



# HOW CAN WE COLLECT AND USE THE EQ-5D-Y-5L IN ROUTINE PAEDIATRIC OUTPATIENT CLINICS TO MEANINGFULLY IMPACT CHILDREN'S CARE? CO-DESIGN OF THE P-PROM ROCK TRIAL.

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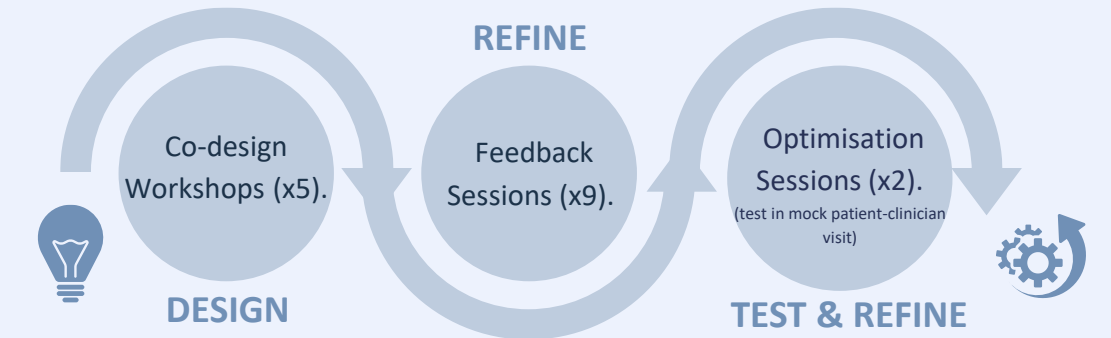
## OBJECTIVE

To co-design use of the EQ-5D-Y-5L, a Paediatric PROM (P-PROM), in Routine Outpatient Care for Kids (ROCK), to maximise its impact on individual patient-clinician visits.

## METHODS

**Co-design:** Informed by co-design framework for public service design (Trischler et al 2019) & Double Diamond design process (Design Council. 2015).

**Participants:** Service providers, adolescents, & caregivers with lived experience of providing or receiving tertiary outpatient care (hospital based office visits) at The Royal Children's Hospital, Melbourne, Australia.



## RESULTS

- **Adolescent patients** (n=2)
- **Caregivers of patients** (n=3),
- **Service providers** (n=11), including doctors (n=4), nurses (n=3), & EMR specialists (n=4).

### EXAMPLE CLINICIAN DISPLAY, INCLUDING ALERTS AS IDENTIFIED BY PATIENT/CAREGIVER:

Questionnaires	
EQ-5D-Y-5L, General Health Tracking Questionnaire	
	19/02/24 12:54PM AEST
Question	Filled by child/patient
Who will fill out the questions today?	Child or patient
Question	
MOBILITY	No problems walking around
LOOKING AFTER MYSELF	No problems washing or dressing self
DOING USUAL ACTIVITIES	Some problems doing usual activities
HAVING PAIN OR DISCOMFORT	No pain or physical discomfort
FEELING WORRIED SAD OR UNHAPPY	Quite worried, sad or unhappy
YOUR HEALTH TODAY (range 0 [0-the worst health imaginable] - 100 [100-best health imaginable])	86
Thinking about the questions you have just answered, which of these would you like to talk to your doctor/nurse about at your upcoming appointment?	<b>DOING USUAL ACTIVITIES!</b>

### CO-DESIGNED P-PROM ROCK PROGRAM:

#### CLINICIAN SUPPORT TO USE EQ-5D-Y-5L IN PATIENT-CLINICIAN VISIT:

Resources for Urgent Concerns (1 pg resource, QR code S5).  
Decision Support Tool (1 pg resource, QR code S5).

#### PATIENT & CAREGIVER SUPPORT AFTER COMPLETING EQ-5D-Y-5L:

Patient resources for concerns (2 pg flyer, QR code S4).  
Caregiver resources for concerns (2 pg flyer, QR code S4).

#### SCORE & DISPLAY EQ-5D-Y-5L TO PATIENTS, CAREGIVERS & SERVICE PROVIDERS:

Display in a table (using item & level wording - QR code S3) & display multiple responses in a line graph over time (higher = better).  
System for patients to flag responses that require action (QR code S2).

#### INTEGRATION OF EQ-5D-Y-5L INTO PATIENT FLOWS & CLINICIAN WORK FLOWS:

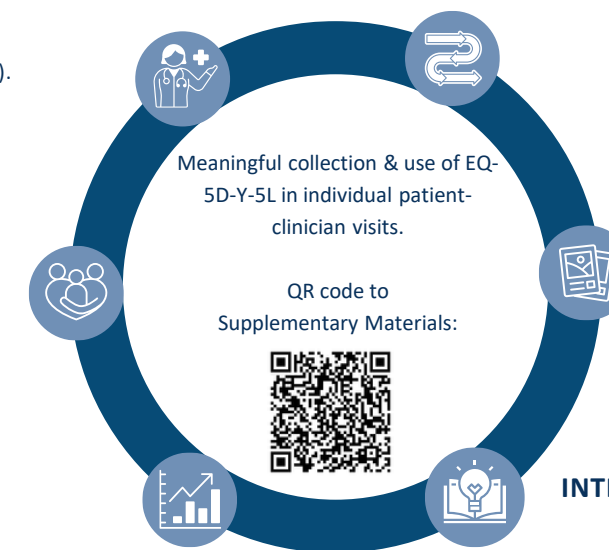
Journey map (patient journey and clinician workflow with EQ-5D-Y-5L, QR code S1).

#### EDUCATE CLINICIANS ON USING THE EQ-5D-Y-5L IN CLINICAL CARE:

Clinician training (60 minute group training).

#### INTRODUCE PATIENTS & CAREGIVERS TO USING THE EQ-5D-Y-5L IN CLINICAL CARE:

Information package prior (flyer & video).  
Introduce as 'general health tracking questionnaire'.



EVALUATION OF CO-DESIGNED PROTOTYPE IN A WAY THAT IS MEANINGFUL TO STAKEHOLDERS

## CONCLUSIONS

**Working together:** Feasible & essential to get deep engagement from all participant groups.



**"If we ask, we need to act":** EQ-5D-Y-5L information needs to be used meaningfully in individual patient-clinician visits.



**Supports for use:** Families & clinicians want & need supports, including education, training & resources.



**Scoring in clinical settings is different to other contexts:** Summarising into a single score was seen as removing meaning.



**Positively framed displays:** Patient displays should not be negatively framed. No traffic light colours & not to look like school report.



**Next steps:** Usefulness of co-designed program will be tested in a randomised controlled implementation trial.