"If we ask, we must act": Co-designing the implementation of the EQ-5D-Y-5L as a Paediatric Patient Reported Outcome Measure (P-PROM) in Routine Outpatient Care for Kids (ROCK) to meaningfully impact clinical visits (Phase 2).

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Abstract

Background: Routinely collecting Patient Reported Outcome Measures (PROMs) in clinical settings does not guarantee usefulness in patient-clinician visits. This study aimed to co-design use of the EQ-5D-Y-5L, a generic Paediatric PROM (P-PROM), in Routine Outpatient Care for Kids (ROCK), to maximise impact on patient-clinician visits. This study also aimed to reflect on the co-design process.

Methods: Co-design methodology was utilised, involving data collection via facilitated co-design workshops, feedback sessions, and optimisation sessions. Data collection was guided by the seven-step co-design framework for public service design, and the Double Diamond model for facilitation. Eligible participants included service providers (allied health staff, electronic medical record analysts, doctors and nurses), adolescents, and caregivers with a lived experience of providing or receiving paediatric outpatient care at the largest tertiary paediatric hospital in Australia.

Results: Five co-design workshops were conducted, including two workshops with a mixed group of service providers (n=9), adolescents (n=2) and caregivers (n=3), and three workshops with only service providers (n=4). Nine feedback and two optimisation sessions were also conducted. To engage families in completing the EQ-5D-Y-5L, resources were designed that introduced the EQ-5D-Y-5L as a 'general health tracking questionnaire' rather than a quality-of-life questionnaire. These resources also explained why and how their responses would be used. Participants designed EQ-5D-Y-5L responses to be displayed back by item, using item wording rather than a numerical score. A display of results over time was also developed, where higher scores reflected better health. A process was designed where the patient or caregiver could alert their clinician to EQ-5D-Y-5L item(s) for discussion. Resources to support the use of EQ-5D-Y-5L responses in patient-clinician visits were also designed, including clinician training, a clinician decision support tool, and resource pathways. These design elements were combined into a final prototype, known as the P-PROM ROCK program.

Conclusion: Engaging patients, caregivers, and service providers in the design process was feasible and essential to generating a user-centric P-PROM program. EQ-5D-Y-5L information collected as part of clinical care warrants clinical review and action. Consequently, supports are needed to ensure patients and service providers feel supported to act on this information. Additionally, displays and dashboards including EQ-5D-Y-5L responses should be engaging and avoid negative framing.

Visual abstract available online: https://tinyurl.com/PPROM-ROCK

Introduction

Patient Reported Outcome Measures (PROMs) are standardised tools used to understand a patient's health, functioning, or quality of life from their perspective.(1) Paediatric PROMs (P-PROMs) are specifically designed for use by children and young people.(2) Where possible, P-PROMs are reported by the child themselves (child self-report) however, where the child is too young or not able to self-report, P-PROMs may be reported by the caregiver or parent (caregiver/parent proxy report).(3) PROMs can be used in a range of contexts, including routine clinical care, population health research, clinical trials and registries, and health technology assessment.(1, 4-6) While the use of PROMs in research and health technology assessment is well established, their use in routine clinical care is more recent.(4, 7) PROMs can be a way to support patient-centred clinical care, by systematically bringing the patient's perspective to the clinical visit.(4, 7) When PROMs are implemented with the purpose of improving the patient-clinician visit, PROM data can improve communication, decision-making, patient engagement, and satisfaction within individual patient-clinician visits.(4, 8) PROM data can also be used at the health system level to inform quality improvement and policy decisions.(4) Despite some uptake and evaluation of PROMs in adult clinical care, there has been limited uptake in paediatrics. A 2018 systematic review aiming to assess randomised controlled trial (RCT) evidence on the effectiveness of PROMs in clinical care identified 22 studies, of which only two were paediatric.(9) A 2020 systematic review that included a broader array of study designs identified only seven studies investigating the impact of P-PROMs in paediatric clinical care.(10) These systematic reviews highlight the lack of PROM research in the paediatric clinical care space.(9, 10)

P-PROMs can be condition-specific or generic, and each has different benefits when used in routine clinical care.(7) Condition-specific P-PROMs measure aspects of health relevant to that condition, and may have more face validity to patients (i.e., the questions can seem more applicable).(4, 7) Importantly, they can only be used in that specific condition population and can be lengthy.(7) Generic P-PROMs have a wider application, as they measure aspects of health common to most children and can be used in any paediatric population.(7) Consequently, they can prove easier to implement systematically across a health system and produce data that can be aggregated and compared across populations.(4) Despite these benefits, there is limited evidence regarding how a generic P-PROM can be collected and used to meaningfully impact patient-clinician visits in routine paediatric care. Of the seven studies identified by the Bele et al systematic review, all had trialled a generic P-PROM; in five of these, the 23-item PedsQL was used.(10) Given the range of generic P-PROMs now available,(2) as well as further evidence becoming available on the comparative performance of these generic P-PROMs,(11) other shorter generic P-PROMs should be explored for their potential use in paediatric clinical care.

Evidence suggests that P-PROMs with fewer items and with good measurement properties could lead to improved response rates and lower patient burden when used in routine clinical care.(1, 12) The EQ-5D-Y-5L is a short generic P-PROM with 5-items. It has been shown to be easy and quick to complete, with a sample of 759 hospital patients or their proxy caregivers completing the EQ-5D-Y-5L in a median time of 36.6 seconds.(11) Recent evidence from a paediatric multi-instrument study comparing the performance of common generic P-PROMs in over 6,000 Australian children, identified the EQ-5D-Y-5L as having one of the strongest psychometric performances across a range of childhood conditions.(13) Although the EQ-5D-Y-5L has not been trialled in routine clinical care, the adult version of the instrument, the EQ-5D-5L, has been found feasible for use in routine clinical care.(14) Furthermore, in principle, the instrument can be used to estimate quality adjusted life years, to support economic evaluation of paediatric interventions. Given these potential advantages combined with the availability of funding support, the EQ-5D-Y-5L was selected as the instrument to explore in P-PROM ROCK.

Phase 1 of P-PROM ROCK qualitatively explored patient, caregiver and service provider perspectives regarding the potential use of EQ-5D-Y-5L in routine clinical paediatric care.(15) The study identified that although stakeholders are supportive of using a generic P-PROM such as the EQ-5D-Y-5L, simply collecting the EQ-5D-Y-5L was considered unlikely to have a meaningful impact on care.(15) Stakeholders highlighted that careful consideration is needed to ensure families are supported in completing EQ-5D-Y-5L prior to their clinical visit and emphasised that service providers need to be equipped to use and act on data captured.(15)

EQ-5D instruments can be scored in a range of ways.(16) They can be combined into a single score using a level sum score approach, where each item level is attributed a number between 1 and 5, and the responses to each item are summed together.(17) They can also be accompanied by preference weights, where either the general public or, more recently, individuals,(18) can weigh the different items and levels. These weights can then be used to create a single utility for each health state.(16) The public preference weights are the way in which EQ-5D instruments would usually be scored when used in clinical trials for health technology assessment. However, the P-PROM ROCK qualitative study identified that the approach to scoring and valuing the EQ-5D-Y-5L in clinical care may need to be different to approaches taken in health technology assessment – specifically, the use of general public preference weights is considered less useful.(15) Furthermore, the qualitative study identified that the use of EQ-5D-Y-5L may only be valuable in certain clinical contexts, such as outpatient clinics (hospital-based office visits), where children are receiving care for chronic or ongoing health problems.(15) Hence, prior to implementation, more research is needed to understand exactly how the EQ-5D-Y-5L should be implemented in routine clinical care to ensure it is both feasible and useful.

The International Society for Quality of Life Research (ISOQOL) has developed a user guide for implementing PROMs in clinical practice.(19) The guide and accompanying manuscript acknowledge that the implementation of a PROM is context specific and is more likely to be successful if there is meaningful and substantial engagement with stakeholders.(19, 20) Of the seven studies identified by Bele et al systematic review,(10) only three reported engaging clinician stakeholders in the design of the P-PROM intervention or implementation.(21-23) No studies reported engaging parents or children. Since that systematic review,(10) a 2023 study assessing the feasibility of a generic P-PROM program that was co-designed with children, parents and service providers has been published.(24) It reported that the P-PROM program, known as the KidsPRO programme, was co-designed for use in routine paediatric asthma outpatient care in Canada and included the collection and display of the PedsQL generic and asthma module.(24) However, no details on the co-design process or final output were able to be identified. Research is needed to engage and understand the perspectives of parent and child consumers, as well as service providers, prior to the implementation of a generic P-PROM in the Australian paediatric outpatient care context.

Building on Phase 1, this paper reports Phase 2 of the P-PROM ROCK co-design. This study aimed to co-design use of the EQ-5D-Y-5L, a generic Paediatric PROM (P-PROM), in Routine Outpatient Care for Kids (ROCK), to maximise impact on patient-clinician visits. A further aim of this study is to reflect and report on the co-design process. Implementation of the co-designed P-PROM ROCK will be evaluated in a pilot study at The Royal Children's Hospital (RCH), Australia (Phase 3).

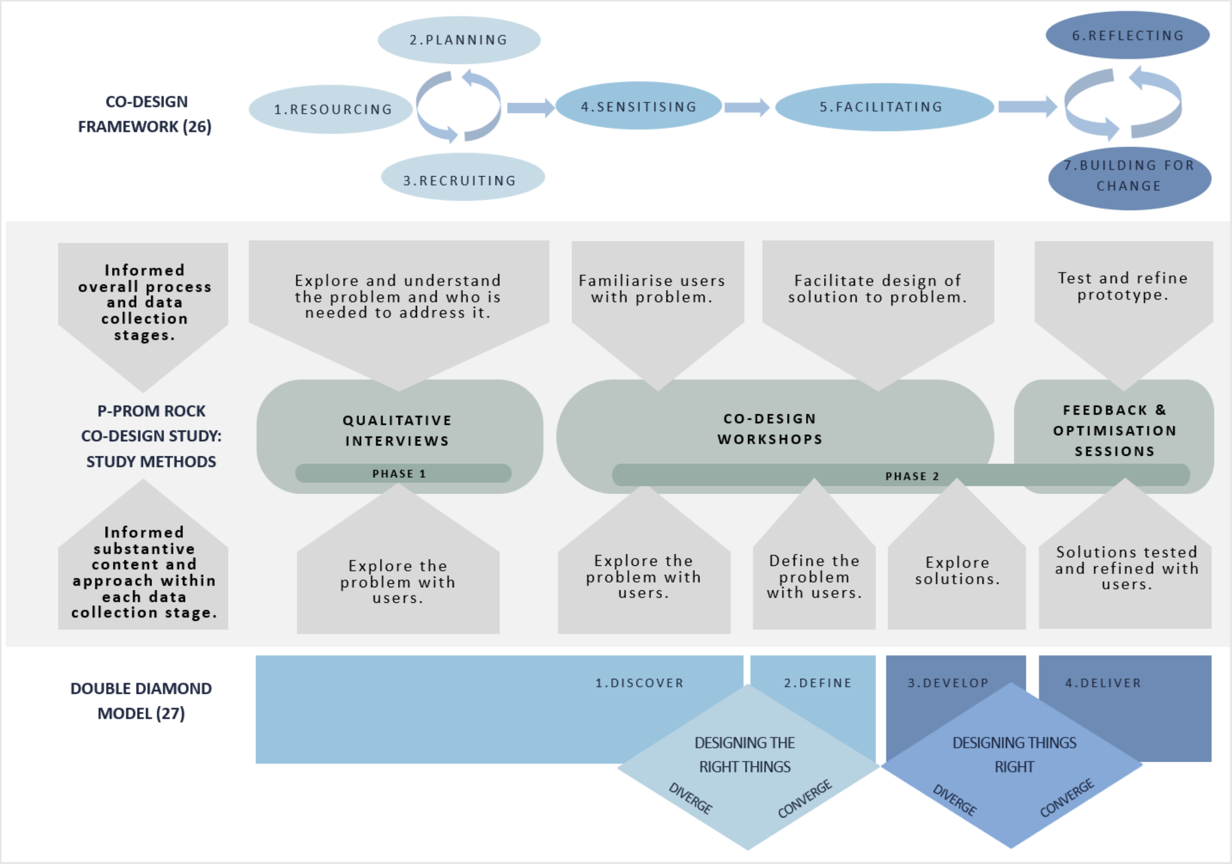
Methods

Study design

This study utilised co-design methodology. Co-design is an iterative process involving collaboration between key stakeholders to design the solution and implementation to an established problem.(25) In this study, the established problem is not knowing how a short generic P-PROM, such as the EQ-5D-Y-5L, can be collected and used to meaningfully impact patient-clinician visits.

Two methodological frameworks were utilised: 1) a co-design framework for public service design,(26) and 2) the Double Diamond model.(27) The co-design framework for public service design includes seven steps: 1) resourcing (explore and understand the problem), 2) planning (specify design task and aims), 3) recruiting (identify and recruit participants most suitable to address problem), 4) sensitising (engage and familiarise potential participants on underlying topic prior to facilitation), 5) facilitating (engage participants to design solution to problem), 6) reflecting (reflect on feasibility of design in local context), and 7) building for change (test and refine design).(26) These seven steps informed the overall process and data collection for this study, which included co-design workshops (sensitising and facilitating), feedback sessions (reflecting and building for change), and optimisation sessions (reflecting and building for change).(26) The Double Diamond model includes four phases: 1) discover (explore problem and end user needs - divergent thinking), 2) define (define problem - convergent thinking), 3) develop (explore solutions - divergent thinking), and 4) deliver (test and refine solutions - convergent thinking).(27) These four phases informed the substantive content and approach within each data collection stage.(27) For example, where data collection was informed by the 'discover' phase, participants were prompted to think broadly with no constraint of feasibility. Figure 1 outlines how these two methodologies informed study methods.

Figure 1. Application of methodological frameworks to P-PROM ROCK study methods.



Context

The co-design and evaluation of the P-PROM ROCK program is made up of several phases. Phase 1 involved a review of the literature, qualitative interviews, and informal planning meetings and was informed by the 'resourcing', 'planning', and 'recruiting' steps of the seven-step co-design framework.(26) This paper reports Phase 2 and was conducted to co-design a solution to the problem. This Phase 2 study is informed by the 'sensitising', 'facilitating', 'reflecting', and 'building for change' steps of the seven-step co-design framework.(26) Phase 3 will involve a pilot trial to evaluate the co-designed P-PROM ROCK program.

Setting and participants

The RCH is the largest tertiary paediatric hospital in Melbourne, Australia. The RCH uses the Epic Electronic Medical Record (EMR) for all clinical documentation and storage of patient medical information (www.epic.com/). The RCH has over 300,000 outpatient specialist paediatric care appointments per year (hospital-based office visits with paediatric specialist). Children and young people cared for by these outpatient clinics were determined to be highly suitable for a P-PROM program given the benefit of PROMs in chronic care management.(8)

Eligible participants included service providers (allied health staff, doctors, EMR analysts, nurses, and Virtual Care consultants), adolescents aged between 12 and 18 years, or caregivers of children aged between 2 and 18 years, who had experience providing or receiving outpatient care at RCH. Participants from Phase 1, the qualitative interview study, were eligible to participate in this Phase 2 study. Only one adolescent or caregiver per family was eligible.

Participants were recruited between July and August 2023. A range of recruitment methodologies were utilised. Firstly, participants who took part in the qualitative interviews in Phase 1, including service providers, adolescent patients and caregivers of patients were emailed and asked if they would also like to take part. Secondly, to recruit additional adolescents and caregivers, eligible caregiver participants from the Australian Paediatric Multi-Instrument Comparison Study (P-MIC) study,(28) who reported their child had received outpatient care from RCH and had consented to being contacted for future research were emailed and asked to take part in this study. To enable recruitment of adolescents aged 12 to 18 years to this study, caregivers were asked if their adolescent child would like to take part. Finally, to recruit additional service providers, the study team's professional network was emailed to ask if they would like to take part. Snowball sampling was also utilised,(29) whereby service providers were asked to pass on the email to anyone in their network.

Ethics approval was obtained from The RCH Human Ethics Committee (HREC/92769/RCHM-2023). All participants, including adolescents, provided informed consent prior to data collection.

EQ-5D-5-5L

The EQ-5D-Y-5L is a new generic P-PROM that improves on the EQ-5D-Y-3L.(30) The EQ-5-Y-5L is expected to be launched by the EuroQol Research Foundation in September 2024. Permission was granted by EuroQol to use the EQ-5D-Y-5L for this study. EQ-5D-Y-5L has five items: mobility, self-care, usual activities, pain/discomfort and sad/worried/unhappy. Each item has five outcome levels on a severity scale of no problems to extreme problems or cannot do, compared to the EQ-5D-Y-3L which only has three levels.(30) EQ-5D-Y-5L includes a visual analogue scale (VAS), known as the EQ VAS. The EQ VAS asks about the child's health today on a scale of 0 (worst health) to 100 (best health).(30)

Data collection

Data collection included co-design workshops, feedback sessions, and optimisation sessions, described in detail below. Co-design workshops were conducted between August and November 2023. Feedback sessions were conducted in November 2023 and optimisation sessions in February 2024.

Co-design Workshops

Co-design workshop topics were informed by Phase 1 (Figure 1). The following were identified as key topics to be addressed in co-design workshops: 1) scoring and displaying EQ-5D-Y-5L, 2) integrating EQ-5D-Y-5L into patient-/ work- flows, 3) how to respond when a child reports a problem on EQ-5D-Y-5L, 4) how to get patients & caregivers engaged, and 5) evaluating the P-PROM ROCK program.

Prior to co-design workshops, participants undertook a series of tasks to familiarise themselves with workshop topics, to encourage thinking and reflection on the problem (known 'sensitisation' in co-design framework).(26) These tasks included an introductory video that outlined what a P-PROM is, how and why P-PROMs are used in clinical care, what EQ-5D-Y-5L is, why we are doing the study, and what to expect from the workshops. Additionally, participants were asked to complete the EQ-5D-Y-5L. Additional sensitisation tasks were conducted within workshops to introduce participants with topics, further detail on this is available in the results.

To meet the requirements of participants, workshops were held online, in person and/or via a hybrid format. Zoom (including 'break out rooms' and 'Zoom Whiteboard') was used for online and hybrid workshops (Zoom Video Communications Inc., 2016, www.zoom.us/). The interactive presentation software Mentimeter was also used to get general anonymous thoughts from the group (Mentimeter North America Inc., www.mentimeter.com). All workshops were recorded, and notes were taken.

During each workshop, participants were introduced to the topic and given an opportunity to discuss the topic as a group. This initial discussion was not constrained by feasibility (known as 'discover' in Double Diamond Model).(27) Following this, facilitators prompted participants to consider feasibility and consensus (known as 'define' in Double Diamond Model).(27) After initial discussions, participants were given an activity. These activities were often creative.(31, 32) Where possible, participants were given the opportunity to complete the activity alone, enabling independent thought. Everyone then discussed their activity output/response in the group (known as 'develop' in Double Diamond Model).(27) Following this, participants were prompted to engage in consensus discussions, moving towards a final prototype (known as 'deliver' in Double Diamond Model).(27)

Feedback and Optimisation Sessions

Data from the co-design workshops was used by the study team to develop draft prototypes. Several rounds of design iteration and feedback proceeded to reach a prototype that would best fit the local context. Feedback was obtained from participants on these prototypes at the next workshop (known as 'reflecting' and 'building for change' steps in co-design framework).(26) Adolescents and caregivers were also offered the opportunity to provide further feedback via online interviews and service providers via email. Following the co-design workshops and feedback sessions, a full prototype was drafted. Optimisation sessions were conducted to test the prototype in mock patient-clinician visits, assessing performance in a real-world context, and making final refinements (known as 'reflecting' and 'building for change' steps in co-design framework).(26)

Results

Five co-design workshops, nine feedback sessions and two optimisation sessions were conducted.

Participants:

Across the five co-design workshops, two adolescent patients, three caregivers of patients, and 11 service providers participated. The two adolescent patients were aged 14 and 16 years old. One adolescent took part alongside their parent, and the other took part without a parent. The three caregivers were mothers of patients aged between 7 and 11 years. Adolescent and caregiver participants had experience receiving care from outpatient clinics at RCH, including endocrinology, continence, behaviour, development, asthma, sleep, and neurology clinics. The 11 service providers included four doctors, three nurses, and four EMR specialists, of which two also have allied health experience. These service providers have experience providing care to children in outpatient clinics at RCH, including, asthma, sleep, continence, colorectal surgery, gastroenterology transplant, and hearing clinics, as well as providing specialist EMR support across RCH. Not all participants attended all workshops; a summary of the number of participants who attended each workshop is provided in Table 1.

Co-design Workshops:

Two two-hour workshops were conducted with service providers, adolescent patients, and caregivers of patients. Following these first two workshops it was identified that additional workshops were required to further design aspects of the solution that related to service providers only. Hence, an additional three one-hour workshops were also conducted with only service providers. A summary of these five workshops, including the format, length, participants, topics covered, sensitisation tasks, workshop activities, and outputs is described in Table 1.

Table 1. Summary of workshop participants, format, topics, sensitisation tasks, activities, and outputs.

Workshop	Participants	Topic(s)	Sensitisation	Activities
Workshop 1, 2-hours, online.	Adolescent (n=1), Caregivers (n=3), & Service Providers (n=6). Facilitators (n=4).	• Scoring & displaying EQ-5D-Y-5L. • Integrating EQ-5D-Y-5L into patient-/ work-flows.	• Presentation on scoring and display options & examples.(14, 33, 34) • Group asked to vote on preferred options & to rank EQ-5D-Y-5L items.	• Design ideal EQ-5D-Y-5L display in Zoom Whiteboard. • Design patient journey and workflow via group discussion with use of case vignette.
Workshop 2, 2-hours, online.	Adolescent (n=2), Caregivers (n=3), & Service Providers (n=9). Facilitators (n=4).	• Scoring & displaying EQ-5D-Y-5L (Feedback) • How to respond when a child reports a problem on EQ-5D-Y-5L. • How to get patients & caregivers engaged.	• Introduced workshop 1 draft prototype. • Presentation on ways to respond if a child reports a problem. • Vote on preferred ways to respond & anonymous open text to group. • Presentation on examples of how patients previously engaged in PROMs.	• Refine prototype from workshop 1 - via group discussion. • Design ideal plan for introducing patients and caregivers to completing and using EQ-5D-Y-5L – via group discussion. • Design where in EMR system the display should appear – via live demonstration in EMR system.

Workshop	Participants	Topic(s)	Sensitisation	Activities
Workshop 3, 1-hour, in person.	Service Providers only (n=4). Facilitators (n=2).	• How to respond when a child reports a problem on EQ-5D-Y-5L (focus on resources).	• Presentation on examples of clinician P-PROM resources from Netherlands.(34) • Introduced workshop 2 draft prototype.	• Comment likes & dislikes in margins of a printed draft prototype. • Design ideal resource via group discussion & using pen/paper.
Workshop 4, 1-hour, in person.	Service Providers only (n=4). Facilitators (n=2).	• How to respond when a child reports a problem on EQ-5D-Y-5L (focus on clinician training).	• Presentation PROM clinician training literature.(35) • Introduction to example training program from Netherlands.(34, 35)	• Group reflection on their likes & dislikes of example training. • Design training challenges, goals, length, format, & content.
Workshop 5, 1-hour, hybrid (in person and online).	Service Providers only (n=5). Facilitators (n=2).	• Integrating EQ-5D-Y-5L into patient-/ work-flows (Feedback). • How to respond when a child reports a problem on EQ-5D-Y-5L (Feedback). • Evaluating P-PROM ROCK program.	• Presentation on journey map draft prototype. • Presentation on resources draft prototype. • Presentation on plan for trial design.	• Discuss ways journey map could be improved. • Discuss ways resources could be improved. • Discuss feasibility of trial length. • Group asked to discuss & prioritise trial outcomes. • Define outcomes & how they will be captured.

Feedback and optimisation sessions

Five feedback sessions were conducted within workshops as outlined in Table 1. Four feedback sessions were conducted after workshops via individual online meetings with participants, three with caregivers of patients and one with an adolescent patient. Additional feedback was also obtained from service providers via email. Finally, two optimisation sessions were conducted where a mock patient-clinician visit was acted out using two different case vignettes. These mock sessions required patients to use the Patient Portal to complete the EQ-5D-Y-5L, and clinicians to refer to answers via the EMR in a mock consultation.

Designing the different prototype elements:

Participants designed different prototype elements, guided by the co-design workshop topics. A description of the process to design these different elements are described by topic in Table 2. Ideal design aspects that were not feasible for inclusion in the final design are described in Supplementary Table 1.

Table 2. Description of prototype element development, by workshop topic.

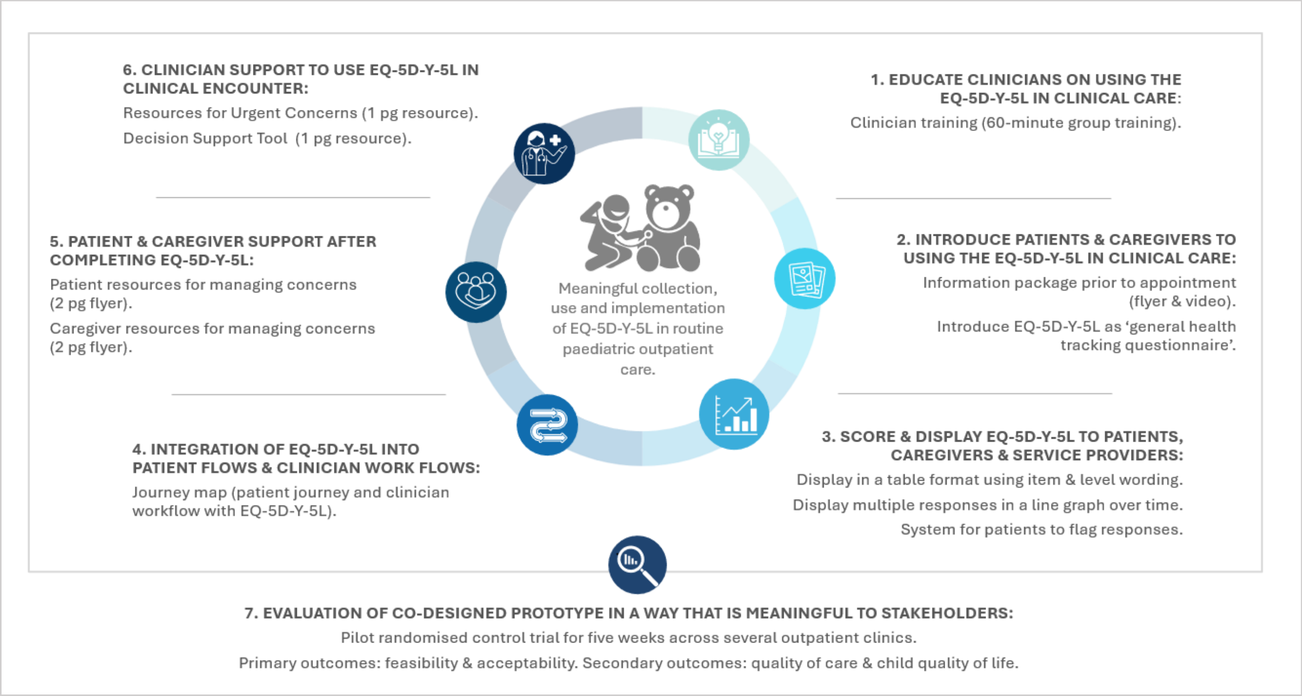
Topic	Description of prototype design element	Reasoning for design / response from participants
Scoring & displaying EQ-5D-Y-5L	EQ-5D-Y-5L single time point table display: • Two columns, one with the EQ-5D-Y-5L items (wording) & the other with the response level selected (wording). • Date of completion and who completed it (i.e., child or caregiver). • Visible to patient or caregiver immediately after completion. • Visible to service providers in EMR system.	• Table format easy to understand & interpret. • Displaying responses by item was preferred as this easily highlights areas of concern. • Summarising responses into a single score decreased interpretability. • Important to know who completed, as may impact clinical conversation. • Important to know when completed, due to short recall period & change.
	EQ-5D-Y-5L line graph display over time: • Each EQ-5D-Y-5L item appears as a separate line. • Higher score reflects better health, i.e., no problems = five & extreme problems/unable to = one. • Y axis numbered 1-5 & X axis is date of completion. • Visible to service providers by clicking into a section of EMR system that provides summaries of patient information.	• Line graph perceived as concise summary of responses over time. • Higher point on a graph instinctively meant 'better' or 'good', whereas a lower score instinctively meant 'worse' or 'bad'. Hence the level sum score approach was flipped. • Preference for labelling the Y axis with the response levels was not possible in the available infrastructure. Hence, the simple labelling approach was used. • Table format display considered easier to interpret, hence was the first available summary to patients, caregivers and service providers.
	Flagging system: • Patient or caregiver to select which EQ-5D-Y-5-L item(s) they would like to discuss with their service provider in appointment. • Item(s) they identify to appear in the clinician table display in bold with yellow highlight to draw the clinician's attention to this.	• Designed to give autonomy to patient. Automated approaches to flagging felt to cause external negative value judgement & may highlight a non-concern. • For patients & caregivers, red alerts were associated with 'bad'. Negative framing reminded participants of a 'school report' or something they might be 'failing'. • The visual alert in the clinician display was appropriate as similar visual alerts are used for other results.
Integrating EQ-5D-Y-5L into patient-work- flows	Journey map (patient journey and clinical workflow): • Completion of EQ-5D-Y-5L attached to outpatient visit. Service provider responsible for visit is responsible for reviewing EQ-5D-Y-5L response. • Patients/caregivers able to complete up to 7 days before via patient portal system (online, links to EMR) or paper. • Designed table display to appear in the main outpatient clinic view in the clinician EMR. Designed line graph to appear in the summary view in the clinician EMR.	• Important a service provider was responsible for reviewing response. Service only available at clinic visits to do this. • Completing prior to entering appointment room important as no time to do in the appointment. Also means families can complete in more relaxed environment. • Although portal completion was preferred, it was important to provide options. • Table display designed to appear in EMR outpatient view as this is where service providers already go to review results and take notes for that visit. • Although service providers less familiar with the summary view on EMR, they felt with appropriate training and resources they would be able to locate this.
How to respond when a child reports a problem on EQ-5D-Y-5L	Clinical decision support tool (1 page document for clinicians): • Four sections: 1) locate (where to locate EQ-5D-Y-5L response), 2) identify (how to identify a problem), 3) discuss (how to engage in a conversation about response), and 4) act (how to act or respond). • 'Act' section has three options: 1) condition related support (green box), 2) urgent support (red box) and 3) mild or moderate concern appropriate for community support (blue box).	• Service providers not sure how to engage in quick conversation about EQ-5D-Y-5L responses, hence discussion prompts included to help navigate conversation swiftly. • Service provider scope in outpatient clinics is specific & might not be best placed to support children with general concerns. Hence, pathway to community supports designed.

Topic	Description of prototype design element	Reasoning for design / response from participants
	Resource pathway documents: • Resource pathways for urgent concerns (clinician only – red document), mild or moderate concerns (patient/ caregiver – blue document) • All resources cover ways in which families can get support for the different EQ-5D-Y-5L domains. • Colour-coded to match with the clinician decision support tool. • Patient/ caregiver to automatically receive mild/moderate resource pathway document directly after EQ-5D-Y-5L completion. • Paper copies to have QR codes, online copies to have links.	• Participants encouraged the red and blue resources to be designed in collaboration with the experts from RCH. Consequently, the mental health team, allied health team, and pain team were all consulted in the design of these resources. • For EQ-5D-Y-5L to be meaningfully used in clinical visits, it was important there were clear strategies to support children or caregivers where the child had a problem on one of the EQ-5D-Y-5L domains(s) and wanted support for this. • Some patient and caregiver participants felt that general resources were not always helpful to them. Hence, it was made clear to service providers in the training & clinical decision support tool that responses should be discussed.
	Clinician training (30-60 minutes): • Conducted during an existing meeting time slot. • Content includes: 1) introduction to P-PROM ROCK Study, 2) introduction to PROMs, 3) why PROMs in clinical care? 4) introduction to the EQ-5D-Y-5L, 5) where to locate in EMR, 6) what to do if a child has a concern, & 7) case examples.	• Service providers needed training on using the EQ-5D-Y-5L in clinical care in addition to an introduction to the different resources. • Training designed to overcome potential obstacles (time poor, funded time), and to address key goals (selling P-PROMs, practical aspects, and what to do if a child has a problem). • Participants were clear that most of the training should be dedicated to points 5 (where to locate responses) and 6 (how to act on responses).
How to get patients & caregivers engaged	Information package for patients/caregivers: • Sent to families before appointment. Short summary available directly before & after EQ-5D-Y-5L completion. • Includes: 1) why they are being asked to complete the EQ-5D-Y-5L, 2) how this might benefit them/their child, 3) how they should complete it, 4) how long it will take, 5) what questions are included, 6) who will be able to see their responses, & 7) what will be done with their responses. • Available in both written & video (with cartoons) format as participant information and consent form (PICF).	• Felt all information should be provided in advance so families could make an informed choice. • Felt that key information from this package should be included directly before and after completing the EQ-5D-Y-5L as a reminder. • Information package should be easy for families to understand and engage with, hence both a written and video version of the information was designed. • Given the context of the co-design workshops was to inform a pilot trial, participants used this introduction package design to inform a trial participant information and consent form (PICF) and video.
	EQ-5D-Y-5L introduced as 'general health tracking questionnaire'.	• Terms 'EQ-5D-Y-5L' or a 'quality of life questionnaire' associated with something very serious that could mean possible judgment. Hence, new language designed.
Evaluating P-PROM ROCK program	Participants contributed to the design of the pilot trial: • 5-week randomised trial, with a control arm (usual care) and intervention arm (co-designed prototype), was decided upon. • Feasibility and acceptability outcomes were considered primary outcomes, and usefulness outcomes were secondary outcomes. • Outcomes to be collected from service provider, patient and caregiver perspective.	• Service providers nervous about trialling co-designed prototype for any longer than a few weeks as not sure how it might impact clinic times. • Need to evaluate feasibility & acceptability to determine sustainability of long-term use or long-term trial. • Randomised design seen as a beneficial design to service providers, as they are only impacted by half the participants & get the benefit of a robust design. • Important to capture different perspectives, use validated tools where possible & that outcomes were captured in a way that minimised burden.

Final co-designed prototype (P-PROM ROCK Program):

The different design elements were combined and refined to make a final prototype, known as the P-PROM ROCK program. The P-PROM ROCK program includes seven key elements which are summarised in Figure 2 and described below.

Figure 2. Final P-PROM ROCK Co-designed Prototype (P-PROM ROCK Program).



1. Educate clinicians on using EQ-5D-Y-5L in clinical care – Clinician Training

Education of clinicians on using EQ-5D-Y-5L via a 60 minute, in person, small group training session. Training session to be conducted in an existing meeting or blocked out clinical time where possible.

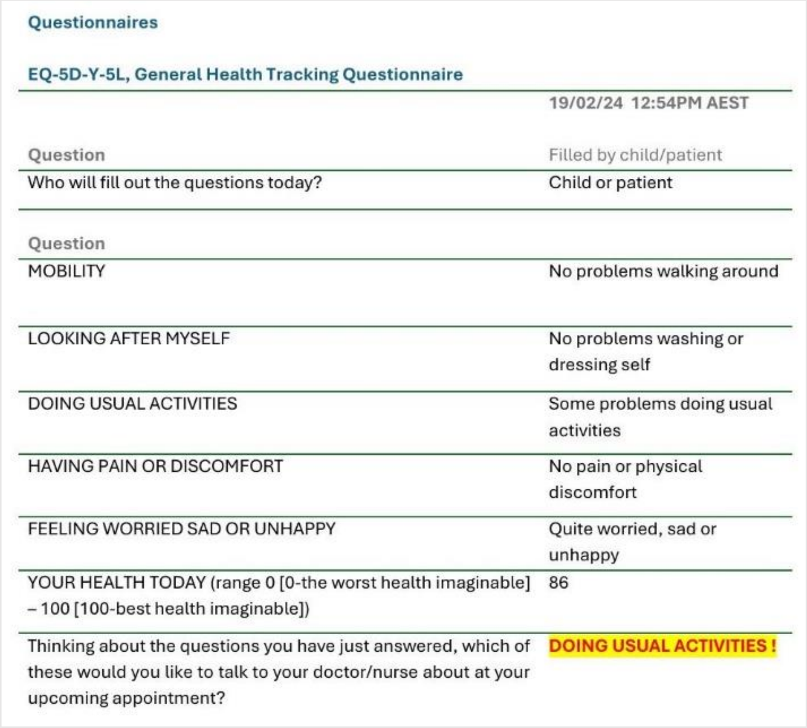
2. Introduce patients and caregivers to using EQ-5D-Y-5L in clinical care – Information Package

Patients and caregivers are introduced to using EQ-5D-Y-5L prior to their appointment via an information package available in flyer and video format. Additionally, core information is provided directly prior to and after completing the EQ-5D-Y-5L (Supplementary Figure 1). The EQ-5D-Y-5L is introduced in all documentation as the 'general health tracking questionnaire'.

3. Score and display of the EQ-5D-Y-5L in a clinically meaningful way – EQ-5D-Y-5L Displays

EQ-5D-Y-5L responses are displayed to patients/caregivers, and clinicians in two different displays: A table format using item and level wording (Figure 3), and as multiple responses in a line graph over time, where a higher score reflects better health. Additionally, the patient or caregiver can indicate which EQ-5D-Y-5L items they would like to discuss with their service provider (Figure 4), which appears as an alert (red text with yellow highlight) in the service provider display (Figure 3).

Figure 3. Example of EQ-5D-Y-5L clinician display (single time point table).

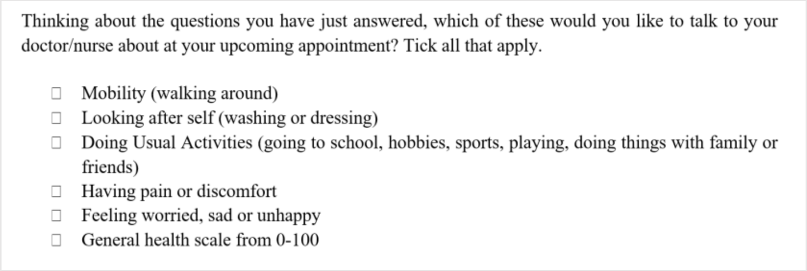


Questionnaires

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?	**DOING USUAL ACTIVITIES !**

Figure 4. Additional question used to flag EQ-5D-Y-5L domains to service providers.



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? Tick all that apply.

☐ Mobility (walking around)
☐ Looking after self (washing or dressing)
☐ Doing Usual Activities (going to school, hobbies, sports, playing, doing things with family or friends)
☐ Having pain or discomfort
☐ Feeling worried, sad or unhappy
☐ General health scale from 0-100

4. Integration of EQ-5D-Y-5L into patient flows and clinical systems – Journey Map:

Completion of EQ-5D-Y-5L attached to outpatient visit and the clinician allocated to that visit is responsible for reviewing the response. Patients/caregivers can complete the EQ-5D-Y-5L up to seven days before their outpatient appointment visit, and receive a reminder at seven days, two days, and in visit waiting room to complete the EQ-5D-Y-5L. The second reminder will only happen if the P-PROM is yet to be completed. Patients/caregivers complete EQ-5D-Y-5L via the patient portal app or website (integrated into the EMR system) or on paper on the day of the appointment. If completed via paper, this is done in the waiting area on the day of the appointment, is handed to the service provider in the appointment, and scanned into the patient's EMR as a media file. If completed via the portal, EQ-5D-Y-5L responses are displayed to the service provider in the EMR system for the corresponding outpatient appointment. Supplementary Figure 2 provides a visual overview.

5. Supports for patients and caregivers after completing EQ-5D-Y-5L – Family Resources

Directly after completing EQ-5D-Y-5L, patients/caregivers automatically receive a list of resources explaining how they could access support if they had a concern with one of the EQ-5D-Y-5L domains. There are two versions of this to better meet the needs of the recipient. If the child self-reports, they receive a patient/young person resource, and if the caregiver/proxy reports they receive the caregiver/parent resource (Supplementary Figure 3).

6. Supports for clinicians to use EQ-5D-Y-5L in clinical visits – Clinician Resources

Clinicians receive a clinical decision support guide that includes where to locate the result, how to identify a problem, how to engage in a conversation about the results, and suggestions on how to action or respond to a concern (Supplementary Figure 4). Clinicians receive an urgent support resource that outlines available service options if a child has an urgent concern with one of the EQ-5D-Y-5L domains (Supplementary Figure 5). The final section of the clinical decision support tool connects clinicians to corresponding family or urgent clinician resources.

7. Evaluate P-PROM ROCK program in a way that is meaningful to stakeholders – Pilot Design:

The P-PROM ROCK program was designed to be piloted for five weeks in a range of outpatient clinics using a randomised design (Phase 3). Primary outcomes for the trial are designed to focus on the feasibility and acceptability of the P-PROM ROCK program. Secondary outcomes are to focus on the impact on quality of care and child quality of life.

Discussion

In this study, adolescent patients, caregivers of patients, and service providers co-designed use of the EQ-5D-Y-5L in routine paediatric outpatient care, developing the P-PROM ROCK program. This co-designed P-PROM ROCK program acknowledges that just *collecting* data using a generic P-PROM such as the EQ-5D-Y-5L in a clinical context, without additional resources to support its implementation, completion, or use, is unlikely to result in a meaningful impact. Consequently, the P-PROM ROCK program is multi-dimensional, wrapping around the patient, their caregiver, and service providers, delivering support at different points along the journey of EQ-5D-Y-5L implementation, completion and use in routine clinical care. The P-PROM ROCK program includes clinician and patient education, a clinically meaningful display of EQ-5D-Y-5L responses, a patient-centred approach to flagging a concerning response, integration into local workflows and systems, and resources to support patients, caregivers, and service providers to appropriately respond to EQ-5D-Y-5L information. Engaging patients, caregivers of patients, and service providers in the co-design process was feasible, with all participants able to engage and contribute to the design process. Furthermore, this engagement was considered essential to generating a user-centric design.

This is the first published study to include patients, their caregivers, and service providers, in the design of a P-PROM program. Previous studies had either not involved any end users in their P-PROM program design, or had only included service providers.(21-23) Furthermore, this is also the first study to report use of EQ-5D-Y-5L in clinical settings,(10) a concise P-PROM found to have desirable psychometric properties.(13) The inclusion of adolescents and their caregivers in this co-design process was pivotal to ensuring the design was acceptable and applicable to patients and their families. It was important to include both adolescent patients as well as caregivers of patients, as the voices of patients differ to that of their caregivers. The adolescent patient participants brought energy, joy, and immense creativity to the co-design team. One service provider participant reflected that the creativity of these young patients served as a reminder to the co-design team that they were designing something to be used in a children's hospital. Bringing service providers together with patients and caregivers in the co-design sessions helped to highlight the relevance and importance to patients of being seen as 'whole individuals' which reinforced the utility of a P-PROM to service providers. Their joint involvement kept a focus on patient relevance and guided decisions back to toward patient benefit. Additionally, after the co-design workshops, several participants reflected on the benefits of this joint involvement, stating that this broadened their thinking beyond their individual experience and enabled them to bounce ideas off a broader range of people. Importantly, involvement of service providers in the co-design was critical to their buy-in. Service providers were enthusiastic about contributing to this design process as they wanted to be part of shaping something that might impact their service provision in future.

Including patients, caregivers, and service providers together in the co-design process was not without its challenges. Scheduling a time for co-design workshops that all participant groups could attend was difficult. Patients could only meet after school hours, which meant that service providers needed to attend after work hours. Consequently, only two co-design workshops were able to be conducted with all participant groups present and feedback was largely obtained on an individual basis via feedback sessions. This may have resulted in different feedback than a group context. Additionally, to ensure all participant groups could attend co-design workshops, they were hosted online. A limitation to hosting the workshops online was that quite a few participants were not familiar with the technology, which may have impacted their ability to fully engage with the group or tasks. Although a general introductory slide on how to use the technology was included at the beginning, future studies may consider meeting with participants one-on-one beforehand to ensure they are familiar and confident with the technology. Given the creative nature of co-design workshops, the other limitation of the online format was the use of the Zoom Whiteboard function. This was challenging for some, and pen and paper may have obtained more creative output from participants. A study by Woodyatt et al seems to indicate that the content from online focus groups is not dissimilar to that obtained from in person focus groups, despite the process of participants sharing this content being different.(36) Potential power imbalance between different participant groups may be another limitation of this study; however, efforts were made to minimise this, including setting ground rules, a careful facilitation approach, and giving participants different ways to engage in discussion, including anonymously. After the co-design workshops, an adolescent participant reflected that the creative activities were a great way to reduce power imbalances in the group. Additionally, a caregiver participant reflected on how respectful all participants were to one another even when disagreeing on something. This should be carefully considered in other patient groups considering dynamics between patients and clinicians may differ to the current study. Several participants reflected on ‘key ingredients’ that contributed to this respectful environment where they felt comfortable sharing openly. These included: 1) having a consistent relationship with a single research team member/facilitator, 2) having the same participants in each workshop, enabling relationship building, 3) trust in facilitator, ensuring participants felt that any contributions will be valued, and 4) involvement in initial design, refinement and write up, ensuring their voices are heard at all points along the way. Non-English-speaking participants were not represented in this study, which is a limitation and should be a focus of future research. Finally, although the co-design participants did represent a wide range of clinical areas and service providers (i.e., allied health, EMR, nurse, doctor), this study was focused on the outpatient context, hence a limitation of this study is its generalisability to other contexts such as inpatient care or primary care.

When the P-PROM ROCK program is compared with other existing PROM programs, there are important differences and similarities. In terms of displaying PROMs for use in routine clinical care, different programs have taken different approaches. For example, a P-PROM program in the Netherlands, known as KLIK, displays PedsQL domain scores using a traffic light colour system.(34) Additionally, an adult kidney care PROM program in Canada, known as the EMPATHY trial, displays EQ-5D-5L responses in a report card style, with different response levels categorised as a tick, a caution sign or an exclamation mark.(14) These approaches differed to the display co-designed in P-PROM ROCK program, as participants were very conscious of avoiding displays that looked like school reports, framing responses in a way that could be perceived as failure, and avoided applying external thresholds or value judgements to responses, preferring to leave alerts up to the patient and their family. Both these programs displayed PROMs by item or domain, which is similar to the P-PROM ROCK program and may suggest this approach could be applied more widely in routine clinical care. This approach to scoring and displaying a generic P-PROM such as the EQ-5D-Y-5L differs to how it may typically be scored when used in clinical trials and is an important finding of this study.(16) In terms of resources and supports, service provider participants in the P-PROM ROCK study appreciated the simplicity of the decision support tool used in the KLIK P-PROM program.(34) Consequently, a very similar approach was taken in this study. However, detailed supports on how to action concerns from EQ-5D-Y-5L, and categorising these supports into urgent and community supports is unique to this co-designed P-PROM ROCK program. The differences and similarities between the co-designed P-PROM ROCK program and other programs may be due to the local context or the addition of patients and their caregivers in the design process.

This study builds on Phase 1, which aimed to explore perspectives on the use of generic P-PROMs such as the EQ-5D-Y-5L. For example, in the Phase 1 qualitative interviews, it was identified that outpatient clinicians did not know what services were available to support the types of concerns that the EQ-5D-Y-5L might identify. During the co-design workshops, participants designed a series of resources and supports to overcome this barrier. A strength of generic P-PROMs, such as the EQ-5D-Y-5L, is that they may pick up on general health and quality of life issues such as mental health, that may not otherwise be detected in specialised clinical contexts. Although these general issues, such as mental health challenges, may be related to the reason for visit to the specialised clinical context, a challenge is that service providers in these contexts are often skilled in specific medical areas. Hence, providing resources (e.g. referral guidelines) is important, as generic P-PROMs may bring more generalised concerns to the surface that are outside this specialised skillset. A particular focus of the supports created as part of the P-PROM ROCK program was how service providers could respond to mental health concerns. Participants also suggested that having a condition-specific P-PROM alongside a generic P-PROM may also help to overcome the broad nature of generic P-PROMs, however, this was outside the scope of this study. Previous studies have explored the use of both generic and condition-specific P-PROMs, and such approaches may be explored in future adaptations of the P-PROM ROCK program.(10)

This Phase 2 study provides a co-designed program for implementing, collecting and using a generic P-PROM, the EQ-5D-Y-5L, in clinical outpatient care (hospital-based visit), in an Australian tertiary paediatric hospital. It is unknown how elements of this design may be generalised to other clinical and geographic contexts, and this should be the focus of future research. Overall, this study has shown that involving children, caregivers and health care service providers in the co-design of P-PROM implementation leads to important insights for the local context that might otherwise be missed. Patients felt that generic P-PROMs, such as the EQ-5D-Y-5L, supported them being viewed as 'whole individuals' in their clinic visits if this information was used, and clinicians stressed that where P-PROM information was asked of their patients they felt a duty of care to respond appropriately. Co-design of P-PROM collection processes, displays, training and supports to respond, provides opportunity for P-PROMs to have the best possible chance of successful implementation and impact on individual patient care. However, the ultimate test of whether routine use of P-PROMs is beneficial rests on how actively the data are used in health care decisions, whether health care is delivered in a way that better meets patients' needs and whether patients benefit. The planned evaluation of the P-PROM ROCK will provide evidence on these outcomes.

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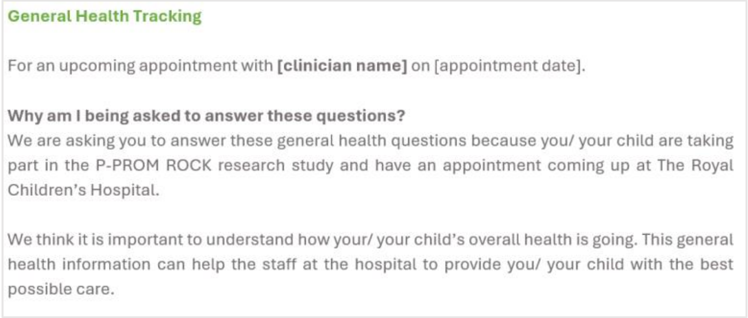
Supplementary material

Supplementary Table 1. Description of design elements not feasible in local context, by workshop topic.

Topic	Description of design elements not feasible in local context
Scoring and displaying EQ-5D-Y-5L.	Extra context: Participants noted that it would be ideal if patients or their caregivers could have the option to add extra context to their EQ-5D-Y-5L response by having an open text box available at the end of the EQ-5D-Y-5L. Participants felt this would save patients and caregivers needing to remember such information when the EQ-5D-Y-5L responses are discussed in the appointment and it would also potentially save clinic time by enabling a more targeted conversation in the clinical visit. Unfortunately, the ability to add extra context was not feasible in the available IT infrastructure.

	Making displays fun: Participants also explored ways of making the completion and display of EQ-5D-Y-5L more fun and engaging for children. Some ideas included children being able to select a cartoon that would guide them through the process of completing the EQ-5D-Y-5L and would also appear in the display or results. Unfortunately, this was also not possible in available IT platforms. Figure 2b, is a Zoom Whiteboard drawing from an adolescent participant that depicts the idea of using shapes to flag certain results as well as using cartoons or pictures to better engage children.
	Storing EQ-5D-Y-5L responses in dashboard: Participants, particularly patients and caregivers of patients felt that it was important for EQ-5D-Y-5L responses to be displayed alongside any other clinically relevant information, such as condition-specific P-PROMs and medication or treatment changes. Although such a dashboard was not feasible in currently available IT systems, an approach was designed whereby EQ-5D-Y-5L responses would be stored within systems where this other clinically important information was available.
Integrating the EQ-5D-Y-5L into patient- / work- flows.	**Frequency of EQ-5D-Y-5L completion, between visits**: Adolescent patient and caregiver participants discussed the benefits of completing the EQ-5D-Y-5L just before each visit as well as at multiple time points between each visit. They noted that as they often have outpatient appointments every three to six months, being able to monitor and pick up on any issues between visits would be helpful. However, it was decided that current models of care were not suitable to support patients completing the EQ-5D-Y-5L between visits, as there was no clinical resourcing to review and action any patient EQ-5D-Y-5L responses between visits. Service provider participants felt strongly that there was a responsibility to review and action EQ-5D-Y-5L responses once they are submitted by the patient.
Engaging families in EQ-5D-Y-5L.	**Other languages:** Participants explored having the information package available in different languages. Although this would have been ideal, it was not feasible for this project.

Supplementary Figure 1. EQ-5D-Y-5L Introduction.



General Health Tracking

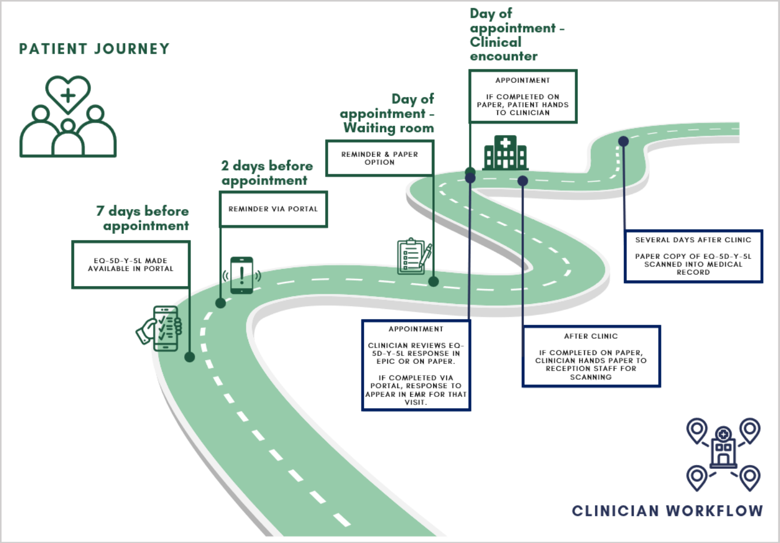
For an upcoming appointment with **[clinician name]** on [appointment date].

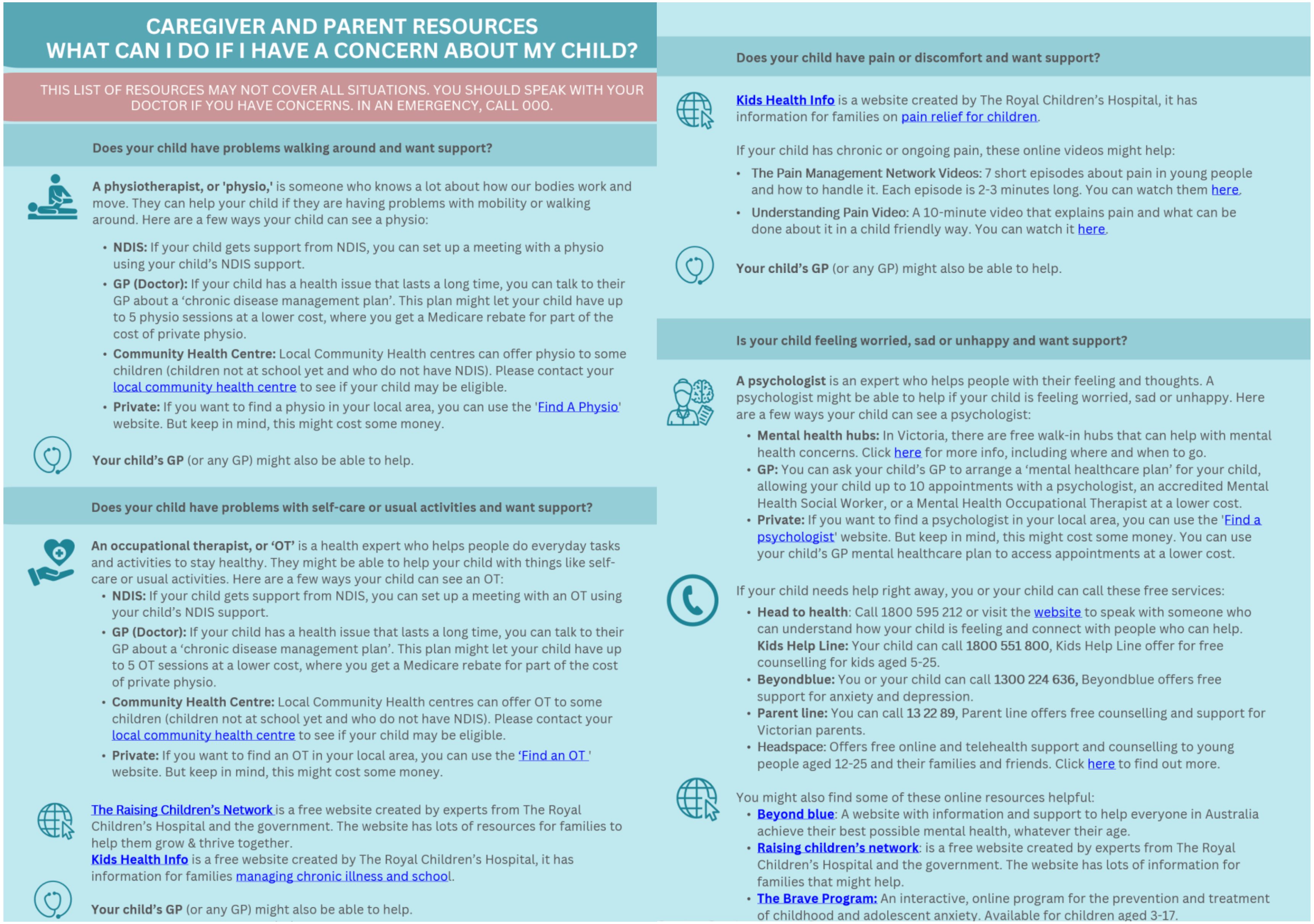
Why am I being asked to answer these questions?

We are asking you to answer these general health questions because you/ your child are taking part in the P-PROM ROCK research study and have an appointment coming up at The Royal Children's Hospital.

We think it is important to understand how your/ your child's overall health is going. This general health information can help the staff at the hospital to provide you/ your child with the best possible care.

Supplementary Figure 2. Journey Map.





Supplementary Figure 3. Example of Caregiver Resources.

CAREGIVER AND PARENT RESOURCES
WHAT CAN I DO IF I HAVE A CONCERN ABOUT MY CHILD?

THIS LIST OF RESOURCES MAY NOT COVER ALL SITUATIONS. YOU SHOULD SPEAK WITH YOUR DOCTOR IF YOU HAVE CONCERNS. IN AN EMERGENCY, CALL 000.

Does your child have problems walking around and want support?

A physiotherapist, or 'physio,' is someone who knows a lot about how our bodies work and move. They can help your child if they are having problems with mobility or walking around. Here are a few ways your child can see a physio:

- **NDIS:** If your child gets support from NDIS, you can set up a meeting with a physio using your child's NDIS support.
- **GP (Doctor):** If your child has a health issue that lasts a long time, you can talk to their GP about a 'chronic disease management plan'. This plan might let your child have up to 5 physio sessions at a lower cost, where you get a Medicare rebate for part of the cost of private physio.
- **Community Health Centre:** Local Community Health centres can offer physio to some children (children not at school yet and who do not have NDIS). Please contact your local community health centre to see if your child may be eligible.
- **Private:** If you want to find a physio in your local area, you can use the 'Find A Physio' website. But keep in mind, this might cost some money.

Your child's GP (or any GP) might also be able to help.

Does your child have problems with self-care or usual activities and want support?

An occupational therapist, or 'OT' is a health expert who helps people do everyday tasks and activities to stay healthy. They might be able to help your child with things like self-care or usual activities. Here are a few ways your child can see an OT:

- **NDIS:** If your child gets support from NDIS, you can set up a meeting with an OT using your child's NDIS support.
- **GP (Doctor):** If your child has a health issue that lasts a long time, you can talk to their GP about a 'chronic disease management plan'. This plan might let your child have up to 5 OT sessions at a lower cost, where you get a Medicare rebate for part of the cost of private physio.
- **Community Health Centre:** Local Community Health centres can offer OT to some children (children not at school yet and who do not have NDIS). Please contact your local community health centre to see if your child may be eligible.
- **Private:** If you want to find an OT in your local area, you can use the 'Find an OT ' website. But keep in mind, this might cost some money.

The Raising Children's Network is a free website created by experts from The Royal Children's Hospital and the government. The website has lots of resources for families to help them grow & thrive together.

Kids Health Info is a free website created by The Royal Children's Hospital, it has information for families managing chronic illness and school.

Your child's GP (or any GP) might also be able to help.

Does your child have pain or discomfort and want support?

Kids Health Info is a website created by The Royal Children's Hospital, it has information for families on pain relief for children.

If your child has chronic or ongoing pain, these online videos might help:

- The Pain Management Network Videos: 7 short episodes about pain in young people and how to handle it. Each episode is 2-3 minutes long. You can watch them here.
- Understanding Pain Video: A 10-minute video that explains pain and what can be done about it in a child friendly way. You can watch it here.

Your child's GP (or any GP) might also be able to help.

Is your child feeling worried, sad or unhappy and want support?

A psychologist is an expert who helps people with their feeling and thoughts. A psychologist might be able to help if your child is feeling worried, sad or unhappy. Here are a few ways your child can see a psychologist:

- **Mental health hubs:** In Victoria, there are free walk-in hubs that can help with mental health concerns. Click here for more info, including where and when to go.
- **GP:** You can ask your child's GP to arrange a 'mental healthcare plan' for your child, allowing your child up to 10 appointments with a psychologist, an accredited Mental Health Social Worker, or a Mental Health Occupational Therapist at a lower cost.
- **Private:** If you want to find a psychologist in your local area, you can use the 'Find a psychologist' website. But keep in mind, this might cost some money. You can use your child's GP mental healthcare plan to access appointments at a lower cost.

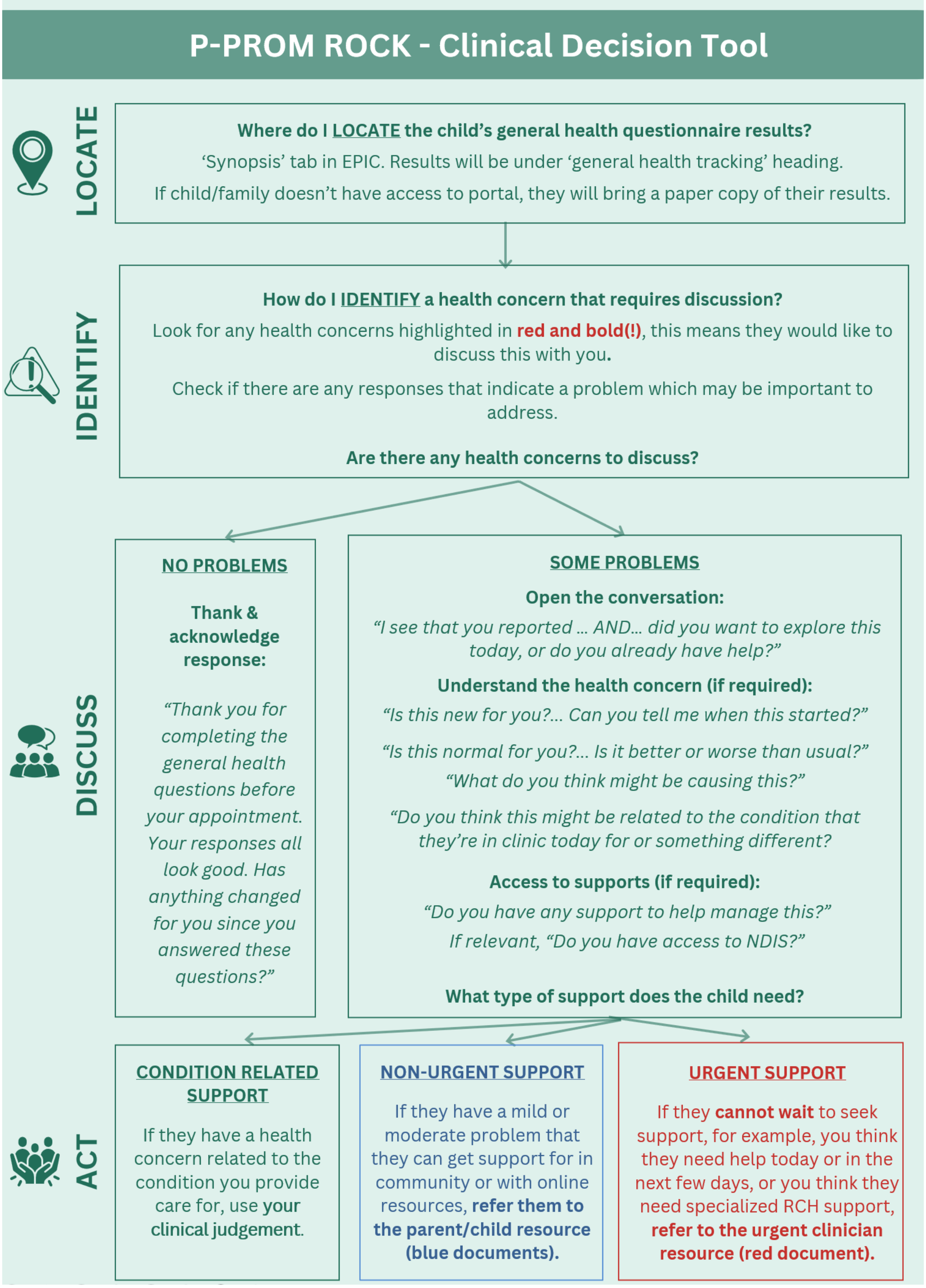
If your child needs help right away, you or your child can call these free services:

- **Head to health**: Call 1800 595 212 or visit the website to speak with someone who can understand how your child is feeling and connect with people who can help. **Kids Help Line:** Your child can call **1800 551 800,** Kids Help Line offer for free counselling for kids aged 5-25.
- **Beyondblue:** You or your child can call **1300 224 636,** Beyondblue offers free support for anxiety and depression.
- **Parent line:** You can call **13 22 89,** Parent line offers free counselling and support for Victorian parents.
- **Headspace:** Offers free online and telehealth support and counselling to young people aged 12-25 and their families and friends. Click here to find out more.

You might also find some of these online resources helpful:

- **Beyond blue**: A website with information and support to help everyone in Australia achieve their best possible mental health, whatever their age.
- **Raising children's network**: is a free website created by experts from The Royal Children's Hospital and the government. The website has lots of information for families that might help.
- **The Brave Program:** An interactive, online program for the prevention and treatment of childhood and adolescent anxiety. Available for children aged 3-17.

Supplementary Figure 4. Clinician Decision Support Tool.



P-PROM ROCK - Clinical Decision Tool

LOCATE

Where do I LOCATE the child's general health questionnaire results?

'Synopsis' tab in EPIC. Results will be under 'general health tracking' heading.

If child/family doesn't have access to portal, they will bring a paper copy of their results.

IDENTIFY

How do I IDENTIFY a health concern that requires discussion?

Look for any health concerns highlighted in **red and bold(!)**, this means they would like to discuss this with you**.**

Check if there are any responses that indicate a problem which may be important to address.

Are there any health concerns to discuss?

DISCUSS

NO PROBLEMS

Thank & acknowledge response:

"Thank you for completing the general health questions before your appointment. Your responses all look good. Has anything changed for you since you answered these questions?"

SOME PROBLEMS

Open the conversation:

"I see that you reported … AND… did you want to explore this today, or do you already have help?"

Understand the health concern (if required):

"Is this new for you?... Can you tell me when this started?"

"Is this normal for you?... Is it better or worse than usual?"

"What do you think might be causing this?"

"Do you think this might be related to the condition that they're in clinic today for or something different?

Access to supports (if required):

"Do you have any support to help manage this?"

If relevant, "Do you have access to NDIS?"

What type of support does the child need?

ACT

CONDITION RELATED SUPPORT

If they have a health concern related to the condition you provide care for, use **your clinical judgement**.

NON-URGENT SUPPORT

If they have a mild or moderate problem that they can get support for in community or with online resources, **refer them to the parent/child resource (blue documents).**

URGENT SUPPORT

If they **cannot wait** to seek support, for example, you think they need help today or in the next few days, or you think they need specialized RCH support, **refer to the urgent clinician resource (red document).**

Supplementary Figure 5. Clinician Resources for Urgent Concerns.

CLINICIAN ONLY - Resources for URGENT health concerns

These resources are options you may want to consider. They are not exhaustive and may not cover every situation. For non-urgent problems, please refer to the family resources document (blue document).

Urgent problems with mobility? Such as sudden unexplained change in weight bearing, for example, suddenly being unable to walk.

- **Same day GP/Priority Primary Care Centre:** Ask them to book an urgent appointment with their regular GP. If they are not able to you can ask them to attend a priority primary care centre.
- **RCH Physio referral:** If the patient has a sudden change in weight bearing, for example, is suddenly unable to walk, you can order an RCH Physio referral in EPIC.
- **ED:** If you think the patient has mobility issues that require urgent medical treatment, for example, you think the patient may have a broken bone, you can ask them to attend the RCH Emergency Department.

Urgent problems with self-care or usual activities? Such as urgent inability to meet medical or safety needs of child, for example, parent mental health issues preventing medical care for child or concerns about family violence.

- **RCH social work referral:** If you are concerned about the medical or safety needs of the patient, for example, parent mental health issues preventing medical care or concerns about family violence, you can order an RCH social work referral in EPIC.
- **If problems relate to mobility issue, see above.**
- **If problems relate to mental health issue, see last box.**

Urgent problems with pain or discomfort?

Key things to understand about their pain: **Site** – where is the pain?, **Severity** – how bad is the pain?, **Chronicity** – how long have they experience pain?

If the pain is acute and severe, the following options might be appropriate:

- **Same day GP/Priority Primary Care Centre:** Ask them to book an urgent appointment with their regular GP. If they are not able to you can ask them to attend a priority primary care centre.
- **ED:** If you think the patient has pain issues that require urgent medical attention, you can ask them to attend the RCH Emergency Department.

Urgent problems with feeling sad, worried or unhappy? Such as concerns about self-harm or family violence.

- **Head to health**: You can ask families to call [phone number], this will put them onto someone who can triage their mental health and connect them with the right service.
- **RCH child and adolescent mental health psychiatry liaison service:** To discuss a referral - call [phone number] or email [email]. The intake team can help work out how if they are the best service to support the child or if other services might be more appropriate.
- **RCH social work referral:** If you are concerned about parent mental health impacting on the child's health, psychosocial issues impacting the child's treatment, complex family dynamics / significant conflict impacting the child's health, psychosocial complexity impacting on child's care, family violence, or child protection, you can order an RCH referral in EPIC.