

Measuring Outcomes in Paediatric Chronic Pain

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Why?

- Augment history & examination
- Screen for problems, e.g. mental health issues
- Improve provider-patient communication
- Inform clinical decision making
- Assess treatment efficacy
- Quality improvement, audit & research
- Benchmarking & comparison

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With what?

- Patient-Reported Outcome Measures (PROMs)
- Patient-Centred Outcome Measures (PCOMs) / Goal-Based Outcomes (GBOs)
- Carer and clinician proxy versions
- Pre-existing, validated measures
or
- Develop a new measure

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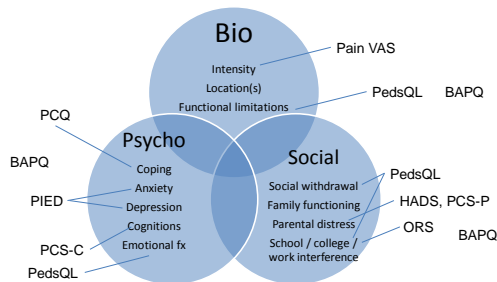
With what?

Some relevant considerations:

- Appropriateness
- Validity, reliability, sensitivity & responsiveness
- Age range
- Language and cultural context (?translation / interpretation)
- Patients with cognitive impairment / communication difficulties
- Length & time to complete
- Licensing & copyright

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With what? (e.g.)



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How?

Method	Pros	Cons
Pen and paper	<ul style="list-style-type: none"> - Easy to administer - Low cost - Can be posted out to patients 	<ul style="list-style-type: none"> - Missing answers - Manual calculation (time and error) - Data not available right away - Storage
Handheld computer	<ul style="list-style-type: none"> - Calculated automatically - Data available immediately - Can prompt for missing answers - Can be administered anywhere in the building 	<ul style="list-style-type: none"> - Requires on-going technical support - Potential higher cost (hardware) - Respondent may not be used to using computers
Fixed terminal	<ul style="list-style-type: none"> - As above but... 	<ul style="list-style-type: none"> - ... fixed location
Internet	<ul style="list-style-type: none"> - Can be completed elsewhere on variety of devices 	<ul style="list-style-type: none"> - ?Less secure - If done away from clinic, no support from staff - No / less access to people without internet access or hardware

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Where and when?

Location	Pros	Cons
Waiting room before appt	- Always space available - Can ensure patient and carer answer separately	- Less privacy - Need time to complete
Dedicated room before appt	- More private - Can ensure patient and carer answer separately	- Rooms not always available (if available at all) - Need time to complete
At home before appt	- Completed at own pace - Private	- Cannot ensure compliance – families may not receive measures / complete them / may interfere with each other's answers - No support from hospital staff – may have difficulty if low literacy or communication problems - If internet-based, may exclude families without internet access - Postage costs & admin time
After appt	- More time available	- Consultation may influence answers

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Storing and accessing data

- Where will you store the data?
- Electronic database – new or pre-existing
- Controlled in-house or by third party
- If contracting out, think about costs
- How will clinicians be supported in interpreting the data?
 - Crib sheets
 - Graphical displays
- How will results be fed back to families?

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Example measure - BAPQ

- Initially validated in 222 patients; 11 – 18 yrs
- Used patient, family and clinician focus groups
- Patient and carer-proxy versions available
- Free to use

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Example measure - BAPQ

- Asks about experience in past two weeks (compromise between ensuring accurate recall and capture of chronicity / fluctuation of condition)
- Eight sections:

Social fx	Pain-specific anxiety
Physical fx	Family fx
Depression	Development
General anxiety	Free text (not scored)
- Contains 61 items: each subscale produces own score
- Higher score = more impairment
- Some items require reverse scoring

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BAPQ - version 1.0

Example measure - BAPQ

- Reliability: Chronbach's $\alpha \geq 0.8$
- Test-retest reliability: correlations ≥ 0.79 (except development subscale)
- Sensitivity: pain management vs rheumatology samples
- Criterion validity assessed against other measures (relevant subscale correlations ranged from 0.51 to 0.71) – development subscale lacked appropriate comparator
- Construct validity also assessed: sig correlations among most subscales

Eccleston C et al. The Bath Adolescent Pain Questionnaire (BAPQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. *Pain* 2005; 118: 263-270.

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BAPQ - version 1.0

Interpretation

- If population norms available, utilise these in routine practice
- Work out the minimally important difference
- Cannot replace clinical judgment

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BAPQ - version 1.0

Group analysis

Must use sound statistical techniques

- Clinical vs statistical
- The larger the n, other things equal, the smaller the p value
- Construct confidence intervals of the difference
- For before & after, use paired methods
- Two-tailed tests (differences up and down are important)
- Control for sex and age (or conduct analyses separately)
- Missing data: decide whether missingness is systematic and deal with appropriately (e.g. exclusion or imputation – do NOT use last item carried forward or the mean of the group)

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Resources

- Fayers PM and Machin P. *Quality of Life: the assessment, analysis and interpretation of patient-reported outcomes* 2nd edn. Chichester: Wiley; 2007.
- Greenhalgh J et al. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory? *Soc Sci Med* 2005; 60: 833-843.
- Gwaltney CJ et al. Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: a meta-analytic review. *Value in Health* 2008; 11(2): 322-333.
- UCL PROM & PREM Network – reports from service user focus groups on outcomes generally (2012): <http://www.ucl.ac.uk/childproms/publications>
- Vetter TR. A primer on health-related quality of life in chronic pain medicine. *Anesth Analg* 2007; 104(3): 703-718.

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