

Ministry of Business, Innovation & Employment

## *Te Ara Paerangi* - Future Pathways

Submission from **Cure Kids**

16 March 2022

Tena koutou katoa,

**Cure Kids commends the Ministry of Business, Innovation & Employment** for this robust analysis of New Zealand's research, science, and innovation (RSI) system, and of the options available to proactively position the system for future challenges and opportunities. We agree with elements of the case for change, such as the need to improve responsiveness to Māori and to give effect to Te Tiriti o Waitangi. We also believe in retaining aspects of the system that are working well, and that have enabled New Zealand researchers to be globally recognised for the quality of their scientific work.

We consider that **Cure Kids has important contributions to make** to the discussion on *Te Ara Paerangi* Future Pathways, based on 50 years of enabling research to transform the health of children in Aotearoa NZ. The aim of this submission is to describe the RSI system from the vantage point of charitable funders of research, and with a specific focus on **medical and health research**.

We will describe how Cure Kids has **prioritised activities to enable research** with the goal of transforming child health. We will also highlight Cure Kids' achievements in promoting **collaboration and connection across the RSI system**, and describe the benefits of including **philanthropic funders** along with healthcare organisations and businesses in plans to invigorate the public research sector. Cure Kids also has specific expertise and experience in **commercialisation of health research**. Cure Kids Ventures was established in 2008 to invest in early-stage development of products, technologies, and services with potential to benefit child health.

It makes sense for *Te Ara Paerangi* Future Pathways to include philanthropic funders in the scope of the RSI sector, and to develop new approaches for co-investment on agreed priorities with not-for-profit organisations.

### Introduction

Cure Kids was established in 1971, and at our 50-year milestone in 2021, we were inspired to look back and critically evaluate what has been achieved for the health of children to date, and to look forward and plan to accelerate the **transformation of child health**. This included a formal analysis of Cure Kids' support for the RSI system in New Zealand over 50 years, including more than \$60 million invested in research over that time.

Over this time Cure Kids' work has spanned **five mechanisms** for enabling research:

- 1) competitive peer-review to select the most **innovative and scientifically** sound ideas,
- 2) support for **world-class scientists** to build high-performing research teams,
- 3) mission-led investment in **priority areas** for child health,
- 4) targeting of investment based on assessment of **greatest impact**, and
- 5) active **research collaborations** with a range of partners.

Cure Kids' analysis showed that each of these mechanisms had resulted in **breakthroughs for child health**, which cumulatively have transformed and saved the lives of many thousands of children.

Therefore Cure Kids' plans to continue support for research through all five mechanisms, and to employ insights from the retrospective review to further enhance the potential benefit of each one. Cure Kids is also strengthening measurement and monitoring of the impact of funded research in each category to achieve our vision of **healthier children with brighter futures**.

Cure Kids' review also highlighted critical gaps, such as a historical lack of engagement and connection with Te Ao Māori. The organisation is now working to give effect to Te Tiriti o Waitangi, including by building capability in the Māori health workforce, co-designing strategies with Māori communities to maximise impact, and prioritising research that aims to enhance Mātauranga Māori and **redress inequitable health outcomes for tamariki Māori**.

We'd like to answer some specific questions posed by the consultation document.

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1.2.2

What principles could we use to determine the scope and focus of research priorities?

The two founders of Cure Kids – Professor Sir Bob Elliott and Dr Ron Caughey – were determined to improve the health of New Zealand children by investing specifically in child health research. Experts like Prof Elliott have volunteered for many years on Cure Kids' Board and Medical & Scientific Advisory Committee, and over time we have developed robust systems to prioritise investments in research based on their assessment of the core principles of 1) **scientific excellence and innovation**, 2) the **capacity of the research team**, and 3) the **potential impact for child health**. Since 2021, we added a fourth category, to fund and support research that ultimately aims to redress inequity in **health outcomes for tamariki Māori**.

As an organisation which relies on the goodwill and trust of generous donors, 'active listening' has always been central to the way Cure Kids works. We have learned to be **adaptable and responsive**. Since 1971, Cure Kids' research priorities have continuously evolved to adapt to changing concerns about children's health, and in response to feedback from New Zealanders in government agencies, the healthcare sector, research institutions, major corporate and philanthropic donors, and the general public.

Changes in research priorities have also been driven by the researchers themselves. This is critical, since many researchers in the health field are also clinicians, and therefore see first-hand the health issues which affect their patients. Cure Kids is pleased to note that *Te Ara Paerangi* Future Pathways includes a commitment to balance "**investigator-led**" research with research on pre-determined priorities, since this will ensure not only responsiveness, but also innovation, breadth of research, and fostering of the research workforce.

Cure Kids contributed to the thorough process of consultation which underpinned MBIE's 2017 **Health Research Strategy**, and the subsequent **Health Research Prioritisation Framework** in 2019. In 2018, one of Cure Kids' four Professorial Chairs, Stephen Robertson, was one of 13 leading experts chosen to assess input from a range of stakeholders to recommend Strategic Investment Areas for health research. The resulting strategic documents, jointly developed by MBIE, the Ministry of Health, and the Health Research Council to guide health research until 2027, reflect a huge amount of input, and represent a good model for priority-setting processes across the RSI sector.

Another key example of a priority-setting process is the wide public consultation which enabled MBIE to identify 11 **National Science Challenges** in 2014. In 2017 and 2020, Cure Kids partnered with the National Science Challenge most closely allied to child health – **A Better Start *E Tipu e Rea***. To support

the government's efforts to tackle these challenges, Cure Kids ran and co-fund a series of research projects to develop practical solutions to achieve healthy weight, mental wellbeing, and early learning and development for children growing up in Aotearoa NZ. If anything, the urgency of these priorities has only increased, although the Challenges were identified more than 8 years ago.

In 2019, Cure Kids approached leading researchers at the Paediatric Society, the Child & Youth Epidemiology Service at the University of Otago, and the Royal Australasian College of Physicians to identify the most urgent challenges for child health in New Zealand. In 2020, these collaborating organisations published the first of a series of annual reports, the **State of Child Health in Aotearoa NZ**. The first issue of this Report highlighted data on hospitalisations for respiratory conditions, skin infections, and dental disease. It showed that too many children go to hospital with these issues – and that rates are seriously inequitable and rising.

Many of these hospitalisations can be prevented by evidence-based medicine, but some vital evidence is lacking – we just don't understand these diseases well enough to prevent, diagnose, treat, or cure them. The aim is to use an evidence-based approach to identify where **mission-led funding for research** can achieve the greatest impact for the health of children. Cure Kids has already been working with experts to define the unanswered questions, and is currently funding research to promote respiratory, skin, and dental health. Cure Kids will also use the State of Child Health Report to get consensus on priorities, and to build a critical mass of targeted investment from philanthropic funders, investors, corporate donors, and the government.

Cure Kids' 50-year evaluation also offers two main insights relevant to priority-setting in the RSI sector.

- 1) The **scope** of Cure Kids impact on child health has been very broad, encompassing both rare and common diseases, and diverse areas such as disability, dental health, mental health, and early learning, which sometimes fall outside the purview of narrowly medical fields or disciplines. Cure Kids has also always included the Pacific Islands in its remit, in recognition of New Zealand's status within the region, and the interconnectedness of the health and wellbeing of our people. The advantage of this over 50 years has been that challenging boundaries has often led to impactful collaborations and breakthroughs.
- 2) Cure Kids has regularly **focused** a portion of its investment on specific priorities for child health – which has sometimes (although not always) led to significant impact. It is tempting in the medical field to determine priorities solely based on health issues. However, some of Cure Kids' greatest breakthroughs over the past 50 years have not come from efforts to cure a particular health issue, but from discovery of a novel method or technology (such as using stem cells to grow artificial skin in the lab), which has later proved to be useful in a range of unexpected contexts (e.g. burns, genetic conditions, and laboratory models of disease).

In summary, although it might seem counterintuitive, any future priority-setting process for the RSI sector should begin with a very **broad scope**, and when selecting areas of focus, should consider not only areas of scientific study (e.g. specific health issues), but also opportunities to leverage **New Zealand's unique knowledge, skills, or resources**. For example, New Zealand could prioritise research to utilise an innovative methodology, a valuable data source (e.g. a longitudinal cohort study), indigenous flora and fauna, or a critical mass of experts in a particular field. Equally, New Zealand could prioritise research to develop a unique response to threats, such as pandemic preparedness or disease surveillance. Finally, the process could consider prioritising aspects of "how" NZ does research, by mechanisms to enable ingenuity, collaboration, a commitment to equity and inclusion, or translation of results into impact. Note that the relative 'size' of each priority might well differ markedly, and therefore need different amounts of investment and support based on the extent of the knowledge gap, the ability to link to global research, and the existing workforce, tools, and infrastructure needed to make major gains.

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1.3.2

How could a national priority-setting process best give effect to Te Tiriti?

Cure Kids recognises the **inequity of health outcomes for Maori children**, and is actively promoting equity through health research. Cure Kids' Board member Dee-Ann Wolferstan, who is Chief Executive for Te Iwi O Ngati Kahu, Te Whare Ruruhou O Meri Trust, and Te Kahui Mana Ririki Trust, is advising Cure Kids on how to take an active approach to **honouring the principles** of Te Tiriti o Waitangi, including through the process of priority-setting, and development and protection of Mātauranga Māori. Under the guidance of Professor Te Kani Kingi (MRSNZ, Ngāti Pūkeko, Ngāti Awa, Ngāi Tai), Cure Kids is revising all processes for assessing and selecting research to reflect these aims. Professor Kingi provides Māori leadership within Cure Kids Medical & Scientific Advisory Committee. The redesign of policies and processes includes peer review by an expert in Māori health or health research for every proposal which Cure Kids assesses for funding. These Māori experts advise on whether the research proposals include 1) kaupapa Māori methodologies, 2) Māori researchers, collaborators, or participants, 3) potential impact for the health of tamariki Māori, or 4) expansion of Mātauranga Māori.

For the government to honour the principles of Te Tiriti o Waitangi, the broader RSI sector should embrace priorities which are set by, with, and for Māori. This means **true long-term collaborative partnerships** to jointly agree priorities that will improve health outcomes for tamariki Māori. The RSI system should also ensure that Māori are welcome throughout the sector, including at all levels of research activities (as funders, consultants on ethical issues, researchers, and active and knowledgeable participants). *Te Ara Paerangi - Future Pathways* should also include ways to promote equity of access to the outcomes of research, including translation of research results into Māori, novel methods for sharing and disseminating results, and actions to ensure that the best current evidence is implemented into standards of care in every part of the health system, including those which serve tamariki Māori.

The 2020 **State of Child Health in Aotearoa NZ** clearly identified that respiratory conditions, skin infections, and dental disease disproportionately affect Māori children. In 2021, the Advisory Group for the **State of Child Health** expanded the focus to describe the burden on children due to rheumatic heart disease (RHD), and the inequitable rates of rheumatic fever and RHD for tamariki Māori. Because this disease has been eliminated in most wealthy countries, New Zealand cannot rely on diagnostic tests, treatments, or vaccines being developed overseas. In 2020, Cure Kids invested \$3 million into research to generate a pipeline of solutions that will enable the government to eradicate rheumatic fever and RHD. Some of this research focuses on how to provide culturally appropriate health services to rangatahi Māori. RHD also disproportionately affects Pasifika youth, both in New Zealand and in the Pacific Islands, and Cure Kids has a separate but linked programme involving \$3 million of research to prevent and control RHD in Fiji.

As described in the previous section, a national priority-setting process should not only focus on health issues where research is needed to understand and redress inequities for tamariki Māori. To give effect to Te Tiriti o Waitangi, New Zealand could also prioritise **research which can only happen in Aotearoa**, such as investing in kaupapa Māori research design, supporting expertise in Mātauranga Māori, fostering iwi collaborations, enabling joint studies of whakapapa and genetics, funding investigations of traditional knowledge about indigenous flora and fauna, and translating research evidence into targeted benefits for Maori.

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## 2.3

### How can mātauranga Māori be enabled and protected in the research system?

Cure Kids is committed to promoting the **health and wellbeing of Māori children** by enabling research to fill key evidence gaps. Experts has advised that an important way to achieve this is through research by Māori, with Māori, and for Māori. Before funding any research, we now always ask how well it incorporates and advances Māori **tikanga, knowledge, and partnerships**. We also ask researchers to involve Māori collaborators wherever possible, including in prioritisation of research areas, ethical review, co-design of research methodology, incorporation of Mātauranga Māori, active participation, consultation and engagement with the wider community, sharing of the final results, and translation into impact for tamariki Māori. Ideally, this should foster sustainable ongoing relationships between research teams and communities that generate benefits for both. Cure Kids is guided by lead experts who whakapapa Māori, such as Professor Te Kani Kingi, to ensure that the key principles are upheld throughout our journey to develop sound platforms to influence Mātauranga Māori .

Over the past 5 years, Cure Kids has noted an increase in small **regionally based research institutions** and wananga, including institutions with close links to iwi. This phenomenon has increased Cure Kids' workload in terms of administrative management and due diligence for investment, but on balance, the quality of the research has been good, and we see benefits for the diversity of the research sector, its output, and its impact for child health. *Te Ara Paerangi* Future Pathways should support researchers and research institutions to give effect to the principles of Te Tiriti o Waitangi by creating platforms to build stronger connections with tangata whenua based in the regions, including mātauranga practitioners.

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#### 4.4.1

### How could research institutions be more collaborative, adaptive, and agile?

The *Te Ara Paerangi* Future Pathways document observes that **lack of connectivity** across the RSI system means that priorities are often determined without broad consultation and not sufficiently communicated, and that this prevents potentially valuable collaboration and knowledge-sharing, and even risks duplication of effort. From Cure Kids' perspective, the lack of connectivity and alignment between the various institutions, businesses, public sector organisations, and government is sometimes clearly apparent. It is also notable that the philanthropic sector is often not considered as a potential collaborator, despite significant contributions over many years.

Cure Kids notes the proposal in *Te Ara Paerangi* Future Pathways to create **fewer, larger, and more resilient research organisations**, and agree that this could potentially foster interdisciplinary research, and enhance connectivity, flexibility, and resilience. However, the risk is that large institutions would be more insular, and even less likely to engage and collaborate with the host of smaller philanthropic organisations which together contribute many millions to the RSI system every year.

Over the past 50 years, Cure Kids has expanded the **range of institutions** it supports. For many years, medical research occurred exclusively at the Universities of Auckland and Otago, but over time, Cure kids has received proposals for health research from eight Universities around the country, plus an increasing range of other non-traditional research organisations. New institutions which Cure Kids has registered in its online portal including District Health Boards, Primary Care Organisations, Hospitals, Wananga, and Clinical Research Organisations. Cure Kids has never funded research directly at a Crown Research Institute, although we have engaged with Landcare Research through funding research to identify potential medicinal compounds in some of their collections. It is notable that some DHBs are very active in child health research, while others are not (or at least have not applied for



funding from Cure Kids). Some of the new research institutes are led by Māori and Pasifika researchers, such as Mātai Medical Research Institute, Hāpai te Hauora Tāpui Ltd, and Moana Research. On balance, Cure Kids sees benefits from this decentralisation of research for the diversity of the research sector, its output, and its impact for child health.

One potential way to manage the issue of connectivity would be a **national online hub**, building on the government's [National Research Information System](#), where individuals and different organisations could log scientific challenges worthy of prioritisation, and propose ideas for **collaboration** (whether through research, co-funding, or commitment to implement the results of research). This should help to avoid duplication of projects which are already underway, and stimulate fertile links between parallel streams of investigation. This hub might be particularly useful for small research institutions, charities, or regional researchers wanting to link with others to generate critical mass. It could enable smaller institutions to access **research services** which are standard for universities and other large institutions. These include ethical review, support for matauranga Māori, statistical calculations, grant-writing, legal advice, and support for managing contracts and budgets. A national platform could also include support for knowledge exchange and impact generation, by connecting researchers with potential end-users or investors, helping them to disseminate information more widely or in different forms, and advising on commercialisation of products and technologies.

The hub could collate information about how to apply for the **diverse streams of available funding** (including from philanthropic funders). By tracking investments across the sector, it could help to quantify the total investment in the sector, and identify which priorities which are already attracting investment, and which need additional resources and support. Ideally, the hub should allow members of the general public to see at a glance where the national research effort is focused, have input on the priorities, and even participate in research studies (e.g. by linking to clinical trial networks). One advantage of an online platform is that it would be dynamic, since priority-setting should always be an ongoing process, to enable rapid organic changes in light of new information or advice. It could also potentially be extended to include researchers from the Pacific Islands, generating mutual benefits.

Cure Kids and other **philanthropic funders together contribute a significant amount of funding** to the system. For example, in 2018, 18 medical research charities<sup>1</sup> distributed almost \$60,000,000 in research grants, and the combined capital reserves of these organisations is nearly \$ 560,000,000. The 2017 Health Research Strategy set out the government's intention to "develop new approaches for co-investment with the not-for-profit sector on the agreed priorities". It would make sense for *Te Ara Paerangi* Future Pathways to incorporate mechanisms to promote collaboration and connection that includes philanthropic funders.

Health research often has specific nuances due to ethical implications and clinical applications which means that it should ideally be managed by specialist funders. Cure Kids funding can be seen as providing a **niche opportunity** for researchers to apply for relatively small grants (\$50,000 or \$110,000) which let them "prove a principle" before they go on to a more thorough (and expensive) trial. This also enables researchers to test innovative ideas which are relatively high risk, similar to MBIE's Smart Ideas grants, which often exclude health research. Cure Kids sees an ongoing need for a range of philanthropic funders to provide a diversity of options for the RSI system, particularly if most of the funds in future are administered through a small number of large organisations.

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<sup>1</sup>Hugh Green Foundation, Neurological Foundation, Auckland Medical Research Foundation, National Heart Foundation of NZ, Freemasons Charity, Cure Kids, Maurice and Phyllis Paykel Trust, Child Cancer Foundation, Cancer Research Trust NZ, Green Lane Research Fund, Canterbury Medical Research Found, Mackenzie Foundation, Manchester Trust, Starship Foundation, Wellington Medical Research Fund, Middlemore Clinical Trial Trust, Leukaemia and Blood, Otago Medical Research Foundation, and the Duncan Trust.

Cure Kids sees a distinction between **health research and the rest of the RSI sector** in that the 2017 Health Research Strategy and the creation of Hauora Aotearoa and the Māori Health Authority mean that priorities are already clear, and relevant organisations are already in the process of major consolidation. Since a large proportion of grant funding currently goes to overheads for research institutions, the proposal for changes to base funding introduces the risk of an overall negative effect for health research if a portion of the money which is currently allocated to health research is given directly to research institutions as base grants. Given that the funding for health research in New Zealand is relatively low compared with comparable countries, Cure Kids supports the argument that direct government investment in health research should be increased to 2.4% of direct government health care costs over the course of the next decade. One mechanism could be to maintain the current amount allocated specifically for health research, but to allocate additional money to base grants to maintain the institutions.

The *Te Ara Paerangi* Future Pathways document analysis suggests that competition for grant funding can create barriers to **collaboration and connections** between research institutions. Cure Kids' experience is that researchers themselves see huge benefits to collaboration; for example, paediatricians around New Zealand have an active national network and to some extent research is already coordinated through that structure. In 2019, Cure Kids launched an effort to combat RHD with a broad range of stakeholders from across both the health and research sectors. The researchers, clinicians, and community representatives collectively defined the most urgent research questions, and then separately developed detailed proposals which were pitted against each other in a competitive funding round. In 2020, Cure Kids awarded \$3 million, split between six research teams. Cure Kids has continued to meet with this group, the Pu Manawa Research Alliance to end RF/RHD. Cure Kids is in talks with the Manaaki Manawa Healthy Heart Centre for Research Excellence to plan further co-funding collaboration for RHD, and would also welcome engagement with the government.

Cure Kids sees an ongoing need for a component of the overall national funding for research to be administered via competitive processes, using peer review, since this approach has been shown to promote **innovation and scientific excellence**. The proposal to merge research organisations into larger institutions which are more financially independent has potential benefits. However if it means that these organisations rely less on competitive processes for funding rounds, they might be less likely to respond to signals from businesses, charities, government and communities. Larger organisations might not stimulate the diversity of ideas, knowledge, and capabilities which will be needed to generate innovative solutions to future challenges.

Cure Kids has a proven track record for accelerating child health through effective collaborations with government, for example partnering in 2014 with the Health Research Council of NZ, the Heart Foundation, Te Puni Kōkiri, and the Ministry of Health to invest a total of \$3.2 million into research on Rheumatic Fever. In 2017, Cure Kids partnered with *E Tipu E Rea* A Better Start, to invest a total of \$2.8 million (matched funds) in the three National Science Challenges of mental wellbeing, healthy weight, and early learning. After a review of the success of the collaboration for each organisation's goals, the collaboration was repeated in 2021, with a combined investment of \$4 million (matched funds).

Cure Kids has also co-invested with other charities which focus on specific areas of child health, and need help to understand which investments in research will generate the most impact towards their aims. Examples include co-investment with the Child Cancer Foundation (more than \$1.5 million since 2018), Rotary, the Cystic Fibrosis Foundation, and Red Nose Australia. Cure Kids has also partnered with companies such as A2 Milk, which funded the Research Programme for one of Cure Kids' Professorial Chairs for several years, and Fisher & Paykel Healthcare, which launched a joint research initiative in respiratory disease with Cure Kids in 2019 (currently on-hold). Finally, Cure Kids has

developed long-term trusted relationships with corporate donors such as Briscoes, ARAMEX, Armacup, Accor Hotels, and Bayleys Real Estate, which have raised millions for health research as part of their corporate social responsibility programmes.

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4.6

How can the RSI sector prioritise generation of impact and exchange of knowledge?

Cure Kids funds research at any stage on the **pathway to impact**, including proof-of-concept, pilot, and translational studies. We ask all applicants to describe how their research could eventually either 1) fill a gap in knowledge about the cause of a disease, 2) improve care for children living with health challenges, or 3) lead to a new method to prevent, treat, or cure disease. Always mindful of ensuring that any investment of donors' funds should deliver returns for child health, Cure Kids supports researchers to **maximise the value** of the results of their research. For example, over many years, Cure Kids has funded separate programmes of work by Prof Ed Mitchell and Prof Lesley McCowan to understand the causes of sudden unexpected death in infancy and stillbirth, respectively. Both researchers, who also received significant funding from the Health Research Council and other sources, identified modifiable sets of risk factors. However, in order to ensure that these results could actually be translated into reductions in the numbers of deaths and stillbirths, Cure Kids supported these researchers to deliver educational awareness messages, such as the "The NZ Cot Death Campaign", the "Sleep On Side" campaign, the "Safe Sleep Calculator", and the "Survive & Thrive 2025" online tool. Cure Kids has been able to give these and other researchers a voice by publicising their work in an engaging and relatable way, and generating opportunities for them to communicate their research with a wide audience. Over many years, and with broad collaborations with DHBs and primary care, particularly in Counties Manukau, both research programmes have prevented thousands of deaths, and delivered huge advances in health and wellbeing for mothers and babies.

A recent **quantitative analysis of the return on investment** generated by Prof Ed Mitchell's work concluded that for every \$1 invested by Cure Kids into this programme over a 20-year period, \$14.20 was returned to NZ society. This quantification of benefit to society was calculated based on improved health for mother and baby, and reduced rates of smoking and other additions. These benefits were over and above the measurable benefits for health (more immunisations, more breastfeeding, safer sleeping, and a significant decrease in the rate of sudden unexpected death in infancy).

Another example of the **generation of tangible impact**, and **dissemination of knowledge** from research is the creation of innovative digital tools, which are now being offered online to counter New Zealand's high and increasing rates of depression and mental distress, particularly among young Māori. Since 2015, Cure Kids has supported a dedicated Chair in **Child & Adolescent Mental Health**, Professor Sally Merry, to build a high-performing research team which develops practical tools to help young people develop resilience through cognitive behavioural therapy. Cure Kids has also supported other researchers around the country to develop a range of telemedicine services which reduce barriers to access and democratise care.

The impact of health research can range from academic outputs such as publications, to public good outcomes such as clinical care guidelines, to commercial products and technologies. Since 2008 **Cure Kids Ventures** has invested in a portfolio of companies which have developed medical devices, medications, diagnostics, health information, or healthcare delivery systems. Cure Kids Ventures adds value for researchers by advising these companies on the biotechnology, healthcare, and medical devices industries. The Board has expertise in early-stage company development, protection of intellectual property, global expansion, science, finance, and mergers and acquisitions. This is



particularly important, since commercialisation of research in the health sector can be particularly challenging due to high costs of entry, regulatory hurdles, and long timeframes.

Cure Kids also funds implementation science to pilot new healthcare initiatives, and then monitor and evaluate their effectiveness. For example, since 2006, Cure Kids has been investing in health research in Fiji. Current work focuses on two mission-led priorities: research to prevent and control RHD and to ensure sustainable access to oxygen for respiratory diseases. These programmes in Fiji mean that Cure Kids has insights into the health challenges and inequities for Pasifika children in New Zealand, and the parallel research programmes enable two-way benefits for researchers in New Zealand and Fiji.

Many breakthroughs due to Cure Kids investment over 50 years have changed the way child-health conditions are diagnosed and treated. Cure Kids' experience is that **connectivity between all parts of the system** is crucial to the 'pathway to impact'. Cure Kids asks researchers to connect with potential end-users at the start of their research, to make sure they are asking the right questions, and that clinicians and communities are aware of the research as early as possible. For health research, Cure Kids experience is that when institutions encourage researchers to dedicate a proportion of their time to clinical work with patients, they often deliver research with greater and more immediate impact. Could this model be applied in other parts of the RSI sector?

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## 5.2

### How should the RSI sector prioritise development of the workforce?

The proposal in *Te Ara Paerangi* Future Pathways for a base grant which covers salaries would provide maximum stability to researchers. Cure Kids is relatively unusual among other health research funders in that it supports four **Professorial Chairs** at research institutes around New Zealand, along with smaller career awards such as studentships. These positions provide each Chair with a platform to establish and lead a substantial programme of research. Cure Kids pays for their full salaries, as well as a generous grant for research costs. Each Chair is asked to build a productive research team, and to mentor students, graduates, and more senior staff. Professorial Chairs also contribute to teaching, graduate supervision, service, and leadership within their institutions, and advise and assist Cure Kids with its strategy, policies, and processes for funding health research.

Over 50 years, a series of Cure Kids **Professorial Chairs** have delivered research programmes which have saved thousands of lives, such as Prof Ed Mitchell's ground-breaking research into the risk factors for sudden unexpected death in infancy. In most cases, the Chairs use part of their time to continue clinical work and use the remainders of their salary grants to fund **PostDoctoral Fellows**. Therefore, Cure Kids funding supports not only the very top level of research scientists, but also allows them to build high-performing teams and to plan for succession by mentoring less experienced researchers and students in their research teams.

Cure Kids' 5-year research strategy includes the intention to support **expertise in Māori health**. We are actively consulting on what form this should take – whether another Professorial Chair or an equivalent investment for early or mid-career researchers. It may be possible to work with paediatricians around the country to identify Māori who have potential to contribute to child health research.

Every 2 years, Cure Kids now offers a **Repatriation Fellowship**. The aim is to reverse the 'brain drain' by attracting outstanding candidates to return to New Zealand to further their career in child health research. Fellows are expected to continue innovative and globally important research, while adding value to the research workforce. In recruitment for any of these roles, the recruitment process now

includes a strong emphasis on the importance of Māori culture and systems of knowledge, equity and inclusion, and a sound understanding of Te Tiriti o Waitangi and New Zealand's place in the Pacific.

## Conclusion

In summary, Cure Kids is broadly supportive of the vision set out in *Te Ara Paerangi - Future Pathways*, particularly the need to improve responsiveness to Māori and to give effect to Te Tiriti o Waitangi. An emphasis on investment in high-quality science will always be central to Cure Kids reputation and strategy, alongside mission-led investment in priority areas for child health. To achieve this, Cure Kids' strategy is to use robust competitive processes to offer research grants, to invest in the ability of world-class scientists to build high-performing teams, to stimulate productive research partnerships, and to measure the impact of investments in research.

Cure Kids has partnered with experts to establish a process for setting priorities for child health research, working within the government's 2019 Health Research Prioritisation Framework. Cure Kids is continuing to take advice from leaders who whakapapa Māori on how best to engage with Māori at all levels to enhance Mātauranga Māori, enable kaupapa Māori research, foster the workforce of Māori researchers, and prioritise translation of research to improve health outcomes for tamariki Māori.

We are proud that the combination of a clear vision set by passionate founders, experienced governance oversight, rigorous processes for assessing research, collaboration with world class researchers, and enthusiastic support from a wide range of New Zealanders has enabled Cure Kids to grow the size and impact of its investments in health research over 50 years. We are refining our strategies and redoubling our efforts to transform health for children, and strongly believe that collaboration, communication, and commercialisation with organisations across the RSI sector will be key to success. Cure Kids has particular expertise in these areas, and would welcome the opportunity to meet with MBIE to discuss how Cure Kids can contribute to *Te Ara Paerangi - Future Pathways*.

## Appendix

### **Cure Kids Board**

The Independent Board comprises individuals appointed for their commitment and capability, across a diverse range of business and health sector backgrounds and experiences.

Franceska Banga (ONZM)	Cure Kids NZ Chair, Cure Kids Ventures Chair, Auckland
Dee-Ann Wolferstan	Cure Kids Director, Chief Executive for Te Iwi O Ngati Kahu (Social Services for Ngati Kahu Runanga), Te Whare Ruruhau O Meri Trust (Te Pihopatanga O Te Tai Tokerau Social Service), and Te Kahui Mana Ririki Trust.
Barrie Campbell	Cure Kids NZ Director, ACA Secretary/Treasurer Cure Kids, Consultant to BKR Walker Wayland, Auckland
Alaister Wall	Cure Kids NZ Director, Deputy Managing Director Briscoe Group Limited
Dr Bruce Scoggins	Cure Kids NZ Director & Chair of Medical & Scientific Advisory Committee
Russ Hewitt	Cure Kids NZ Director, Senior Executive Vodafone
Prof Stephen Robertson	Cure Kids NZ Director & Cure Kids Chair Of Paediatric Genetics, University of Otago, Dunedin

The Board is supported by an extremely able and experienced Chief Executive, Frances Benge, and her team.

### **Medical & Scientific Advisory Committee**

The Committee assesses proposals for funding of research on the diagnosis, prevention, and treatment of conditions affecting children, and makes recommendations about their ethical and scientific merit.

Dr Bruce Scoggins (BAgrSc, MAgrSc, PhD) Chair of Committee

\*Professor Stephen Robertson (BMedSc, MBChB, FRACP, DPhil, FRSNZ)

\*Professor Stuart Dalziel (MBChB, FRACP, PhD)

\*Professor Andrew Day (MBChB, MD, FRACP, AGAF)

Dr Patricia Anderson (BSc(Hons), SRN, MPhil, PhD)

Professor Sally Merry (MBChB, MD, FRANZP, CCAP)

Professor Te Kani Kingi (MRSNZ, Ngāti Pūkeko, Ngāti Awa, Ngāi Tai)

Dr Teuila Percival (QSO, MBChB, FRACP) is a

Professor Ian Morison (MBChB, BMedSc, PhD, FRCPA(Haem))

Professor Barry Taylor (FRACP, MBChB)

\*Cure Kids Professorial Chairs