Australian Paediatric Multi-Instrument Comparison (P-MIC) Study: Technical Methods Paper

Version 1, Data Cut 1, 06 May 2022

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Table of contents:

1. Purpose and scope of this document

The purpose of this document is to outline the methods used to conduct the Australian Paediatric Multi-Instrument Comparison (P-MIC) Study. A study protocol for the P-MIC has previously been published, providing an overview of the planned P-MIC methodology.(1) This document provides a detailed description of the methodology used to conduct the P-MIC study, providing additional detail to that which is publishable via peer reviewed journals, both to be fully transparent about study design, and to help others who may be interested in undertaking similar studies in future. As recruitment is ongoing (see Table 1), data will be cut at certain time points and a new version of the technical methods paper will be produced for each data cut to transparently summarise the data available in each cut. Updated versions of this document will be available on the QUOKKA Research Program website. The data cut for this version of the technical methods paper, version 1, was taken on the 6th May 2022 and includes 6,247 children and their caregivers (see Table 1).

2. Study aim

The broad aim of this study is to compare the performance of a range of paediatric generic and condition specific Health Related Quality of Life (HRQoL) instruments in terms of validity, reliability, responsiveness, acceptability, feasibility, measurement relationship, and consistency across age, proxy and self-report, and health condition groups.(1) Within this overall aim, there are many specific aims that will be investigated. These will be reported in subsequent papers, reports and other dissemination activities.

3. Study design

The P-MIC study prospectively collected multiple generic and condition specific paediatric HRQoL instruments concurrently in a single online survey collected at two time points, initial and follow-up. Most participants receive the follow-up survey 4-weeks after completing the initial survey to assess change in health and instrument responsiveness, however, a small sub-set of children from the general population sample receive the follow-up survey at 2-days to assess test-retest reliability. A 4-week follow-up was selected to assess responsiveness as it was considered enough time for children with acute health conditions at the time of initial survey to change their health status for the follow-up survey and was also a short enough so as to not place pressure on follow-up survey completion rates. Recruitment was conducted across both a tertiary hospital and an online panel. This study was overseen by study investigators and guided by input and feedback from 1) the wider Quality Of Life in Kids: Key Evidence to Strengthen Decisions in Australia (QUOKKA) Project investigators, 2) a Consumer Advisory Group, made up of parents and caregivers of children with and without health conditions, and 3) a Decision Makers Panel, made up of industry and government stakeholders. This study was approved by The Royal Children's Hospital (RCH) Human Research Ethics Committee (HREC/71872/RCHM2021) on 20th May 2021 and registered with the Australia New Zealand Clinical Trials Registry (ACTRN12621000657820) on 31st May 2021.

4. Timelines

The P-MIC study received ethics approval in May 2021. Hospital recruitment began in June 2021 and online panel recruitment began in October 2021. Recruitment for most samples was ongoing at the time of this data cut (see Table 1).

5. Participants

5.1. Overview of P-MIC samples

The P-MIC study includes three key samples: Sample 1) recruited via hospital, Sample 2) general population recruited via online panel, and Sample 3) health condition-specific groups recruited primarily via online panels (see 6.3 for further information).

- Sample 1 includes participants recruited via hospital and has two subsamples:
    - Sample 1a, general hospital sample recruited via The RCH, Melbourne, Australia. Sample 1a includes any participant recruited via the hospital, the children were not required to have any particular condition nor were they required to be a patient of the hospital.
    - Sample 1b, specialised hospital sample recruited via The RCH, Melbourne, Australia or The Royal Women's Hospital (RWH), Melbourne Australia. Sample 1b includes five samples: 1) children receiving care in the intensive care unit (ICU), 2) children receiving care in the Emergency Department (ED) or Short Stay Unit (SSU), 3) children born extremely premature, 4) children with a rare genetic condition.
- Sample 2 is the general population sample not reporting one of the health condition groups recruited via online panels and includes two sub-samples:
    - Sample 2a, general population sample with a four-week follow-up (same as the rest of the samples), and
    - Sample 2b, general population sample with two-day follow-up.
- Sample 3 is the health condition groups primarily recruited via online panels and includes nine sub-samples:
    - Sample 3a, attention deficit hyperactivity disorder (ADHD),
    - Sample 3b, anxiety or depression,
    - Sample 3c, autism spectrum disorder (ASD),
    - Sample 3d, asthma,
    - Sample 3e, eating disorders,
    - Sample 3f, epilepsy,
    - Sample 3g, recurrent abdominal pain,
    - Sample 3h, sleep problems, and
    - Sample 3i, tooth problems.

Table 1: Summary of P-MIC samples, number recruited to each sample and recruitment status for data cut 1.

Sample	Sub-sample	N	Recruitment status
Total	n/a	6,247	Ongoing
1) Recruited via hospital	1a) general hospital sample	883	Ongoing
	1b) specialised hospital sample, including the following five groups:	121	Ongoing
	ICU	20	Ongoing
	ED or SSU	16	Ongoing
	Born premature	20	Ongoing
	Rare genetic condition	65	Ongoing

2)	General population sample recruited via online panels	2a) general population sample with a four-week follow-up	1,624	Ongoing
		2b) general population sample with two-day follow-up	251	Complete
3)	Health condition-specific groups primarily recruited via online panels	3a) ADHD	517	Ongoing
		3b) Anxiety or depression	470	Ongoing
		3c) ASD	521	Ongoing
		3d) Asthma	370	Ongoing
		3e) Eating disorder	140	Ongoing
		3f) Epilepsy	196	Ongoing
		3g) Recurrent abdominal pain	370	Ongoing
		3h) Sleep problems	376	Ongoing
		3i) Tooth problems	408	Ongoing

Note: All ongoing samples are subject to change in future data cuts as recruitment is still open. Additionally, all ongoing samples may not have had all data quality checks completed.

A sample of children recruited via a large tertiary hospital (Sample 1) was selected to ensure children with a range of moderate to severe health conditions were included in the sample, enabling the assessment of instruments in children who are very unwell. Additionally, the specialised hospital sample (Sample 1b) was included to ensure children who are extremely unwell who likely have severe decrements in quality of life were represented in the sample. The condition groups for Sample 3 were chosen based on the following criteria:

1) evidence of reduced quality of life and documented change in quality of life over time,(2) this was based on an internal analysis of data from Longitudinal Study of Australian Children (LSAC) across child ages for 30 conditions able to be identified in the data,
2) being common conditions so as to be feasible for recruitment via an online panels,(3)
3) preference-based measures have not previously been extensively studied or validated extensively in the condition group,(4)
4) conditions that would give a balance of impacts across different common dimensions (e.g., pain, participation in usual activities, mental health, mobility), for example, two pain focussed conditions would not be selected, and
5) having a suitable validated condition-specific measure of quality of life or symptoms available.

5.2. Inclusion criteria

Any parent, caregiver, or guardian of a child(ren) aged 2–18 years (inclusive) at study enrolment. Additional criteria apply to Sample 3, health condition groups (see section 5.4).

5.3. Exclusion criteria

Any parent who is unable to communicate in written English, unable to answer or comprehend the survey questions or those who do not reside in Australia.

5.4. Screening for health condition samples

Additional eligibility criteria were applied to Sample 3, health condition groups. Screening questions were used to determine eligibility (see Table 2). Screening questions were designed to capture children currently experiencing the condition or if episodic, a recent episode of the condition, as diagnosed by a doctor or relevant health professional. Where possible, screening questions were derived from previous surveys such as the Longitudinal Study of Australian Children (LSAC) or through consultation with clinical experts.(5) The age range eligibility for each health condition sample was

based on the validated age range for the corresponding health condition instrument selected as well as expert clinician advice.

Table 2: Screening questions and eligibility for health condition samples (Sample 3)

Health condition sample	Screening and eligibility questions	Child age range in years
3a. ADHD	Do you have a child aged 4-18 years with attention deficit hyperactivity disorder (ADHD) as diagnosed by a health professional?(5) Yes - *inclusion* No - *exclusion*	4-18
3b. Anxiety or depression	Do you have a child aged 7-18 years with anxiety or depression as diagnosed by a health professional? (5) Yes - *inclusion* No - *exclusion*	7-18
3c. ASD	Do you have a child aged 5-18 years with autism spectrum disorder (ASD) as diagnosed by a health professional? (5) Yes - *inclusion* No - *exclusion*	5-18
3d. Asthma	Do you have a child aged 5-18 with asthma as diagnosed by a doctor? (5) Yes - *go to next question* No - *exclusion* Has your child had symptoms of asthma or used an asthma treatment in the last 12 months? Yes- *inclusion* No - *exclusion*	5-18
3e. Eating disorder	Do you have a child aged 14-18 with an eating disorder (such as anorexia, bulimia, or avoidant restrictive food intake disorder) as diagnosed by a health professional? (5) Yes - *inclusion* No - *exclusion*	14-18
3f. Epilepsy	Do you have a child with epilepsy, or a seizure disorder as diagnosed by a doctor? (5) Yes - *inclusion* No - *exclusion*	4-18
3g. Recurrent abdominal pain	Do you have a child with the ongoing condition 'recurrent abdominal pain'? (5) *Recurrent abdominal pain is at least three episodes of pain that occur over at least three months and affect the child's ability to perform normal activities.(6)* Yes - *inclusion* No - *exclusion*	5-18
3h. Sleep problems	Thinking about your child aged 3-18 with sleep problems, how much is their ongoing sleeping pattern or habits a problem for you? (5) Not a problem at all- *exclusion* A small problem- *exclusion*	3-18

Health condition sample	Screening and eligibility questions	Child age range in years
	A moderate problem- *inclusion* A large problem - *inclusion*	
3i. Tooth problems	Do you have a child who **currently has** or has **experienced in the last 3 months,** any of the following **tooth problems**? (5) *This includes problems that have been treated, untreated or are still undergoing treatment.* Yes, cavities, dental decay or hole(s) in teeth - *inclusion* Yes, tooth or teeth filled because of dental decay - *inclusion* Yes, teeth pulled because of dental decay - *inclusion* Yes, accident causing breakage or loss of teeth - *inclusion* Yes, crowded teeth - *inclusion* Yes, problems with bite (e.g., crossbite or overbite) - *inclusion* No, my child has not experienced any of the above tooth problems - *exclusion*	5-18

5.5. Caregivers with multiple eligible children

Where caregivers had multiple eligible children for any given sample, they were directed to respond to the survey questions based on the child with the highest health needs. Caregivers were directed to complete the survey in relation to one child only.

6. Recruitment

6.1. Sample 1, hospital sample recruitment:

6.1.1. Sample 1a, general hospital sample:

Research Assistants (RAs) approached caregivers for recruitment from a range of RCH departments, including outpatient clinics and surgical department waiting rooms. Poster advertisements with QR codes linking to the study were placed in high traffic areas of The RCH. Online advertisements with a link to the study were placed on RCH telehealth appointments virtual platform, appearing for any family attending a hospital appointment via telehealth. Additionally, the study advert was shared with caregivers from the onsite RCH childcare centre.

6.1.2. Sample 1b, specialised hospital sample:

In addition to the above recruitment strategies (6.1.1), which were also used to recruit children to the specialised hospital samples, several specific recruitment methods were also used:

- **ICU:** ICU research staff approached potential participants for consent prior to the child's admission to ICU (e.g., pre-operative clinic visits or while in hospital). Elective admissions were the focus of active recruitment. This approach ensured avoiding approaching families in high stress or where an approach from the study was considered inappropriate. For example, where the child was unlikely to survive. The ICU research staff notified the study team when the consented participant was admitted to ICU and the study team then sent the family the survey link with a friendly reminder to complete the survey.

- **ED or SSU:** Recruitment of ED and SSU patients needed a specialised approach due to the COVID impacts on the RCH and the use of the SSU as a COVID-19 ward. This limited study research staff from physically attending these spaces to recruit. A strategy was used whereby advertisements were printed and handed to an attending doctor to hand out to families in SSU. Advertisement study posters were also displayed within ED.
- **Born premature:** Participants from the study 'Preventing Chronic Lung Health condition in Extremely Preterm Infants Using Surfactant + Steroid' (PLUSS) trial (ACTRN12617000322336), an interventional trial of children born less than 28 weeks' gestation, were approached for recruitment to the study (if the child was 2 years or older, corrected for prematurity). Potential participants were approached for recruitment by a member of the PLUSS research team when they attended The RWH for the developmental clinic/PLUSS study 2 year follow-up. Participants were provided with an advertisement inviting them to also participate in this survey.
- **Rare genetic condition:** Eligible participants (children currently aged 2-18 years old who are still alive) from Australian Genomics study cohorts who consented to be contacted for future research as part of their involvement in a previous study with Australian Genomics were sent an email from Australian Genomics inviting them to take part in the study.

6.2. Samples 2 and 3, online panel sample recruitment:

The recruitment of online panel samples was managed by Pureprofile Pty Ltd Australia (www.pureprofile.com, accessed on 14th June 2022). Potential participants were randomly selected from this panel to take part in the study if they met eligibility criteria. Participants were selected based on quotas for age. As children may have multiple health conditions, entry to the different samples was managed on a 'least fill' basis, with samples filled from least to most prevalent (see Table 3). Where estimated prevalence was the same, the study team discussed and prioritised the condition they felt would be the hardest to fill. Hence, children with rarer conditions were invited to take part for the rarer condition, even if the child had another health condition. If a child had none of the nine health conditions (i.e., they did not meet the eligibility for Sample 3), they were invited to take part in the general population survey (Sample 2).

Table 3: Least fill hierarchy of health condition samples and estimated prevalence for age range (Sample 3)

Health condition sample	Estimated prevalence for age range	Least fill priority/ hierarchy
3a. ADHD	3-5% (3)	3
3b. Anxiety or depression	5-10% (3, 7)	6
3c. ASD	2-5% (3)	2
3d. Asthma	10-15% (3, 7)	9
3e. Eating disorders	4-16% (8)	4
3f. Epilepsy	0.5-1% (3)	1
3g. Recurrent abdominal pain	3-5% (3)	5

Health condition sample	Estimated prevalence for age range	Least fill priority/ hierarchy
3h. Sleep problems	10-15% (3)	8
3i. Tooth problems	10-30% (3)	7

6.3. Sample 3, hybrid recruitment for hard-to-fill health condition samples:

Two of the health condition samples, epilepsy and eating disorders, were not able to be filled to the desired sample size by the online survey panel company. Hence, these samples were recruited via a hybrid approach of online survey panels and supplementary recruitment methods managed by the study team.

The supplementary recruitment methods used by the study team included:

- **RCH Telehealth appointments:** We advertised in the virtual waiting room and at the end of all TH appointments. The advert included a short description of the study and a link to the PICF and survey.
- **Social media:** Facebook advert targeting families of children with an eating disorder.
- **Relevant newsletters/ email subscription lists:** The study advert was shared via e-newsletter, email subscription lists and notice boards of relevant organisations who are interested in sharing the study information with their subscribers (e.g. The Victorian Centre of Excellence in Eating Disorders (CEED) etc.). The newsletter adverts and emails were only sent to people who opted in to/ subscribed to receive the email/newsletter.
- **Opt-in letter of invitation from RCH clinics:** Using patient lists from relevant RCH clinical departments, a letter of invitation was sent to eligible participants. The letter was an opt-in style letter with a short description of the study and a QR code linking to the survey.

7. Instruments

7.1. Paediatric HRQoL instruments

Paediatric HRQoL instruments included in the P-MIC study were classified as 'core', included for all samples, or 'additional', included for only a portion of samples (see Table 5 for a summary of which samples were allocated which instruments). To minimise responder burden in the sample recruited via hospital (Sample 1), only core instruments were included in the survey. To minimise responder burden in the online panel samples (Samples 2 and 3), participants were randomised to receive one additional instrument block. The Paediatric Quality of Life Inventory (PedsQL) Core Generic Version 4.0, EQ-5D Youth 3 level (EQ-5D-Y-3L), EQ-5D Youth 5 level (EQ-5D-Y-5L), and Child Health Utility 9D (CHU-9D) were included as core instruments following a recent systematic review identifying these instruments as common, well performing, paediatric HRQoL instruments requiring further evidence regarding their psychometric performance.(4) The Toddler and Infant Questionnaire (TANDI) version 2 was also included as a core instrument as it is an experimental generic paediatric HRQoL instrument designed and validated for younger children, requiring further evidence on performance.(9) The Patient-Reported Outcome Measurement Information System 25 (PROMIS-25), Assessment of Quality of Life (AQoL-6D), Health Utilities Index Mark 2/3 (HUI 2/3), and EQ-5D-5L were included as additional instruments. The PROMIS-25 was included as an additional instrument because it is a new tool requiring further validation work with the adult version being routinely used as a PROM in some Australian hospitals. The AQoL-6D is a tool used less frequently internationally but was included as an additional instrument because of its use in Australian populations. The HUI 2/3 was included as an

additional instrument because it has been used in Australian health technology assessment decision making for children, however, was not included as a core instrument as there is mixed evidence regarding its performance compared to other instruments.(4, 10) The EQ-5D-5L was included to build on a research agenda focused on transitions between EuroQol instruments across the lifespan. Table 4 summarises instrument characteristics. See Appendix Table 1 for a summary of instruments and instrument properties.

7.1.1. PedsQL generic core 4.0

The PedsQL generic core 4.0 is a proxy or self-report 23-item generic paediatric HRQoL instrument with 5 item response levels, a 1 month recall period, covering 4 domains: physical functioning, emotional functioning, social functioning, and school functioning.(11) Validated versions exist for children aged 2–18 years.(11) Respondents are asked to rate the frequency of each item over the past month on a 5-point scale from 0 (Never) to 4 (Almost always). The PedsQL generic core was developed specifically for a paediatric population through cognitive interviews and focus groups.(12) The PedsQL generic 4.0 was iteratively adapted from previous versions and was designed to ensure the core health dimensions outlined by the World Health Organisation were measured.(11)

7.1.2. TANDI

The TANDI is a proxy report 6-item generic paediatric HRQoL instrument designed for children <4 years of age with 3 item response levels, a 'today' recall period, covering 6 dimensions: movement, play, pain, social interaction, communication, and eating.(9) The TANDI was developed from the structure of the EuroQol Youth version (EQ-5D-Y) using cognitive interviews with caregivers of young children and a Delphi study with experts to design the instrument for children <4 years of age.(9)

7.1.3. EQ-5D-Y (3L and 5L)

The EQ-5D-Y is a proxy or self-report 5-item generic paediatric HRQoL instrument.(13, 14) Both have a 'today' recall period and cover 5 dimensions: mobility, looking after self, usual activities, pain/discomfort, and worried/sad.(13) Respondents are asked to rate the severity of each item on a 3-point scale for the EQ-5D-Y-3L and on a 5-point scale for the EQ-5D-Y-5L. The EQ-5D-Y also includes a general health Visual Analogue Scale (VAS). The EQ-5D-Y-3L was adapted from the EQ-5D adult version using cognitive interviews and the EQ-5D-Y-5L was adapted from the EQ-5D-Y-3L.(13, 14) The EQ-5D-Y has been validated in children aged 4-18 years. Additionally, an adapted proxy version of the EQ-5D-Y for age 2-4 years with guidance notes is also trialled for children of this age.

7.1.4. CHU9D

The CHU9D is a proxy or self-report 9-item generic paediatric HRQoL instrument with 5 item response levels, a 'today' recall period, covering 9 dimensions: worried, sad, pain, tired, annoyed, schoolwork/homework, and sleep.(15, 16) Respondents are asked to rate the severity of each item on a 5-point scale. The CHU9D was developed specifically for use in younger children aged 6 to 11 years old, however, has been validated in children up to age 17.(15, 16) Additionally, a proxy version of the CHU9D with guidance notes available for under 5 years (method of development is unclear, but assumed to be adapted by instrument developers) and is being trialled for children of this age.

7.1.5. AQoL-6D Adolescent

The AQol-6D adolescent is a proxy or self-report 20-item generic adolescent HRQoL instrument with 4 to 6 item response levels, a 1 week recall period, covering 6 domains: independent living, mental health, coping, relationships, pain, and senses.(17, 18) Respondents are asked to rate the severity of each item on a 4- to 6-point scale. The adult AQoL-6D was adapted by instrument developers to develop the AQoL-6D for adolescents aged 12–18 years, however, has been used in children aged 11 years.(18, 19)

7.1.6. PROMIS-25 paediatric profile

The PROMIS-25 paediatric profile is a proxy or self-report 25-item generic paediatric HRQoL instrument with 5 item response levels (except for the pain item which is 10 levels), a 1 week recall period, covering 6 domains: physical function mobility, anxiety, depressive symptoms, fatigue, peer relationships, and pain interference.(20) Respondents are asked to rate the severity of 5-items and the frequency of items on a 5-point scale. Except for the pain item which is on a scale from 0-10. The PROMIS-25 was developed from the PROMIS-37 which was developed from the PROMIS-49. The PROMIS-25 is recommended for use in children aged 5 years and older.(20)

7.1.7. HUI 2/3

The Health Utilities Index Mark 2 and 3 (HUI2/3) is a proxy or self-report 15-item generic HRQoL instrument with 4 to 6 levels that can be used in paediatric populations.(21-23) The HUI2/3 instrument can be used to classify a participant's health according to either the HUI2 or HUI3 classification system.(21-23) The HUI3 classification system has 8 domains (vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain) and was developed to address issues in the HUI2 classification system which has 7 domains (sensation, mobility, emotion, self-care, cognition, pain, and fertility), however the fertility domain is dropped when being used in paediatric populations.(21-23)The HUI 2/3 has current a range of validated recall options. These recall options include 'current' recall versions (e.g., "during the past 1 week", or "during the past 2 weeks", or "during the past 4 weeks") or a 'usual' recall version. The usual recall version, which asks the participant to respond based on their usual health, was used for this study. Respondents are asked to rate the severity of each item on a 4- to 6-point scale. The HUI 2/3 is HUI is recommended for use in children 5 years or older, however, some studies have used the instrument in children as young as 1 year old.(24)

7.1.8. EQ-5D-5L

The EQ-5D-5L is a 5-item generic adult HRQoL instrument with 5 item response levels, a 'today' recall period, covering 5 dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.(25) Respondents are asked to rate the severity of each item on a 5-point scale Although the EQ-5D-5L is generally self-report, a proxy report version is available. The EQ-5D-5L was adapted from the 3-level version, the EQ-5D-3L.(25)

7.2. Health condition-specific instruments

Due to the survey nature of this study, all health condition-specific instruments were required to be self or carer-reported (as opposed to clinician-reported or interview format). Additionally, the following criteria were applied to guide the choice of health condition-specific instrument: 1) well validated for children, 2) quality of life measure, 3) functional impairment measure, and 4) symptom measure. For example, if a condition-specific quality of life measure had been validated in children, this would be selected over a condition-specific functional or symptom measure that has been validated in children. Where there was ambiguity about the best choice, clinical experts were consulted.

7.2.1. ADHD

The Strengths and Weaknesses of Attention-Deficit/Hyperactivity Disorder Symptoms and Normal Behaviour Scale (SWAN) is a proxy-report ADHD symptom scale used as the health condition specific instrument for the ADHD group in this study, Sample 3a.(26) The SWAN has 18 items, 7 item response levels, a 1 month recall period, and covers 3 symptom areas: inattention, hyperactivity, and impulsivity.(26) The SWAN has been validated in children aged 6 to 18 years, however, has been used in children as young as 4 years.(27)

7.2.2. Anxiety or depression

The Revised Children's Anxiety and Depression Scale (RCADS-25) is a proxy or self-report anxiety and depression symptom scale used as the health condition specific instrument for the anxiety and depression group in this study, Sample 3b.(28) The RCADS-25 has 25 items, 4 item response levels, no specified recall period, and covers 6 domains: generalized anxiety disorder, major depressive disorder, obsessive compulsive disorder, panic disorder, separation anxiety disorder and social phobia.(28) The RCADS-25 has been validated in children aged 7 to 18 years.(28)

7.2.3. ASD

The KIDSCREEN-27 is a proxy or self-report generic paediatric HRQoL instrument used as the health condition specific instrument for the ASD group in this study, Sample 3c.(29, 30) Although the KIDSCREEN-27 is a generic HRQoL instrument, it was chosen as the health condition-specific instrument for the ASD group as no appropriate ASD-specific HRQoL instrument or symptom scale was available and the KIDSCREEN-27 has previously been recommended as a robust HRQoL instrument in children with ASD. The KIDSCREEN-17 has 27 items, 5 item response levels, a 1 week recall period and covers 5 domains: physical wellbeing, psychological wellbeing, autonomy/ parent relation, peer/social support, and school environment.(29, 30) The KIDSCREEN-27 is designed for use in children aged 8 to 18 years.(30)

7.2.4. Asthma

The PedsQL Asthma Module Version 3 is a proxy or self-report asthma paediatric HRQoL instrument used as the health condition specific instrument for the asthma group in this study, Sample 3d.(31) The PedsQL Asthma Module has 28 items (26 items in the 2–4-year-old version), 5 item response levels, a 1 month recall period, and covers 4 domains: asthma, treatment, worry, and communication.(31) The PedsQL asthma module has validated versions available for children aged 2 to 18 years.(31)

7.2.5. Eating disorders

The Eating Disorder Quality of Life Scale (EDQLS) is an adolescent and adult eating disorder specific quality of life instrument used as the health condition specific instrument for the eating disorder group in this study, Sample 3e.(32) The EDQLS has 40 items, 5 item response levels, a 1 week recall period, covering 12 domains: cognitive, education/vocation, family and close relationships, relationships with others, future outlook, appearance, leisure, psychological, emotional, values and beliefs, physical, and eating.(32) A self-reported version of the EDQLS has been validated in adolescents and adults aged 14-60 years old.(32) A proxy version was generated for the purposes of this study (see Section 7.4 for further information).

7.2.6. Epilepsy

The Quality of Life in Childhood Epilepsy Questionnaire (QOLCE-16) is a proxy report epilepsy specific paediatric HRQoL instrument used as the health condition specific instrument for the epilepsy group in this study, Sample 3f.(33) The QOLCE-16 has 16 items, 6 item response levels, a 4 week recall period, covering 4 domains: cognitive functioning, emotional functioning, social functioning, and physical functioning.(33) The QOLCE-16 has been validated in children with epilepsy aged 4-12 years, however, the QOLCE-57 has been validated in children up to the age of 18 years.(33)

7.2.7. Recurrent abdominal pain

Two pain visual analogue scales (VASs) asking about pain today and pain at last pain episode were used as the health condition specific instrument for the recurrent abdominal pain group in this study, Sample 3g. The pain VAS scales were adapted from the Paediatric Pain Questionnaire.(34)

7.2.8. Sleep problems

The Sleep Disturbance Scale for Children (SDSC) is a proxy report paediatric sleep disturbances and sleep behaviour instrument used as the health condition specific instrument for the sleep problem group in this study, Sample 3h.(35) The SDSC has 26 items, 5 item response levels, a 6 month recall period, and covers 6 domains: parasomnias, difficulty in initiating and maintaining sleep, sleep disordered breathing, disorders of excessive somnolence, sleep hyperhydrosis and non-restorative sleep.(35) The SDSC is validated in children aged 6 to 16 years, however, it has been used in children as young as 3 years.(36)

7.2.9. Tooth problems

The Child Perceptions Questionnaire (CPQ) 11-14 short form is paediatric oral HRQoL instrument used as the health condition specific instrument for the tooth problem group in this study, Sample 3i.(37, 38) The CPQ 11-14 short form has 16 items, 5 item response levels, a 3 month recall period, and covers 4 domains: oral symptoms, functional limitations, emotional well-being, and social well-being.(37, 38) The CPQ 11-14 was designed and validated in children aged 11 to 14 years, however, evidence suggests it may be applicable in children as young as 5.(39) A proxy version was generated for the purposes of this study (see Section 7.4 for further information).

7.3. Other instruments and survey questions

7.3.1. EQ-HWB-S

The EuroQol health and wellbeing short form (EQ-HWB-S) is an instrument assessing the impact of health and wellbeing being as a care recipient or caregiver.(40) The EQ-WHB-S has 9 items, 7 day recall period, and covers 8 domains: mobility, usual activities, energy, cognition, social relationships, control, anxiety/depression, and pain.(40, 41) A carer quality of life instrument was included in the study following advice from the study Consumer Advisory Group who noted the strong relationship between child and carer QoL in children who have chronic conditions. The EQ-HWB-S was chosen as the carer quality of life instrument to include in the study because it is a promising new instrument that requires further validation work.

7.3.2. SDQ

The strengths and difficulties questionnaire (SDQ) is a paediatric behavioural screening instrument.(42, 43) The SDQ has 25 items, 3 item response levels, a 1-month recall, and covers 5 domains: emotional symptoms, conduct problems, hyperactivity/inattention problems, peer relationship problems, and prosocial behaviour.(42, 43) Validated versions of the SDQ are available for children aged 2–17 years, with self-report available for children aged 11 years and older.(42, 43) The SDQ was included in the study to capture emotional wellbeing of child participants to enable the performance of HRQoL instruments to be compared across validated scales of emotional wellbeing.

7.3.3. Other survey questions

A core set of demographic questions was included in the initial survey and completed by the caregiver. Where possible, demographic questions were adapted from LSAC to allow for comparison with a nationally representative sample.(5)

For each health condition group in Sample 3, several health condition severity questions were added to the initial survey to help approximate self or carer reported health condition severity (see Appendix Table 2). Health condition severity questions were designed with clinical experts to be no more than 3 questions, where possible, questions were derived from previous research studies.

Questions regarding the impact of COVID-19 on both caregivers and children were added to initial and follow-up surveys. As the COVID-19 impact questions were added after recruitment for Sample 1 had

begun and prior to recruitment for Sample 2 and 3 beginning, all online panel samples (Samples 2 and 3) received the COVID-19 impact questions. However, only a portion of the sample recruited via hospital (Sample 1) received the questions. These questions were designed to allow for testing of potential self-reported COVID-19 impacts on HRQoL and to aid with generalisability of results considering data were collected during periods of pandemic.

The following additional questions were added to the follow-up survey that were not in the initial survey to capture any change in health since the initial survey was completed:

- Caregiver report of child's change in general health between initial and follow-up survey, adapted from similar SF-36 question.(44)
- If relevant, caregiver report of child's change in main health condition between initial and follow-up survey, adapted from similar SF-36 question.(44)
- Caregiver report of any major health event between initial and follow-up survey and if this event made the child's health better worse or it had no change. Major health events asked about included new treatment or therapy, new medication, new accident or injury, new condition diagnosed, new illness, unplanned doctor visit, unplanned hospital visit.

7.4. Survey adaptations

Some minor adaptations were made to the wording of some health condition-specific instruments, these are outlined below in Table 4. Where a health condition-specific instrument only had a self-report version (CPQ 11-14 and EDQLS), a proxy-report version was generated for the purpose of this study. A proxy-report version was required for this study as the survey was designed so that a caregiver could proxy-report the entire survey if they felt the child was not currently able to self-report their HRQoL or the child was younger than 7 years of age.

Table 4. Health condition-specific instruments adaptations

Health condition-specific sample	Instrument	Report type	Adaptations
3a. ADHD	SWAN	Proxy only	Adapted wording of questions with permission from developer. Adaptations were made to ensure the wording of the instrument was appropriate for a caregiver to understand.
3b. Anxiety or depression	RCADS-25	Proxy and self-report	-
3c. ASD	KIDSCREEN-27	Proxy and self-report	-
3d. Asthma	PedsQL asthma module	Proxy and self-report	-
3e. Eating disorder	EDQLS	Proxy (adapted) and self-report (original)	Generated proxy version for the purpose of this study from self-report version.
3f. Epilepsy	QOLCE-16	Proxy only	-
3g. Recurrent abdominal pain	Pain VAS	Proxy and self-report	Two pain VAS' adapted from Paediatric Pain Questionnaire. (34)

Health condition-specific sample	Instrument	Report type	Adaptations
3h. Sleep problems	SDSC	Proxy only	-
3i. Tooth problems	CPQ-11-14	Proxy (adapted) and self-report (original)	Generated proxy version for the purpose of this study from self-report version.

8. Survey development, piloting, and testing

Six rounds of survey piloting and testing were conducted with colleagues, consumer advisors, associate investigators, decision makers, caregivers, and children prior to the final survey being launched. Survey piloting was instrumental in improving the design, length, and wording included in the survey. Additionally, all survey pathways were quality checked prior to launch to ensure no survey errors.

9. Data collection and survey administration

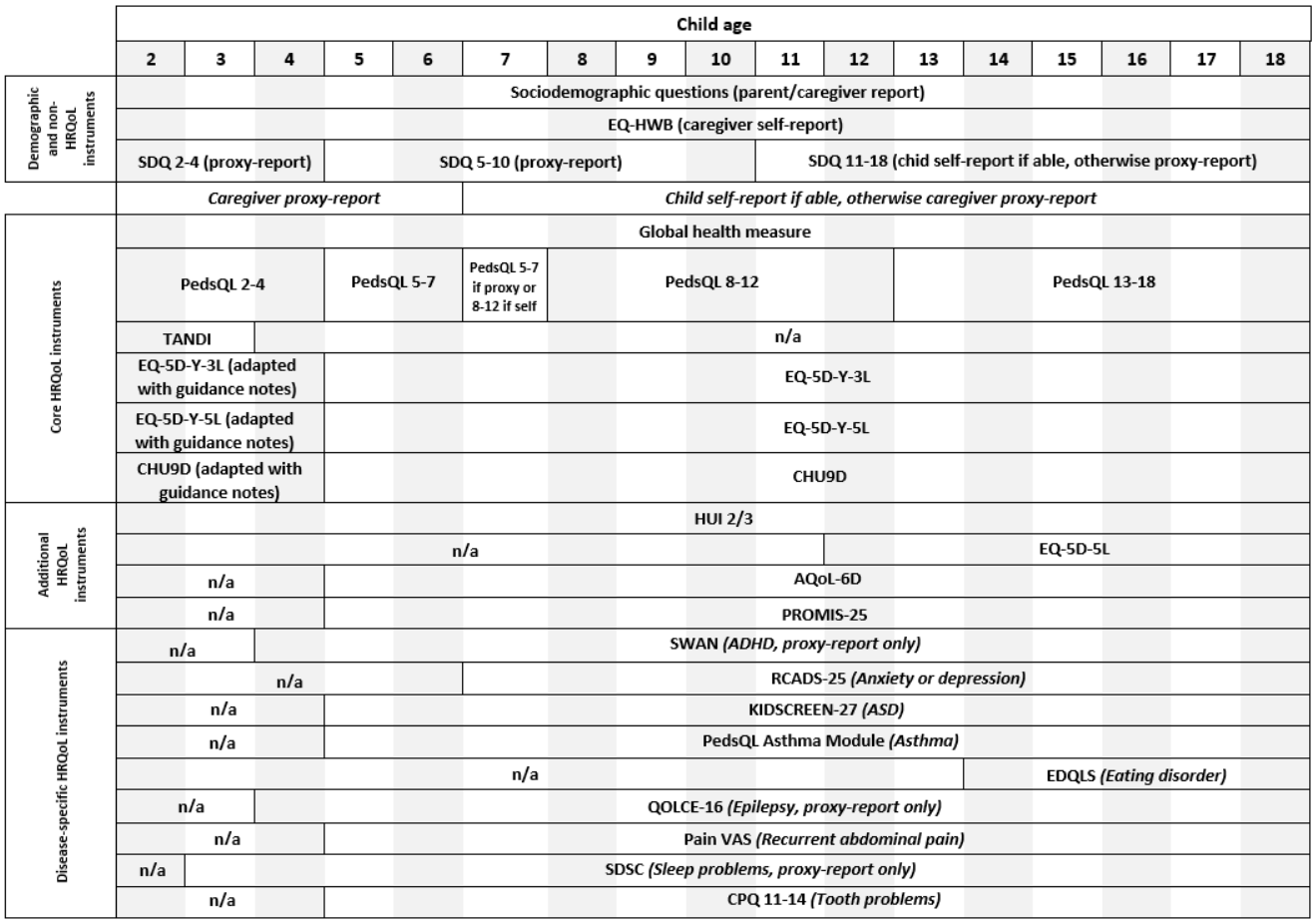
Participants completed surveys online via REDCap (Research Electronic Data Capture) hosted at The Murdoch Children's Research Institute (MCRI) (www.redcap.mcri.edu.au, accessed on 14th June 2022). All participants received a core set of questions and instruments, some samples also received additional instruments, instrument blocks, and/or questions. The schedule of instruments for each sample collected at the two time points is outlined in Table 5. As some instruments have different versions for different child ages, participants were allocated to receive the instrument version most appropriate for their child's age (see Figure 1). Children aged 7 years and older were asked to self-report the HRQoL instruments and health condition instruments if a self-report version was available and if the child was considered currently able to report on questions about their health and wellbeing by their caregiver.

The order of the demographics, EQ-HWB-S, SDQ, core HRQoL instruments, additional HRQoL instruments, and health condition-specific instruments was decided based on two criteria: 1) an order that minimises the survey being handed back and forth between caregivers and children, with only one handover point occurring if the child is 7 years or older and able to self-report, and 2) the order reflects the priority of questions as decided by the study team. For the initial survey, participants were first screened and consented into the survey, following this, participants completed the demographic questions (including health condition severity questions if relevant, see Appendix Table 2). The additional HRQoL instrument blocks were always presented to participants after the core HRQoL instruments. Condition-specific instruments that had both a proxy and self-report version available were always presented after the core and additional HRQoL instruments. Where only proxy-report versions of the condition-specific instruments were available, the condition-specific instrument was presented prior to the core HRQoL instruments, this was to prevent the caregiver and child having to hand the survey back and forth. The follow-up survey followed the same structure as the initial survey albeit with a smaller number of required instruments (see Table 5).

Within the core HRQoL instruments, the order of instruments was randomized to minimize order and survey fatigue effects. Additionally, the EQ-5D-Y-3L, EQ-5D-Y-5L, and, if relevant the EQ-5D-5L, were presented with another HRQoL instrument separating them, given their similarities. Participants received the same order of instruments for both the initial and follow-up survey.

Except for Sample 2b (the online panel general population sample with a 2-day follow-up), all samples were followed up at 4 weeks and received up to three reminders at consistent time intervals. Sample 2b received a 2-day follow-up timeframe to allow for test-retest analysis. For consistency, 4-week follow-up time was decided for the remainder of the samples, this longer follow-up time was chosen to allow for analysis of instrument responsiveness to perceived change in health between time points, which is a key gap in the current literature.(4) A 4-week follow-up time was considered enough time to for children who were acutely unwell at the time of recruitment to recover before the follow-up survey and a short enough time frame to minimise attrition.

Figure 1. Instruments and questions by child age.



Abbreviations: AQoL-6D Assessment of Quality of Life, CHU9D Child Health Utility, CPQ Child Perceptions Questionnaire, RCADS Revised Children's Anxiety and Depression Scale, EDQLS Eating Disorder Quality of Life Scale, EQ-HWB EQ Health and Wellbeing Short Version, EQ-5D-Y EQ-5D Youth, HRQoL health-related quality of life, HUI2/3 Health Utilities Index Mark 2/3, PedsQL Paediatric Quality of Life Inventory, PROMIS-25 Patient-Reported Outcome Measurement Information System 25, QOLCE Quality of Life in Childhood Epilepsy Questionnaire, VAS Visual Analog Scale, SDSC Sleep Disturbance Scale for Children, SDQ Strengths and Difficulties Questionnaire, SWAN Strengths and Weaknesses of Attention-Deficit/Hyperactivity Disorder Symptoms and Normal Behavior Scale, TANDI Toddler and Infant Questionnaire.

Table 5: summary of instruments and questions by sample

Instrument	Sample 1, Recruited via hospital		Sample 2, General population		Sample 3, Health condition-specific groups	
	Initial survey	Follow-up survey	Initial survey	Follow-up survey	Initial survey	Follow-up survey
Demographic and non-HRQoL instruments						
Informed Consent	x		x		x	
Demographic Information	x		x		x	
EQ-HWB	x		x		x	
SDQ	x		x		x	
Core HRQoL instruments						
PedsQL	x	x	x	x	x	x
TANDI (if <=3yrs)	x	x	x	x	x	x
EQ-5D-Y-3L (inc VAS) & 5L original (if >= 5 years)	x	x	x	x	x	x
EQ-5D-Y-3L (inc VAS) & 5L adapted (if <=4 years)	x	x				
EQ-5D-Y-3L original (inc VAS) & adapted OR EQ-5D-Y-5L original (inc VAS) & adapted (if <=4 years)			x*	x*	x*	x*
CHU9D	x	x	x	x	x	x
Global Health Measure	x	x	x	x	x	x
Additional HRQoL instruments						
AQoL-6D (if =>5yrs)			x*	x*	x*	x*
HUI2 (if >=2yrs) & EQ-5D-5L (if >=12yrs)			x*	x*	x*	x*
PROMIS-25 (if =>5yrs)			x*	x*	x*	x*
Health condition-specific instruments						
SWAN *(ADHD)*					x*	
RCADS-25 *(Anxiety or depression)*					x*	
KIDSCREEN-27 *(ASD)*					x*	
PedsQL Asthma Module *(Asthma)*					x*	
EDQLS *(Eating disorder)*					x*	
QOLCE-16 *(Epilepsy)*					x*	
Pain VAS *(Recurrent abdominal pain)*					x*	
SDSC *(Sleep problems)*					x*	
CPQ 11-14 *(Tooth problems)*					x*	

*X- indicates the instrument will be collected from the sample/time point. *Participant will only receive, if allocated, instrument based on health condition group, and/or randomization to receive additional instrument, and/or randomization to receive EQ-5D-Y 3L original and adapted or EQ-5D-Y 5L original and adapted. Abbreviations: AQoL-6D Assessment of Quality of Life, CHU9D Child Health Utility, CPQ Child Perceptions Questionnaire, RCADS Revised Children's Anxiety and Depression Scale, EDQLS Eating Disorder Quality of Life Scale, EQ-HWB EQ Health and Wellbeing Short Version, EQ-5D-Y EQ-5D Youth, HRQoL health-related quality of life, HUI2/3 Health Utilities Index Mark 2/3, PedsQL Paediatric Quality of Life Inventory, PROMIS-25 Patient-Reported Outcome Measurement Information System 25, QOLCE Quality of Life in Childhood Epilepsy Questionnaire, VAS Visual Analog Scale, SDSC Sleep Disturbance Scale for Children, SDQ Strengths and Difficulties Questionnaire, SWAN Strengths and Weaknesses of Attention-Deficit/Hyperactivity Disorder Symptoms and Normal Behavior Scale, TANDI Toddler and Infant Questionnaire.*

10. Participant reimbursement

Participants from Sample 1, sample recruited via hospital, were reimbursed with a $15 online gift voucher once they had completed the follow-up survey. Participants from Samples 2 and 3, the online panel samples, were reimbursed for their time by Pureprofile Australia. Participants in both the online panel general population sample and health condition-specific groups sample (Samples 2 and 3) were reimbursed $3-$5 for completing the initial survey and $3-$4 for the second. Total reimbursement ranged from $6-$9.

11. Quotas

For the online panel general population sample (Sample 2), participants were selected based on quotas for age. Other characteristics such as child gender, family income, regionality, state, number of caregivers in the home, and caregiver education were monitored to ensure a diverse sample was obtained from the online panel.

12. Quality monitoring

Minimum quality indicator criteria were applied to each sample to ensure that legitimate responses were being obtained. Survey responses were removed across all samples if they met one of the following poor-quality indicator criteria:

- Child age outside of eligibility
- Caregiver age less than 18 years
- Survey completed in less than 1/3 of the median time, for both initial and follow-up surveys
- Caregiver not reporting child health condition they have screened for in initial survey condition list (Sample 3 only, online panel condition group sample)
- Child age reported at follow-up is not consistent with child age reported in initial survey.

Several additional quality criteria were monitored to ensure these occurrences were minimal, however, participants were not removed from the sample based on these criteria. Additional monitoring quality criteria were:

- Child self-report during school hours
- Child does not screen as having a special healthcare need but does report having a condition where this would be expected

Duplicate records in the online panel samples (Sample 2 and 3) were identified using the unique online panel identifier. Duplicate records in the hospital sample (Sample 1) were identified using the email address entered by caregivers in the survey. In deciding which record to keep, the following criteria was applied:

1) Keep the most complete record.
2) If both records were equally complete, keep the record that was completed first.

N=18 participants were removed from the current data cut for being a duplicate record.

Where a caregiver had completed the survey more than once for different children, this was noted so duplicate caregivers could be removed from relevant analysis such as for the EQ-HWB.

13. Decision to close samples

Samples were closed if target sample sizes were reached.

14. Funding

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15. Conflicts of interest

K.D., N.D., B.M., H.H., R.J. have all received previous or current funding from the EuroQol Foundation who is the developer and copyright holder of some instruments included in this study. N.D. and B.M. are members of the EuroQol Group. The EuroQol Foundation are providing some direct funding for this research.

16. Appendix

Appendix Table 1: Summary of HRQoL instruments included and key instrument characteristics

Instrument	Descriptions	Number of items	Item response levels	Recall	Domains/dimensions/scales
Core HRQoL instruments					
PedsQL generic core 4.0 (11, 12)	Generic paediatric HRQoL instrument.	23 items	5 levels	1 month	Physical functioning, emotional functioning, social functioning, and school functioning.
EQ-5D-Y-3L(13)	Generic paediatric HRQoL instrument.	5 items	3 levels	Today	Mobility, looking after self, usual activities, pain/discomfort, and worried/sad.
EQ-5D-Y-5L (13, 14)	Generic paediatric HRQoL instrument.	5 items	5 levels	Today	Mobility, looking after self, usual activities, pain/discomfort, and worried/sad.
CHU9D (15, 16)	Generic paediatric HRQoL instrument.	9 items	5 levels	Today	Worried, sad, pain, tired, annoyed, schoolwork/homework, daily routine, activities, and sleep.
TANDI (9)	Generic toddler and infant HRQoL instrument.	6 items	3 levels	Today	Movement, play, pain, social interaction, communication, and eating.
Additional HRQoL instruments					
AQoL-6D (17)	Generic adolescent HRQoL instrument.	20 items	4 to 6 levels	1 week	Independent living, mental health, coping, relationships, pain, and senses
PROMIS-25 paediatric profile (20)	Generic paediatric HRQoL instrument.	25 items	5 levels, except for the pain item which is 10 levels.	1 week	Physical function mobility, anxiety, depressive symptoms, fatigue, peer relationships, and pain interference.

Instrument	Descriptions	Number of items	Item response levels	Recall	Domains/dimensions/scales
HUI 2/3 (21-23)	Generic HRQoL instrument that can be used in paediatric populations.	15 items	4 to 6 levels	The HUI 2/3 has 'current' recall versions with a specified recall time period or a 'usual' recall version. The usual recall version was used for this study.	The HUI3 classification system: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain. The HUI2 classification: sensation, mobility, emotion, self-care, cognition, pain, and fertility. However, the fertility domain is dropped when being used in paediatric populations.
EQ-5D-5L (25)	Generic adult HRQoL instrument.	5 items	5 levels	Today	Mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.
Health condition-specific instruments					
SWAN (ADHD) (26)	ADHD symptom scale	18 items	7 levels	1 month	Inattention, hyperactivity, and impulsivity.
RCADS-25 (Anxiety/ depression) (28)	Anxiety and depression symptom scale	25 items	4 levels	n/a	Generalized anxiety disorder, major depressive disorder, obsessive compulsive disorder, panic disorder, separation anxiety disorder, and social phobia.
KIDSCREEN-27 (ASD) (29, 30)	Generic paediatric HRQoL instrument	27 items	5 levels	1 week	Physical wellbeing, psychological wellbeing, autonomy/ parent relation, peer/social support, and school environment.
PedsQL asthma module (Asthma) (31)	Asthma paediatric HRQoL instrument	28 items (26 items in 2-4 year old version)	5 levels	1 month	Asthma, treatment, worry, and communication.
EDQLS (Eating disorder) (32)	Eating disorder adolescent and adult	40 items	5 levels	1 week	Cognitive, education/vocation, family and close relationships, relationships with others,

Instrument	Descriptions	Number of items	Item response levels	Recall	Domains/dimensions/scales
	quality of life instrument				future outlook, appearance, leisure, psychological, emotional, values and beliefs, physical, and eating.
QOLCE-16 (Epilepsy) (33)	Epilepsy specific paediatric HRQoL instrument	16 items	6 levels	4 weeks	Cognitive functioning, emotional functioning, social functioning, and physical functioning.
Pain VAS (Recurrent abdominal pain) (34)	Pain VAS adapted from the Paediatric Pain Questionnaire	2 items	VAS scale	Today and last pain episode.	n/a
SDSC (Sleep problems) (35, 36)	Paediatric sleep disturbances and sleep behaviour instrument	26 items	5 levels	6 months	Parasomnias, difficulty in initiating and maintaining sleep, sleep disordered breathing, disorders of excessive somnolence, sleep hyperhydrosis and non-restorative sleep.
CPQ-11-14 short form (Tooth problems) (37, 38)	Paediatric oral HRQoL instrument	16 items	5 levels	3 months	Oral symptoms, functional limitations, emotional well-being, and social well-being
Other instruments					
EQ-HWB-S (40, 41)	Instrument assessing the impact of health and wellbeing being as a care recipient or caregiver.	9 items	5 levels	7 day	Mobility, usual activities, energy, cognition, social relationships, control, anxiety/depression, and pain.
SDQ (42, 43)	Paediatric behavioural screening questionnaire.	25 items	3 levels	1 month	Emotional symptoms, conduct problems, hyperactivity/inattention problems, peer relationship problems, and prosocial behaviour

Appendix Table 2 Health condition-specific questions to approximate health condition severity

Health condition-specific sample	Severity questions	Source
3a. ADHD	1. Does your child currently take regular medication for their ADHD? Yes No 2. Thinking about your child's ADHD and its impact on school, would you say their ADHD has: No Little impact Some impact A large impact 3. Thinking about your child's ADHD and its impact on home, would you say their ADHD has: No Little impact Some impact A large impact 4. Thinking about your child's ADHD and its impact on social life, would you say their ADHD has: No Little impact Some impact A large impact	Consultation with clinical expert.
3b. Anxiety or depression	N/A, severity measured using SDQ.	N/A
3c. ASD	1. What type of school does the Study Child attend? A special school Does not attend school Mainstream school with integration support funding Mainstream school with no integration support funding	Consultation with clinical and research experts. Derived from severity question used in ASD study at MCRI, iSAID project.
3d. Asthma	1. Since they were first diagnosed, has your child ever required an overnight hospital stay for their asthma? Yes- *go to a and b* No- *go to 2* a) How many times have they required an overnight hospital stay for their asthma? b) When was their most recent overnight hospital stay for their asthma? 2. Since they were first diagnosed, has your child ever had to attend an Emergency Department for their asthma? Yes- *go to a and b* No- *go to 3*	Consultation with clinical expert.

Health condition-specific sample	Severity questions	Source
	a) How many times have they attended an Emergency department for their asthma? b) When was their most recent attendance to an Emergency department for their asthma? 3 months/6 months/12 months/ more than 12 months/ I'm not sure 3. Does your child currently have a prescription for an oral corticosteroid (also called a 'preventer') medication for their asthma? *This includes medications such as Flixotide®, Pulmicort®, Alvesco® and Symbicort®* Yes No	
3e. Eating disorder	1. Since they were first diagnosed, has your child ever required an overnight hospital stay for their eating disorder? Yes- *go to a and b* No- *go to 2* a) How many times have they required an overnight hospital stay for their eating disorder? b) When was their most recent overnight hospital stay for their eating disorder? 2. Since they were first diagnosed, has your child ever had to attend an Emergency Department for their eating disorder? Yes- *go to a and b* No- *go to 3* a) How many times have they attended an Emergency department for their eating disorder? b) When was their most recent attendance to an Emergency department for their eating disorder? 3. Is your child regularly meeting with a health care provider for their eating disorder (e.g. counsellor or mental health professional, eating disorder service, CAMHS, paediatrician, GP, headspace, dietician)? Yes No	Consultation with clinical expert.
3f. Epilepsy	1. How old was your child when they had their first seizure?	Consultation with clinical expert.

Health condition-specific sample	Severity questions	Source
	2. When was your child's last seizure? 3. How frequently does your child experience seizures? 4. How many daily medications does your child take for their epilepsy?	
3g. Recurrent abdominal pain	1. Overall, would you describe the child's recurrent abdominal pain condition as mild, moderate or severe? 2. Would you describe the child's last abdominal pain episode as mild, moderate or severe?	Adapted from LSAC.(5)
3h. Sleep problems	1. Thinking about your child with sleep problems, how much is their ongoing sleeping pattern or habits a problem for you? Not a problem at all A small problem A moderate problem A large problem	Adapted from LSAC.(5)
3i. Tooth problems	1. Which of the following tooth problems has the study child **experienced in the last 3 months?** Cavities, dental decay or hole(s) in teeth Tooth or teeth filled because of dental decay Teeth pulled because of dental decay Accident causing breakage or loss of teeth Crowded teeth Problems with bite (e.g., crossbite or overbite) a) Has your child been hospitalised for this problem? b) Has the problem been treated? c) *If Yes to b,* How long ago was this problem treated? 2. How would you describe the health of your child's teeth and gums? *(Respond on the following scale for both teeth and gums)* Excellent Very good Good Average Poor Very poor Don't know	Consultation with clinical expert and adapted from World Health Organisation (WHO) oral health questionnaire.(45)

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