

# RIO TINTO CHILDREN'S DIABETES CENTRE

A JDRF Global Centre of Excellence

RioTinto

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LIVES.  
CURING  
TYPE 1  
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COMMUNITY INVOLVEMENT

# FRAMEWORK

## Foreword

As Co-Directors of the Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence, we are pleased to release our *Community Involvement Framework*.

Our aim is to improve health outcomes for all children and young people living with type 1 diabetes (T1D) and their families; now and into the future. Over the last decade or so, it has become strongly evident that it is necessary for consumers and the community to be consulted with and included in decision-making processes when it relates to their own health care and research. Without understanding the real-life experiences of people living with type 1 diabetes, the investigation of new treatments and better disease management will not be successful in delivering better life outcomes.

There are many ways and on varying levels that community involvement can be considered and implemented. The medical and health research sector has an important role to play in developing clear principles and standards that acknowledges the importance of consumer and community involvement and set expectations for their inclusion in research practices. The National Medical and Health Research Council of Australia has developed the *Statement on Community and Consumer Involvement in Health Research* and the Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence recognises this statement as the benchmark for quality community involvement in research.

The Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence has developed this *Community Involvement Framework* to guide and assist its members to work in partnership with those living with type 1 diabetes, their families and their communities, authentically embedding them in our governance structure and research projects. Involving and consulting through project co-design, planning, implementation and evaluation. This will ensure that our research is relevant, quality outcomes are achieved and the translation into clinical care is successful. Working together will deliver better life outcomes for children and young people living with type 1 diabetes across Australia, and the globe.



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## Introduction

This Community Involvement Framework provides a best practice model to consumer and community involvement in type 1 diabetes (T1D) research for the Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence ("the Centre"). 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*<sup>1</sup> 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. In the Centre, 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 health care 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 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 partnership and 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.

<sup>1</sup> 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 experience of the T1D community adds value to health and medical research. Through their vested interest in their own health care, or the health care of their child, their genuine involvement will ensure that new models of care are translated quickly into clinical practice that benefits children and young people living with T1D sooner than ever before.





## What is the Community Involvement Framework?

The Community Involvement Framework provides 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.

Setting clear principles and standards for community involvement, the Framework establishes 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 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 those who live with T1D by understanding who they are, where to find them in the community, how to engage them and addresses the importance of recognising the ethical issues to involving children in research. When implemented, the Framework will add value, inform decisions and benefit the advancement of personalised T1D healthcare across Australia.

## Our aims for community involvement





## The Principles: our commitment to community involvement

The commitment of the Centre to genuine T1D community involvement will be bound by the following principles:

### 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.





## The Standards: our levels of involvement

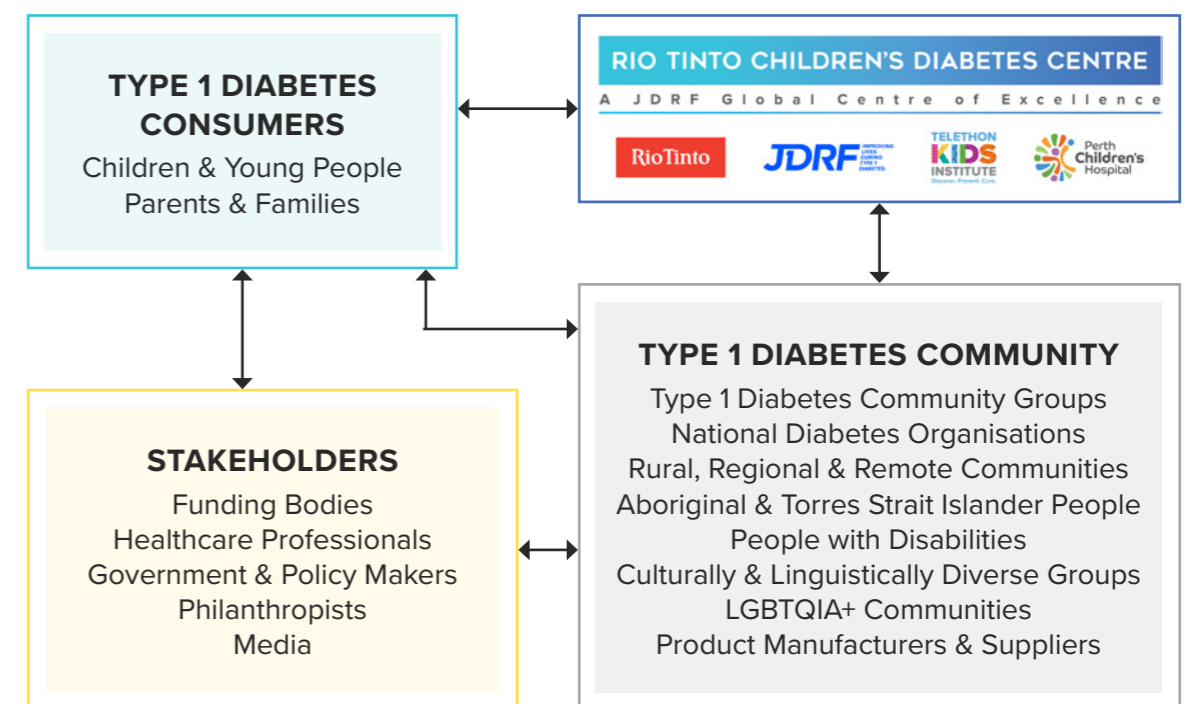


## Knowing who to involve

The Framework acknowledges the diversity in the T1D community, including the unique needs of people living in regional, rural and remote areas of Australia. The Centre has an obligation to keep the T1D community informed of research opportunities and outcomes.

A Stakeholder and Community Involvement Plan provides a pathway for the Centre to understand and reach the T1D community across Australia. Well researched in itself, the Plan aims to involve those living with T1D and the T1D community as Consumer Representatives, from all diverse walks of life across regional, rural and remote areas of Australia on Centre committees, sub-committees and working groups, 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 engage with those living with T1D and the T1D communities across Australia through best practice methods that facilitate relationship building and two-way communication principles.

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.







## How we will implement and monitor the Community Involvement Framework

Guided by the Principles and Standards set out in this Framework and read in conjunction with the Community Involvement Guidelines, the Framework informs the Centre's Stakeholder and Community Involvement Plan to guide engagement and involvement of not only those living with T1D and the T1D community, but also the Centre's wider stakeholder group.

The Centre will assist Consumer Representatives in their roles, to provide information about specific research projects and share research findings with the T1D community. Consumer Representatives 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.

Research partners and researchers will access the Community Involvement Coordinator's expertise and knowledge that will support their work and embedding community involvement into their research to ensure it is meaningful.

The role of the Community Involvement Coordinator is crucial in implementing, monitoring and evaluating the Community Involvement Framework and the Stakeholder and Community Involvement Plan. A robust evaluation process ensures that the Framework is being adhered to and involvement activities are taking place. It ascertains whether this Framework is creating value for researchers in the work they are doing and is it creating impact for the Centre as a whole. It will measure how often and how well the translation of outcomes is implemented into clinical practice, ultimately providing better health outcomes for children and young people living with T1D. More importantly, it will provide an opportunity to ensure authentic involvement and consultation with those living with T1D and the T1D community occurs in all of the Centre's research projects.

The Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence Management Steering Group are responsible for overseeing the overall implementation of the Framework. The Community Involvement Coordinator will be responsible for developing and implementing the Community Involvement Framework, Community Involvement Guidelines and the Stakeholder and Community Involvement Plan, monitoring its success and reporting on outcomes. These documents are fluid and flexible, allowing for changes to be made as needed to keep it relevant. Regular feedback from the T1D community and the Centre's wider stakeholder group will inform the Framework's future direction. A Community Relationship Management system will be used to support Consumer Representative recruitment and participation, coordination of involvement activities and monitoring to ensure the Principles and Standards are met.



## How we want you to use the Community Involvement Framework

The intention of this Framework is to not only guide the Centre in embedding those who live with T1D and the T1D community into every aspect of its research activities, but to also be a tool for researchers, research partners, clinicians and other healthcare professionals to recognise the importance of community involvement and involving the T1D community in their own research activities, wherever they are in the world. It asks you to consider who needs to be involved in a research project and how to best involve them so that it is meaningful and not tokenistic.

Using the Principles and Standards in this Framework, and the Community Involvement Guidelines as the foundation to develop a Stakeholder and Community Involvement Plan, will lead to successful and meaningful community involvement. Appendix A Community Involvement Process for Researchers provides a best practice process model that guides researchers in understanding when to seek support and implement community involvement activities during their research cycle.



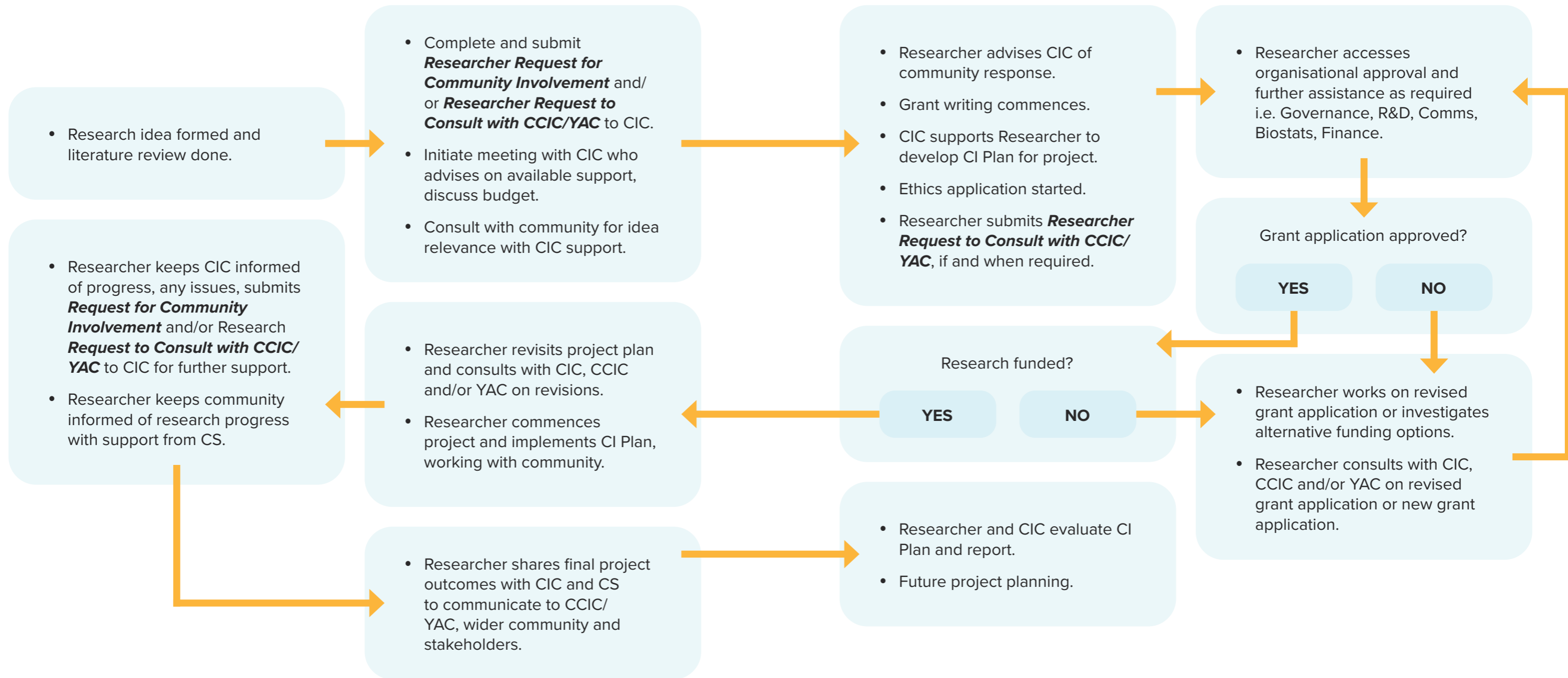
## Acknowledgements

Consultation and feedback on this Framework 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 this Framework, in particular:

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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
- Jessie Ingram – Research Assistant, Children's Diabetes Centre, Telethon Kids Institute, Perth Western Australia
- Leah Laurenson – Clinical Data Manager, Children's Diabetes Centre, Telethon Kids Institute, Perth Western Australia
- Julie Dart – Clinical Research Nurse, Perth Children's Hospital, Perth Western Australia
- Wendy Chan She Ping-delfos – Technology Program Manager, Children's Diabetes Centre, Telethon Kids Institute, Perth Western Australia
- Lee Bevan – Project Manager, Kulunga, Telethon Kids Institute, Perth Western Australia
- 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



# Community Involvement Process for Researchers



<b>KEY</b>	<b>CI</b>	Community Involvement
	<b>CIC</b>	Community Involvement Coordinator
	<b>CCIC</b>	Community & Consumer Involvement Committee
	<b>YAC</b>	Youth Advisory Committee
	<b>CS</b>	Communications Specialist
	<b>RD</b>	Research Development
	<b>Comms</b>	Communications Department

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### 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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### FOR FURTHER INFORMATION ABOUT THIS FRAMEWORK

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Email: [community@childrensdiabetesresearch.org.au](mailto:community@childrensdiabetesresearch.org.au)







[diabetes.telethonkids.org.au](https://diabetes.telethonkids.org.au)