



Health Research *with* the Community rather than *for* the Community. Two experiences of excellence in Canada and Australia

**Nicky Lewis**

CEO, Kids Brain Health Network, KBHN, Vancouver BC, Canada

**John Challis**

Founding Executive Director, West Australian Health Translation Network, WAHTN, Perth WA, Australia

## A message from the Government of Canada

“I believe that we have a very strong reputation in our basic pure sciences research. I don’t see that changing. But what we need to change is the other end of the scale, which is getting those ideas and those discoveries...out of our laboratories and onto our factory floors”

*Gary Goodyear,*

*Minister of State for Science and Technology*



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“I believe that we have a very strong reputation in our basic pure sciences research. I don't see that changing. But what we need to change is the other end of the scale, which is getting those ideas and those discoveries...out of our laboratories and onto our factory floors”

.....and into our health care system, health care practices, health care policy, health care products and in a manner that *involves and informs* Canadians of strategies that promote “wellness” in an equitable manner

# Women's Health

**Environment Special:**  
The oceans—why 70%  
of our planet is in danger

**The Facebook Movie:**  
The secret history of  
social networking

# TIME

**How the  
first nine  
months  
shape  
the rest  
of your life**

The new science  
of fetal origins



**AUTISM SPEAKS™**  
It's time to listen.

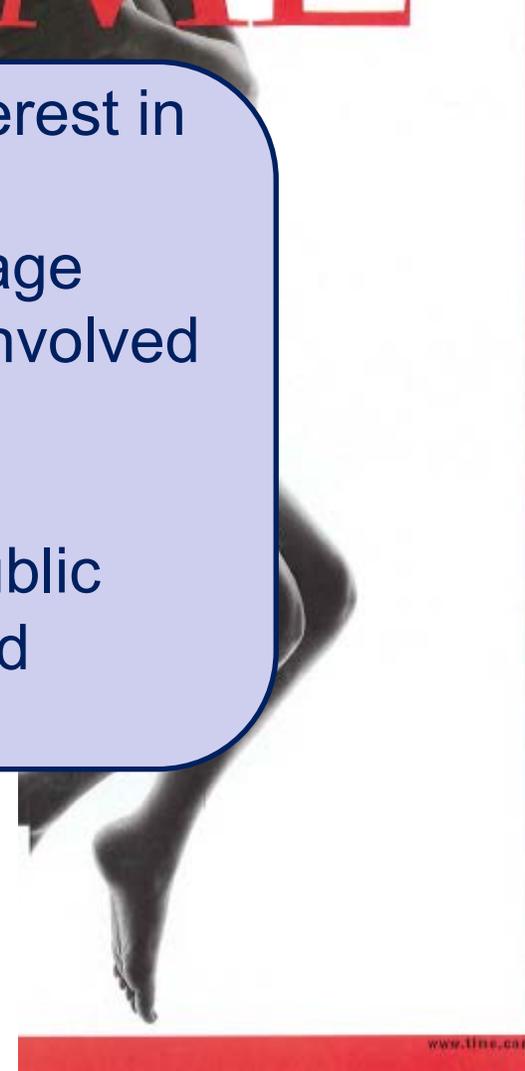
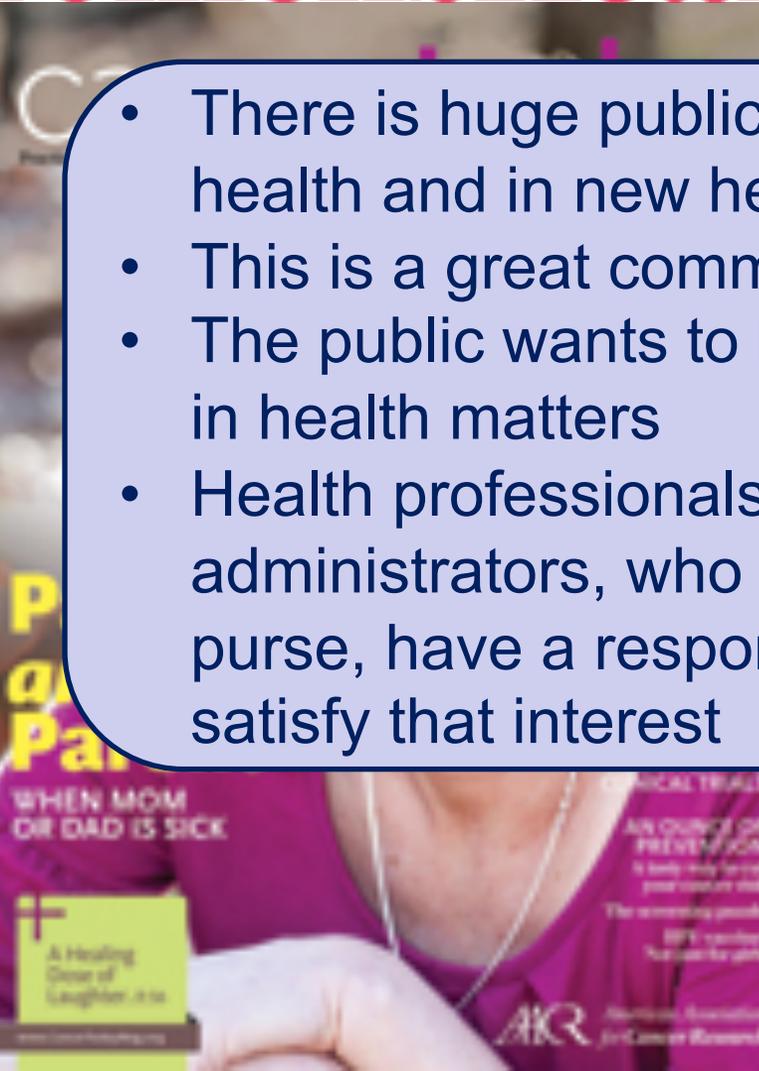
# Women's Health

**Environment Special:**  
The oceans—why 70%  
of our planet is in danger

**The Facebook Movie:**  
The secret history of  
social networking

# TIME

- There is huge public (and political) interest in health and in new health research
- This is a great communication advantage
- The public wants to be informed and involved in health matters
- Health professionals, scientists and administrators, who spend from the public purse, have a responsibility to feed and satisfy that interest



# Science and the Social Contract

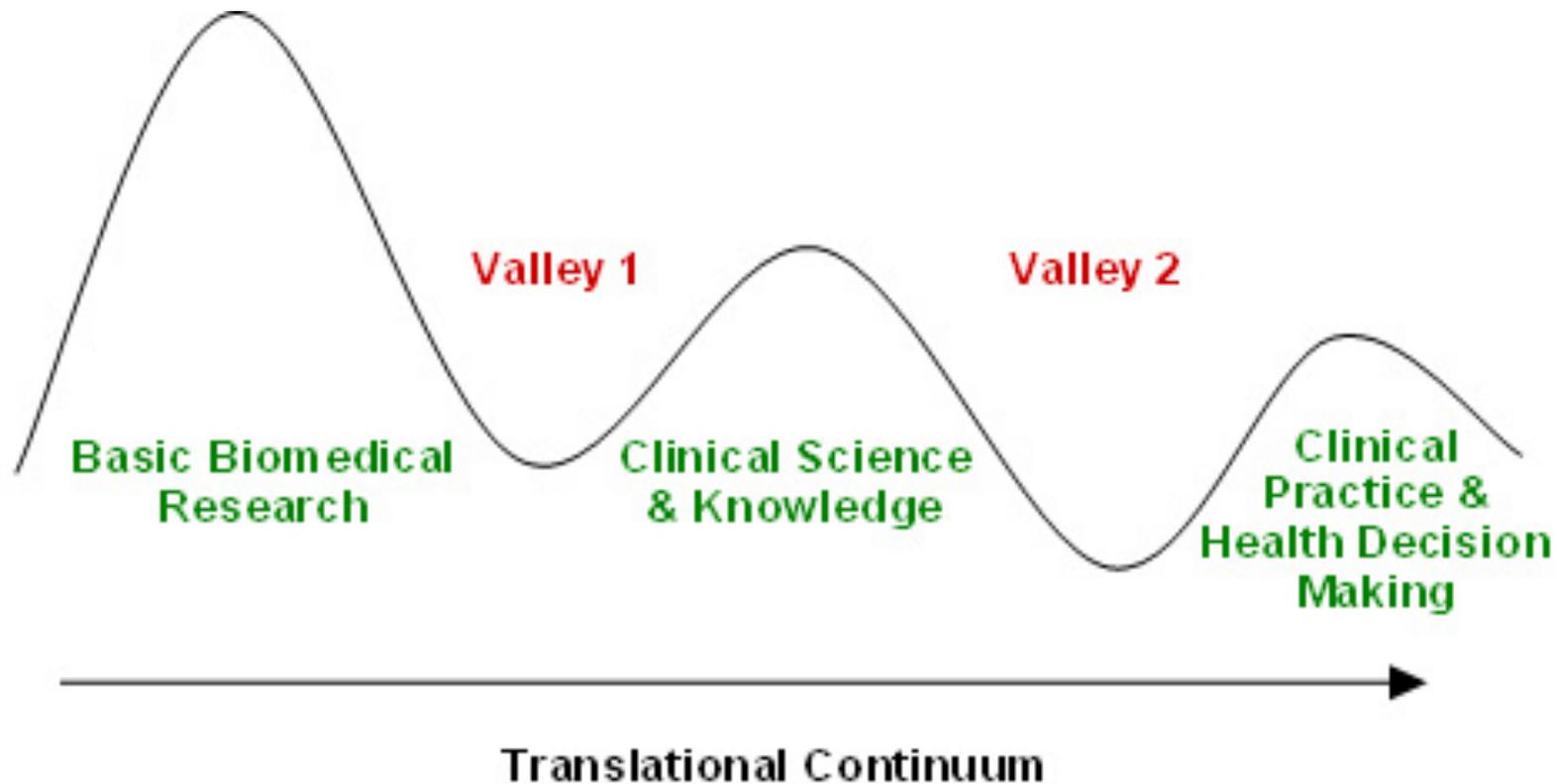
.....as scientists we are in the privileged position of being able to indulge our passion for science, to do so with freedom of enquiry and lack of constraint.....

**Our research is generally funded, in whole or part, through the public purse,** in Canada, provincially or federally. But, ..... **we have no entitlement to those funds. We have to justify their receipt and usage and show the return on investment.** .....we have a responsibility to offer something back to Society for the trust that has been placed in us.

## KE, KT requires EC, Effective Communication

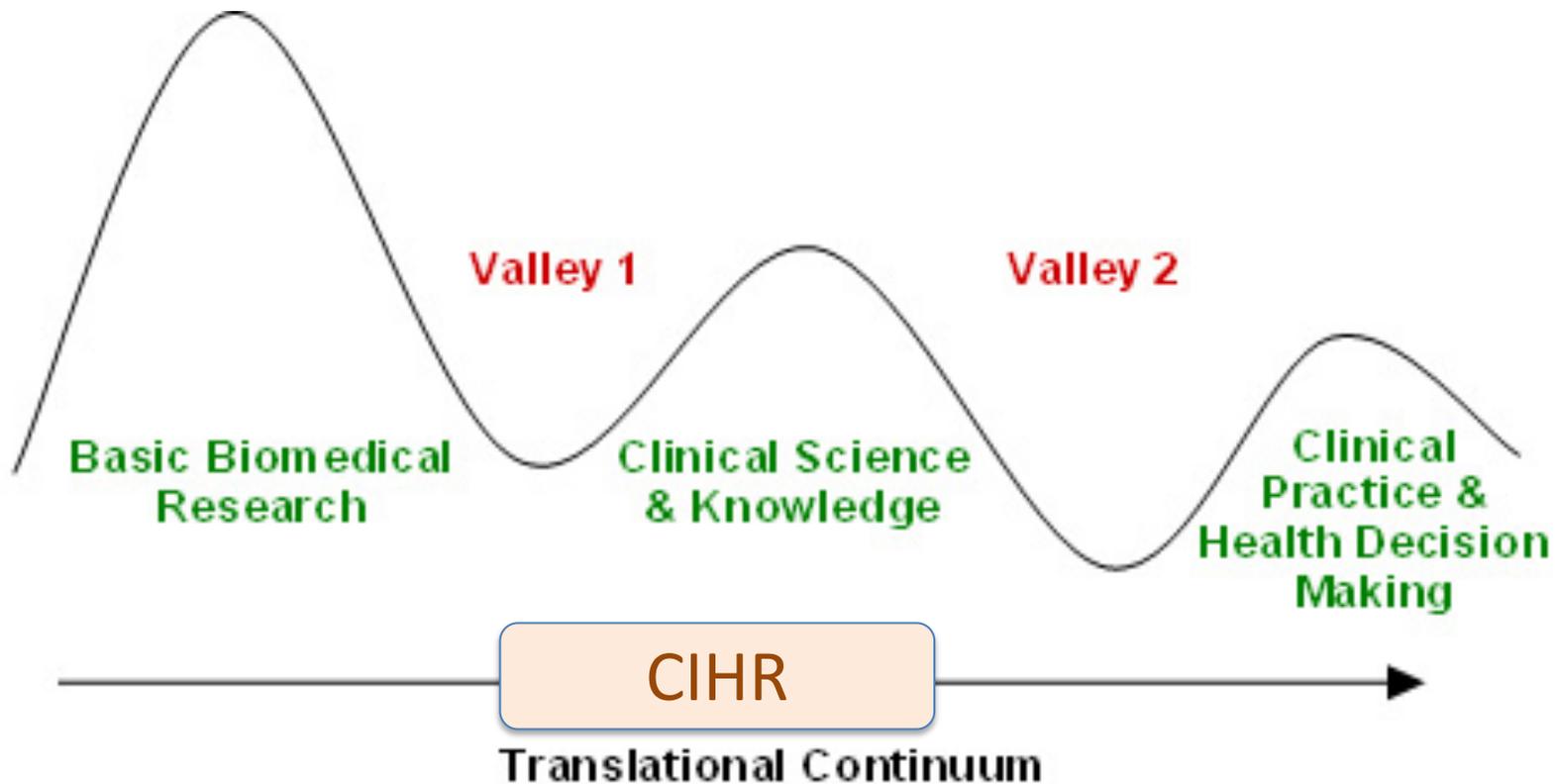
- Knowledge Transfer/Exchange, (KE)
- *leading to* Knowledge Translation, (KT)
- *require* Effective Communication (EC) between partners (producers and end users)
- *needs* Receptor Capacity and understanding
- *avoiding* miscommunication, false claims and false hopes

## The two "Death Valleys" of the clinical translational continuum



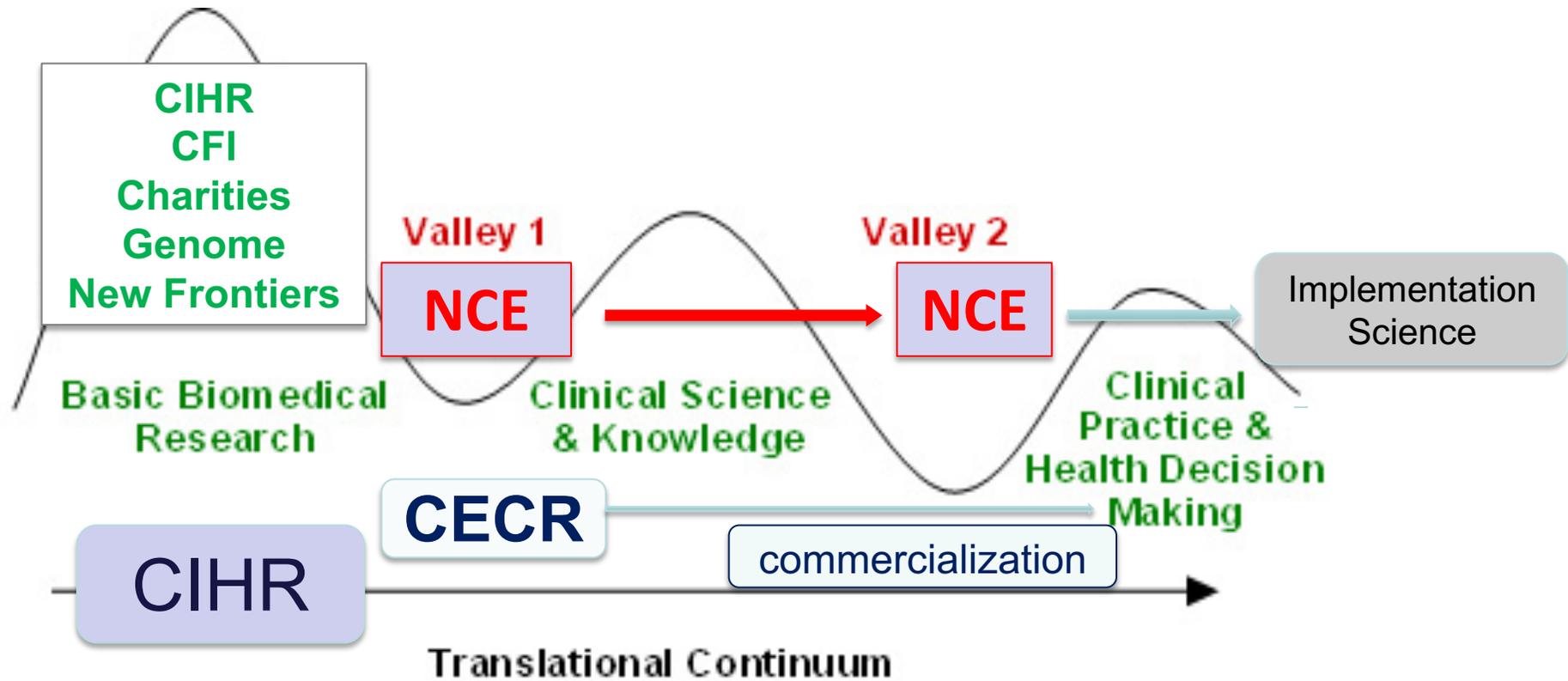
This figure illustrates the points at which Canada experiences decreased capacity to translate research results to the next stage, affecting, first, our ability to commercialize research results (Valley 1), and, second, our effectiveness at moving results into clinical practice (Valley 2) *Figure from Steven Reis, University of Pittsburgh and Harold Pincus, Columbia University; Adapted from CIHR.*

## The two "Death Valleys" of the clinical translational continuum



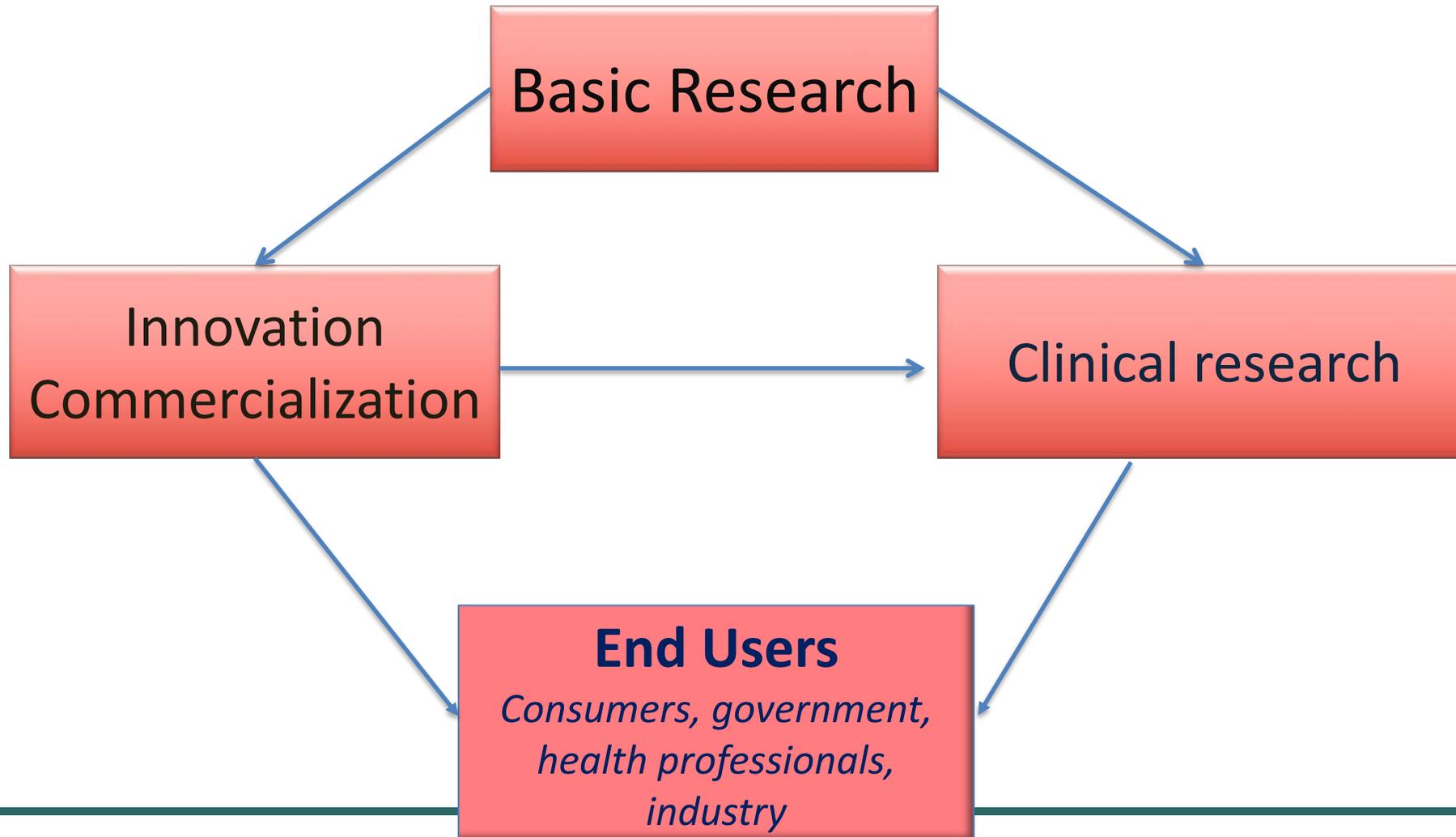
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# The two "Death Valleys" of the clinical translational continuum

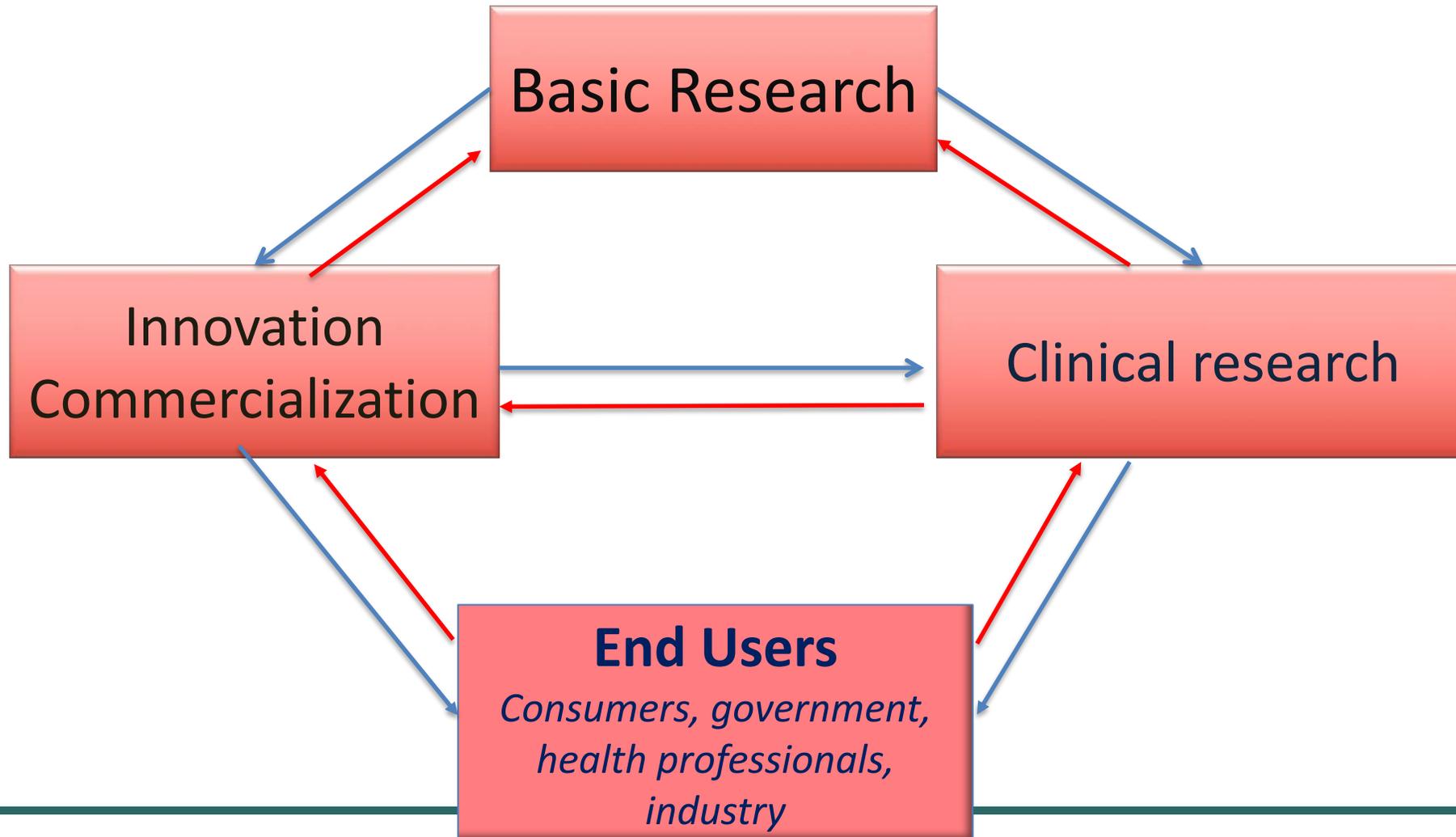


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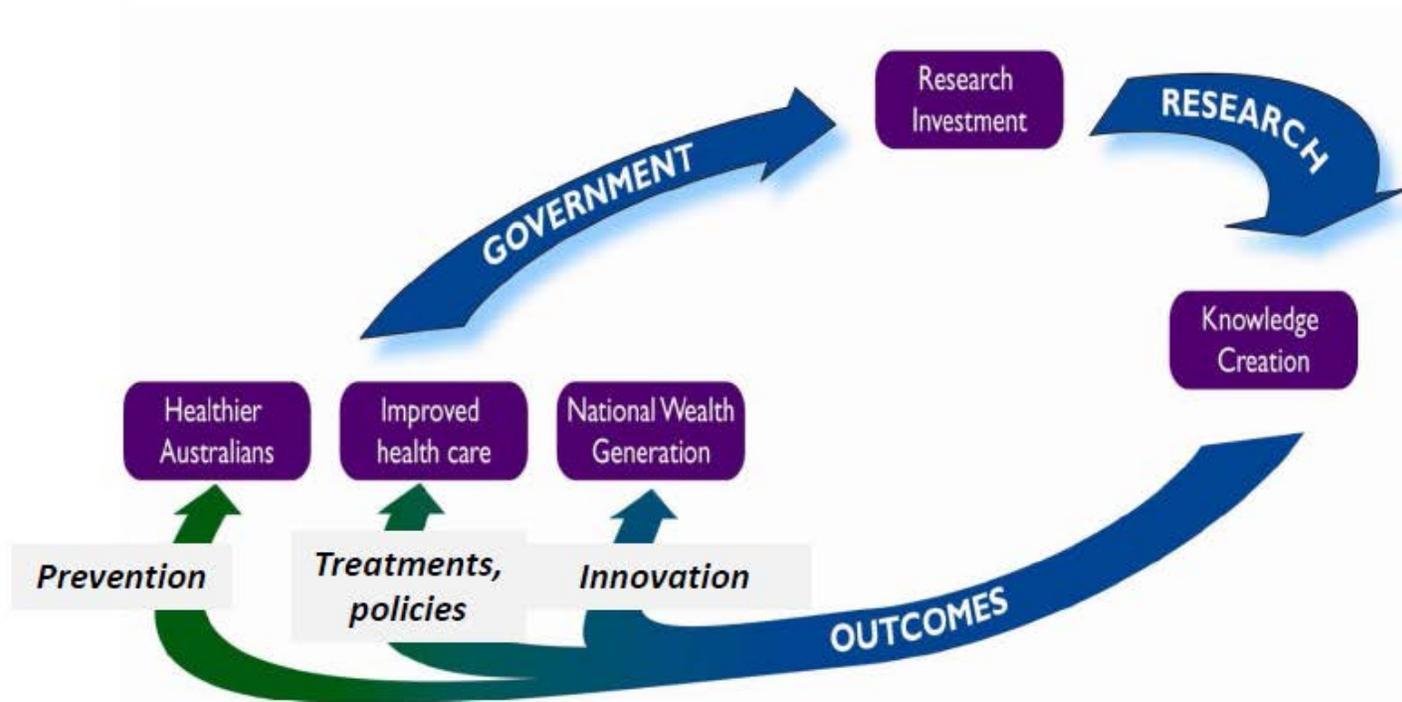
# KT may appear as a linear pipeline.....



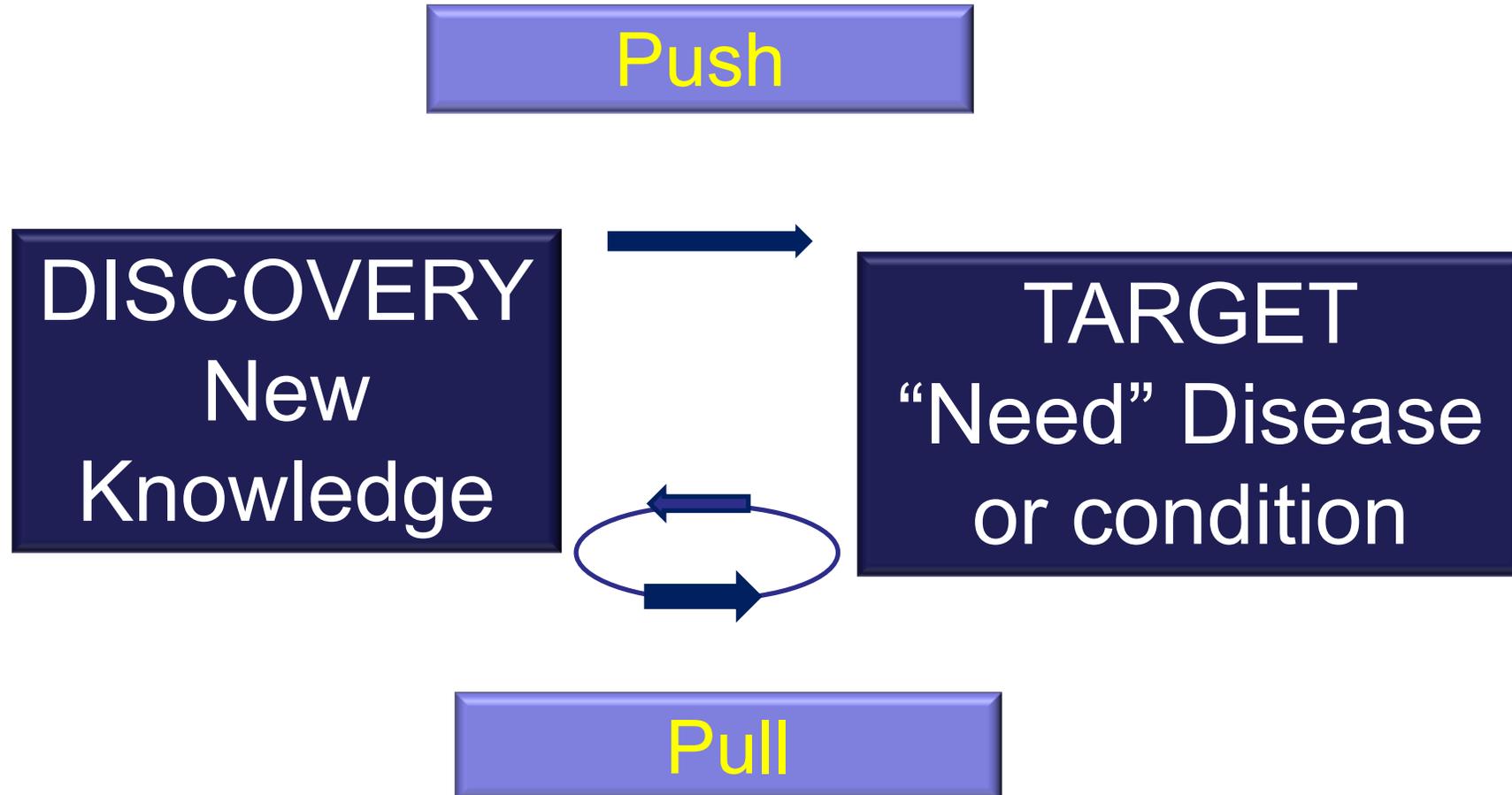
# KT is bidirectional at every step



# Health Research Translation. The Pipeline is really a Feedforward Continuum



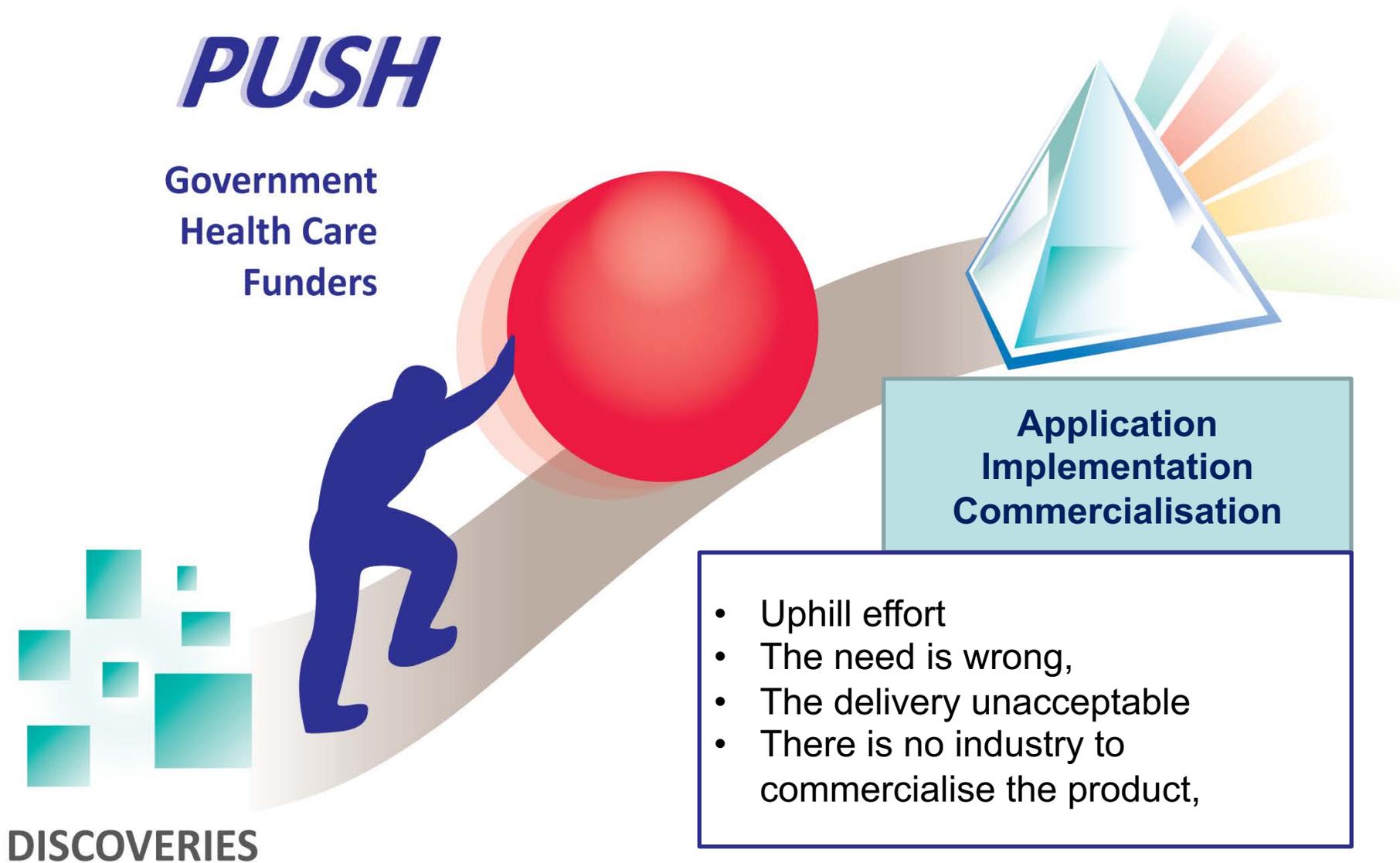
# Discovery or Target driven Research



# Translation Forces in Implementing Discovery

## ***PUSH***

Government  
Health Care  
Funders



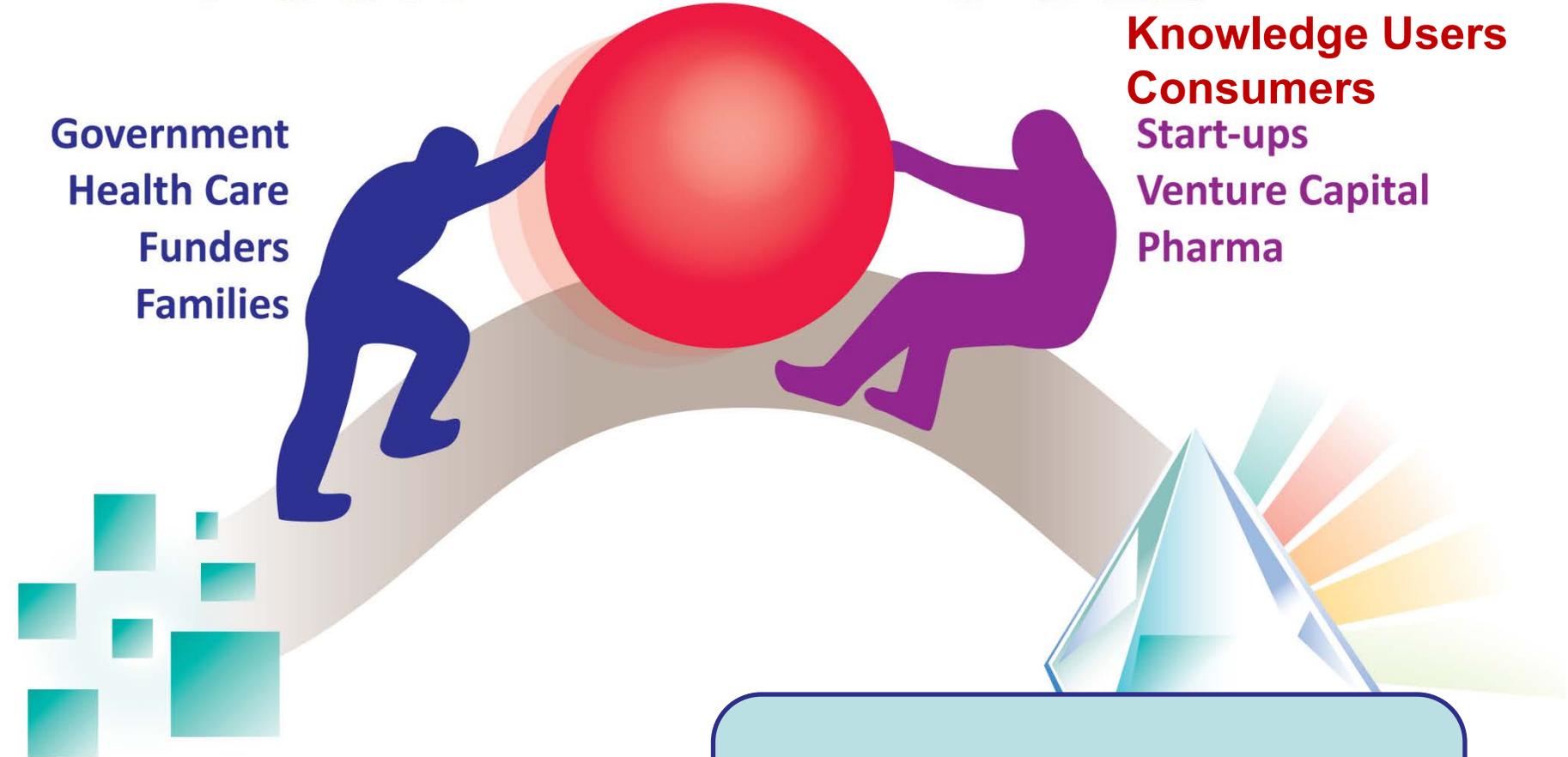
# Translation Forces in Implementing Discovery

***PUSH***

***PULL***

Government  
Health Care  
Fundors  
Families

Knowledge Users  
Consumers  
Start-ups  
Venture Capital  
Pharma



**DISCOVERIES**

Consumer-driven by need  
Application apparent and wanted  
Implementation and commercialise

# CIHR Knowledge User Engagement

CIHR has identified two broad approaches to KT:

## **Integrated KT (iKT)**

Potential knowledge users are engaged throughout the research process.

## **End of Grant KT**

The researcher develops and implements a plan for making potential knowledge-user audiences aware of the knowledge that is gained during a project.

# CIHR Knowledge User Engagement

CIHR has identified two broad approaches to KT:

## **Integrated KT (iKT)**

Potential knowledge users are engaged throughout the research process.

**YES!**

## **End of Grant KT**

The researcher develops and implements a plan for making potential knowledge-user audiences aware of the knowledge that is gained during a project.

**WRONG!**

# NHMRC; Advanced Health Research and Translation Centre (AHRTC)

“leading centres of collaboration in health and medical research, research translation, research-infused education and training and outstanding health care” *July 2014*

“operating at an internationally competitive level”

*Consumer involvement was not embedded in the original government brief, but became a priority of the new national partnership, The Australian Health Research Alliance, AHRA*

## Part 2: Outline

- Introduce Canada's Networks Centres of Excellence Program
- Kids Brain Health Network
- Communication Strategies
- KTEE Strategies
- Next steps: Moving evidence into practice – Implementation approaches
- Case Studies – Policy, Intervention
- Q & A



NCE RCE

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of **Excellence** of Canada | d'**excellence** du Canada



Government of Canada  
Networks of Centres  
of Excellence

Gouvernement du Canada  
Réseaux de centres  
d'excellence

Canada



## Networks of Centres of Excellence of Canada

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NCE H

Canada's global economic competitiveness depends on **making** new **discoveries** and **transforming** them into products, services and processes that **improve** the **lives** of Canadians.

News and Events

Reports & Publications

Proactive Disclosure

Canada's global economic competitiveness depends on making new discoveries and transforming them into products, services and processes that improve the lives of Canadians. To meet this challenge, the Networks of Centres of Excellence (NCE) offers a suite of programs that mobilize Canada's best research, development and entrepreneurial expertise and focus it on specific issues and strategic areas.



NCE RCE

# WHO ARE WE

Canada's go-to networks and centres for  
**research, commercialization and knowledge  
mobilization.**



Government of Canada  
**Networks of Centres  
of Excellence**

Gouvernement du Canada  
**Réseaux de centres  
d'excellence**

Canada 



NCE RCE

# WHAT WE DO

We connect entrepreneurs, researchers, investors, accelerators and innovators from **across Canada** to create a critical **mass of expertise** to develop, test and evaluate proven solutions. We then share, adapt and scale up those **solutions nationally and globally**.



Government of Canada

Networks of Centres  
of Excellence

Gouvernement du Canada

Réseaux de centres  
d'excellence

Canada



NCE RCE

# WHY IT WORKS

**Diversity** and **inclusion** are Canada's strengths. The NCE **brings together** diverse scientific fields, industry sectors and public and local partners to **develop practical solutions** that empower Canadian families, communities and job-creators.



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of Excellence

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Canada



# NCE PROGRAMS

## Networks of Centres of Excellence (NCE) Program

Knowledge Mobilization Initiative (NCE-KM)

Canada-India Research Centre of Excellence Initiative (CIRCE)

International Knowledge Translation Platform Initiative (NCE-IKTP)

## Centres of Excellence for Commercialization and Research (CECR) Program

## Business-Led Networks of Centres of Excellence (BL-NCE) Program



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of Excellence

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Canada

## NCE-KMs transfer knowledge to end users by:

- Supporting national and international networks between knowledge users and producers for the benefit of Canada's social, health and/or economic development
- Enabling knowledge mobilization activities that will bring together researchers from different disciplines to share and nurture ideas and methods that challenge research



# Kids Brain Health Network A Network of Centres of Excellence



NCE RCE

Networks of Centres of Excellence of Canada | Réseaux de centres d'excellence du Canada

# Making a difference in the lives of children with NDDs:



Diagnose



Treat



Support



## The Challenge

**10-17% of kids aged 4-14 in Canada have a neurodevelopmental disability (NDD) but face barriers to early identification, intervention and support**



**Currently, +90% of children with NDDs do not** grow out of challenges that affect quality of life and activities of daily living



**Wait times** for access to NDD diagnosis and treatment as long as **2-3 years** during critical periods of child development



**Parents of children with NDDs** have significantly higher stress levels, employment challenges, feelings of isolation, and mental health issues



**Only one** Canadian province has studied the policy and organizational obstacles to coordinated care for children with disabilities

## Our Vision

**All children with neurodevelopmental disabilities enjoy quality of life, inclusion in all aspects of society, and reach their full potential**

## Research Activities

Our research outcomes empower our partners to mobilize **early identification, effective intervention** and **family support** programs that improve quality of life and outcomes for children with NDDs



**Over 90 disciplinary principal and co-investigators, 150-200 trainees** (average # per year)



**24 Academic Research Institutions** across Canada



**500+ Implementation Partners, frontline staff and practitioners**



**Authentic engagement of families**



## Research Outputs



**Clinical/Practice Guidelines**  
**Commercial Products**  
**Training Packages**

**Publications**  
**Patents**  
**Policy Documents**



**\$39.1M** from NCE

+

**\$48.3M** Partner Contributions

=

**\$87.4M** Investment to Date

## Our Impact

**More children with NDDs are identified in early life**



**Adoption of more research-tested interventions for children and families**



**More families receive the training and support they need**

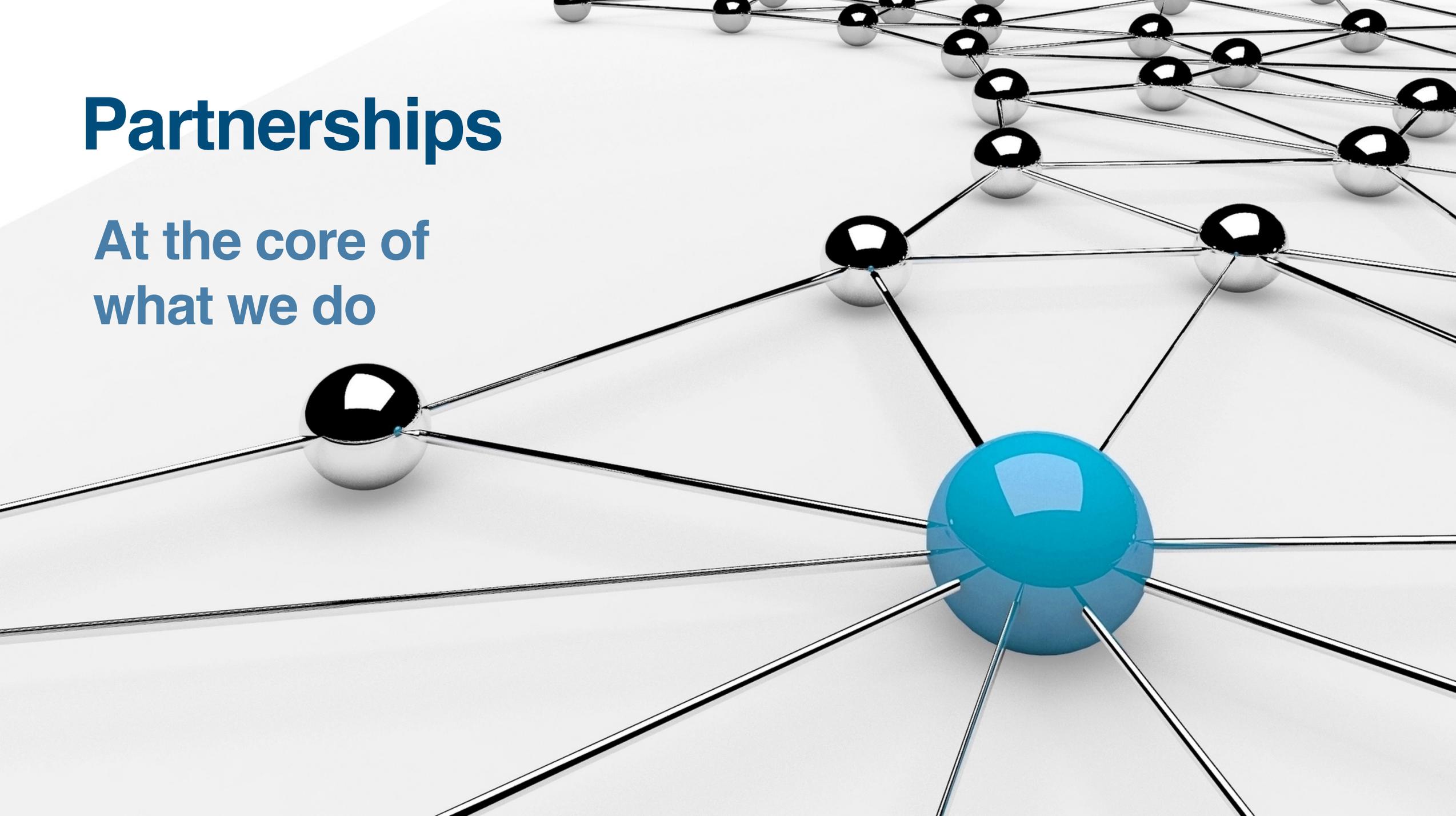


**Children are empowered to reach their full potential**

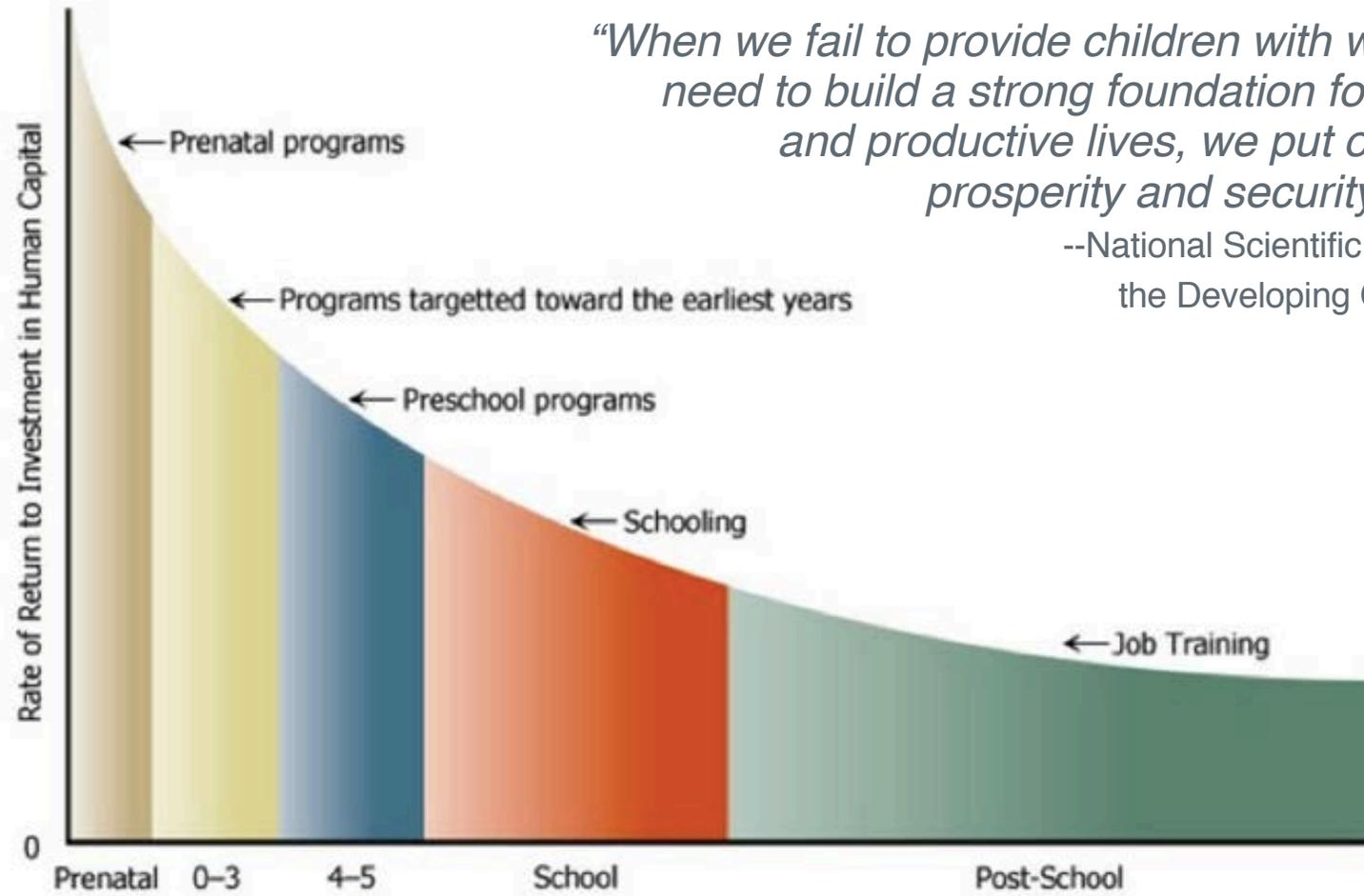


# Partnerships

At the core of  
what we do



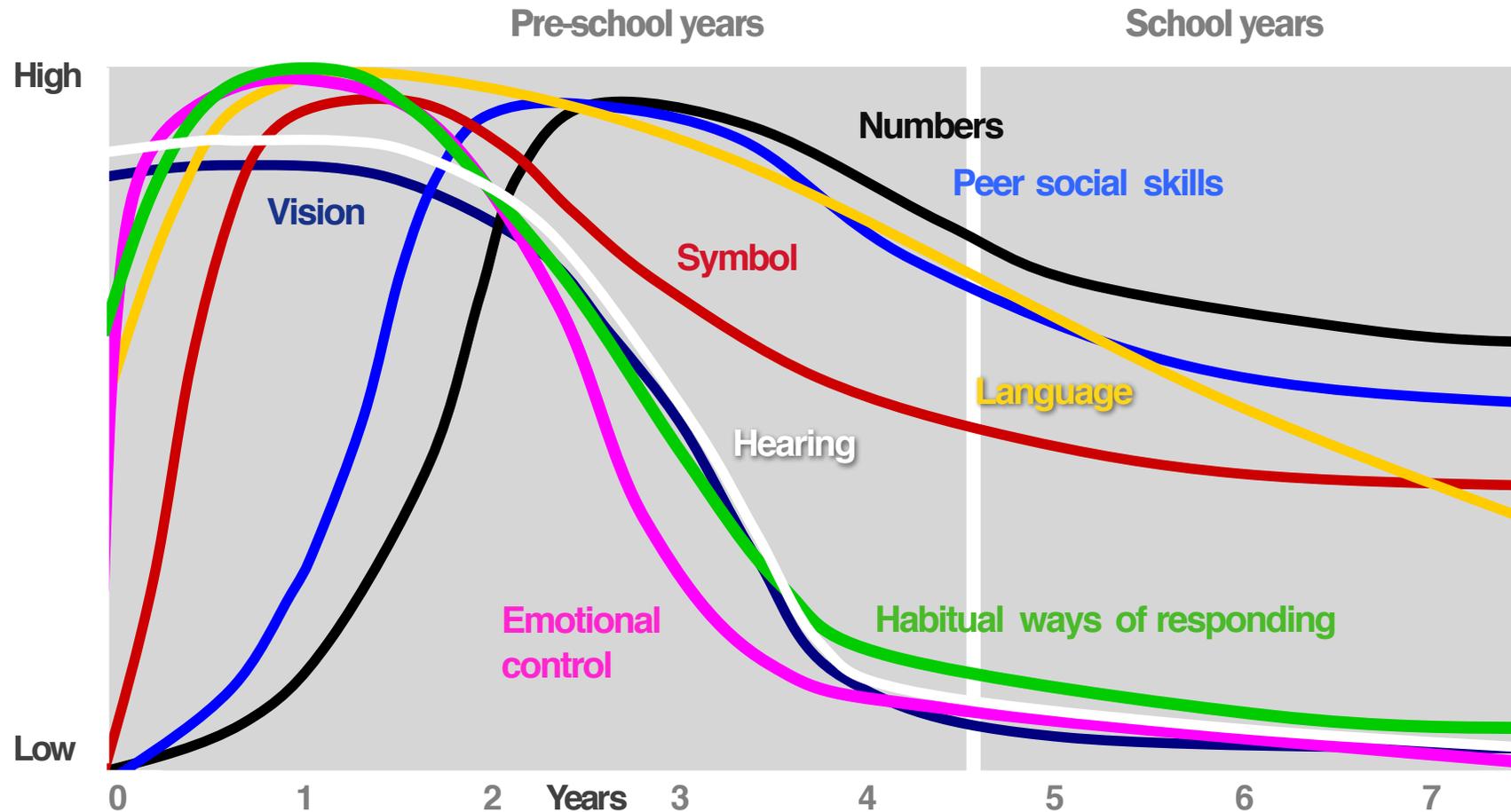
# Optimization of Investment



*“When we fail to provide children with what they need to build a strong foundation for healthy and productive lives, we put our future prosperity and security at risk.”*

--National Scientific Council on the Developing Child, 2007

# Sensitive periods in early brain development



'Sensitive periods' in early brain development – this slide is based on the following references:

- Doherty, G. (1997). *Zero to Six: the Basis for School Readiness*. Applied Research Branch R-97-3E Ottawa: Human Resources Development Canada.
- McCain & Mustard (1999). *Early Years Study*. Toronto, Ontario: Publications Ontario.
- Shonkoff, Jack (Ed) (2000). *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, D.C.: National Academy Press.

# Network Activities

## Research

- tools for earlier identification
- evaluate effective interventions
- assess and scale supports for families

## Knowledge Translation

- build capacity and engagement of families, caregivers and front-line community agencies
- mobilize findings into improved guidelines, policies and practices for better outcomes

## Highly Qualified Personnel

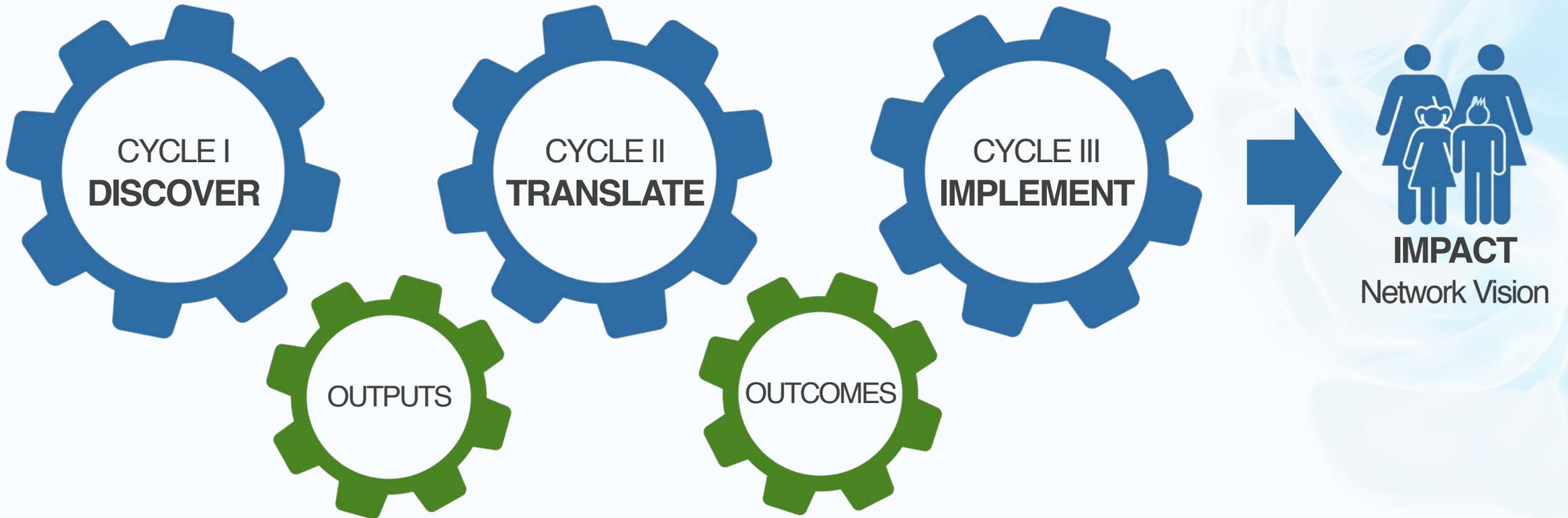
- train the next generation of multi-disciplinary neurodevelopmental scientists

## Partnerships

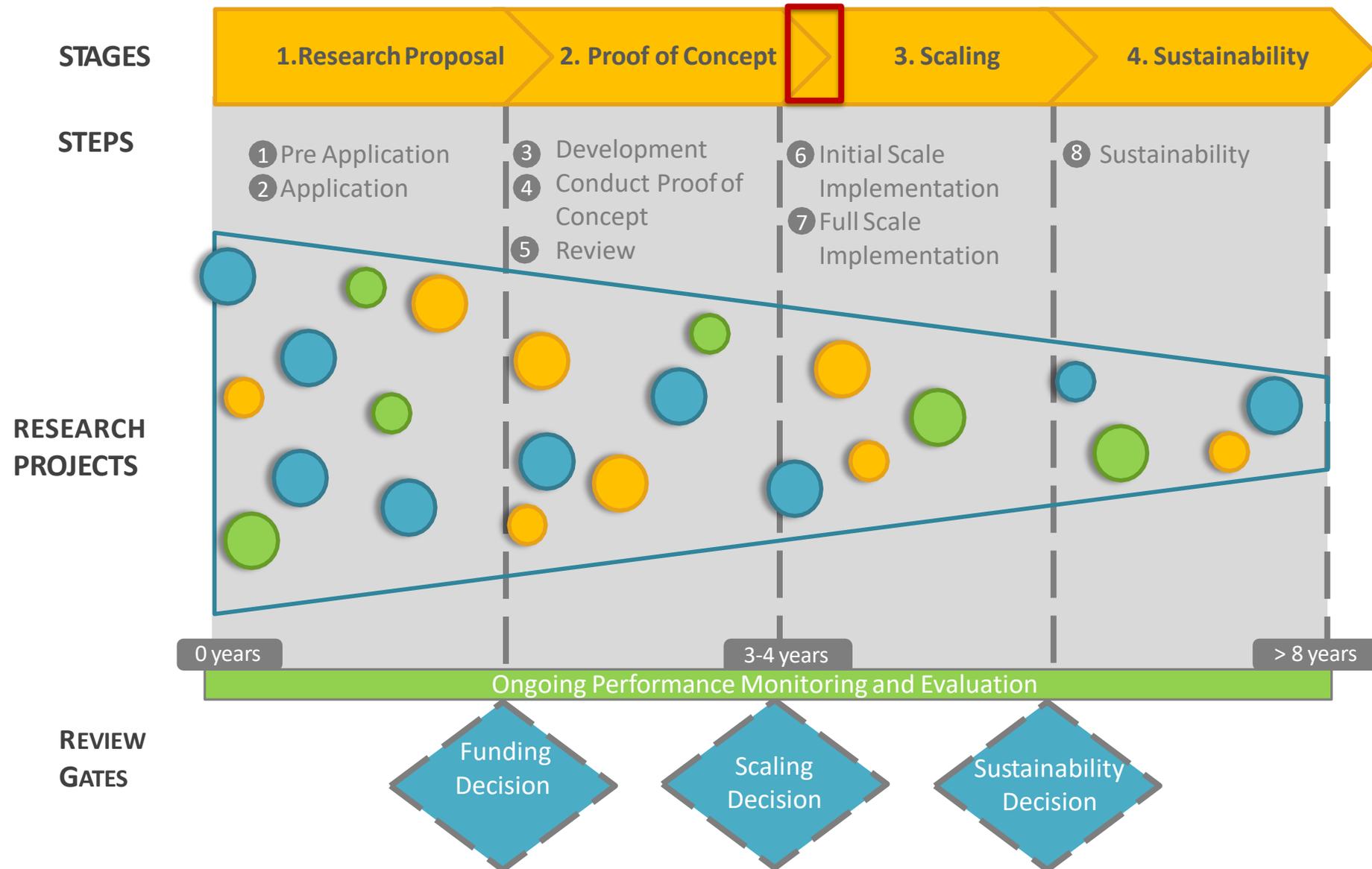
- engage and partner with community groups, non-profit organizations, industry, parents, clinicians, health professionals, provincial and federal governments

- (1) EARLY IDENTIFICATION
- (2) EFFECTIVE INTERVENTION
- (3) CHILD & FAMILY SUPPORT

BEYOND NCE



# KBHN – PROGRESSION TOWARDS IMPACT



# Communication Strategies - Outreach

- Annual Conference
- Annual reports
- Government engagement & advocacy
- Workshops and Webinars
- Udemy Course – Co-Produced Pathway to Impact
- Social Media - Facebook, Twitter & LinkedIn
- Website
  - Research Snapshots
  - Impact Stories
  - Videos
  - Publications
  - Stakeholder Engagement
  - Newsletters and Announcements
  - Tools for impact



# Communications

 Kids Brain Health Network  
Published by KidsBrainHealth CA [?] · August 15 at 10:23 AM · 🌐

"People would say, 'well, we don't really know what challenges these kids have...Well, now we know, with evidence from a very substantial sampling."

KBHN is proud to support the only comprehensive #FASD database of its kind across the globe. The Canadian Fetal Alcohol Spectrum Disorder Database is an international leader in providing insight into unanswered questions about the neurodevelopmental disability. Read more: <https://bit.ly/2Z7J4Km>



KIDSBRAINHEALTH.CA  
**Canadian Fetal Alcohol Spectrum Disorder Database Demonstrates International Leadership in FASD Research**

1,119 People Reached      224 Engagements      [Boost Post](#)

  17      1 Comment 17 Shares

 Like       Comment       Share      

 Kids Brain Health  
@KidsBrainHealth

When a child receives a neurodevelopmental disability diagnosis, families are often left unsure who to turn to. The new Navigation Resource Project supported by Kids Brain Health Network hopes to change this for families across Canada: [bit.ly/30ufobz](https://bit.ly/30ufobz)



 Vanessa Hrvatin and 6 others

10:20 AM · Jul 10, 2019 · [Twitter Web Client](#)

 View Tweet activity

16 Retweets      20 Likes

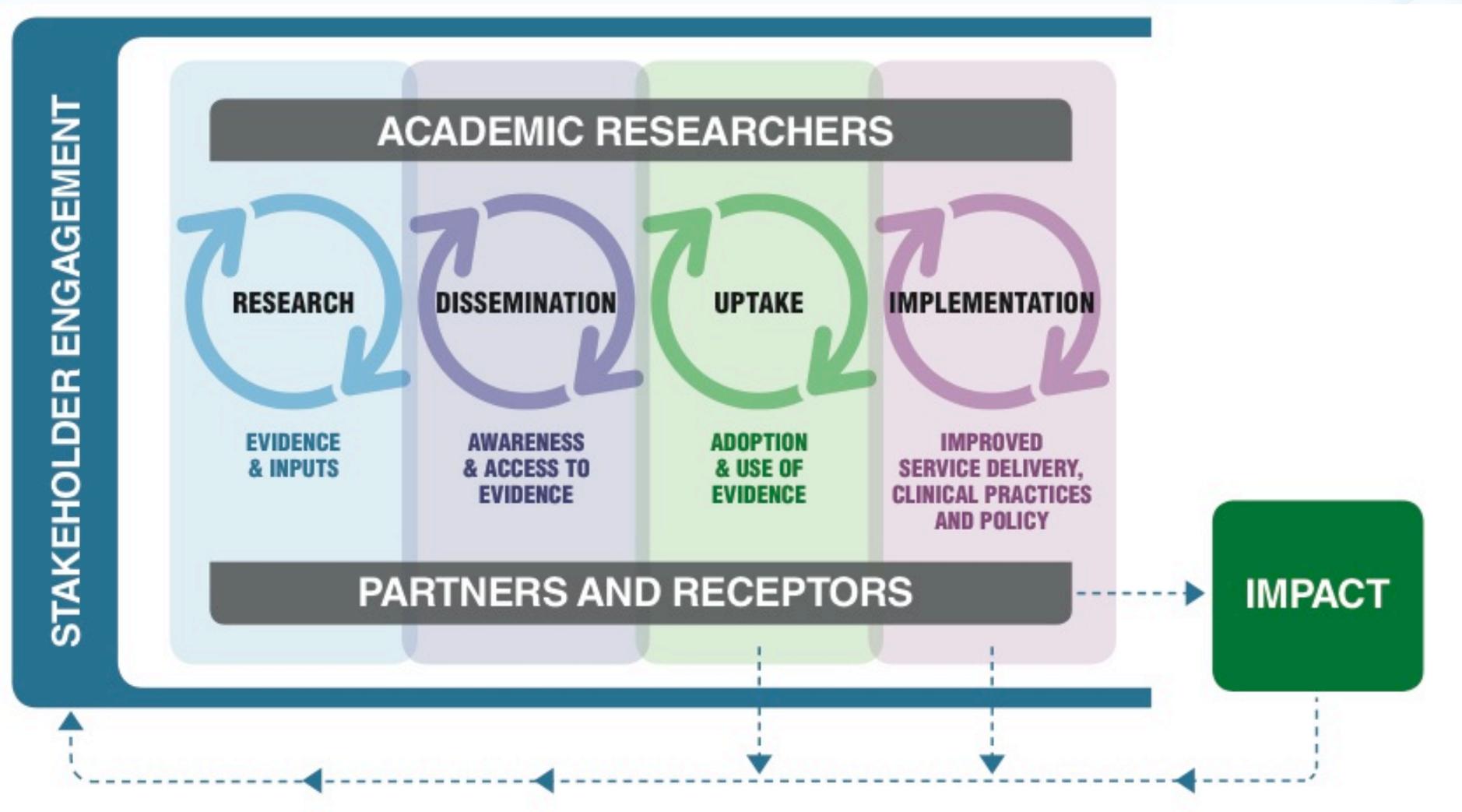
# Knowledge Translation Core Services



**research snapshot**  
summarize | mobilize



# Co-Produced Pathway to Impact

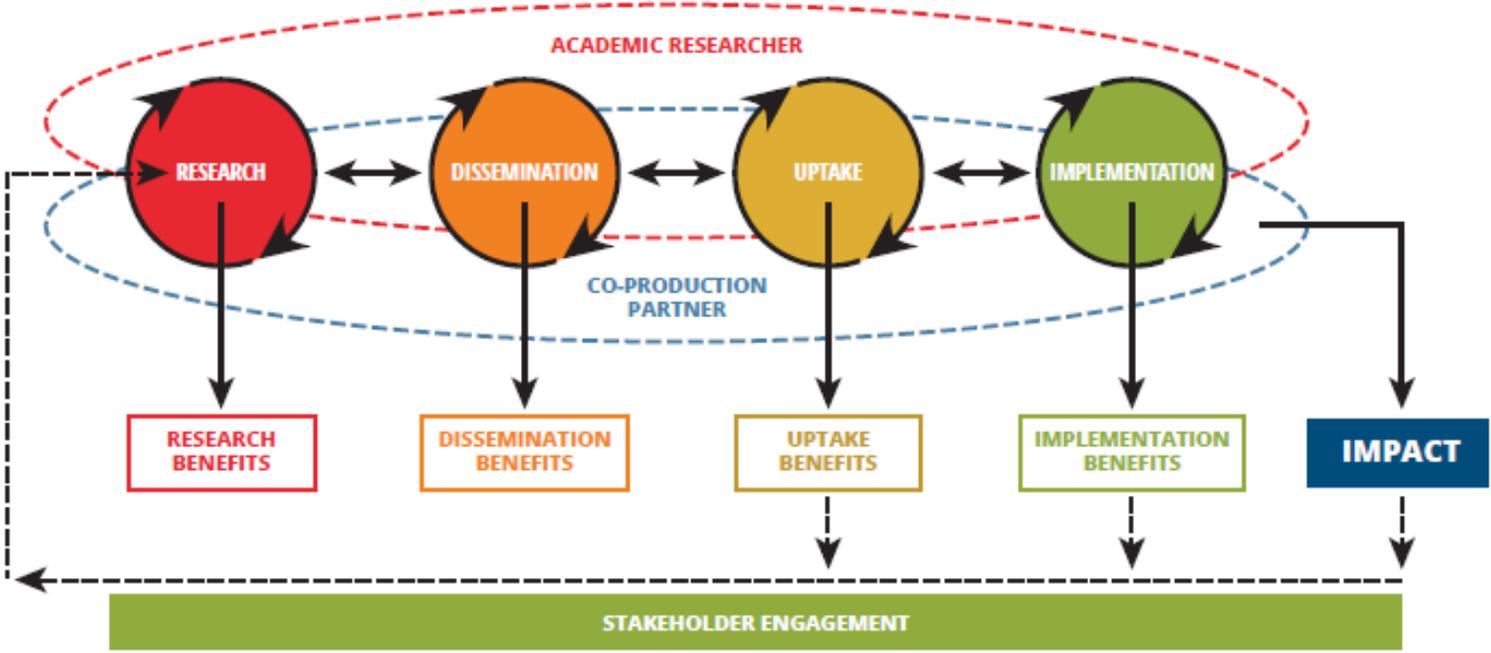


# Social ABCs



- Parent-facilitated intervention that develops social and language skills in children
- Training manuals created for individual and group-based programs

# Co-Produced Pathway to Impact project example: Social ABCs



**NEED**

Parents need:  
#1: specialized training for educators  
#3: more (efficient use of) resources  
#5: treatment for child as soon as possible

**CO PRODUCED RESEARCH**

Bloorview, ECE practitioners, MCYS funding for testing in community setting

**DISSEMINATION**

Developed parent manual; peer reviewed publications; presentations at conferences and family events

**UPTAKE**

Researchers training ECE (train the trainer)  
ECE training parents, MCYS evaluating this intervention in Hamilton

**IMPLEMENTATION**

ECE practice in community settings; Parents trained at home, MCYS funds Social ABCs to make it a publicly available intervention across Ontario

**IMPACT**

<http://bit.ly/2ijG4uY> ,  
Future: better trajectories for kids & outcomes for kids when in school, etc.; cost savings to health care system



# Knowledge Brokering



**Facilitate introductions**

**Organize meetings**

**Support networks**

**Facilitate ongoing  
collaboration**



*"The KT Core can help investigators to link with other experts in the field ...our work...related to stem cells for neurodevelopmental disorders including cerebral palsy has been enhanced by our linkages with the KT Core" - Michael Fehlings, Scientific Advisor NeuroDevNet*

# KT Events



**Event planning**

**Stakeholder consultations**

**Evaluation forms**

**RedCap**

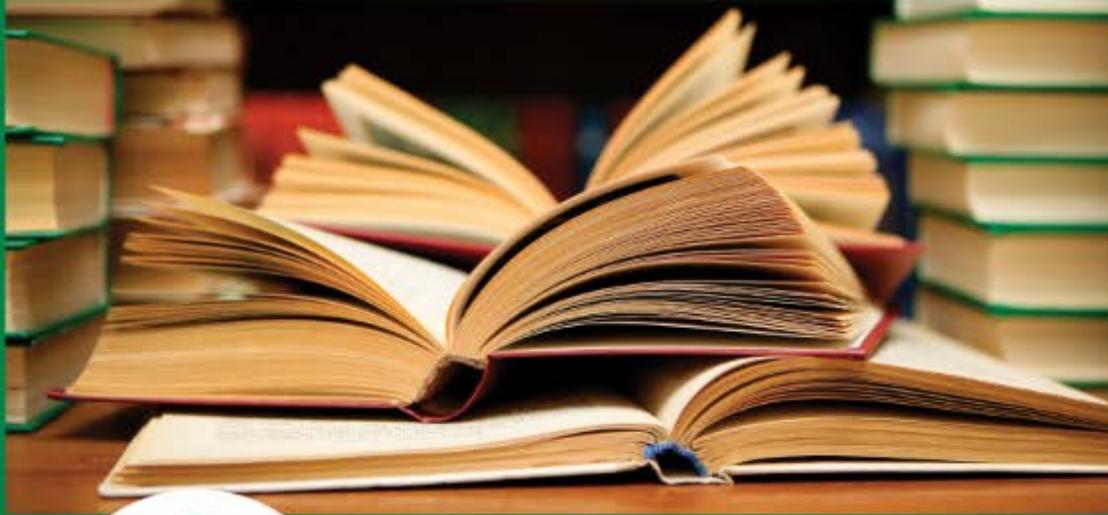
**Videos**

**Feedback on slides**



*"The KT Core...provided us with some really valuable tools for coordinating and registering participants for our workshop (Eventbrite.ca). We have continued to use these tools for other events...additional support from KT staff in advertising our event really made the difference in reaching interested teachers" - Parker Holman, NeuroDevNet trainee*

# KT Products



**ResearchSnapshots**

**Social media strategy**

**Videos**

**Infographics**

**PPT slides**

**Apps & websites**

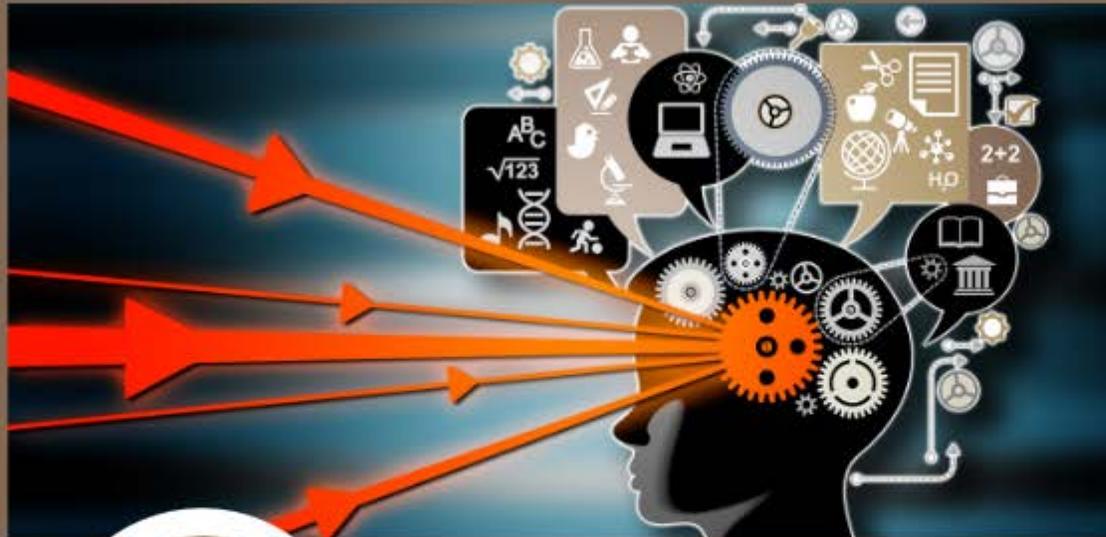


*"I did review the snapshots and thought they were fantastic! As the head of communications for a Network of FASD services and supports we could absolutely post these on our website and link to Facebook and Twitter. We also produce a monthly newsletter where it would be great to include a current research section! And lastly it would be great to include these as a part of the trainings that I provide to community and social service agencies."*

*- Lisa Rogozinsky, Fetal Alcohol Network Society, Edmonton, AB Canada*



# KT Capacity Building



**Workshops**

**Webinars**

**In situ learning through  
service provision**

**Conference presentations**

**KT Core-ner Blog**



*"We were talking about knowledge translation and the use of social media...and it was actually really interesting and there are definitely areas that we can apply that within our own research" - Kristina Calli, NeuroDevNet trainee, workshop attendee*

# KT Evaluation



**Interviews for evaluation  
and KT needs assessment**

**Database and indicators**

**Evaluations for events**

**Success story writing**



*"...this is very helpful, and thank you again for a very impactful webinar!"  
- NCE Secretariat*

# KT Planning



**Grant review**

**End-of-grant KT**

**Integrated KT**

**Budgeting for KT**

**Letters of Support**



*"The NeuroDevNet KT Core worked with me to develop a detailed KT plan for my CIHR application. They helped me identify stakeholders and formulate a plan to involve them throughout my research project - using an initial consultation meeting, ongoing communication, and ways to disseminate our final research findings. The advice and support provided by the KT Core was instrumental to creating this plan, and I believe it was a significant contributor to the success of my application. The KT Core has also committed to supporting me as I execute these plans, which ultimately means my project will have a bigger impact on the populations I hope to help." - Dr. Catherine Lebel*



# Knowledge Translation Tools

- **Guide to stakeholder engagement**

- <https://www.slideshare.net/NeuroDevNet/stakeholder-engagement-guide-of-guides-accessible2>

- **Guide to impact planning**

- <https://www.slideshare.net/NeuroDevNet/kt-planning-guide-of-guides>

- **Guide to Infographics**

- <https://www.slideshare.net/NeuroDevNet/infographic-guide-of-guides-accessible2>

- **Guide to evaluation**

- <https://www.slideshare.net/NeuroDevNet/evaluation-guide-of-guides-121240895>

- **Guide to dissemination**

- <https://www.slideshare.net/NeuroDevNet/dissemination-guide-of-guides>

# Case Studies

## Stakeholder Engagement

- Identification of KBHN Stakeholder Needs and Priorities
- Family Engagement in Research Certification Project
- Parents Participating in Research – Facebook Forum

## Implementation – Evidence to Practice

- Three evidence based interventions
- Policy Dialog



# Identifying and Prioritizing Stakeholder Needs in Neurodisability: An Environmental Scan



- First ever cross-Canada survey that identified the needs of parents raising children with neurodisabilities, service providers, front line workers and policy makers.
- Targeted interviews and an online questionnaire
- More than 700 people contributed their input
- [Stakeholder Engagement Activity Report](#) (Spring of 2017)
- Additional in-person prioritization of the issues identified in the survey, as well as an [online survey](#) further refined our understanding of what is most important to policy makers, practitioners and parents.

# We asked. You answered.

Results of  
Stakeholder Engagement at  
Kids Brain Health Network



## Why Stakeholder Engagement?

Stakeholder engagement helps KBHN know and respond to the current needs of individuals and families affected by Cerebral Palsy, Fetal Alcohol Spectrum Disorder and/or Autism Spectrum Disorder.

Stakeholder Needs Identified

44 needs  
9 themes

Stakeholders identified 44 priorities that were grouped into nine themes:

- Diagnosis
- Treatment
- Services
- Education
- Health Care
- Mental Health / Quality of Life
- Life Course Perspective
- Culture and Context
- Broader System and Society

Stakeholder Engagement Report 2017

Read the full report.

Stakeholder Engagement Activity Report:  
<http://bit.ly/2GRqjjs>

Online Prioritization Survey

Stakeholder

Stakeholder Report Addendum 2018

Prioritization Survey

Read the full report.

Stakeholder Report Addendum:  
<http://bit.ly/2Ej8UB3>

656 respondents

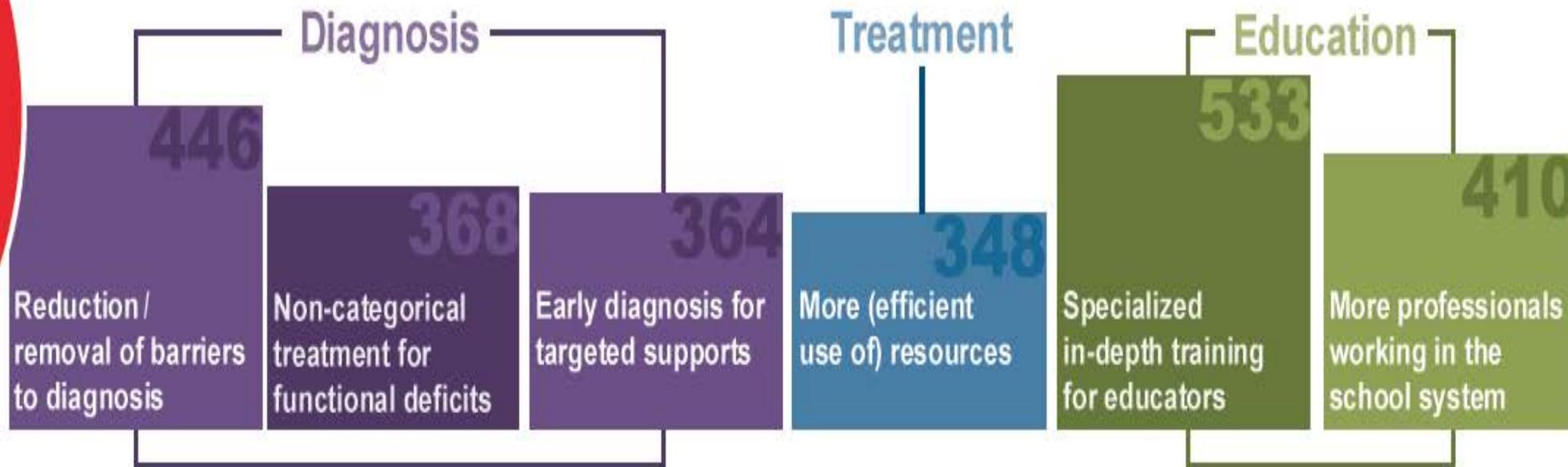
from across Canada responded to the prioritization survey. Six of their top ten priorities fit within KBHN's mandate.

Top 6 priorities for KBHN

[kidsbrainhealth.ca](http://kidsbrainhealth.ca)

see priorities on reverse

# Top 6 priorities for Kids Brain Health Network



"... that wait is tremendously detrimental to the child and to the family."  
~ Clinician

"... Does it really matter if they have cerebral palsy or autism or fetal alcohol spectrum disorder to get things like the behavioural, emotional and family interventions they need? ... It's how do we work with them after identifying the particulars of their functional status and needs to find the best solution."  
~ Clinician

"... the challenge is the kids that come into our service and not necessarily with one of these diagnoses but just are having difficulties, they're not really fitting into any category ... they're just different. That's tough."  
~ Clinician

Contact:  
Kids Brain Health Network  
Knowledge Translation Core  
York University  
Ph: 416.736.2100 x44310  
email: apostz@yorku.ca

"... she was one of the few educators I met, at that level, who... understood immediately what these kids needed to learn and that they were all different."  
~ Parent

"... classroom aides are just typical individuals that obviously love what they do but they're not therapists and so if they don't catch on right away they could be doing it wrong for six months out of the year. ...therapies that are offered through the school system are limited."  
~ Parent

Numbers inside bars indicate the total votes each priority received in the online prioritization survey.





# Family Engagement in Research Certificate Program

# Family Engagement in Research Certificate

- National online Training Program(10 weeks)
- Partnership between KBHN and McMaster University Centre for Continuing Education
- Co-developed and co-instructed by parents and researchers
- Brings together families and researchers who have an interest in child neurodevelopmental research
- Aims to develop the next generation of leaders in the field of family engagement.
- Recruitment through KBHN Network & online through social media



## Family Engagement in Research Certificate

### Course Details

This course is for Kids Brain Health Network trainees and families who have an interest in child neurodevelopmental research. This course is unique in that it will bring trainees and families together in a fully integrated online course. Learners will gain a better understanding of;

- ▶ Family engagement in research (why it is important)
- ▶ How to engage families throughout the research process
- ▶ Barriers/facilitators to engagement
- ▶ Ethics surrounding engagement
- ▶ Tools and resources to support and evaluate engagement activities

By the end of the course, learners will be ready to partner on integrated research teams.

### Course Dates

January 21st - March 31st 2019

### Course Location

Online through the McMaster Continuing Education Program

### Course Length

10 weeks (30 hours)

### Course Completion

Earn a McMaster Certificate of Completion

For more information contact Andrea Cross, Course Coordinator [crossac@mcmaster.ca](mailto:crossac@mcmaster.ca)

# Course Goals

- Create a cohort of *family members* who are:
  - Knowledgeable about the research process and can make informed decisions with regards to partnering on a research project
  - Capable and confident to engage with researchers at various levels of the research process and recognize the impact they can have on the research community.

# Course Goals cont.

- Create a cohort of *research trainees* who are:
  - Knowledgeable about patient-oriented research and patient/family engagement.
  - Capable and confident in engaging with families and other stakeholders in various stages of the research process.

# Course Schedule

Week	Topic
Week 1	Family Engagement in Research: What do we really mean?
Week 2	Family Engagement in Research: Why is it important?
Week 3	Building an integrated research team: How can we find each other?
Week 4	Building an integrated research team: How can we work together?
Week 5	Roles and responsibilities of families and researchers
Week 6	Ethics of family engagement in research
Week 7	Barriers and facilitators to family engagement
Week 8	Family engagement tools & resources
Week 9	Evaluation of family engagement activities
Week 10	Next Steps: Building a community for family-researcher partnerships

# Weekly Materials

- Session Outline
- Readings & Resources
  - Journal Articles
  - Blogs
  - Websites
  - Webinars
  - Podcasts
- Learning Activity



 EDIT

# Parents Partnering in Research >

SECRET GROUP · 182 MEMBERS



- Chats
- Watch Parties
- Photos
- Ever

# Case studies: Evidence to Practice

# Neuro-Exergaming- A customized exercycle

## Current Challenges:

1. Motivation
2. Social connection



A screenshot of a Facebook post by Carolyn Spahn, posted 17 minutes ago. The post features a profile picture of two children and a three-dot menu icon. The text of the post is a letter addressed to Nintendo, written by a 10-year-old boy named Joseph Spahn-Vieira. He expresses his love for Nintendo games but mentions a physical disability that prevents him from playing. He asks Nintendo to create better controllers for children with disabilities and offers to help design them. The post has 5 likes (represented by a blue thumbs-up and a red heart icon) and 3 comments. At the bottom of the post, there are buttons for 'Like' and 'Comment'. Below the post, there are additional 'Like' and 'Comment' buttons.

**Carolyn Spahn**  
17 mins · 

Dear Nintendo,  
My name is Joseph, I'm 10 years old and I think your games are really fun. I think, I don't know actually know because I have a physical disability that stops me from being able to play your games, but I really want to. I'm writing to you because I want to be able to play your games. I'm asking you to make bigger, better controllers for children like me. So please write back to me. I can help you design it and we can crate a whole new world where anybody disabled or not can play anything they want to.  
Thanks,  
Joseph Spahn-Vieira

  5 3 Comments

 Like  Comment

 Like  Comment

**Neuro-Exergame - A customized exercycle whose pedals, powered by youth with CP, run customized multi-player videogames played both remotely and in person via headsets.**

**Successes:**

1. Creation of the **therapeutic** video game
2. Increase **motivation and social connectedness**
3. Scientific validation – **better rehabilitation benefits**



# Physical Activity Program (PAP) effects on children and youth with neurodevelopmental disability

## Challenges:

1. Several programs exist with no clear recommendations
2. No official or scientific guidelines
3. No connection between patients and their family and those types of programs



# Physical Activity Program (PAP) effects on children and youth with neurodevelopmental disability

## Successes:

1. Environmental scan study
2. Scientific validation of those programs benefits
3. Partnership with Special Olympics
4. Creation of a Framework for the organization of such physical programs for NDD patients
5. Creation of guidelines
6. Creation of a network between patients and their families and physical programs

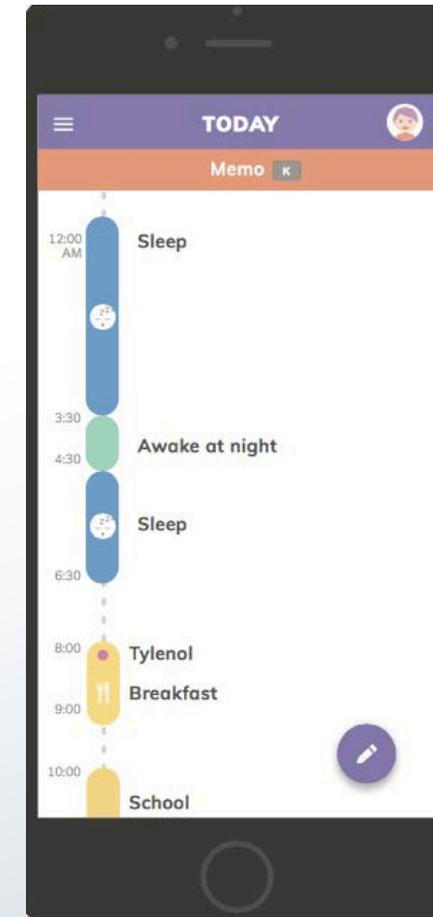




# Sleep/Wake Application (SWAPP) for children with neurodevelopmental conditions

## Successes:

1. Data collection tool
2. Visualization and analysis tool for practitioners
3. Providing parents with information on their child's health care needs
4. Navigation of effective health care



# Partnership between



&



## BOTTOM LINE RECOMMENDATIONS: Caring for Children with Developmental and Intellectual Disabilities in the ED

Children with developmental delays or disorders (DD) are ten times more likely to use emergency department (ED) services compared to their peers.<sup>1</sup> This can include children with conditions such as autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD) and other conditions. This document will provide recommendations for the medical approach to these children.

### CHALLENGES

Individuals with DD have different abilities across domains, including their ability to communicate and understand.<sup>2</sup> Children with DD may exhibit behaviours that are considered unusual for their chronological age, but are normal in the context of their developmental age. These can include non-compliance, aggression, hyperactivity, self-injury, sensory sensitivities, and self-stimulating behaviours.

### ASSESSMENT APPROACHES IN THE ED

Most children with DD present to the ED for an acute behavioural change. This can result from a variety of medical, behavioural, and environmental factors.<sup>3</sup>

1. **Identify:** It is important to identify children with developmental/intellectual disabilities. **Note:** See Environmental Interventions below for immediate actions that can be taken at triage.
2. **Communication:** Determine how the child communicates and their ability to comprehend. Are they non-verbal? Do they communicate with pictures/technology? Determine who to communicate with (child or caregiver) and who makes decisions for the child.
3. **Role of the caregiver:** Caregivers serve as important interpreters of a child's behaviour and can help ED staff effectively interact with the patient to deliver appropriate medical care.
4. **High-yield assessment questions:** The following questions can identify strategies for caring for children with DD.

- Based on Family experience
- Outreach to Kids Brain Health Network
- Partnership with *trekk*
- Parent engagement in development of tool
- Lived experience expertise to review and finalize tool

## Day on the Hill and Policy Dialogues



Teams of researchers and key Network personnel have been meeting with members of parliament, senators and senior policymakers since our first “Day on the Hill” in 2012, to familiarize them with Kids Brain Health and its work – and to discover what needs these officials have with respect to decision-making that touches upon neurodisability.

# Federal Policy Dialogue on Rights-Based Approaches for Children with Disabilities

- **Scoping review** to identify the rights-based approaches in childhood disabilities
- Researcher/expert **consultation** to validate and provide context on the findings from the review
- Grassroots/disability organizations **consultation** to validate the importance, relevance, and stories associated with these approaches in Canada,
- perspectives from all these stakeholders and discuss possible **action plans**.

# Federal Policy Dialogue (cont'd)

- **Survey/consultation** with parents
- **Consultation** with youth (focus group/voice elicitation).
- Policy Dialogue was a meeting with federal and provincial and territorial decision-makers to **discuss** these findings and perspectives from all these stakeholders and discuss possible action plans.

## Outputs and Impact

- Informed legislation – Accessibility Act 2019
- Two policy briefs
- Three research manuscripts (in preparation)



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# Canada's first federal accessibility legislation receives Royal Assent

From: [Employment and Social Development Canada](#)

## News release

June 21, 2019

Ottawa, Ontario

Employment and Social Development Canada

Every Canadian deserves the opportunity to participate fully in their community and workplace, and to have an equal chance at success. The Government of Canada developed the *Accessible Canada Act* to remove the barriers to inclusion persons with disabilities continue to face in society every day.

<https://www.canada.ca/en/employment-social-development/news/2019/06/canadas-first-federal-accessibility-legislation-receives-royal-assent.html>

# Annual Conference: Policy Forum

## Breaking down barriers: Informing Policy Through Research



 Children's Healthcare Canada

 kids brain health network

### Save the Dates!

Two Conferences - One Location

Children's Healthcare Canada  
Annual Conference  
December 8-10, 2019  
Ottawa, Ontario | The Westin

Kids Brain Health Network  
Annual Conference  
December 10-11, 2019  
Ottawa, Ontario | The Westin

- Communication of research findings to decision makers and stakeholders is critical in the development of policies
- A panel of decision makers and community stakeholders will discuss their perspectives on the role of researchers in informing policy development, including practical approaches for communicating evidence to decision makers.
- The session will explore approaches for communicating findings and reflect on the role of researchers and stakeholders in the policy development process.



**Thank you!**



[www.kidsbrainhealth.ca](http://www.kidsbrainhealth.ca)

# The WA Health Translation Network, WAHTN

**John Challis** PhD FRCOG FCAHS FRSC

Founding Executive Director WAHTN

University Professor Emeritus, University of Toronto

# WAHTN Objectives



- To increase the integration, efficiency, success and recognition of health and medical research across WA, nationally and internationally
- To enhance the translation of outcomes from health and medical research in WA into evidence based practice, policies and innovation opportunities
- To develop a suite of programs as enabling platforms that include enhanced communication strategies and consumer involvement

# NHMRC; Advanced Health Research and Translation Centre (AHRTC)

“leading centres of collaboration in health and medical research, research translation, research-infused education and training and outstanding health care” *July 2014*

“operating at an internationally competitive level”

*Consumer involvement was not embedded in the original government brief, but became a priority of the new national partnership, The Australian Health Research Alliance, AHRA, and was led by WAHTN.*



# WAHTN

Western Australian Health Translation Network

- WAHTN is a partnership (UJV) between
- All 5 Universities
- All 6 Medical Research Institutes
- All 5 State health Service Boards
- The 2 major Private Health Providers
- Dept of Health
- Office of Premier and Cabinet

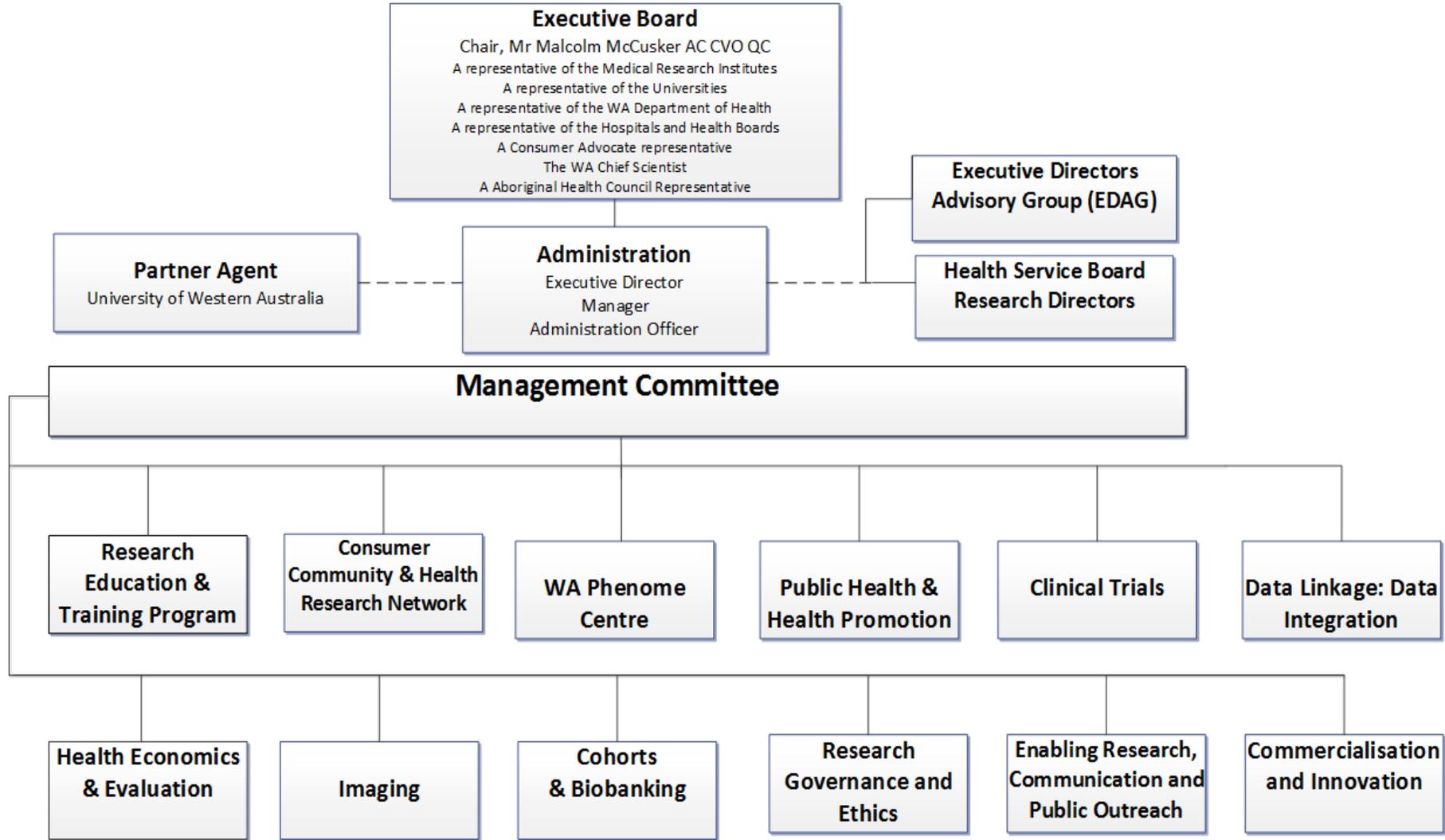


# WAHTN Principles



- *Catalyse*, new research, new initiatives
- *Facilitate*, conduct of translational health research
- *Unify*, partnerships and partners across the network

**Western Australian Health Translation Network – Organisation Chart**  
July 2016



# Welcome to



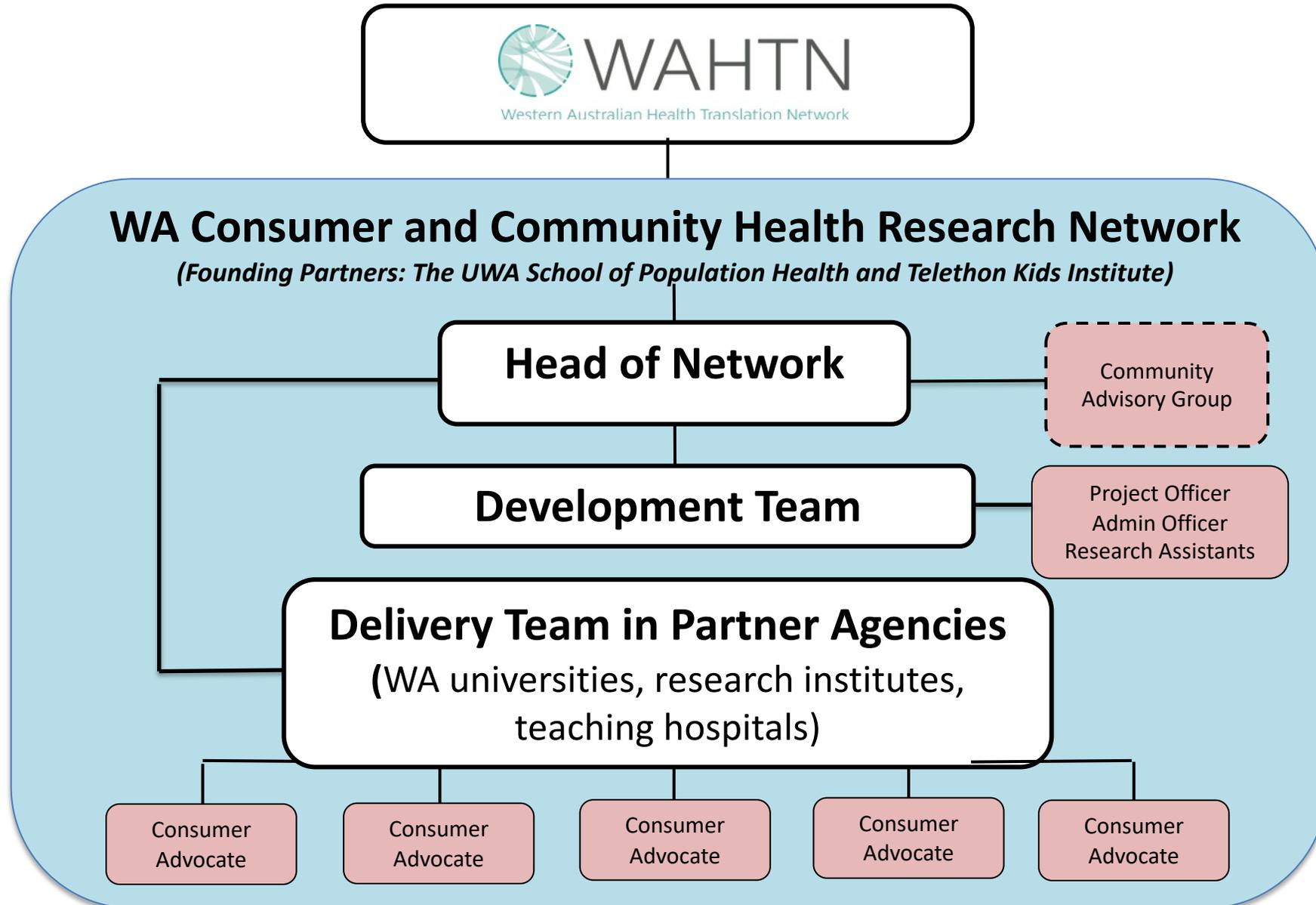
# SCIENCE ON THE SWAN

## Inaugural Conference 2015



## Hot Topics in Life Course and Development

# Our structure



## CCHRN Activities: July 2016 – June 2017



## CCHRN New activities: July – November 2017

- 11 Training workshops (3 x Tasmania, 2 x Sydney, 2 x Brisbane)
- 9 Community conversations (7 x Perth, 1 x Broome, 1 x Bunbury)
- 42 Grant applications supported with new involvement activities
- 1 National priority setting partnership project on FASD and Alcohol & Pregnancy

## THE CONSUMER AND COMMUNITY HEALTH RESEARCH NETWORK

The Consumer and Community Health Research Network is dedicated to enabling meaningful consumer and community involvement in health research. We facilitate and build capacity for researchers, consumers and community members to work in partnership together. Our key role is to:

**Bring together consumers, community members and researchers to make decisions about health research priorities, policy and practice.**

**Support consumer and community involvement to become standard practice in health research.**

**Promote the community 'voice' in health research through our services, resources, events and training programs.**

### ABOUT US

The Consumer and Community Health Research Network (previously known as the Consumer and Community Involvement Program) was established on 1st July 2016 with funding from Lotterywest. It is an enabling platform of the Western Australian Health Translation Network.

The University of Western Australia's School of Population Health and the Telethon Kids Institute founded the Consumer and Community Involvement Program in 1998, in response to community concerns raised by the Health Consumers' Council of WA about linked data research.

### WHAT WE DO

Provide researchers, consumers and community members with:

- Advocacy and support
- An evidence base
- Community links and networks
- Methods for involvement
- Resources
- Teaching and training

We have strong national and international links and collaborations with researchers, research organisations, government agencies and consumer organisations.



## INVOLVEMENT NETWORK

Established in 2012, the Involvement Network is a database of people who share an interest in consumer and community involvement in research. The Network was established to:

- Raise awareness of the value of consumer and community involvement
- Communicate information about events, training opportunities and hot topics
- Promote opportunities to be involved in research
- Provide a link between different groups
- Share the activities of the Consumer and Community Health Research Network

There are 1920+ researchers, consumers and community members currently registered on the Involvement Network.

## RESOURCES

An important aspect of the support we provide to researchers, consumers and community members is the range of resources we have developed. These are available through our website which also houses publications and other information:

[www.involvingpeopleinresearch.org.au](http://www.involvingpeopleinresearch.org.au)

## TRAINING

A core aspect of our Network is a suite of training workshops for researchers, consumers and community members on implementing involvement activities in research. Since 2007 we have facilitated 105 training workshops across Australia. Customised training workshops can be developed to meet specific needs of organisations.

Please contact Anne McKenzie to discuss opportunities for collaboration, training workshops or resource development.

 [ipir@telethonkids.org.au](mailto:ipir@telethonkids.org.au)

 +61 8 64888176 or  
 +61 8 94897742

 @InvolvingAus

 InvolvingAustralia

 @InvolvingAustralia

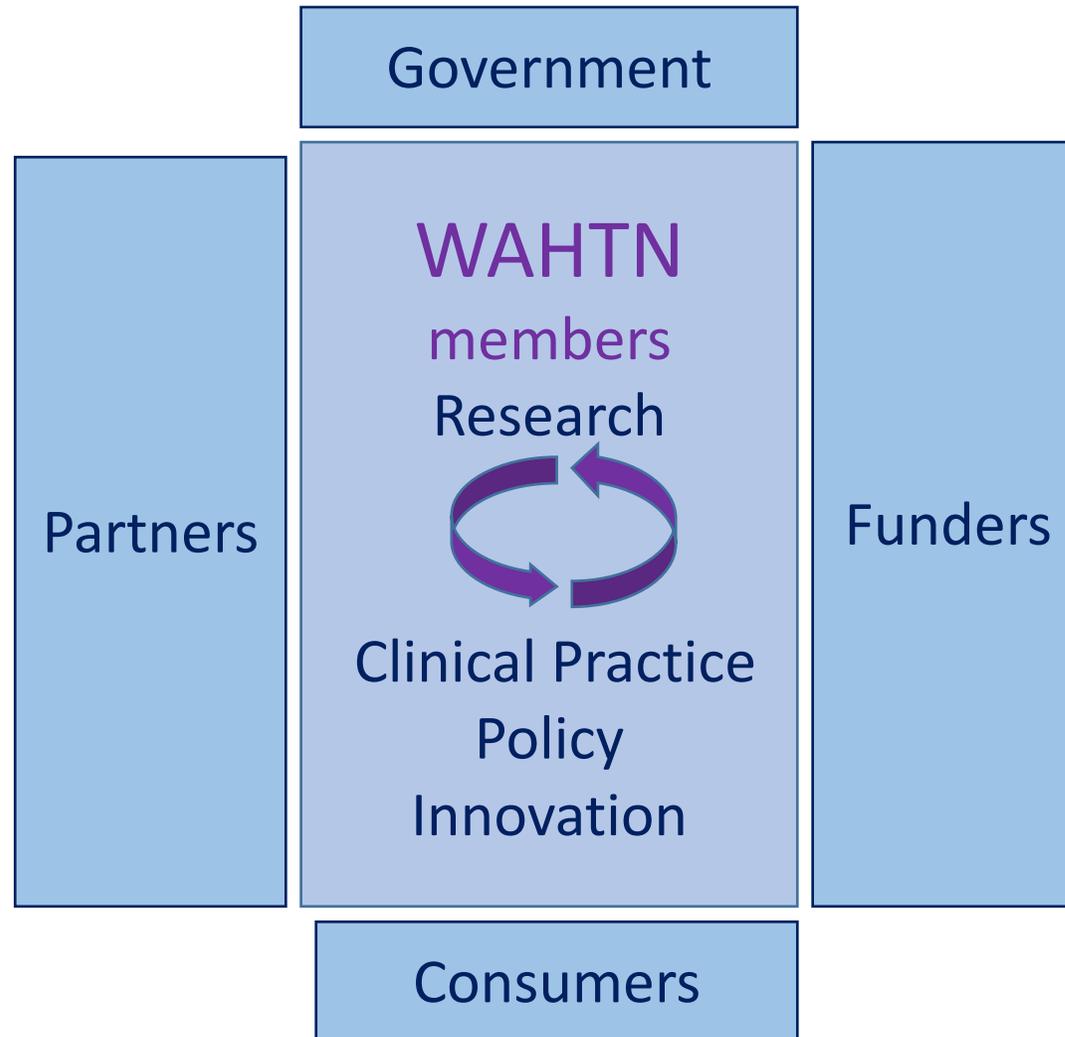


[www.involvingpeopleinresearch.org.au](http://www.involvingpeopleinresearch.org.au)

# Involving Consumers in Health Research

1. WAHTN is a facilitator, the “honest broker” to change the environment
2. WAHTN/CCHRN Advocacy Program
3. Consumers as members of research teams
4. Consumers as members of peer review panels (WACC)
5. Consumers on Clinical Trials Advisory committee
6. Cancer Research Trust, “Cancer perceptions and integrations program” (*\$6.5m+ over 5years*)

# WAHTN Context



# Western Australian Health Translation Network

Themes: **Life course and non communicable disease**

**Genetics and inherited diseases**

**Infection and Immunity**

**Public Health and Health Promotion**



People  
and  
Community

# Western Australian Health Translation Network

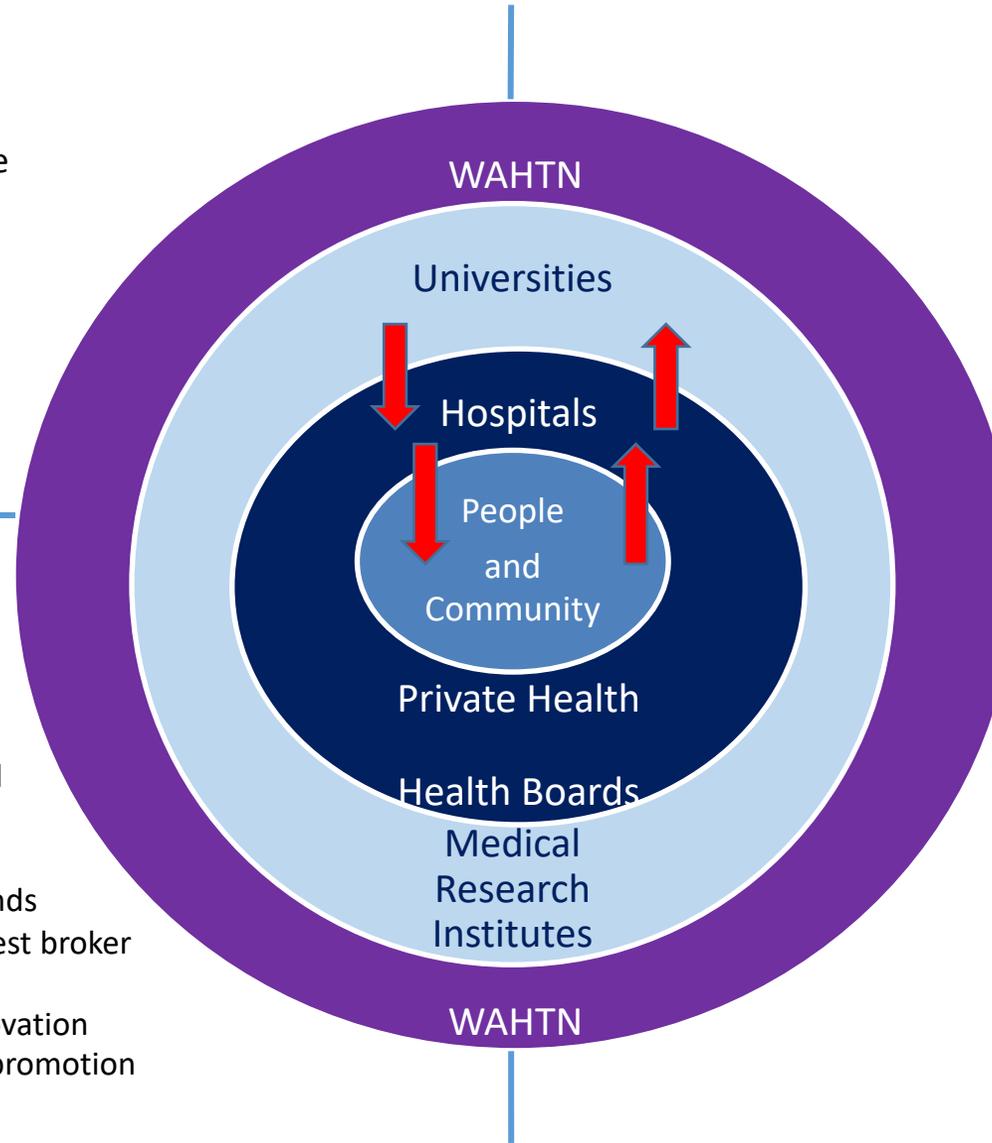
**Themes:** Life course and non communicable disease  
Genetics and inherited diseases  
Infection and Immunity  
Public Health

## Enabling People

- Interdisciplinary biozone
- Thematic Workshops
- Data Linkage
- Governance and Ethics
- Training and Funding
- National / International Networks
- Cross Cutting Platforms

## Building Translation

- Driven by Health Boards and Hospitals
- Integrating fundraising
- Changing the culture
- Integrating research and practice
- Clinical Trials Centre
- Integrate seminars; rounds
- Political credibility; honest broker role
- Commercialisation, innovation
- Evidence-based health promotion
- Foundations of success



## Promoting Research

- Advocacy
- Enabling Research
- Cohorts and Biobanks
- Imaging and big data
- Phenomics and other 'omics
- Infrastructure
- Web sourcing

## Ensuring Health Awareness

- End user engagement
- Consumer networks
- Aboriginal health
- Public health systems
- Precision medicine
- Preventing disease
- Economics and evaluation

# Measuring Success; Collaboration Cohort Diagram

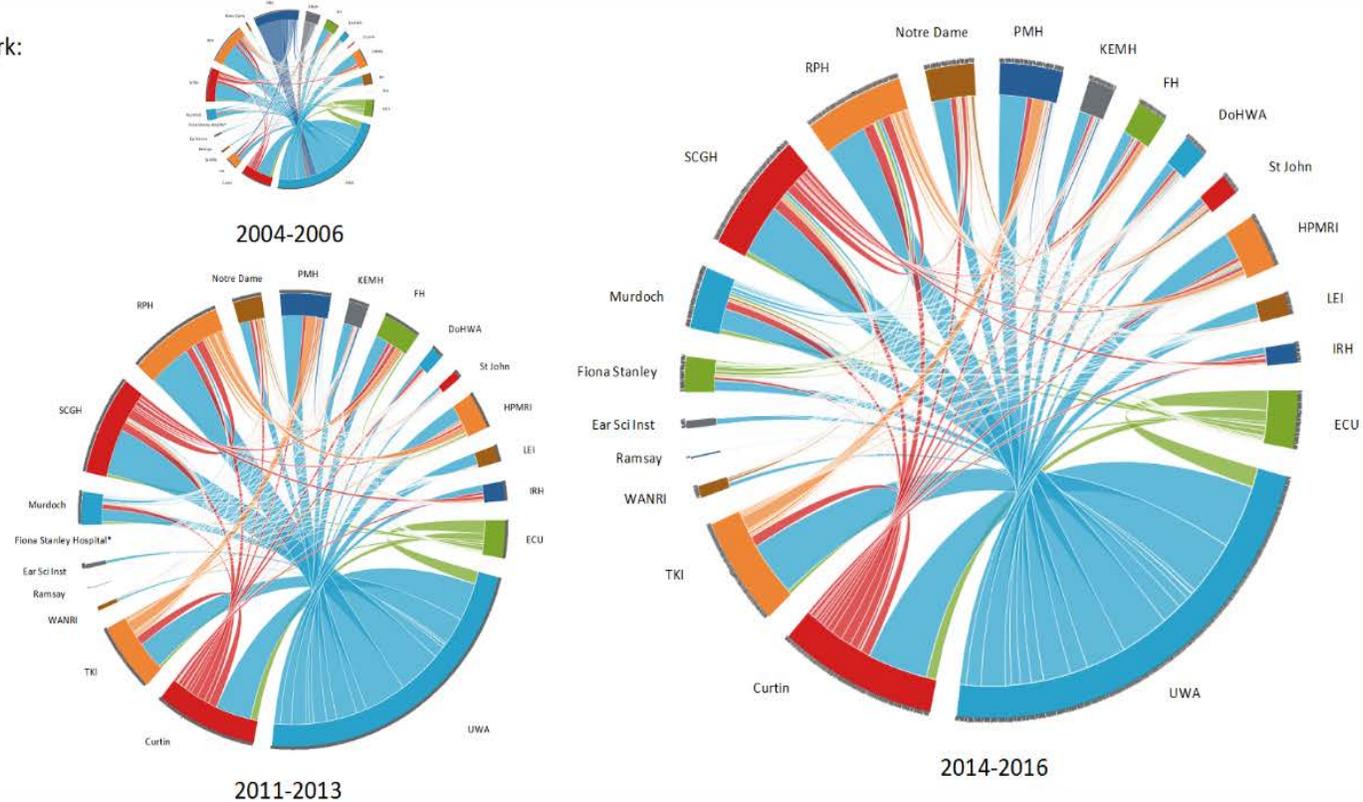
Western Australian Health Translation Network:  
Relative sizes of publication co-authorship

ECU	Edith Cowan University
UWA	The University of Western Australia
Curtin	Curtin University
TKI	Telethon Kids Institute
WANRI	Western Australian Neuroscience Research Institute
Ramsay	Ramsay Health Care
Ear Sci Inst	Ear Science Institute Australia
Fiona Stanley	Fiona Stanley Hospital
Murdoch	Murdoch University
SCGH	Sir Charles Gairdner Hospital
RPH	Royal Perth Hospital
Notre Dame	The University of Notre Dame Australia
PMH	Princess Margaret Hospital for Children
KEMH	King Edward Memorial Hospital for Women
FH	Fremantle Hospital and Health Service
DoHWA	Department of Health Western Australia
St John	St John of God Health Care
HPMRI	Harry Perkins Institute of Medical Research
LEI	Lions Eye Institute, Perth
IRH	Institute for Respiratory Health

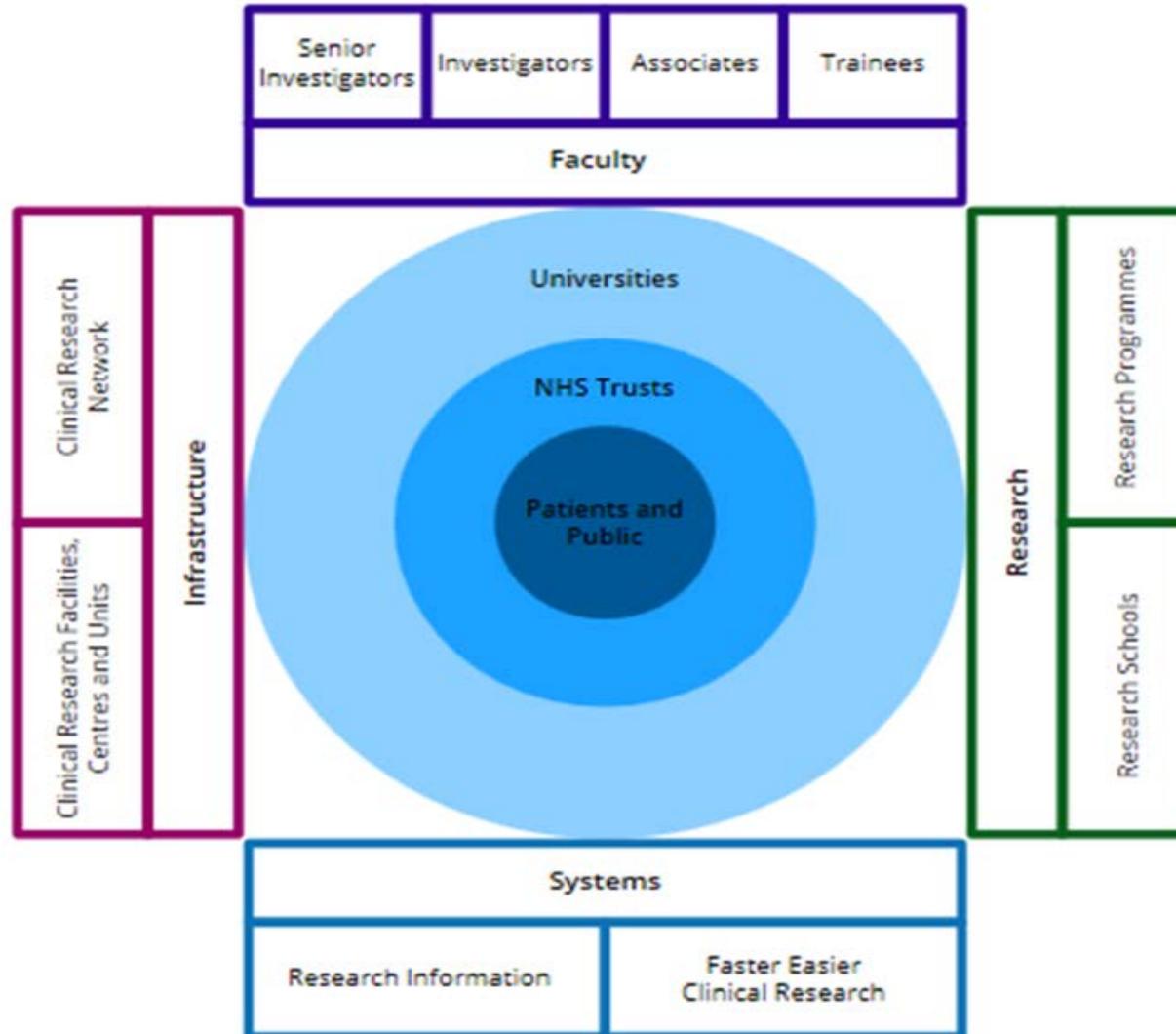
Data sourced from Scopus. Data sourced for 2014-2016 publication range on 7<sup>th</sup> November and 8<sup>th</sup> November, 2016. Data sourced for 2011-2013 publication range on 8<sup>th</sup> November, 2016 and 2004-2006 publication range on 9<sup>th</sup> November, 2016. Publication set limited to the following Scopus subjects: Medicine, Biochemistry, Genetics and Molecular Biology, Psychology, Nursing, Immunology and Microbiology, Neuroscience, Health Professions, Pharmacology, Toxicology and Pharmaceuticals, Dentistry.

\*No publications were found indexed in Scopus in the 2004-2006 and 2011-2013 publication ranges for Fiona Stanley Hospital.

Chord diagram circumference represents the collective total number of instances of co-authorship of each WAHTN member with other WAHTN members. Chord diagram size in this diagram is determined by the relative magnitude of the total number of instances of co-authorship counted for each publication range. The number of instances of co-authorship in 2011-2013 was approximately 2.5 times larger than for 2004-2006, and the number of instances of co-authorship in 2014-2016 was approximately 1.45 times larger than for 2011-2013.



# National Institute for Health Research (NIHR) UK



## Partners



## Associates



## Major Supporters



Jobs, Tourism, Science and Innovation



## Four Themes of Activity

Major themes of health research translation across partners in WA include;

- **life course and non-communicable disease**, with emphasis on development, maternal, child and youth health, respiratory science, cardiometabolic diseases, cancer, ageing; neuroscience; and mental health;
- **genetics and inherited diseases**, with emphasis on muscular dystrophies, neuromuscular and neurodegenerative conditions, eye, ear, respiratory and kidney diseases, prevention of genetic diseases; stem cells and regenerative medicine
- **infection and immunity**, with emphasis on Helicobacter, asthma, immune disorders, ischemic heart disease, vaccine development, blood pathologies and emergency medicine;
- **public health**, with emphasis on, primary and rural health care, disease prevention, health promotion and wellness, aboriginal health and culture, exercise, psychology, nursing, allied health professions, rural and remote health and new health care systems.

