

DATA PAPER

Data from the Multiprofessional Workshop: 'Paediatric Patient-Reported Outcome and Experience Measures (PROMS and PREMS) in Routine Clinical Practice.'

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To explore current challenges surrounding the development and application of PROMS/PREMS in paediatric healthcare, a workshop was held for healthcare professionals and parent representatives from University College London (UCL) Institute of Child Health (ICH) and two clinical partners, Great Ormond Street Hospital and Moorfields Eye Hospital. The workshop aimed to establish an academic-clinical-service user collaborative network to support local development and translation into clinical practice of paediatric PROMS/PREMS. The workshop report summarises invited presentations, small group discussions and key local issues. The report is permanently archived at UCL Discovery and publicly available.

Keywords: paediatric, child, patient-reported outcome measures, prom, patient-reported experience measures, PREM**Funding statement**

The workshop was funded by MRC Centre of Epidemiology for Child Health small grant (ref: G04005546). Patient and parent focus groups were funded by an MRC Public Engagement grant.

(1) Overview**Context****Spatial coverage**

United Kingdom

Temporal coverage

3rd October 2012

Species*Homo sapiens***(2) Methods****Steps**

Invited speakers gave oral presentations to the workshop attendees. The programme of presentations and summaries of each presentation are provided in the report. Break-out discussion in small groups was included in the final session. Individual group discussions are summarised in the workshop appendix and feedback given to the full workshop audience is summarised in the main body of the report.

Sampling Strategy

N/A

Quality Control

The summary of the workshop presentations and discussions was reviewed and approved by all authors.

Constraints

Full presentations are only available on application to the speakers. A detailed report of the public engagement focus groups with patients and parents conducted at Great Ormond Street Hospital will only be available through the hospital website for a limited period, and thereafter only on application to the authors.

Privacy

Delegates and speakers and their affiliations are named in the workshop report.

(3) Dataset Description**Object Name**

MRC PROM&PREM Workshop 03-10-2012.zip

Data Type

Final report

Format Names and Versions

PDF, CSV

Creation Dates

03-10-2012

Dataset Creators

The invited speakers who provided the presentation materials summarised in the report are:

- Ms Rehana Ahmed, Patient and Public Involvement and Experience Officer, Great Ormond St Hospital, UK
- Dr Mandy Bryon, Consultant Clinical Psychologist, Great Ormond St Hospital, UK
- Dr Naomi Dale, Consultant Clinical Psychologist, Great Ormond St Hospital, UK
- Mrs Bridget Hopwood and Mrs Amy Tallett, Child and Young People's Research Team, Picker Institute Europe
- Dr Christina Liossi, Senior Lecturer in Health Psychology, University of Southampton and Great Ormond St Hospital, UK
- Ms Susan Maillard, Clinical Specialist Physiotherapist, Great Ormond St Hospital, UK
- Dr Chris Morris, Senior Research fellow, Peninsula Cerebra Research Unit, University of Exeter, UK
- Dr Prab Prabhakar, Consultant Paediatric Neurologist, Great Ormond St Hospital, UK
- Dr Jo Wray, Research health Psychologist, Cardiorespiratory Unit and Senior Research Fellow – Centre for Nursing and Allied Health Research, Great Ormond St Hospital, UK Great Ormond St Hospital, UK

Repository Location

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January 2013

Language

English

License

CC0

(4) Reuse potential

The information within this workshop report is available to users as a summary of current practice and local initiatives in the development and use of PROMs/PREMs¹ designed for use with children and young people. It is intended to support the development of future cross-disciplinary communication and collaboration in this area.

Acknowledgements

We much appreciate the valuable contribution of Ms Ailbhe Hogan (Research Assistant at the MRC Centre of Epidemiology for Child Health) in organising the workshop. We would also like to thank Ms Lisa Davies (formerly Clinical Outcomes Lead at Great Ormond St Hospital) for helping with the focus group study. We are very grateful to all of the young patients and their family members who participated in the focus groups and would also like to thank everyone who attended and contributed to the workshop.

References

1. **Morris, C Gibbons, E and Fitzpatrick R** 2009 Child and parent reported outcome measures: a scoping report focusing on feasibility for routine use in the NHS. A report to the Department of Health. http://phi.uhce.ox.ac.uk/pdf/PROMs_WithChildren_Oxford_2009.pdf

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