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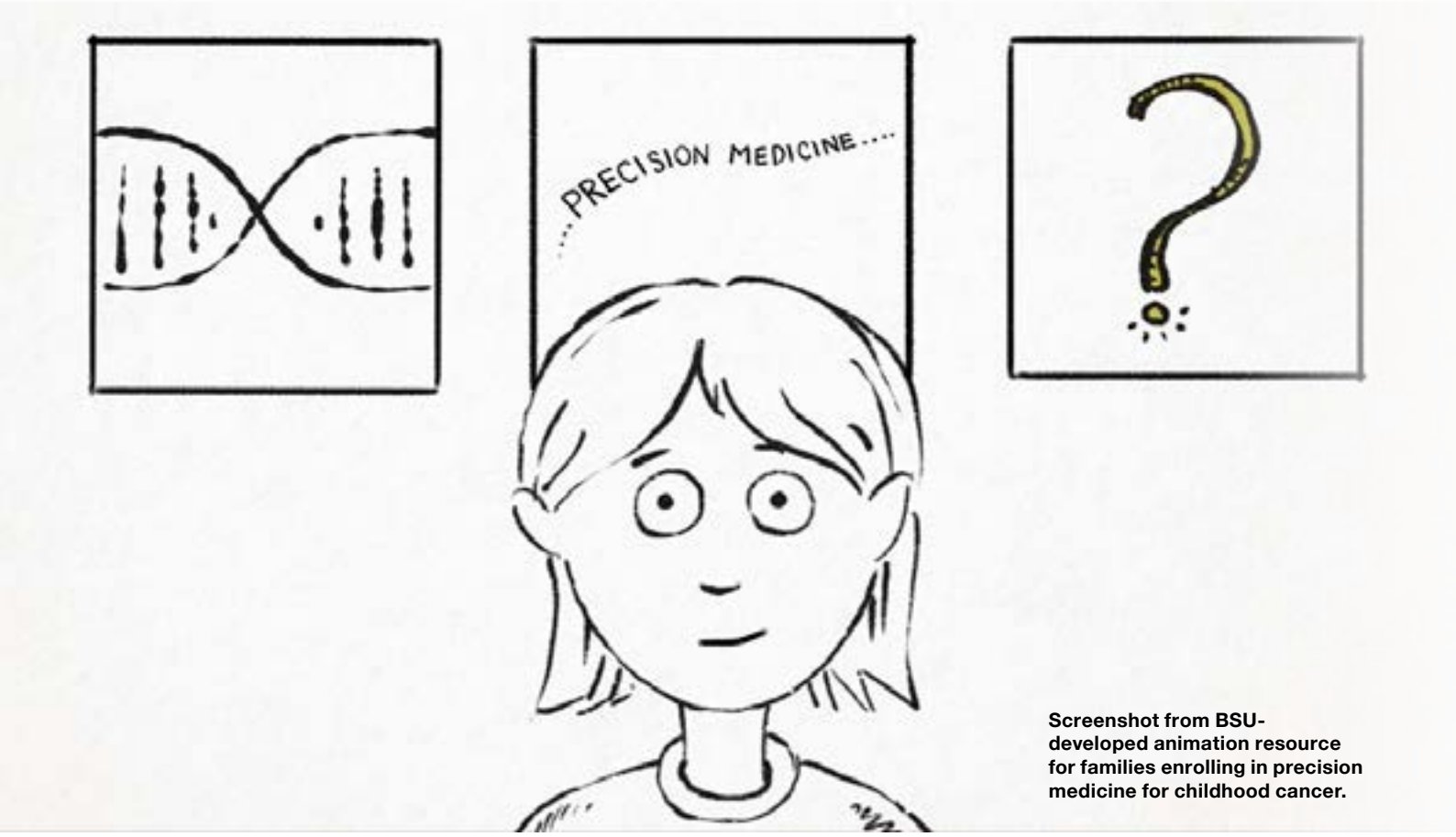
SUPPORTING CHILDREN WITH CANCER AND THEIR FAMILIES IN THE ERA OF PRECISION MEDICINE



Screenshot from BSU-developed animation resource for families enrolling in precision medicine for childhood cancer.

UNSW Sydney is conducting world-leading research into the psychosocial impact of precision medicine on children with cancer and their families.

By tracking the experiences of >400 families and >100 health professionals through Australia's ZERO Childhood Cancer program, our work is driving initiatives to ensure scientific advances translate into improved outcomes for children and families.

Precision medicine offers new hope for children with cancer and their families.

Using genomic technologies along with in vitro and in vivo profiling, precision medicine programs have the potential to identify novel treatment options as well as inform a patient's diagnosis, prognosis, and clinical management. Advances in precision medicine have increased our knowledge of genetics and childhood cancer risk and are expanding the therapeutic options for children diagnosed with cancer. Across Australia, precision medicine has been available to children with a poor prognosis cancer since 2017 through the Zero Childhood Cancer program, and by the end of 2023 will be available to all children diagnosed with cancer in Australia. Although the promise of precision medicine is great, it brings with it challenges for families and healthcare professionals alike.

The Ethics and Genetics team at the Behavioural Sciences Unit (BSU) are conducting an ongoing program of research with the goal of better understanding these challenges, and a view to drive solutions through innovations in psychosocial care and workforce support. So far, through collaborations with our colleagues at the Children's Cancer Institute and the Kids Cancer Centre, the team have captured the experiences of over 400

families and 100 health professionals through the ZERO Childhood Cancer program and the Luminesce Alliance supported PREDICT trial[1].

One of the critical questions we continue to examine is what parents hope for, and what they worry about, when they enrol their child in a precision medicine trial. We found parents tended to hold two hopes simultaneously: that participation would benefit their child, as well as future children[2].

> ***"If it can't save our daughter then it might help someone else" (Mother of child with a sarcoma).***

Although parents told us about several worries, including the potential for a long wait for results, they generally expressed high levels of satisfaction with the trial and few regrets about their child's participation. Importantly, this was true even for bereaved parents.

With any treatment approach, it is important that families feel well-informed. Yet, parents often enrol their child in a precision medicine program at a time of crisis: whether it is shortly after the child's diagnosis or at relapse. We hypothesised that emotional distress, combined with time pressures and the complexity of precision medicine concepts, might understandably impact parents' and patients' comprehension of the precision medicine process.

To explore this, we asked parents and adolescent patients about their perspectives on the information given to them when consenting to a precision medicine trial and their understanding of the trial. Findings identified some gaps in understanding and participants provided useful suggestions for ways the information could be simplified and better formatted to foster engagement and understanding[3]. In a separate study, we focused on parents' perspectives of having received information about their child's genetic (heritable) cancer risk, a notoriously complex yet critical topic area for families to understand, with potentially significant implications for the wider family[4].

Our findings have informed exciting developments in the genetic counselling resources and supports available to families in the next stage of the ZERO program. Our team has also developed and piloted three short animation resources for patients and their parents to support understanding of key precision medicine concepts, which will eventually be available to families across Australia.

Keeping equity at the forefront, we aim to adapt and translate these resources for families from culturally and linguistically diverse backgrounds and have commenced interpreter supported interviews so that all families may share their experiences of precision medicine for their child's cancer.

Developing models of psychosocial care for families participating in precision medicine is another pillar of our research. We documented the emotional and psychological challenges faced by families accessing precision medicine for poor prognosis cancer and found that most patients and parents reported symptoms of anxiety and/or depression[5], and 20% of parents reported needing further psychological support. To understand how best to meet these support needs, our team are examining barriers to accessing psychological support during the precision medicine process, and piloting the acceptability, uptake and impact of clinician initiated, flexibly delivered telehealth for distressed families.

Complementing our work with families, we have also conducted studies investigating the experiences of oncologists and other health professionals at the frontline of precision medicine care[6,7]. While attitudes toward precision medicine are generally positive, many describe how it adds complexity to their role and is resulting in changes, often navigated without formal training. "I hope we get to the stage… where you know…genetic knowledge becomes so integral to the treatment of patients that all members of the treatment group are familiar with it, but I don't feel I have that understanding at the moment." (Surgeon involved in precision medicine care). Findings highlight the need for health professional training, particularly for non-genetics trained professionals and models of care that promote multidisciplinary involvement.

As we strive towards a world in which every child is free from cancer, precision medicine offers a new way forward. By listening closely to the perspectives of patients, parents, healthcare professionals and other key stakeholders, we aim to ensure all families are supported and empowered to participate in precision medicine, during what may be the most challenging time of their lives.


Dr Kate Hetherington

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References can be supplied upon request.