How well do we collect our data? Service evaluation.

Scan our QR Code using your smart phone to be taken directly to our website for more information

Authors: Brooks, Emma[1], Tucker, Peter[1,2], Gosling, Sophie[2]
Affiliations: University of Bristol[1], Recolo UK Ltd[2]

BACKGROUND:

Routinely collected clinical data on children can be flawed, uncertain, proximate and sparse 'FUPS' (Wolpert & Rutter, 2018). Common Data Elements (CDE) group recommend measures in paediatric ABI population (McCauley et al., 2012). Recolo practitioners collect data to identify impairments and monitor outcome, using these measures (Figure 1).

AIMS TO ASK:

Are there gaps in the Recolo clinical dataset? If so, why? What are barriers and challenges to data collection?

METHOD:

Frequency counts of data and practitioner interviews. **Participants:** a) Clients (n=267) have a wide range of age (0-18yrs), brain injury type and severity; b) Practitioners (n=6) interviewed by researcher. **Measures:** a) parent and child completed PedsQL, FAD, BRIEF, SDQ, CASP; b) Interview scripts. **Procedure:** a) Frequency analysis of questionnaires collected 2013-2019; b) A purposive sampling method was adopted, associates recruited as participants for semi-structured interview. Thematic Analysis (Braun & Clarke, 2006) performed.

Figure 2: Graphs showing collection of data at baseline and reviews.

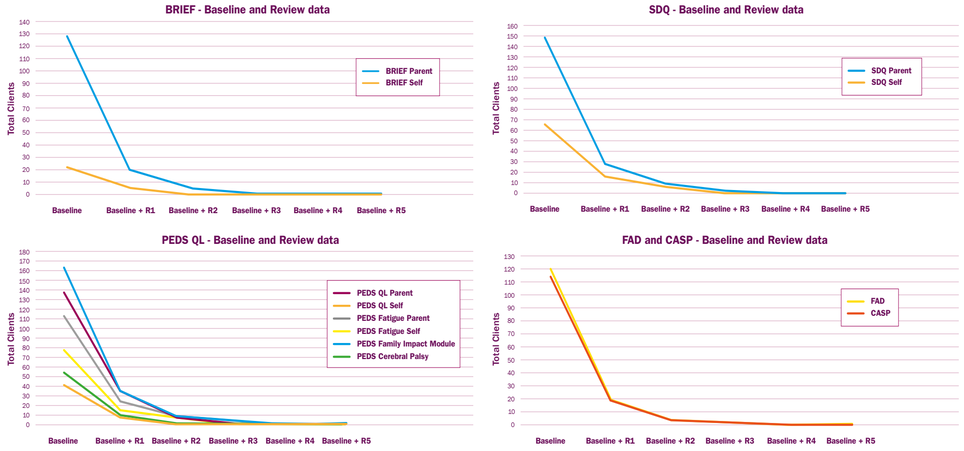
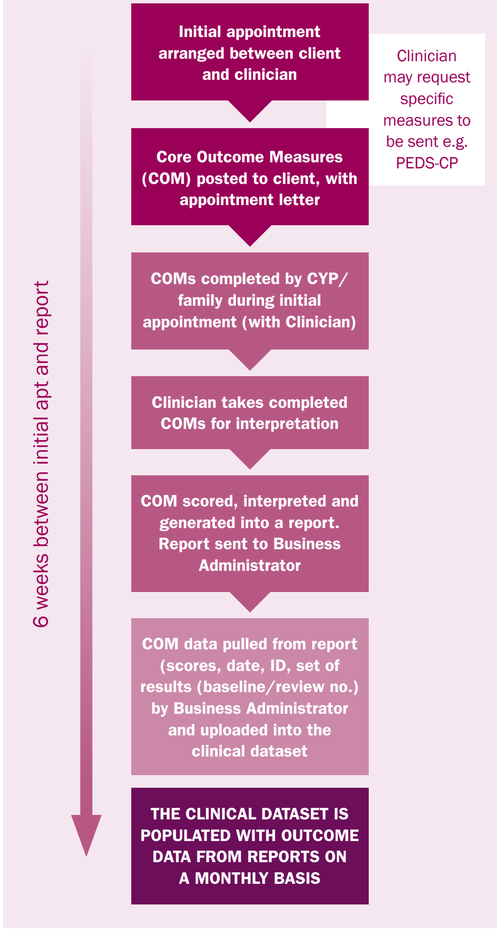


Figure 1: Flowchart showing data collection process in clinical practice.



RESULTS:

a) There were gaps in the database, particularly 'sparse' in reviews. The total completed measures at baseline ranges from n=163 (PEDSQL-FIM-parent) to 41 (PEDSQL core-child). Most commonly reported in review once were PEDS-FIM, PEDS-QL, and SDQ (n=35, 34, 28 respectively) (Figure 2).

b) Five key themes identified from the interview scripts: 1 impact of outcome measures on clients; 2 construct of outcome measurement; 3 culture of goal setting; 4 helpful aspects of outcome measurement; 5 barriers to data collection (Table 1).

RECOMMENDATIONS:

Internal training about purpose and practice of outcome measurement.
CPD to develop shared understanding of culture of outcome measurement.
Integrated remote data collection system for questionnaires and goals.
Supervisors to review and prompt associates' practice in supervision.
Future projects around goal setting and review.

Table 1: Theme five: barriers to data collection.

Sub-theme	Coding strand	Illustrative quote
Responses to measures	Lack of confidence	*Ones that I use but I am not sure of their value particularly*
	Unsuitable measures	*Even that was too much for her really to understand*
	Voice of client	*The tools don't tend to capture the voice of the child*
	Other measures	*Plenty of stuff that I do that is not in the core battery*
Practical challenges	Quantity	*It can feel unhelpful handing out lots of measures*
	Repetition	*The big one is how often they are asked to do it*
	Technical	*I find SharePoint unhelpfully titled*
	Scoring	*Scoring of them all takes me ages*
	Time	*Very time consuming, one of my dilemmas often is whether it is worth it*
	Response rates	*How do you get them back?*
Understanding process		*I could probably do with being a bit more familiar with the measures*
Organisational challenges		*It is really important to create a space for autonomy, and not feel like a top-down approach*
Language barriers		*I had to make sure I had an interpreter present*

References:
McCauley, S. R., et al. (2012). Recommendations for the use of common outcome measures in pediatric traumatic brain injury research. Journal of Neurotrauma, 2: 678-705. Wolpert, M. & Rutter, H. (2018). Using flawed, uncertain, proximate and sparse (FUPS) data in the context of complexity: learning from the case of child mental health. BMC Medicine, 16, 82. Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101.

recolo

www.recolo.co.uk