

2018
TELETHON KIDS INSTITUTE
SCIENTIFIC REVIEW

EXPERT PANEL REPORT
KEY FINDINGS AND RECOMMENDATIONS

21-23 November, 2018
Perth, Australia

i. Scientific Review Panel Members

Expert panel

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ii. Contents

i. Scientific Review Panel Members	2
ii. Contents	3
iii. Introduction	4
Purpose of this Report	
Terms of Reference	
iv. Overview of this Report	4
v. Summary of Recommendations	5
SECTION 1. Main findings: Key strengths of Telethon Kids Institute	6
1.1 Telethon Kids Institute is a highly successful organisation	6
1.2 Key strengths of Telethon Kids Institute	6
SECTION 2. Looking to the future: Realising the institute’s full potential through priority-driven research programs	8
2.1 Focussing the institute’s mission on grand challenges in child health	8
2.2 Using research grand challenges to drive research programs	8
2.3 What are research grand challenges?	8
2.4 What are the strategic advantages of developing challenge-led research programs?	9
2.5 What should be considered when developing the grand challenges and focussing the mission?	10
2.6 Research priority areas that emerged during the review	10
2.6.1 The health of Aboriginal and Torres Strait Islander people	10
2.6.2 Precision pathways in young children	11
SECTION 3. Making the transition: Implementing priority-driven research programs at Telethon Kids institute	12
3.1 Enhancing clinical science through a strong strategic partnership with the Child and Adolescent Health Service	12
3.1.1 Developing greater porosity between the Perth Children’s Hospital, Child and Adolescent Health Service and Telethon Kids Institute	12
3.1.2 Fostering a research culture among clinical staff	13
3.1.3 Investing in resources that reduce or remove barriers for research in the hospital	13
3.2 Prioritising investment in research that is aligned with institute strategy and will create a competitive advantage	13
3.2.1 Encouraging depth rather than breadth through strategic investment	13
3.2.2 Identifying areas for strategic investment	14
3.2.3 Institute expansion into remote areas of Western Australia	15
3.3 Investing in new and existing platforms and resources that support the institute’s research strategy	15
3.3.1 Maintaining support existing platforms at Telethon Kids Institute	15
3.3.2 Platforms and bioresources for development at Telethon Kids Institute	15
3.4 Adjusting the institute’s structure to maximise collaboration and career support for researchers	16
3.4.1 Developing a new, inclusive organisational structure that is guided by function	16
3.4.2 Supporting career paths for all researchers	16
vi. Closing Remarks from the panel	17
vii. Appendices	18

iii. Introduction

Purpose of this report

This report summarises the key findings and recommendations arising from the independent strategic review of the Telethon Kids Institute (TKI), held 21-23 November 2018. The expert panel conducted an independent and informed analysis of the current research portfolio of the TKI to identify where it might direct future efforts and resources to achieve its vision - improving the health and wellbeing of children through excellence in research.

The panel considered internal capacity, culture and structure as well as the new environment at the Perth Children's Hospital campus in their analysis of current activity and in developing their key recommendations, which are presented in this report. The panel's recommendations will provide advice and strategic direction in the development process for the institute's 2019-2023 Strategic Plan.

Terms of reference

The expert review panel was asked to review the institute's current performance focussing on the following six key areas:

- The institute's breadth and depth
- The institute's talent and workforce
- New research areas and platforms
- New opportunities presented by co-location with the Perth Children's Hospital and the Child and Adolescent Health Service
- The institute's reach and footprint
- The institute's organisational structure

The panel was asked to consider which research areas and activities the institute should (i) continue and potentially expand by investing further resources; (ii) stop, if they are not contributing to the achievement of the institute's vision, and (iii) start, which would contribute to achieving institute's vision.

iv. Overview of this report

The key findings and recommendations outlined in this report are divided into three main sections:

SECTION 1. Main findings: Key strengths of Telethon Kids Institute

SECTION 2. Looking to the future: Realising Telethon Kids Institute's full potential through priority-driven research

SECTION 3. Making the transition: Implementing priority-driven research programs

APPENDIX A. Performance of the Institute

APPENDIX B. Aboriginal Research

v. Summary of recommendations

Based on the main findings from the review, the panel has made six recommendations for the institute going forward, which have been summarised below.

1. Continue to invest in resources and activities that support the institute's key strengths:

- Broad technical diversity and highly skilled personnel
- Exceptional community engagement and support
- Life course approach to child health research
- Research focus on health issues affecting vulnerable populations
- High level of enthusiasm for the institute's mission and brand among all institute personnel

2. Focus the institute's mission and research agenda on two to three grand research challenges that address internationally significant unmet needs in child and adolescent health research.

2a. Continue to prioritise the health of Aboriginal and Torres Strait Islander people as a core theme of one or more research programs addressing grand challenges.

2b. Continue to consult with consumers and the wider community on their highest priorities for health to be considered during development of the institute's research agenda.

3. Establish a strong strategic partnership with the Child and Adolescent Health Service (CAHS) and Perth Children's Hospital to prioritise research and support for clinical science as part of the hospital's strategic objectives and core activities.

3a. Develop greater porosity between the Perth Children's Hospital, CAHS and Telethon Kids Institute to encourage creative opportunities for exchanging ideas, formulating important research questions and establishing collaborative research teams across the organisations.

3b. Foster a research culture among clinical staff by providing opportunities and career support at the institute. (Includes all health professionals and is not limited to doctors).

3c. Invest in new and existing resources that reduce barriers for research in the hospital. For example, establishing electronic health records, continuing support for the Telethon Clinical Research Centre.

4. Prioritise investment of flexible funding in research that is aligned with the institute strategy and creates a competitive advantage.

5. Expand, develop and invest in platforms and bioresources that best support the priority-driven research agenda and challenge-led research programs.

6. Revise the organisational structure of the institute to facilitate and encourage collaboration, mentorship and career support for researchers.

6a. The organisational structure needs to be guided by function and inclusive of all research staff and students at the institute.

6b. Separate the management reporting structure from the scientific reporting structure to share administrative tasks among researchers.

6c. The organisational structure needs to provide mechanisms for mentorship, training and leadership opportunities to support career paths for young scientists.

SECTION 1. Main findings: Key strengths of Telethon Kids Institute

1.1 Telethon Kids Institute is a highly successful organisation

The panel found that the strongest message emerging from the strategic review was that the Telethon Kids Institute (TKI) is an extraordinarily successful organisation. The institute has shown tremendous growth and built a strong positive culture in the last six years under the leadership of Professor Jonathan Carapetis. This success is not only evident in the research programs and quantifiable metrics but also in the overwhelmingly positive attitudes and enthusiasm of the staff and students at the institute and the wider community.

Through the recommendations presented throughout this report, the panel has focussed on the future and how the unique strengths of the institute, outlined in this section, will provide the foundation to realise the institute's full potential, define its distinct international identity and elevate its profile among the international research community.

1.2 Key strengths of the Telethon Kids Institute

Recommendation

- 1. Continue to invest in resources and activities that support the institute's five key strengths.**

Strength 1: Broad technical diversity and highly skilled personnel

- The institute has a remarkable diversity in technical expertise with research spanning from basic, discovery biomolecular science and population health science right through to experimental medicine and health interventions.
- Highly capable, skilled personnel are working within the institute and out in the community, including in Aboriginal communities.
- High calibre people in the professional services are a strength and key asset of the institute.
- The institute's immediate clinical partners, the Perth Children's Hospital and the Child and Adolescent Health Service (CAHS) provide the whole clinical and care pathway in one organisation.

Strength 2: Exceptional community engagement and support

- The institute's engagement with the community is intense and unusually strong compared to similar organisations within Australia and overseas.
- Strong community engagement is evident through the high level of philanthropic financial support, community and consumer involvement in research and through the emphasis and resources directed towards the health of Aboriginal and Torres Strait Islander people.

Section 1. Main Findings: Key Strengths of Telethon Kids Institute

- The local community in Western Australia (WA) is invested in the institute and interested in research as a way to answer big health questions.

Strength 3: Life course approach to child health research

- While the mission and research effort are concentrated on child health, there is strong recognition that the impact of child health extends through a person's lifetime.
- Strong focus on developing impact of research on societal benefits.
- Co-location with the Perth Children's Hospital, CAHS and University of Western Australia (UWA) provides an excellent opportunity to support this research approach and more rapidly deliver the outcomes of research to patients and the community.

Strength 4: Research focus on health issues affecting vulnerable populations

- There is a strong focus on research in health areas affecting vulnerable populations, including Aboriginal and Torres Strait Islander people and other disadvantaged populations.
- The long-term, very stable clinical cohorts of the WA population are a rare and an invaluable resource to the institute's research programs.

Strength 5: High-level of enthusiasm for the institute's mission and brand among all personnel

- High level of enthusiasm and pride is demonstrated by all people working in the institute.
- All staff demonstrate a strong sense of commitment to the future and direction of the institute.

SECTION 2. Looking to the future: Realising the institute’s full potential through priority-driven research programs

2.1 Focussing the institute’s mission on grand challenges in child health

Recommendation

2. Focus the institute’s mission and research agenda on two to three grand research challenges that address internationally significant unmet needs in child and adolescent health research.

2a. Continue to prioritise the health of Aboriginal and Torres Strait Islander people as a core theme of one or more research programs addressing grand challenges.

2b. Continue to consult with consumers and the wider community on their highest priorities for health to be considered during development of the institute’s research agenda.

2.2 Using research grand challenges to drive research programs

While Telethon Kids Institute (TKI) is driven by a clear mission to positively impact child health, there is an opportunity to unlock the institute’s full potential by focussing a significant part of its research agenda on a small number of “grand challenge” research areas. Through challenge-led research programs and its current research talent, expertise and resources, TKI is poised to tackle large-scale research questions and strive to make step changes, rather than incremental changes, that significantly impact child health globally.

2.3 What are research grand challenges?

These research grand challenges are large scale, multi-million dollar research programs that seek to address the complex unanswered research questions facing child and adolescent health. The challenges are designed to focus the research agenda at the institute towards coordinated programs of goal-driven science with discipline depth and a culture of mentorship and career support for current and future research leadership.

The grand challenges will define ambitious goals that guide large scale research programs pursuing the greatest impact in internationally significant areas of child health research through research excellence.

The research grand challenges need to be:

- **Ambitious but achievable goals.** The grand challenges need to be big and ambitious goals that are measurable, definable and achievable with the unique strengths and resources at the TKI. As an example of an ambitious, achievable and definable goal, a grand challenge could be to reduce suicide in the Aboriginal youth and adolescent population by aiming to “Halve the youth

suicide rate by 2025". Another example could be to generate new hypotheses to uncover early life determinants of health (and illness), thereby building on a current research strength at TKI.

- **Driving highly collaborative programs of research with strong interdisciplinary partnerships.** Research teams working towards achieving the grand challenge goals need to be large collaborative partnerships between TKI researchers and external organisations. Co-location in Perth with the Perth Children's Hospital, the University of Western Australia, R&D heavy industries and mining based in WA is an opportunity for truly large-scale interdisciplinary research, not limited to medical research expertise. A current example of such an interdisciplinary approach is applying research developments in artificial intelligence and machine learning made by the mining industry to automate labour-intensive processes in health settings e.g. diagnostic processing of medical images. Interdisciplinary training of PhD students and supporting career pathways for young scientists should be encouraged and prioritised in the challenge-led research programs to establish future research leaders.
- **Strongly linked to patient and public benefit.** Engagement of Perth Children's Hospital and the Child and Adolescent Health Service in the challenges and recognition of the important role of clinician scientists is essential. They are well placed to understand the context of the health conditions and which discoveries can be translated to deliver the greatest health benefits for patients.
- **Backed by strategic investment of institute funding and resources.** The grand challenges should be multi-million dollar programs of research that will require significant resources and financial investment by the institute to establish. Given the extraordinary level of flexible funding available to the institute through philanthropic support, TKI is uniquely positioned within Australia to make strategic investments to kick-start research programs of this scale. The expectation should be that through these coordinated programs of research, additional financial support will be leveraged from competitive funding schemes and through direct investment by philanthropy, industry and the community.
- **Milestone driven.** To maintain and encourage research excellence, milestones should be built into the research program to track progress and performance. As well as scientific milestones, these could include securing additional funding through award of competitive external grants. The milestones should be reviewed periodically and could be linked to tranches of institute funding.

2.4 What are the strategic advantages for developing challenge-led research programs?

While the TKI has seen substantial growth in the last six years, there is an opportunity to build on this success and boost the institute's research excellence, international profile and competitive edge. Focussing the institute's mission and research agenda on challenge-led, priority-driven research programs provides the opportunity to:

- **Define the institute's point of difference and distinct international identity.** During the recent period of growth at the institute, the research program has developed into a broad range of health conditions and disease areas in child and adolescent health. Focusing the mission on

internationally relevant challenge-led research programs that the institute is uniquely positioned to tackle lays the foundation for defining the point of difference and developing a stronger identity and external brand.

- **Elevate research excellence on the world stage.** The strong institute brand promoted by challenge-led research programs will provide a significant strategic advantage in securing funding through competitive schemes. Striving to address grand challenges, backed by expertise and resources, is well aligned with the current translation and impact focus of major research funding organisations. These include smaller investigator led research projects (e.g. National Health and Medical Research Council (NHMRC) grants) as well as large-scale priority-driven research programs and missions funded through the schemes such as the Australian Government's Medical Research Future Fund (MRFF), or international philanthropic organisations like the Gates Foundation, Wellcome Trust or Cancer Research UK.
- **Promote a positive, united and collaborative culture within the institute.** Uniting researchers around grand research challenges promotes a positive culture through shared goals and can also direct the institute towards a more harmonious and function-driven organisational structure. By striving to reach common goals, researchers at all levels of seniority can develop an enhanced sense of ownership and identity within the institute.
- **Provide the basis for strong international collaborations.** International collaborations can provide the basis for acquiring access to expertise, resources and scientists that can add value to the institute's research programs and goals. New opportunities can be explored through external collaborations involving other institutes and universities within Australia and overseas.

2.5 What should be considered when developing grand challenges and focussing the mission?

The panel advises that the institute develop the grand challenges through a consultative and collaborative process that involves consultation the institute's research staff and leadership team and with the community, who are invested in the mission and health outcomes of the institute.

Whatever topics are chosen for the grand challenges, the research questions must be a top priority driving the research infrastructure rather than the other way around.

While a few focussed grand challenges are an important change in research direction, it is essential that bright ideas and new ways of working are encouraged and accommodated in the focussed mission and new research agenda.

2.6 Research priority areas that emerged during the review

2.6.1 The health of Aboriginal and Torres Strait Islander people

The health of Aboriginal and Torres Strait Islander people emerged as a strong research priority across the institute's entire current research agenda and should be continued. The panel advises that the Aboriginal Health agenda should feature heavily in the grand challenge research programs. During the review, that idea that TKI could lead an Aboriginal Systems Biology Centre involving a

Section 2. Looking to the Future

number of institutes and universities in WA emerged and such a systems approach would and should embrace the social determinants of health as well as new biological drivers of the grand challenges.

Research priority areas for the health of Aboriginal and Torres Strait Islander people that emerged during the review were:

- Child and adolescent mental health
- Strong families
- Intergenerational risk and resilience

2.6.2 Precision pathways in young children

Another strong research theme that emerged was precision pathways in young children, where current research at the institute in this area was focussed on neurodevelopment that utilised and built upon the ORIGINS cohort. This theme could be expanded and developed in a grand challenge-led research program using big internationally-significant research questions as the program drivers.

SECTION 3. Making the transition: implementing priority-driven research programs at Telethon Kids Institute

Four key areas should be considered when designing an implementation plan for a priority-driven focus of the institute, which are discussed below:

- Enhancing clinical science through a strong strategic partnership with the Child and Adolescent Health Service (CAHS)
- Prioritising investment in research that is aligned with institute strategy and will create a competitive advantage
- Investing in new and existing platforms and resources that support the institute's research strategy
- Adjusting the institute's structure to maximise collaboration and career support for researchers

3.1 Enhancing clinical science through a strong strategic partnership with the Child and Adolescent Health Service

Recommendation

3. Establish a strong strategic partnership with the Child and Adolescent Health Service (CAHS) and Perth Children's Hospital to prioritise research and support for clinical science as part of the hospital's strategic objectives and core activities.

3a. Develop greater porosity between the Perth Children's Hospital, CAHS and Telethon Kids Institute to encourage creative opportunities for exchanging ideas, formulating important research questions and establishing collaborative research teams across the organisations.

3b. Foster a research culture among clinical staff by providing opportunities and career support at the institute.

3c. Invest in new and existing resources that reduce barriers for research in the hospital.

3.1.1 Developing greater porosity between the Perth Children's Hospital, the Child and Adolescent Health Service and Telethon Kids Institute

Recent relocation to the Perth Children's Hospital precinct provides the opportunity for a highly-effective environment for research translation across the full spectrum of health sciences, particularly as the main hospital and community health services are under single management. To seize this opportunity, it will be essential to encourage a strong research culture in the hospital and establish research as a priority. The goal should be to evolve from a hospital that does research to a research hospital in which a research culture is the business of all staff. Developing greater porosity between the Perth Children's Hospital, CAHS and TKI will encourage creative opportunities for exchanging ideas, formulating important research questions and establishing collaborative multi-

institute research teams. TKI should continue to work with the Perth Children's Hospital leadership team to solidify a strong strategic partnership and understand opportunities within the hospital on which the TKI could add value and build upon.

3.1.2 Fostering a research culture among clinical staff

TKI should foster the research culture among hospital clinical staff by providing opportunities and career support at the institute for clinician scientists - this includes all health professionals and is not limited to medically qualified staff (doctors). A strong joint mentoring programme for career development should be encouraged, and research should be included as part of the position description of hospital staff to promote a positive research culture. To further encourage joint working, the leadership of the TKI, as well as the two medical charities, should be involved in contributing to the job description and the subsequent appointment of senior academics at the hospital. Some of the grand challenges or starter projects requiring interdisciplinary research across the hospital and TKI could be supported by joint funding with the Perth Children's Hospital Foundation.

3.1.3 Investing in resources that reduce or remove barriers for research in the hospital

Investing in new and existing resources that reduce or remove barriers to conducting research will also significantly increase the research activity in the hospital. One significant logistical barrier that could be addressed is to strongly support the transition to electronic health records which will greatly improve data collection and analysis by clinician scientists. The hospital and TKI could also use existing mechanisms to work together towards common research goals such as the partnership already in place through the NHMRC-accredited academic health science centre, the West Australian Health Translation Network (WAHTN). Support for the Telethon Clinical Research Centre (TCRC) should be continued as it is an excellent resource for clinical science and essential for driving discoveries towards patient benefit. Further major investment in this centre by TKI and the hospital should be encouraged to expand its capabilities to deliver validated diagnostic tests, experimental medicine and first-into-human clinical trials, similar to the National Institute of Health Research (NIHR) Biomedical Research Centre model in the United Kingdom.

3.2 Prioritising investment in research that is aligned with institute strategy and will create a competitive advantage

Recommendation

- 4. Prioritise investment of flexible funding in research that is aligned with the institute strategy and creates a competitive advantage.**

3.2.1 Encouraging depth rather than breadth through strategic investment

TKI currently draws 60% of funding from philanthropic and capital sources. While this can allow for greater freedom, it can encourage expansion in areas of research that are not well aligned with

institute strategy and not necessarily the most compelling. The tendency to bring in funding irrespective of strategic fit might explain the move sideways away from the core mission of the institute and a drift towards research volume rather than quality.

The panel recommends that TKI should prioritise strategic investment of flexible funding to build research programs strongly aligned with institute strategy. The extraordinary level of flexible funding brought into TKI is uncommon for medical research institutes and provides a remarkable opportunity to leverage further competitive funding and elevate research excellence. Kickstarting the challenge-led research programs through institute investment will generate a competitive edge, positioning the institute to attract further funding from high profile government schemes (NHMRC, MRFF), international schemes (Gates Foundation, Wellcome Trust) and directed philanthropic investment. The investment strategy should include a plan for attracting high achieving individual researchers through fellowship schemes when investing in large research programs.

Establishing collaborative links and joint facilities with other research organisations in WA and across Australia should be considered in the areas of data management, metabolomics and particularly the health of Aboriginal and Torres Strait Islander people. There is an opportunity for TKI to build strong research leadership in health areas of the highest priority for Aboriginal and Torres Strait Islander people through a collaborative partnership with other research organisations in WA, South Australia (e.g. South Australian Health and Medical Research Institute) and the Northern Territory (e.g. Menzies School of Health Research, Baker Institute for Heart and Diabetes).

3.2.2 Identifying areas for strategic investment

Starter or seed grants can be used as a process to identify research investments that fit with the institute strategy and challenge-led research programs. TKI has recently run a highly successful and competitive funding round of the “Think Big” initiative, which has similar goals although on a much smaller scale (\$100,000) than the proposed grand challenges. The processes already in place for this initiative, including the independent expert review of applications, could be expanded and developed as a process to identify areas of investment to build the challenge-led research programs, or identify bright ideas and new ways of thinking that are aligned with the institute’s strategic direction.

Financial support for training and recruitment of new talented researchers and PhD students should be included in the investment strategy. Investing in career support for the institute’s researchers at all levels can greatly enhance capacity aligned with the institute’s strategy and challenge-led research programs. This could include professional development courses for current staff and PhD awards for interdisciplinary projects aligned with the challenge-led research programs. Placing PhD students at the interface of different disciplines would lead to a new multi-skilled research fit to take on the research challenges of complex disease. Investing in recruitment and career support for research leaders in Aboriginal and Torres Strait Islander health should be prioritised as part of the institute’s investment strategy and approach to strengthening the institute’s research agenda in this area. Such initiatives will not only support careers of research individuals, but also enhance the institute’s research capacity to provide the opportunity to build future leaders, foster interdisciplinary collaborations across organisations.

3.2.3 Institute expansion into remote areas of Western Australia

The panel was asked to comment on TKI's plans to invest in establishing offices in the remote Kimberley and Pilbara regions of WA, which will support research activities and foster relationships with local communities. While the planned expansion is an excellent opportunity to more effectively engage and positively impact health for people across all of WA, the panel advises that the strategic direction and research agenda for the Perth-based TKI headquarters is finalised as a priority. This would then provide the foundation for investing in resources at the regional TKI offices that are aligned with the new TKI strategy.

3.3 Investing in new and existing platforms and resources that support the institute's research strategy

Recommendation

- 5. Expand, develop and invest in platforms and bioresources that best support the priority-driven research agenda and challenge-led research programs.**

3.3.1 Maintaining support for existing platforms at Telethon Kids Institute

The panel found that platforms and bioresources at TKI are exceptional and the investment in facilities and high-calibre personnel that the institute has made in these resources is a credit to the vision and foresight of the leadership team.

3.3.2 Platforms and bioresources for development at Telethon Kids Institute

The panel advises that the direction and functional model of all new and existing platforms and bioresources at TKI should be aligned with the needs of institute's new strategy and challenge-led research programs.

The panel was asked to advise on the functional model for the data science platform, which has the potential to maintain a focus on service delivery, develop as a research team focussing on specific health problems, or function as a hybrid of the two different models. If translational research is to reach its full potential at the TKI and the Perth Children's Hospital, there will be a need to adequately resource and strengthen several areas in data science including health economics, big data, data visualisation and biometrics. There is an opportunity to create a joint strategic effort in data management across UWA, Curtin University and the Harry Perkins Institute, drawing on the strengths at each organisation.

Establishing a common bioresource (biobank) where samples from multiple studies can be stored and annotated with clinical data should be supported by appropriate data science and bioinformatics. Linked with the Telethon Clinical Research Centre, the data science platform will become a translational hub but also the source of new research ideas and discovery science. The NIHR BioResource for Translational Research in Common and Rare Diseases (NIHR BioResource) is a

new model working in this way that aims to collect samples from 500,000 patients. The TKI bioresource could operate in a similar way on a smaller scale.

3.4 Adjusting the institute's structure to maximise collaboration and career support for researchers

Recommendation

6. Revise the organisational structure of the institute to facilitate and encourage collaboration, mentorship and career support for researchers.

- 6a. The organisational structure needs to be guided by function, and inclusive of all research staff and students at the institute.
- 6b. Separate the management reporting structure from the scientific reporting structure to share administrative tasks among researchers.
- 6c. The organisational structure needs to provide mechanisms for mentorship, training and leadership opportunities to support career paths for young scientists.

3.4.1 Developing a new, inclusive organisational structure that is guided by function

The challenge-led research programs will also need strong leadership and interdisciplinary team science approaches supported by a collaborative and coordinated organisational structure. This will require adjustment of the current organisational structure in place at TKI and significant buy-in from researchers at the institute. The institute has matured beyond the current Research Focus Areas, and while TKI's Centres have been effective in uniting researchers in common topic areas, they currently accommodate only about half the institute's research staff and students.

The panel recommends that the scientific structure should be determined using a highly consultative bottom-up approach which has been used with great success at other organisations, including the University of Southampton. By consulting and encouraging researchers to self-identify their discipline based on their research, the institute can establish a handful of disciplines or themes (about six to eight) within the institute that are highly relevant to the institute's function and encourage collaboration and interdisciplinarity. The nomenclature used for these groups of researchers, whether disciplines, themes or another name, should reflect inclusiveness and accommodate membership across groups without ring-fencing. It is expected that there will be an opportunity for researchers in the institute to cluster organically according to the common research goals.

3.4.2 Supporting career paths for all researchers

The scientific structure will require both discipline leadership as well as leadership within the large challenge-led research programs and needs to be inclusive of all staff. Rotating leadership is recommended to provide more opportunities to develop emerging leaders, introduce fresh ideas and share administrative tasks among research staff.

Mechanisms for mentorship, training and recruitment of new students and staff at all levels should be considered when developing the new organisational structure. This should include capacity for recruitment of PhD students with a clinical background, and to provide opportunities for PhD students without clinical training to participate in research in a clinical setting.

vi. Closing Remarks from the panel

TKI is a very successful organisation with a strong positive culture, outstanding community support and highly skilled and driven personnel. The panel's recommendations are squarely focussed on the future and intended to provide guidance for the institute's strategy to build on the unique combination of key strengths, focus the institute's mission and unlock its full potential.

By focusing TKI's research direction towards priority driven research programs addressing grand research challenges, there is an opportunity to elevate the institute's research profile on the world stage and benefit child and adolescent health not only in WA, but across Australia and the world.

vii. Appendices

Appendix A: Performance of the Institute

Term of reference 1

How well has the Institute performed in relation to its strategic goals and the achievement of its Vision - paying particular attention to the impact and local, national and international reach in key areas.

The Institute is now established as a very high performing research organisation nationally and internationally. The panel know of no other Institute anything like Telethon Kids Institute anywhere. In their presentation made to all staff at the conclusion of the Scientific Review, the panel made the following comments:

Very few places have such a diverse spread of expertise across so many different fields

The Institute has developed some real research stars – hard hitters in the science world that any institution around the world would be proud to have.

The staff and students have incredible pride in working at the Institute and have huge respect for each other. These are markers of human behaviour that portend well for the future – a desire to create interdisciplinarity and team science.

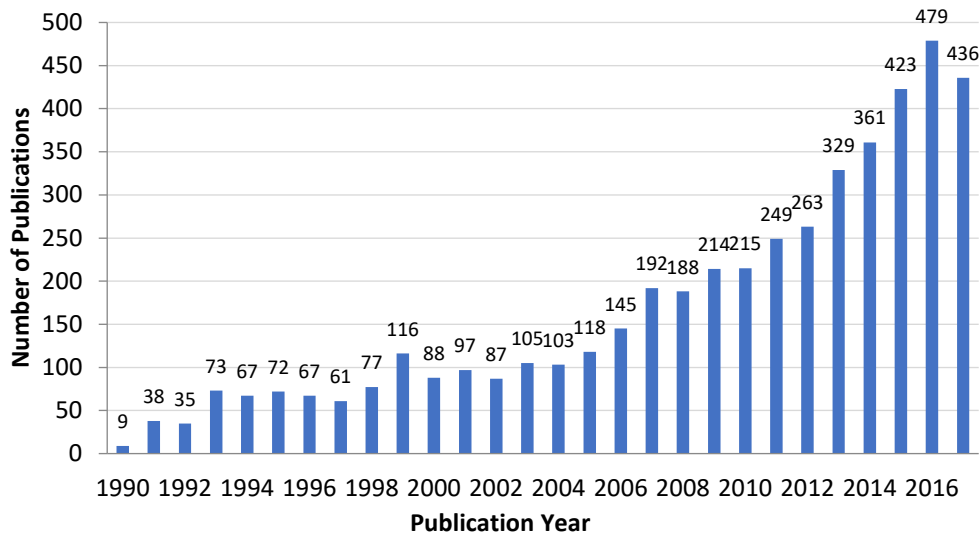
The research support environment is, in the opinion of the panel, second to none in the world. This includes research platforms and professional services. Indeed, the people providing these services are undertaking their own research to improve what they are doing.

Although the Institute does not judge its success solely by traditional research metrics, nonetheless it has performed extremely well using such metrics. As part of its preparation for the Scientific Review, the Institute commissioned Clarivate Analytics to undertake a benchmarking analysis.

The following data provided by Clarivate Analytics are highlighted by the panel as specific examples of the Institute's performance success. The panel was particularly impressed by item 3 below (the Normalised Citation Impact). The NCI is accepted as an excellent comparable measure of the quality of publications, and Telethon Kids Institute's NCI is not only well above that of all other benchmarked Australian organisations, but well above all of the international benchmarked organisations including those considered the very best in the world at child health research (e.g. Great Ormond Street Hospital, Children's Hospital Philadelphia, Boston Children's Hospital, and Sick Kids Toronto).

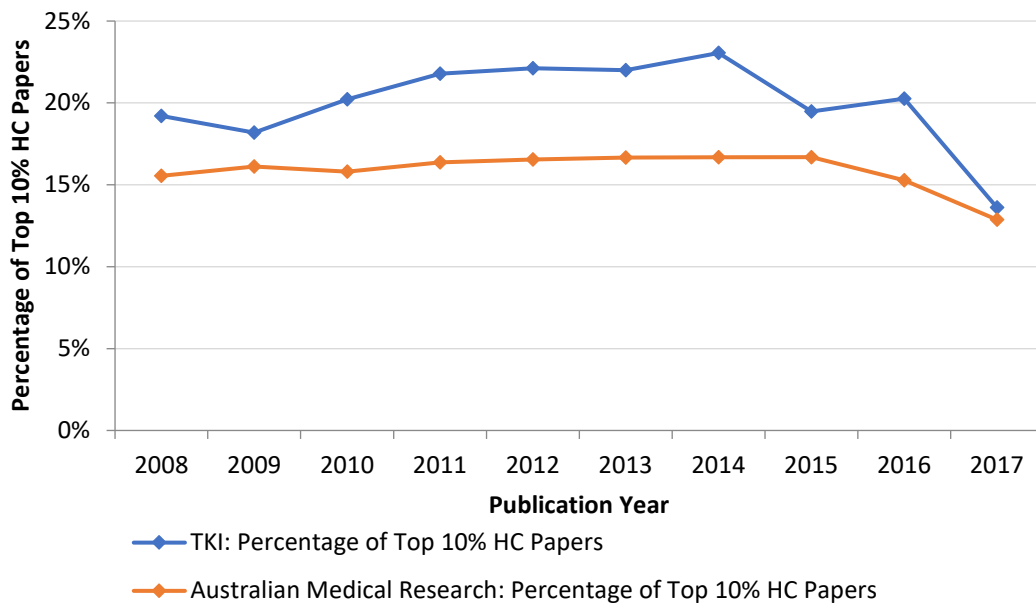
Section 3. Making the transition

1. The Institute’s annual research output has dramatically increased in the last 10 years from an initial average of 61 publications per year to over 420 publications per year for the last three years. Overall, a total of 4,707 Telethon Kids’ publications were published between 1990 and 2017.



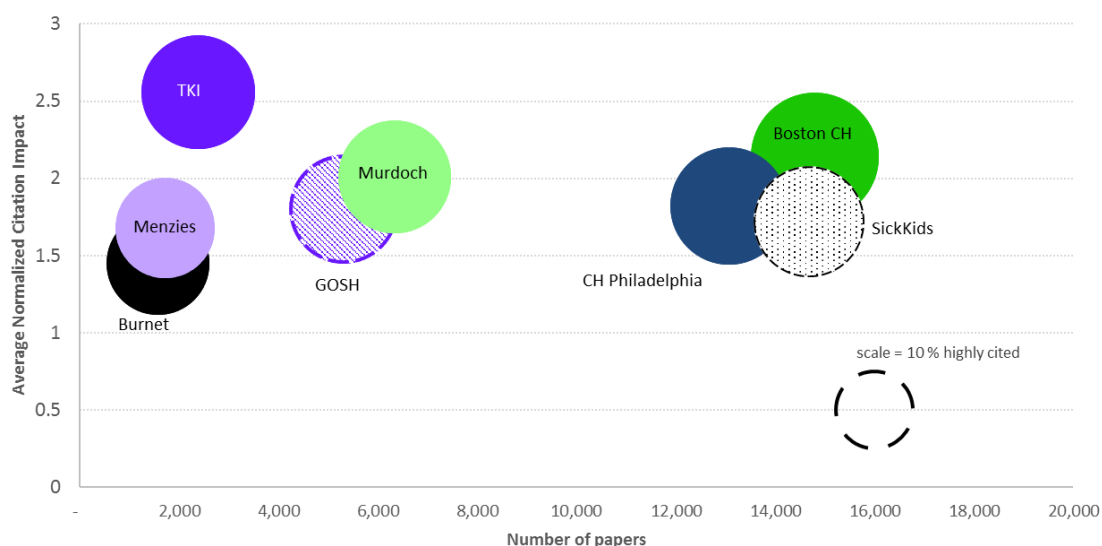
2. For the last 10 years, the Institute has consistently produced above average publications with a higher percentage of top 10% highly-cited papers as compared to the Australian medical research base, all of which are above the world average. Overall, about 20% of the Institute’s recent papers were in the top 10% highly-cited papers, as compared with about 16% of such papers from the Australian Medical Research base.

Highly cited work is recognised as having a greater impact, and Thomson Reuters has shown that high citation rates are correlated with other qualitative evaluations of research performance, such as peer review.



The recent decline is a normal consequence of having a larger percentage of uncited or less cited papers in recent years because they have not had sufficient time to accumulate citations.

- The Institute has a Normalised Citation Impact (NCI) of 2.56, which is two and a half times higher than the world average. Category normalized citation (CNI) is a benchmark measure of the number of times a paper, article or the like, has been cited against similar publications in the same field, in the same year. The higher the CNI is the more the research or paper has been referenced, with zero being the baseline.



Term of reference 2

Is the Institute undertaking and translating research that will lead to achieving its Vision?

The panel felt that the impact and detail of what the Institute is doing to understand the implications of its research and the audiences that are best in receipt of it is spectacular, and that they know of no other Institute that is doing this as well as Telethon Kids.

The panel was impressed by the Institute's specific focus on measuring the impact of its research. They noted the Institute's numerous complex projects incorporating multiple disciplines that were tackling major issues and were impressed by the passion and commitment of those involved. These projects had created a real sense of excitement, collegiality and teamwork. Moreover, the panel was impressed with the high level of community connection at the Institute which had improved its ability to deliver outcomes rather than just academic metrics.

Given the Institute's Research Impact Management System is not yet available, the panel relied on the numerous examples of impact presented in the annual Impact Reports, which outline a much more impressive profile of translation than the panel has seen elsewhere. There are also some more traditional metrics that speak to this impact as shown by the following Clarivate Analytics analysis.

Section 3. Making the transition

Telethon Kids had the highest percentage of research items with the highest interest (>100 Web of Science usage counts) during the period from 2013-2017 and the lowest percentage of papers showing no Web of Science user interest.

Institution	no usage counts	1-10 counts	11-20 counts	21-30 counts	31-40 counts	41-100 counts	>100 counts
TKI	5.80%	60.23%	18.97%	7.76%	3.19%	2.87%	1.17%
Boston CH	20.32%	59.06%	11.70%	3.95%	1.74%	2.51%	0.73%
Burnet	19.45%	60.74%	11.87%	4.15%	1.38%	1.60%	0.80%
CH Philadelphia	24.75%	61.08%	9.27%	2.64%	0.82%	1.12%	0.31%
GOSH	30.23%	58.14%	7.74%	1.99%	0.95%	0.77%	0.17%
SickKids	22.43%	59.11%	11.04%	3.74%	1.42%	1.88%	0.38%
Menzies	20.03%	63.66%	11.27%	3.22%	0.77%	0.98%	0.07%
Murdoch	14.63%	60.94%	14.52%	5.15%	2.14%	2.02%	0.60%

The Usage Count is a measure of the level of interest in a specific item on the Web of Science (WoS) platform. The count reflects the number of times the article has met a user's information needs as demonstrated by clicking links to the full-length article at the publisher's website (via direct link or Open-URL) or by saving the article for use in a bibliographic management tool (via direct export or in a format to be imported later). The Usage Count is a record of activity performed by all WoS users, and these records are updated daily in the online platform.

The panel concluded that the strongest message emerging from the strategic review was that the Telethon Kids Institute is an extraordinarily successful organisation and commended the Institute on two things:

1. Establishing an organisation that performs extremely well when measured by traditional research metrics – among the best in Australia and comparable to many excellent organisations around the world.
2. Creating an environment and culture that is unique in its ability to support researchers and make them feel a real connection to the Institute and its vision.

Appendix B: Aboriginal Research

The Scientific Review Panel found that the Institute is perfectly poised to do excellent things in Aboriginal research, and to aspire to being the best Indigenous health research institution globally.

The Scientific Review Panel recognised that the Institute's strength comes from its cross-disciplinary and translationally minded approach. The Institute's focus on Aboriginal Health came across as a unifying and shared intention across the Institute. Panel member Professor Alex Brown spoke of the Institute's commitment to community and vice versa and how Telethon Kids Institute "is in the blood of WA, it's inseparable."

The Panel identified a number of key areas for the Institute to consider in positioning itself as a leader in Aboriginal health research. The Panel acknowledged that much of this work was already underway, as evidenced from the 2018 ACCARE¹ Key Performance Indicators Report from the Progress on implementation of the Institute's Working Together Strategic Plan (2013-2017) and Commitment to Aboriginal Children and Families (2013-2017) ("the ACCARE Report"), which was provided to the Panel prior to the commencement of the Scientific Review.

A number of the strategic initiatives outlined in the ACCARE Report reflect the key areas identified by the Panel. The following outlines some of these initiatives, together with the observations from the Panel:

1. Aboriginal Governance – To ensure a clear Aboriginal voice is heard and influences the Institute's work, the Institute has successfully established an Aboriginal voice within a number of governance areas including appointing Prof Brown to the Board and the Scientific Advisory Council, establishing ACCARE, the Kulunga Aboriginal Research Development Unit (KARDU) and appointing the Head of Aboriginal Health to the Institute's Leadership Committee. Prof Brown noted that if the Institute is going to recognise the potential of Aboriginal people within the Institute, it needs to invest in and support them so that they can lead the Institute in the future.

2. Setting research priorities that reflect the needs of Aboriginal Families - The Institute has embedded Aboriginal Health into its organisational structure by identifying and implementing measures to prioritise and develop Aboriginal health research projects that target, and have the potential to improve outcomes in, important health and wellbeing issues for Aboriginal children and families. The Panel recognised that the Institute "has a history of developing major, and in many ways, Institute-defining programs in Aboriginal health".

¹ *Aboriginal Collaborative Council Advising Research and Evaluation (ACCARE) is an advisory group reporting directly to the Director*

3. Aboriginal Employment and Career Development Strategy – The Institute has made progress in developing Aboriginal staff and students via the Institute’s five-year Aboriginal Employment and Career Development Strategy (AECD Strategy). The Panel felt the Institute had inherent talent that hadn’t yet been fully unleashed and in order to continue to build the capacity of Aboriginal researchers, strategies must be implemented to recruit, develop and retain Aboriginal researchers at all levels across all research areas.

4. Research Development and Support - building the Institute’s capacity to undertake research that responds to the needs of Aboriginal families. KARDU was established to focus on facilitating research interests and opportunities in research that involve Aboriginal families and communities. Through KARDU, the Institute has established an avenue via which the research capacity of Aboriginal researchers can be built and the development of Indigenous knowledge can be promoted and applied as a strategy to maximise research outcomes for researchers. The panel expressed its support for KARDU and felt that the unit will require further investment.

5. Funding Support for Aboriginal Research and Researchers – the Institute has continued to seek opportunities to secure funding to expand its commitment to Aboriginal research and researchers. The Institute has devised a specific funding strategy that not only draws on competitive research grants such as NHMRC grants but also funding from private donors to build the capacity of Telethon Kids Kimberley. The Panel felt that whilst the Institute has shown it has the necessary structural capability and the skills needed, there needs to be greater investment in capacity building and leadership of researchers working in Aboriginal Health.

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