Vision for the Telethon Institute

FMDHS Research Day
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Outline

• Context for WA research
• Telethon Institute Strategic Planning
• Translational research
• Where to from here?
WA % of National NHMRC Funding

Source: NHMRC
Health and Medical Research Funding 2011

- 88% of all HMR funds in WA came from Commonwealth ($77.2M)
  - NHMRC, ARC etc
- 12% came from the state ($10.7M)
  - MHRIF, Dept of Health

Source: Science Matters report 2012
WA Research – observations

- National profile – Australians of Year / Nobel Prize
- Strengths in basic science and observational studies
- Child health, data linkage, cancer, eye health, immunology
- Insufficient collaborations, too much internal competition
- Aging researchers
- Growing cynicism about usefulness of research focus
- Enormous potential, but currently at risk
Telethon Institute context

• 22 years old.
• Great reputation, high quality research, amazing founding Director, outstanding community support
• Many of the “old guard” retiring over next 5 years
• Now is a great opportunity to take stock and develop a new vision.
Telethon Institute – Strategic Planning

• Set direction for next five years
• Facilitated / consultative process
  – Staff Survey
  – One on one interviews
  – Focus groups
  – Faculty retreat with External Scientific Advisory Committee
  – Internal / external stakeholder workshop
• Aim is to have plan ready for Board sign off in February
  – Living document that is adaptive, flexible and measurable
Principles

• Research is all about:
  – Partnerships
  – Answering important questions
  – Making sure that research makes a difference to health and wellbeing
  – Communication and engagement
  – The people who do the work, and those with whom we work
Vision

• Improving the health and wellbeing of children and young people
• “Big thinking” / Excellence
• Board challenge - Tangible outcomes in the next five years
How?

• Excellent research that asks the right questions, uses the best people, and gets put into action.
• Cast a new concept for a medical research institute – one that embraces its community and judges itself by its ability to make a difference in that community.
• Be an important part of making Western Australia a leading centre of translational research.
Institute Priorities

Discovery

Translation

Engagement

People
Traditional model
Knowledge transfer

Research Push

User Pull
Limitations

• Hit and miss uptake
  – Especially research push
• Buy in from those responsible for implementing
• Miss opportunities to identify and/or mitigate against barriers to uptake
Knowledge exchange

Research Push

Research

Research findings

Policy and practice

User Pull

Exchange
Research translation model

• PARTNERSHIPS
• Multi-directional flow of information which begins at project inception
• Together:
  – Develop research questions, set a research agenda and determine actions
• Partners help with and guide the research
Models of research translation at the Telethon Institute

• Neural tube defects
• Childhood cancer
• Centre for Applied Research and Evaluation
• Developmental Pathways Project
• Fraser Mustard Centre
Neural tube defects, Western Australia 1980-2010

A – introduction of promotion of folic acid supplement use
B – introduction of voluntary fortification of some food with folic acid
C – introduction of mandatory fortification of flour with folic acid

Source: WA Register of Developmental Anomalies
Childhood Cancer

• Partnership between Telethon Institute and Department of Haematology and Oncology at PMH
  – Every child is on a clinical trial
  – Access to samples
  – Clinically relevant research

• Community drivers for research
  – Funding for Brain Tumour Laboratory
  – Medulloblastoma Down Under Feb 2013
CARE = Collaboration for Applied Research and Evaluation

- Research underwritten by a contract
- Trust between partners and CARE built up over the years
- Partners are part of the research in
  - Identifying the research interest
  - Formulating the research question
  - Undertaking the research
  - Assisting in interpreting the findings
  - Disseminating the findings
  - Acting as advocates for change within the system
The Developmental Pathways Project

Telethon Institute for Child Health Research
The University of WA
WA Department of Health
WA Department for Child Protection
WA Department for Communities
WA Department of Housing
WA Mental Health Commission
WA Department of Education
WA Department of Corrective Services
WA Disability Services Commission
WA Department of the Attorney General
WA Police
WA Department of Treasury and Finance
WA Department of Indigenous Affairs
WA Curriculum Council

Telethon Institute for Child Health Research

GOVERNMENT OF WESTERN AUSTRALIA
Aims

- multidisciplinary research
- integration between health and education services with a focus on child development
- build capacity amongst public sector staff and academic researchers to collaborate on useful research and
- attract funding for shared priorities
Consumer and community participation

• Focussed on increasing consumer and community participation in the research programs at the Telethon Institute
• Working together to shape decisions about research priorities, practice and policies
• An active partnership sensitive to changing needs and priorities
• Conducting research that is with the community rather than to or for the community
Translation = Partnerships

- Service providers
- Policy makers
- Academia
- Consumers & Community
- Funders

Research Translation
Where to from here?

Opportunities:

• Research more directly influencing policy, practice and outcomes

• WA as a leader, particularly in translationally-driven research
  – Basic science as the underpinning of great translation

• New generation of research leaders
Where to from here?

• Multi-disciplinary partnerships
  – Especially for complex problems

• Strategy
  – Driver should be important health problems and outcomes
  – Build on strengths
  – Identify strategic advantages (e.g. Asian Century)
  – Recruit/retain workforce

• Investment
Next steps for the Telethon Institute

• Group research into a small number of multi-disciplinary themes
• Partner with non-traditional collaborators
• Build external strategic links, internal collaboration and community participation
  – “An institute without walls”
• Build on strategies to develop and nurture our workforce
Now and the Future