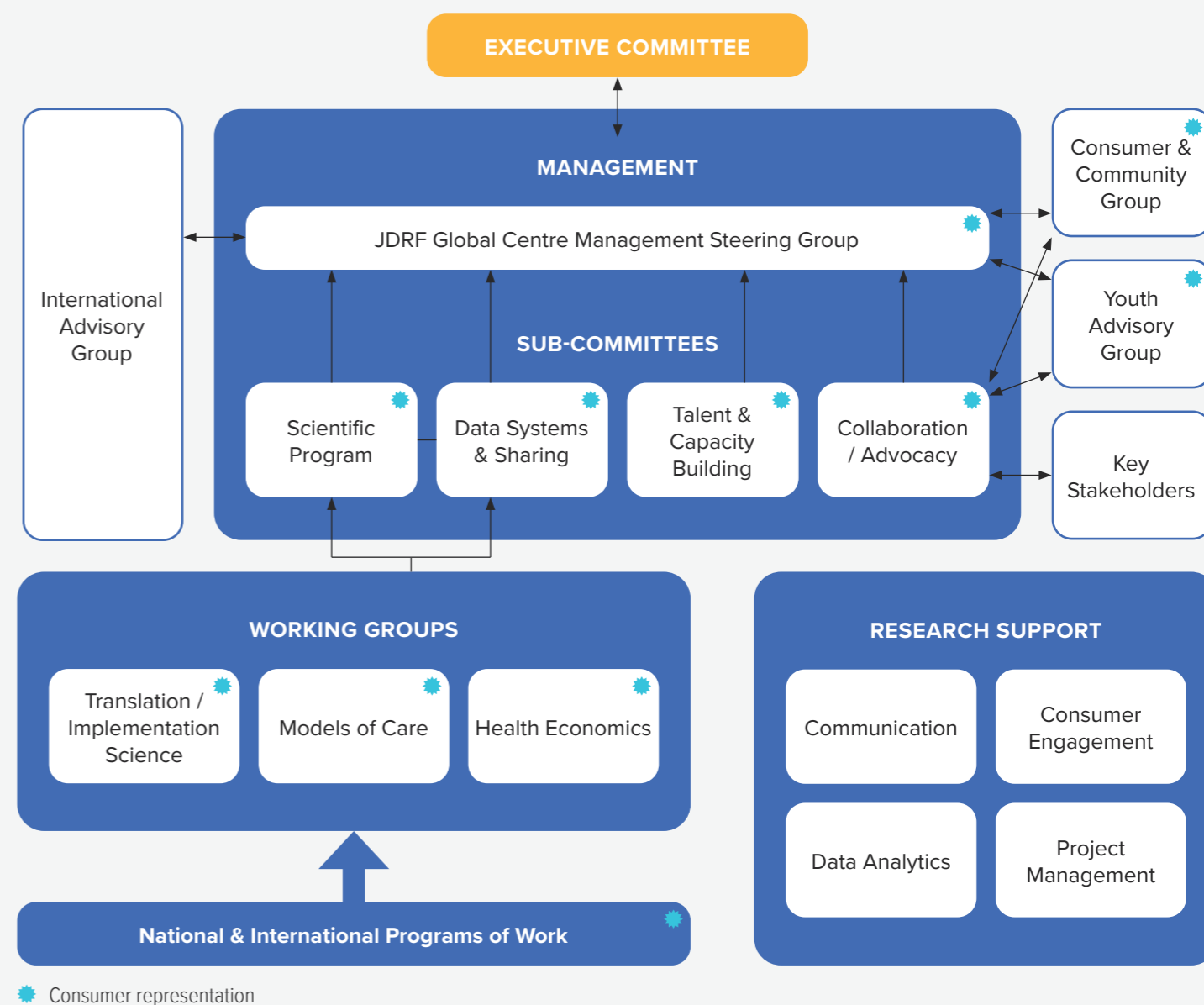
10.2 COMMUNICATIONS STRATEGY

The Communications Strategy and Plan for the Centre, developed by the Communications Specialist, provides best practice strategies to facilitate communication between the Centre’s stakeholders, researchers and the T1D community. It includes specific key messages for each audience that are clear, concise and consistent across all platforms. In order to build the Centre’s reputation as a world-leader in T1D research and clinical practice, it is extremely important that the same consistent language is used throughout the Centre’s communication. Not using the same language or sharing the same key messages creates distrust and may damage the Centre’s reputation. The language used should also be aligned with what the T1D community feel is acceptable. Reference to the *Diabetes Australia Language Statement*¹⁷ is made when key words and messages are created.

¹⁷ Diabetes Australia. Our Language Matters 2021 Position Statement. [Internet]. 2021. [cited 2021 November 2]. Available from <https://www.diabetesaustralia.com.au/wp-content/uploads/Language-Matters-2021-Diabetes-Australia-Position-Statement-1.pdf>

11.0 Centre Governance: an overview

The Centre has a robust governance plan provides a path for decision making to ensure the Centre’s vision is met. It “defines the roles and responsibilities of the various committees that make up the JDRF Global Centre of Excellence Governance Plan”. This structure consists of ways that the T1D community will be involved in T1D research. The following is a diagram taken from the *JDRF Global Centre of Excellence Governance Plan* that explains the relationships where the T1D community are invited to be a Consumer Representative.



12.0 Community involvement governance

In order to ensure that community involvement in the Centre's research is fair, equitable and has a consistent approach, policies, processes and agreements provide structured coordination of involvement activities. They give the Centre's overall governance plan a solid foundation so that the involvement of those living with T1D and the T1D community is safe and expectations of everyone involved are transparent. Part of the two-way communication process, they provide guidance and boundaries for both the Centre's stakeholders as well as those that become Consumer Representatives so that the work of the Centre can take place and achieve its vision.

12.1 POLICIES

The following policies assist with the governance of the Centre:

- Consumer Representative Recruitment and Management
- Telethon Kids Institute Confidentiality
- Telethon Kids Institute Conflict of Interest
- Telethon Kids Institute Honorary Guidelines

12.2 PROCESSES

- Promoting and Advertising Community Involvement Opportunities
- Recruiting Consumer Representatives
- Onboarding Consumer Representatives
- Managing Consumer Representatives
- Honorary Payments for Consumer Representatives
- Chairing Committee Meetings
- Holding a Community Event
- Exiting Consumer Representatives
- Community Involvement Process for Researchers

12.3 AGREEMENTS

Highly sensitive information will be shared and discussed during the term of each committee, subcommittee and working group. It is imperative that the intellectual rights of the Centre and affiliated researchers are protected, and ideas, information and research data are not shared without consent. To protect the Centre's collective intellectual rights over the ideas and projects shared between researcher partners and researchers, Consumer Representatives are required to read and understand the Centre's Confidentiality Policy as well as have read, understood and signed a Confidentiality Agreement as per Telethon Kids Institute requirements, before attending the first committee meeting. When a child or young person under 18 years of age fills a Consumer Representative role, the legal parent or guardian of that child are required to sign the confidentiality agreements.

12.4 PRIVACY

The Centre treats the privacy of everyone involved with the utmost respect and in accordance with the *Privacy Act 1988*¹⁸. Personal information about Consumer Representatives are collected and stored confidentially. When a child or young person under 18 years of age fills a Consumer Representative role, the legal parent or guardian of that child are required to consent to information being collected and stored about their child.

12.5 TERMS OF REFERENCE

It is important to be clear about the commitment required to be a Consumer Representative on a committee, sub-committee or working group. A Terms of Reference for each committee, sub-committee or working group is provided to each Consumer Representative prior to the first meeting. This ensures that the expectations and requirements are fully understood by the Consumer Representative. The Terms of Reference explains the purpose of the committee, sub-committee or working group, how often they will meet and method of reimbursement for time given by Consumer Representatives.

12.6 CONSUMER RELATIONSHIP MANAGEMENT

A Consumer Relationship Management System will be used to track all engagement and involvement activities with the T1D community. It will be a cost-effective solution to storing and recording all information in one platform that will be used and monitored by the Community Involvement Coordinator. This management system will play an integral role when evaluating these Guidelines and the Stakeholder and Community Involvement Plan.

12.7 RECRUITMENT TOOLKIT

A Recruitment Toolkit provides information to guide, support and inform Consumer Representatives about their role within the Centre. It consists of documents such as Information Factsheets about the role of each committee, sub-committee and working group and becoming a Consumer Representative. Documents such as a Consumer Representative Application Form, a Confidentiality Policy and Agreement and a Conflict of Interest Policy and Form are also included in the toolkit.

¹⁸ Australian Government. Office of the Australian Information Commissioner. The Privacy Act 1988. [Internet] 2021. [cited 2021 September]. Available from <<https://oaic.gov.au>>

13.0 Budget

It is important to consider a budget when looking to involve the T1D community in research as committee chairs, committee members or as a Consumer Representative. Sharing their time, experiences and opinions is valuable and should be appropriately acknowledged and rewarded.

Table 1 outlines recommended Consumer Representative Honorarium Rates for community involvement in Centre. These rates are in line with the Telethon Kids Institute and are intended as a reimbursement for travel and other expenses related to attending meetings. However, in most instances meetings will take place online and not face-to-face and therefore payments are made for reimbursement for time including ad hoc advice. Payments are not differentiated by adult or child, but rather as equals. The Centre recognises that should a child or young person hold a position with the Consumer and Community Group or Youth Advisory Group, a parent may also hold a position. Both will be reimbursed individually. Consumer Representatives in all other groups, committees or sub-committees are a young person or adult Consumer Representative. This is due to the technical nature of the committee, sub-committee or group which may not be appropriate for a child to hold a position. Attending a community conversation, focus group or webinar as a once off event attracts the minimum flat rate.

TABLE 1: CONSUMER REPRESENTATIVE HONORARIUM RATES

| Committee/Group | Involvement Role | Level of Involvement | Payment Rate Per Person | Method of Payment |
|--|-----------------------------|----------------------|--------------------------------|-------------------|
| Management Steering Group | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Community & Consumer Involvement Committee | Committee Chair | Lead | \$50.00/hr *includes ad hoc | BT |
| | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Youth Advisory Committee | Committee Chair | Lead | \$50.00/hr *includes ad hoc | BT |
| | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Scientific Program Sub-Committee | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Data Systems & Sharing Sub-Committee | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Talent & Capacity Building Sub-Committee | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Seed Funding Review Panel | Consumer Rep / Panel Member | Lead | \$50.00/hr *includes ad hoc | BT |
| Collaboration & Advocacy Subcommittee | Consumer Rep | Partner | \$37.50/hr *includes ad hoc | BT |
| Working Groups | Consumer Rep | Advise | \$37.50/hr *includes ad hoc | BT |
| Projects | Research Buddy | Partner | \$37.50/hr *includes ad hoc | BT** |
| Community Conversation | Attendee | Advise/Consult | \$37.50 once off payment | BT** |

KEY: Rep = Representative. BT = Bank Transfer.

* Ad hoc work outside of official meetings may be required of Consumer Representatives and reimbursement is included in the payment rate per person.

** Parking vouchers may replace the bank transfer. Meals may also be offered as an incentive, but are not included in the payment rate per person.



14.0 Conclusion

These Guidelines are intended to help researchers and research partners of the Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence and other research institutions authentically embed community involvement into their work. When read in conjunction with the Centre's Community Involvement Framework, it provides a best practice approach to involving and engaging those living with T1D and the T1D community at all levels of involvement. By listening to their real-life experiences and ensuring they are given every opportunity to be kept informed, provide advice, be consulted, partner with researchers and lead the research planning, design and monitoring of research studies, translation and implementation of research outcomes will be successful.



Resources

FACTSHEETS

- Becoming a Consumer Representative
- Management Steering Group
- Community & Consumer Involvement Committee
- Youth Advisory Committee
- Scientific Program Subcommittee
- Data Systems & Sharing Subcommittee
- Talent & Capacity Building Subcommittee
- Collaboration & Advocacy Subcommittee
- Translation/Implementation Science Working Group
- Models of Care Working Group
- Health Economics Working Group

APPLICATION FORMS

- Consumer Representative Application Form

POLICIES & GUIDELINES

- Recruiting, Managing and Supporting Consumer Representatives
- Telethon Kids Institute Confidentiality Policy
- Telethon Kids Institute Conflict of Interest Policy
- Telethon Kids Institute Honorarium Guidelines
- Terms of Reference for each committee, subcommittee & working group

AGREEMENTS

- Telethon Kids Institute Confidentiality Agreement

FORMS

- Telethon Kids Institute Conflict of Interest Form
 - Telethon Kids Institute Consumer Honorarium Claim Form
 - Community and Consumer Involvement Feedback Form
 - Meeting Agenda Template
 - Rio Tinto Children's Diabetes Centre Researcher Request for Community Involvement
 - Rio Tinto Children's Diabetes Centre Researcher Request to Consult with Community and Consumer Involvement Committee and/or Youth Advisory Committee
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FOR FURTHER INFORMATION ABOUT THESE GUIDELINES

Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence
C/o Telethon Kids Institute
15 Hospital Avenue, Nedlands, Western Australia 6009
Locked Bag 2010, Nedlands, Western Australia 6909
Attention: Community Involvement Coordinator
Email: community@childrensdiabetesresearch.org.au

diabetes.telethonkids.org.au