Our impact so far

Precision medicine has the potential to transform the care of children with high-risk cancers, who have tended to have limited treatment options.

New techniques, such as whole genome sequencing, are rapidly changing our understanding and treatment of cancer, rare disease and neurodevelopmental disorders, but the potential impacts of paediatric precision medicine programs on the psychosocial wellbeing of families are poorly understood.

To ensure that all children and young people benefit from precision medicine, it is necessary to extend research beyond the laboratory to address the psychosocial risks of precision medicine and ensure its equitable rollout.

Psychosocial approaches to medicine look at the interrelation of individual thought and behaviour, the surrounding social environment, and how these combine to impact the physical and mental wellness of individuals.

Luminesce Alliance-funded researchers have been developing world-leading programs to improve the understanding of how patients, carers and health professionals deal with the challenges of the introduction of precision medicine, such as the risk of unrealistic expectations and understanding the implications of genetic screening for the extended family.

While it's vital to understand family perspectives on new treatments, improved support can also impact clinical outcomes. Psychosocial factors may influence up to 30 per cent of the long-term morbidity of children with physical illnesses, according to international research. That is because patients' and families' experiences, understanding and communication around treatment are key to health outcomes as well as their level of satisfaction.

World-first psychosocial research into precision medicine for childhood cancer patients

Luminesce Alliance researchers have carried out one of the first studies in the world into the psychosocial implications of precision medicine for children, their families and health care.

Uniquely, our study of the psychosocial implications of ZERO, called PRISM-Impact, is gathering longitudinal data over five years, so it is possible to identify how experiences change and when new issues emerge.

This world-first data on families' wellbeing and quality of life will inform targeted resources and support to enable patient-centred, holistic care, says Prof Claire Wakefield, of the School of Women's and Children's Health at UNSW Sydney and Sydney Children's Hospital.

"If parents aren't coping, that flows onto the child. Ultimately, we would like every family to feel well informed and to feel well supported, no matter what language they speak or where they live," she says.

"It's not about taking away their sadness and grief, but making sure they have the support they need from the moment of diagnosis to the long term, when they go home."

Highlighting the psychological impacts for patients and families

Initial findings suggest parents experience high levels of distress around the time of their child's diagnosis. However, for some this does not resolve long term, and parents are often unable to attend to their own emotional needs when their child is so sick.

Some parents have a lack of understanding and awareness of precision medicine, and feel unclear about what it could achieve.

"If these issues are not addressed, families enrolled in precision medicine trials are at increased risk of long-term distress, and may experience regret, mental health conditions, relationship and family problems, and poorer health outcomes," says Prof Wakefield.

The data collected is being translated into a range of resources such as brochures, videos and telehealth support that are accessible to families whenever they need them during this difficult time in their lives.

The study also gathered the world's first data from children themselves, whose experiences are hard to capture while they are so unwell. The inclusion of children aged 12 and over in PRISM-Impact is providing unique insights into the needs of children having these revolutionary new treatments.

Listening to healthcare professionals and scientists

The experiences of healthcare professionals and scientists were also captured in the study, with participants identifying a recurring problem when caring for families in how to communicate realistic expectations of treatment while maintaining hope.

"Having difficult conversations can be a real challenge for health professionals, and not all of the people involved in a child's care may be aware of

Dr Kate Hetherington

Post-Doctoral Research Fellow
Faculty of Medicine & Health
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Kids Cancer Centre, Sydney
Children's Hospital

the trials the patients are enrolled in," says Dr Kate Hetherington, of the School of Clinical Medicine at the UNSW Sydney.

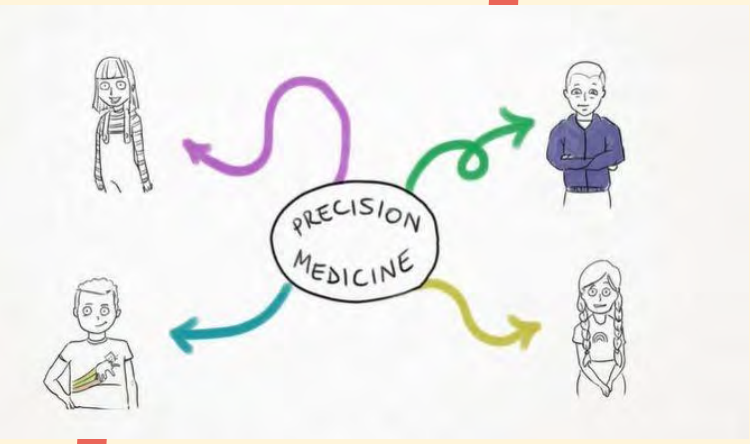
"Delivering precision medicine involves a team of professionals working across many different patient-facing and 'behind the scenes' roles," she adds. "Many of the professionals involved in delivering the ZERO program appreciated being asked about the new developments in their work and how they feel about them; it's unique for them to have this opportunity to share their perspectives and will be important for the successful implementation of precision medicine."

With the upcoming expansion of precision medicine through the extension of ZERO to be available to all children in Australia diagnosed with cancer by the end of 2023, the psychosocial team will build on the achievements of PRISM-Impact. This includes projects to better capture the experiences of culturally and linguistically diverse families enrolling in paediatric precision medicine, and piloting of flexible telehealth support for families experiencing high distress and barriers to accessing existing services.

"This work is a way of translating the intention of the health system into families' experiences of it – of ensuring families get the best experiences possible, even when their child is unwell.

"The interventions we will design are low cost but have a big gain. They will lead to better outcomes for decades, rather than ongoing problems for the rest of patients' lives."

- Prof Claire Wakefield



Supporting families

A series of animated videos have been developed by the team, aimed at supporting families participating in ZERO.

"One of the important pieces of feedback we got was families were sometimes unclear what was going to happen and what the possibilities for precision medicine were," explains Prof Wakefield.

"The other thing families often tell us is that the information provided can be overwhelming and not visually appealing."

The animated video series includes an explanation of precision medicine, examples of possible outcomes of genetic sequencing, and reflections from families who have already been through the process.

It is hoped the videos can be incorporated in the consent process for families being offered whole genome sequencing following a cancer diagnosis for a child.

"The video format will mean that families can refer back to reinforce what the doctors have explained during the consent process or share them with friends and extended family, so that they also understand," Prof Wakefield says.

Global connections

Our researchers have been in demand across the world to share their expertise and form collaborations.

ZERO has formed several international collaborations to build a data sharing framework.

"ZERO data is contributing to global genomic data sharing efforts from St Jude's and Children's Hospital of Philadelphia. Collectively sharing data of approximately 10,000 patients, with rich clinical annotations, will become a game changer for paediatric cancer over time," says Prof Michelle Haber AM, Executive Director of the CCI.

Researchers in our psychosocial program have also forged links across the globe.

"Our team is considered a world leader in the research assessing the psychological impact of emerging genetic technologies and precision medicine on children, their families, and the health professionals at the forefront of this novel field," says Prof Wakefield.

The team at the Behavioural Sciences Unit (BSU) at UNSW Sydney is the largest paediatric psycho-oncology research unit in Australia and has published more than 30 research papers

Prof Claire Wakefield
School of Women's and Children's Health UNSW Medicine
Head, Behavioural Sciences Unit, Kids Cancer Centre
Sydney Children's Hospital

evaluating ethical questions of genetic testing and its psychosocial impact on those involved.

"To be successful in our work - at the intersection of medicine, science, psychology and ethics – and for our work to reach families around the world, we have built a large national and international collaborative network," says Prof Wakefield, Director of the BSU.

The research has led to collaborations across the globe, including in the United States, Canada, the Netherlands, Belgium, Norway, Sweden, Finland and Germany.

The interest in this work has allowed Prof Wakefield to run workshops on the ethics of precision medicine, including for the Pediatric Oncology Group of Ontario and at the annual congress of the International Society of Paediatric Oncology.

Prof Wakefield sits on the advisory board for the iCOPE study, a bi-national precision medicine study offered to eligible children in Denmark and Sweden. In collaboration with Dr Brittany McGill, she founded the Australia and New Zealand chapter of the Li Fraumeni Syndrome Association.

In 2022, Dr Kate Hetherington co-led the organisation of a Nordic-Australian collaborative meeting for researchers whose work focuses on the psychosocial impact of precision medicine and genetic testing for childhood cancer. Research groups from five countries, including Australia, Norway, Sweden, Denmark and Finland, each presented an overview of their relevant research projects and discussed avenues for future collaboration.

1. Dana-Farber Cancer Institute, Boston, **USA**
2. St Jude's & Children's Hospital of Philadelphia, **USA**
3. Montreal Children's Hospital, McGill University Health Centre, **Canada**
4. British Columbia Children's Hospital, Vancouver, **Canada**
5. Hospital for Sick Kids/University of Toronto, **Canada**
6. Princess Maxima Centre for Pediatric Oncology, **The Netherlands**
7. Ghent University, **Belgium**
8. University of Oslo & Oslo University Hospital, **Norway**
9. Karolinska Institute, **Sweden**
10. Rigshospitalet/University of Copenhagen, **Denmark**
11. University of Linkoping & The Finnish Institute of Bioethics, **Finland**
12. Medical University of Hannover, **Germany**