

QUOKKA RESEARCH PROGRAM

Quality Of Life in Kids: Key evidence to strengthen decisions in Australia



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How is evidence on pediatric HRQoL used in estimating QALYs and in decision making in principle?



Paediatric Health-Related Quality of Life (HRQoL) measure (e.g. EQ-5D-Y, CHU9D) comprising questions about various aspects of health & quality of life

Measure child health with the instrument (self-report or proxy)

Value (on scale anchored at 0 (dead) and 1 (full health) each health state described by the PRO, using stated preference methods

Apply the values to health states reported by children/their proxies, to produce 'utilities'

Length of life x utility = quality adjusted life years (QALYs)
The effects of treatment = change in QALYs

Decision-makers use evidence on cost per QALY gained to allocate resources, making trade-offs between interventions for children & adults, & across diseases

Challenges currently facing use of pediatric HRQoL instruments

“Do child QALYs = adult QALYs?” Five reasons why they might not”

1. WHAT IS BEING MEASURED?
HOW IS IT DESCRIBED?

2. HOW DO RESPONDENTS REPORT HEALTH PROBLEMS?

3. HOW ARE THE PROBLEMS REPORTED ON THE PREFERENCE-WEIGHTED?

4. HOW ARE THE UTILITIES COMBINED WITH LENGTH OF LIFE IN ESTIMATING QALYS?

5. HOW ARE QALYS USED IN DECISION MAKING?



RATIONALE

- Approaches to measuring and valuing health-related quality of life (HRQoL) widely used and accepted in adults are problematic when applied to children
- Methods conventionally used to value adults' HRQoL do not work well in valuing paediatric HRQoL & preclude asking children for their views.
- Given these problems, there has been low uptake of these tools in the evidence used to inform healthcare decisions.
- **The resulting gap in evidence risks significant misallocation of funds,** potentially denying access to effective and cost-effective paediatric interventions.
- MRFF Targeted Health System and Community Research Grant Opportunity Call (December 2019)

AIM OF THE RESEARCH

To strengthen tools and evidence on health outcomes in paediatric populations for use in decision making

The research draws on and develop cutting-edge international research to produce improved approaches to measuring and valuing child health outcomes.

The research will:

- Improve ways of seeking child self-reported HRQoL, and better ways of handling proxy reporting
- Find better ways of obtaining values for paediatric HRQoL - including the possibility of seeking children's own perspectives
- Address fundamental issues regarding the way decision makers 'weigh up' health outcomes for children and adults when making decisions about budget allocations and setting priorities for paediatric interventions



RESEARCH PROGRAM OVERVIEW

Project 1: Generating a comprehensive database of patient-level data to understand the performance of alternative pediatric HRQoL measures.

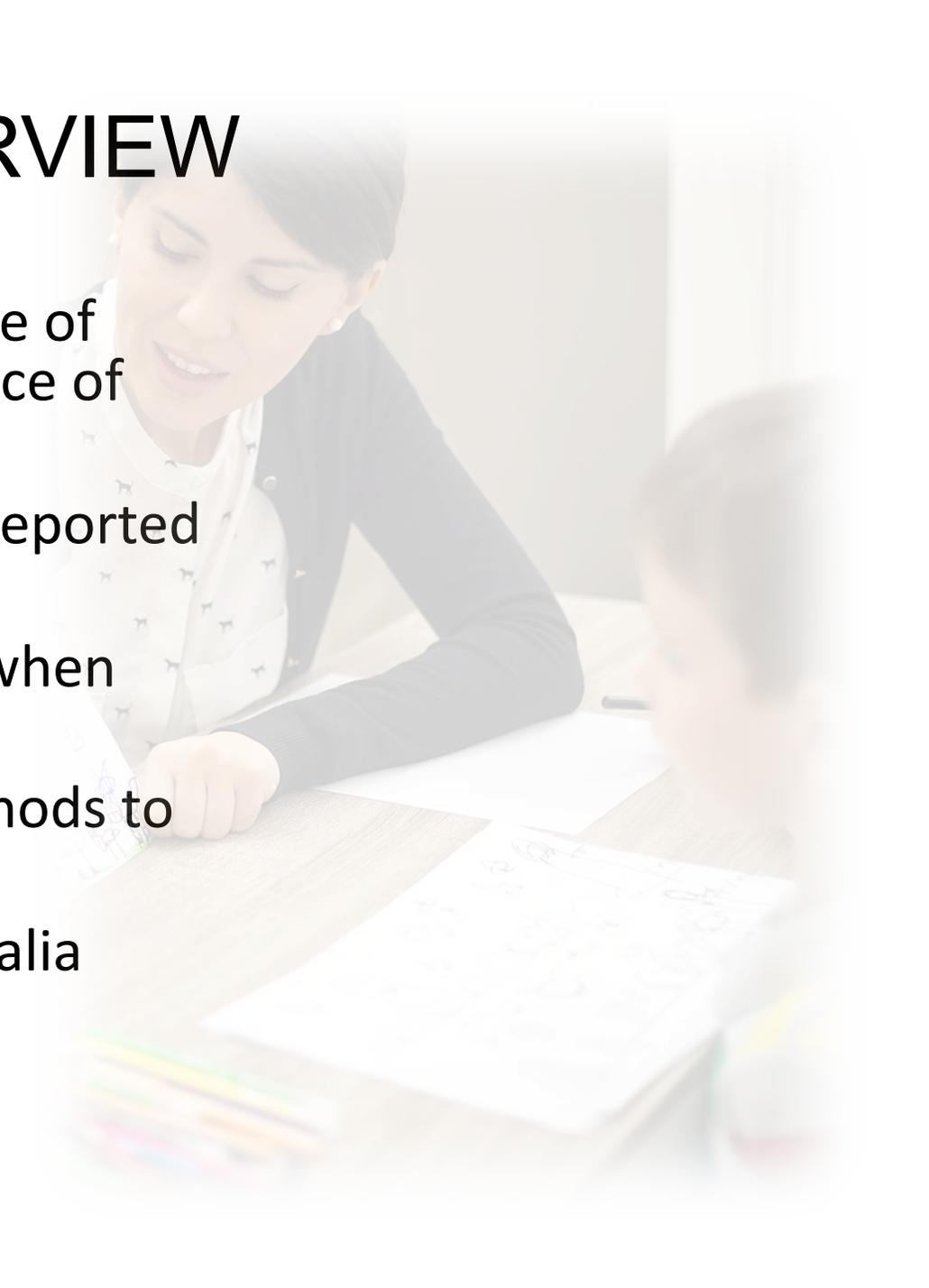
Project 2: Strengthening self-report and proxy-reported measurement of pediatric HRQoL

Project 3: Exploring how people make choices when valuing pediatric HRQoL

Project 4: Improving preference elicitation methods to value pediatric HRQoL

Project 5: A pediatric HRQoL value set for Australia

Project 6: Do child QALYs = adult QALYs?



PROJECT OUTPUTS & KEY DECISION MAKERS

Project	Output	End-Users	What decisions will be improved?
1	Project kick-off: Documenting the current state of play	<ul style="list-style-type: none"> Federal & State Government decision-makers including PBAC and MSAC Children & their families Private industry Health care providers Paediatric researchers 	<ul style="list-style-type: none"> Reimbursement of child health services that represent good value for money Better understanding of the effectiveness of paediatric interventions in improving aspects of HRQoL that matter to patient and families
	Creating a comprehensive database of patient-level data to understand the performance of alternative paediatric HRQoL measures		
2	Strengthening self-report and proxy-reported measurement of paediatric HRQoL		
3	Exploring how people make choices when valuing paediatric HRQoL		
4	Better methods for valuing paediatric HRQoL		
5	Producing new paediatric HRQoL value sets		
6	The use of child and adult QALYs in decision making		

Science vs. Value judgements in measuring and valuing pediatric HRQoL: involving decision makers and consumers in our research



Final choices about methods to value paediatric HRQoL unavoidably involve making value judgements

- For example: should values for paediatric HRQoL be based *only* on opinions of the adult general public (as is conventional) or also include childrens' views and preferences? And while research can tell us whether adults valuing the HRQoL of a 12-year-old give higher/lower values than when valuing HRQoL for a 5-year-old, if we *do* observe a difference in values, a value judgement is needed to decide whether to produce *one* value set covering *all* children, *or* different value sets for specified age ranges.
- These are non-trivial questions which empirical research alone cannot resolve.
- A **Decision Makers' Panel (DMP)** and a **Consumer Advisory Group (CAG)** have been established to ensure that outputs from our research, and all methods choices that require judgement, appropriately reflect a range of important perspectives.
- The DMP and CAG meet quarterly, where results, plans and key questions are presented for deliberation and input. DMP and CAG input into dissemination planning will also be sought to maximise impact.

CONTACT US

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