



The power of people to promote authentic involvement and partnership

Professor Catherine Elliott
Dr Ashleigh Thornton

Telethon Kids Institute acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the land and waters of Australia. We also acknowledge the power of people to promote authentic involvement and partnership Nyoongar Wadjuk, their Elders, their people and their land upon which Telethon Kids Institute is located, and the Sami people of Norway. We seek their wisdom in our work to improve the health and development of all children.



Proudly supported by the people of Western Australia through Channel 7's Telethon



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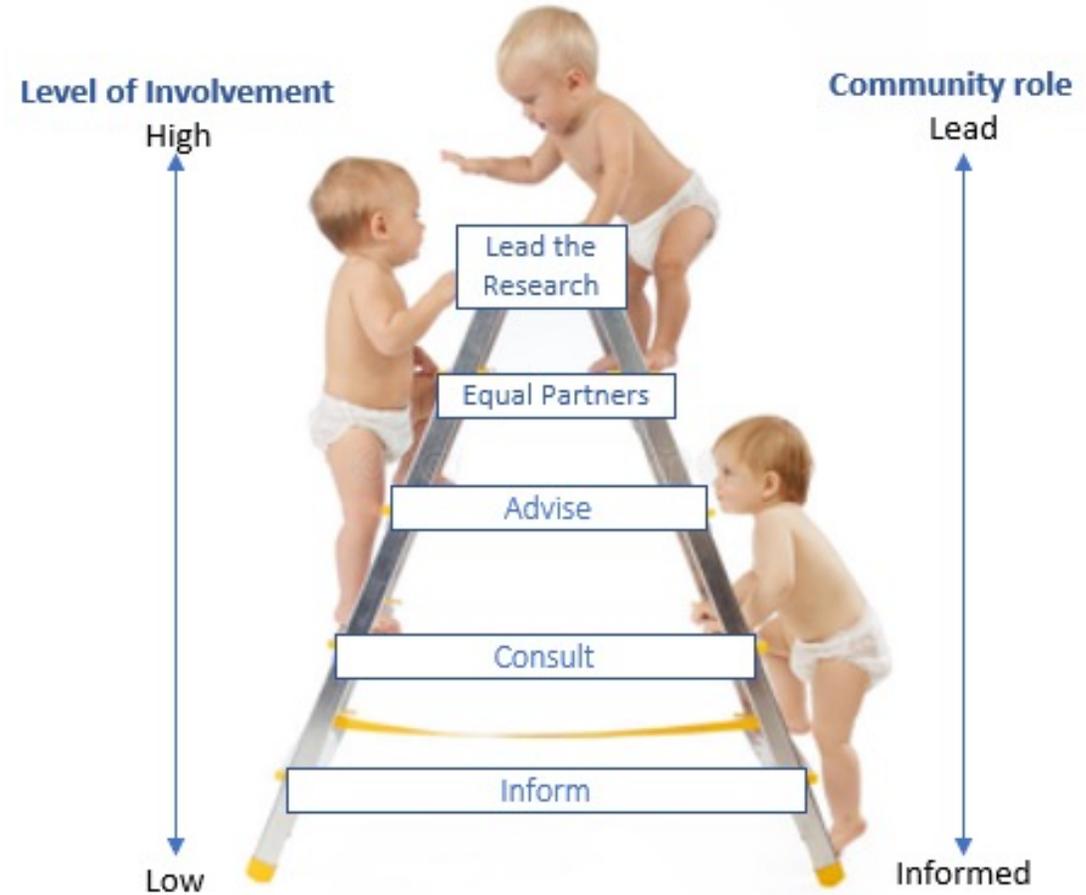


Planning research

Research Design



Consumer Involvement



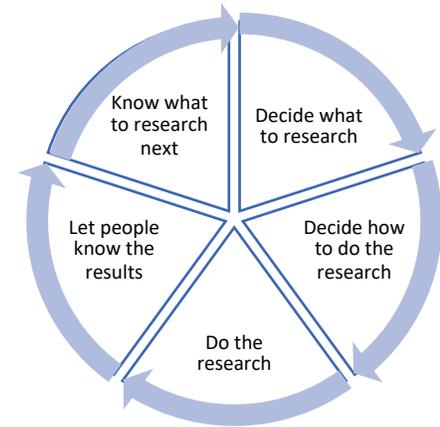
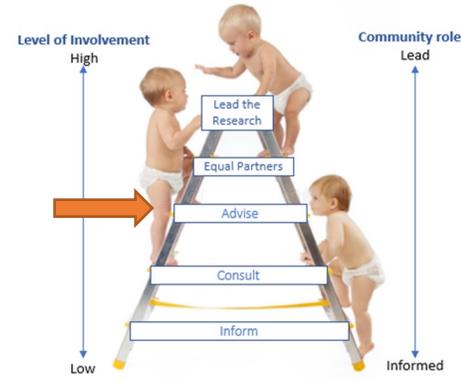


Enabling physical activity participation for children and youth with disabilities: A knowledge-to-action approach

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"Through participation, we acquire skills and competencies, connect with others and our communities and find purpose and meaning in life"
World Health Organisation



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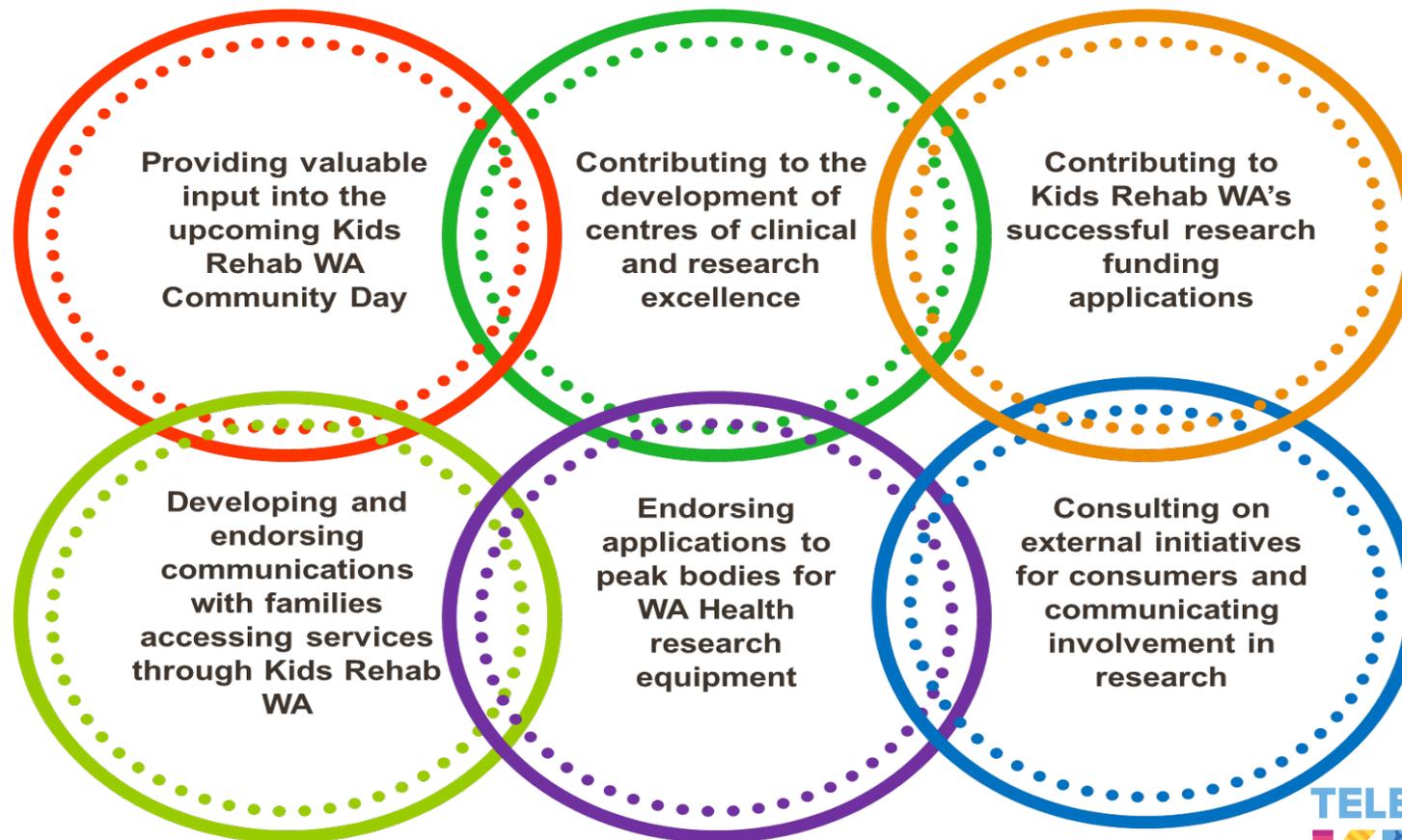
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Hospital**

 **BEITOSTØLEN
HELSESPORTSENTER**



Kids Rehab WA Consumer Reference Group



ParticiPAte CP

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Research Fellow, The University of Queensland Child Health Research Centre

Implementation Project Manager, Cerebral Palsy Alliance

Project team:

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Modifiable barriers Strategies chosen

Motivation, self-efficacy, confidence

- Motivational interviewing
- Scaffolded participation for success and self-efficacy
- Promoting social connection

Knowledge, service availability, community attitudes, equipment/funding

- Provision of information
- Equipment prescription
- Site visits
- Stakeholder partnership

Activity capacity, body structures and functions

- Sport specific skills training
- Motor learning strategies/CO-OP approach
- Balance/strength/endurance training

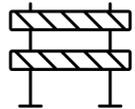




Key elements of intervention



Collaborative goal setting with children and their caregivers on leisure time physical activity goals



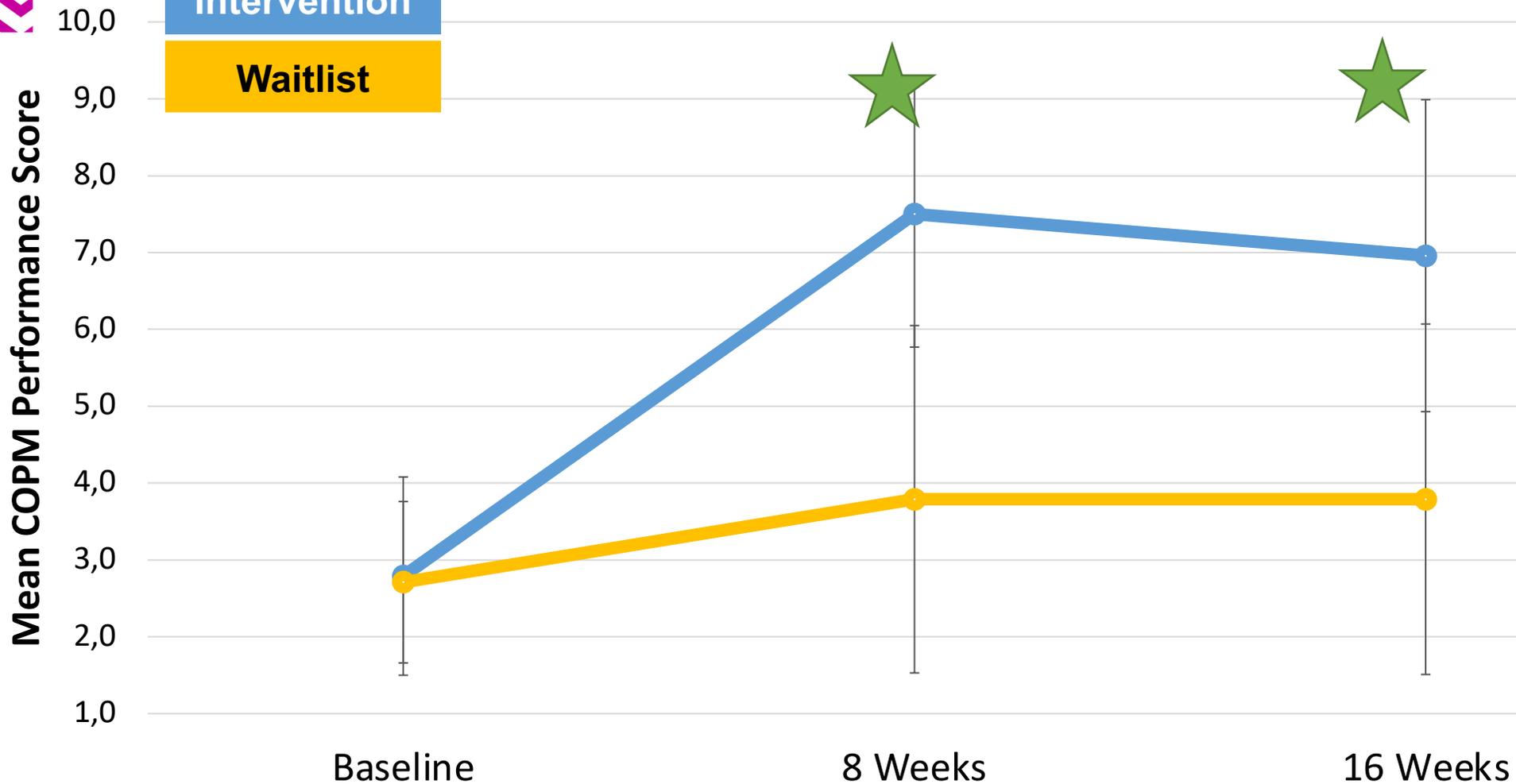
Identify child and family specific barriers to these goals across all life areas/domains



Apply clinical reasoning to address barriers using client-centred, problem-solving communication and functional goal-directed training where indicated

Results: Canadian Occupational Performance

Measure



Adjusted Mean difference at 8 weeks
 = 3.58 (2.19, 4.97)
 $p < 0.0001$

Maintained at 16 weeks
 = 3.02 (1.66, 4.38)
 $p < 0.0001$

MCID for COPM
 = 2 points (Law et al. 2014 COPM manual)

ParticiPAtE CP

DIRECT: 1 hour per week for 8 weeks = 8 hours



build intrinsic motivation through autonomy-support and self-determination for:

using a:

TOOLBOX APPROACH

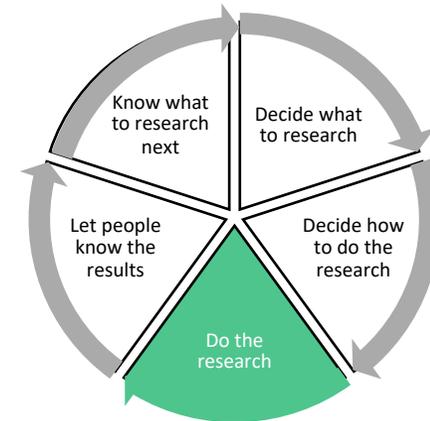
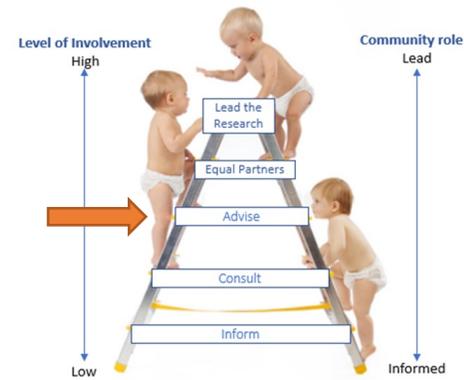


ParticiPAtE CP: Multisite RCT



Goal:

Create an individually tailored, goal-directed intervention model of pragmatic participation-focused therapy using a toolbox approach of evidence-based strategies in the treatment of children with cerebral palsy.

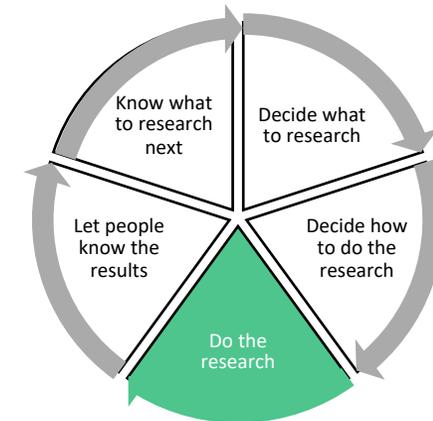
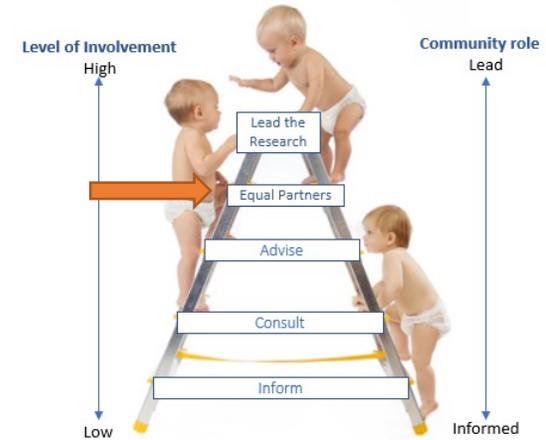




Move to Improve: Prescribing 'exercise as a medicine' in sick children

"When I'm out in the water and I'm surfing, I feel like I'm more free. My body feels stronger, more in control of things. When I have freedom, I feel like I can be myself and when I can be myself, I can be most happy."

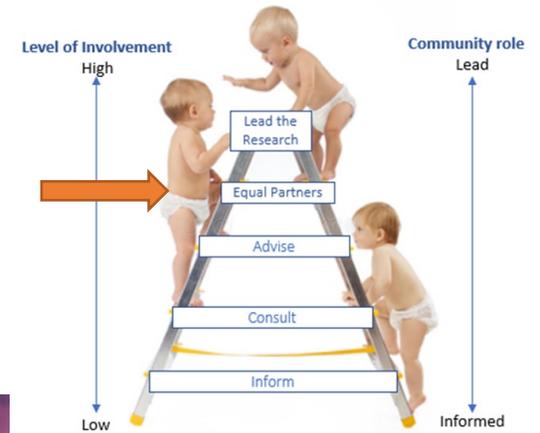
Mary, study participant





TELETHON KIDS CONNECT

THE COMMUNITY VOICE IN RESEARCH



Teletthon Kids CONNECT honours the many ways our community supports us to make our research great and achieve our vision of happy healthy kids.

There's a lot to be proud of and celebrate – our community plays an important role in what we do, how we do it, and what we achieve.





Telethon Kids Institute: Thinking Big!

Goal: Develop a set of community priorities to inform future research to improve child health, development and wellbeing.

Method: James Lind Alliance Priority Setting Partnerships



Current status: We are currently refining questions from answers to ‘What are the most important issues facing you, your family and community today?’

Climate change

- Inaction
- Global impact

Health

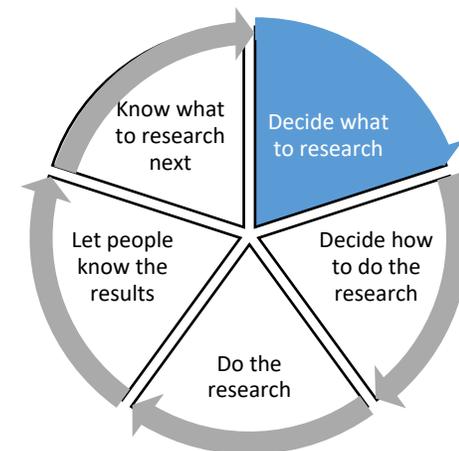
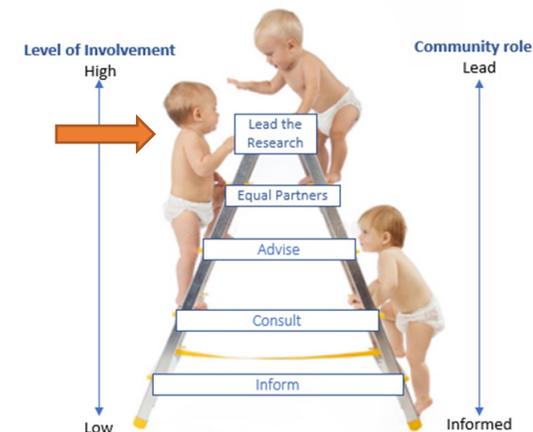
- Mental health challenges
- Accessible health care

Support for caregivers

- Use care systems
- Learn parenting skills

Financial difficulties

- Secure employment
- Rising cost of living





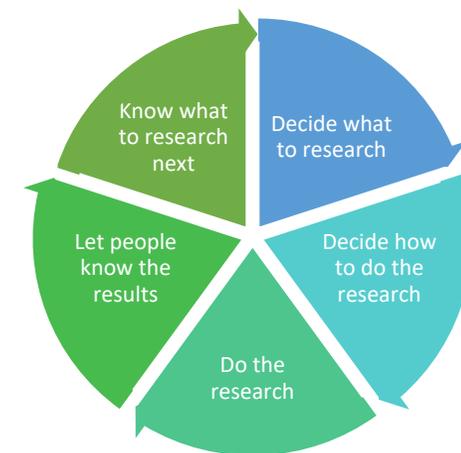
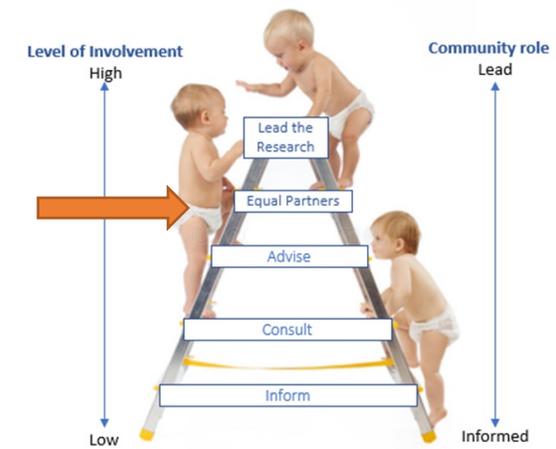
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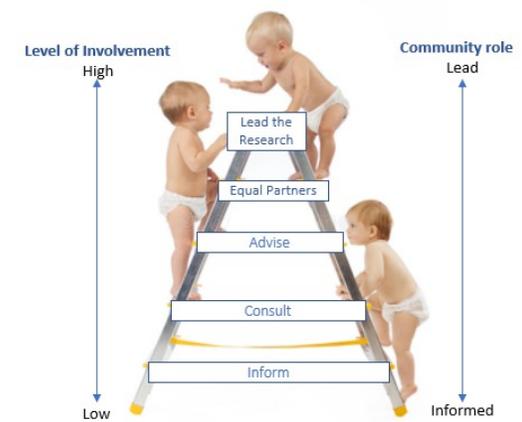
Bush Tucker and Vitamin D



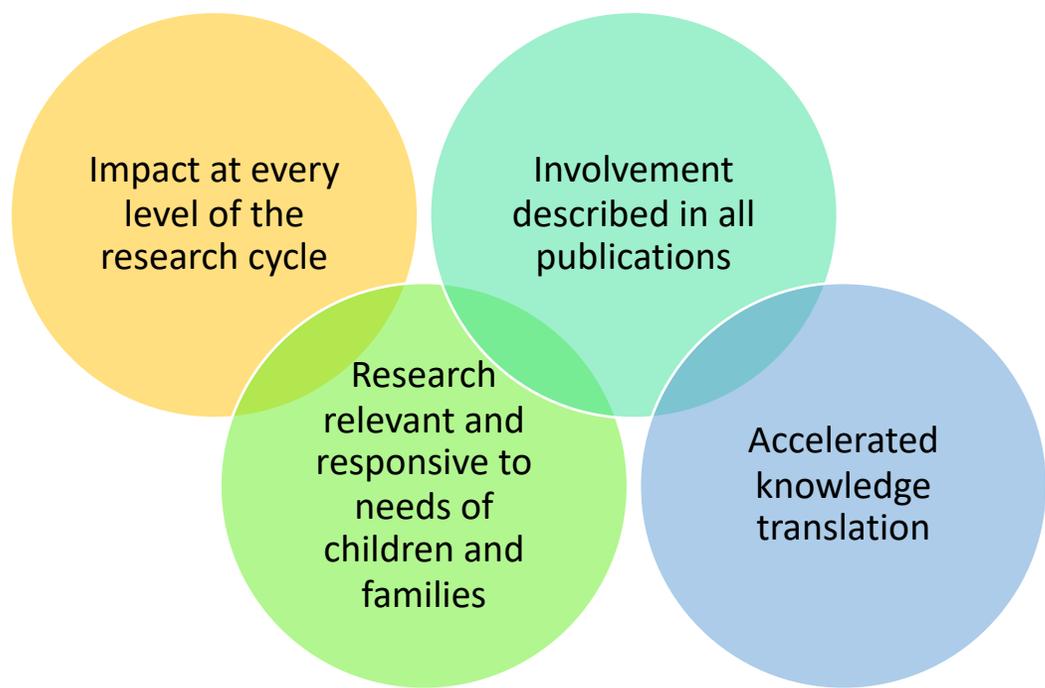


The impact of consumer involvement

Willis, C., et al. (2017) Elements contributing to meaningful participation for children and youth with disabilities: a scoping review. *Disabil Rehabil*, 39(17), 1771-1784.
Thompson, M., et al. (2016). Can, want and try: parents' viewpoints regarding the participation of their child with an acquired brain injury. *PLoS one*, 11(7), e0157951.



"I felt like I could relate to every single statement as I know we have experienced each one of those"
Study participant



Consulting with stakeholders

Our research team recognised the importance of involving consumers and the community in the research process, employing a steering group to guide all aspects of this review and the broader project it was designed to inform. Although described as an optional step,[29] consultation with stakeholders occurred throughout the analysis and reporting of this review to validate findings and inform further stages of our research. Stakeholders included an adolescent with a disability, parents of children and adolescents' disabilities, a disability policy-advisor, clinicians working with children with disabilities in hospital and community settings, and representatives from non-government advocacy and support organisations in the community. Given that the outcomes of this review may be of particular interest to practitioners, community organisations and parents, we viewed consultation as an integral component of ensuring the richness of the research process and the translation of results.

