



**University of  
Sheffield**

**NIHR** | Applied Research Collaboration  
Yorkshire and Humber

# **7<sup>th</sup> National Patient Reported Outcome Measures (PROMs) Research Conference**

## **PROMs Across the Lifespan Event Programme**

University of Sheffield

Inox Dine, Conference Suite, Level 5, Students' Union Building, Western  
Bank, Sheffield, S10 2TG

**Thursday 22nd June 2023**

Hosted by the School of Health Related Research



Clinical Outcomes



**ISOQOL**  
INTERNATIONAL SOCIETY FOR QUALITY OF LIFE RESEARCH

**NIHR** | Research Design Service  
Yorkshire and Humber



## PROGRAMME OVERVIEW

Thursday 22nd June 2023

Programme summary		
09:00 - 09:45	Registration/refreshments	Inox Dine breakout area
10:00 – 10:15	<b>Opening remarks Professor Tracey Young</b> , Professor of Health Economics, School of Health Related Research (SchARR), The University of Sheffield.	Discovery Rooms 1 & 2
Plenary session 1		
10:15 – 10:45	<b>The challenges in the field of measuring patient reported outcomes in the next 5 years</b> , presented by <b>Professor Melanie Calvert</b> , Professor of Outcomes Methodology, Institute of Applied Health Research, University of Birmingham.	Discovery rooms 1 & 2
10:45 – 11:15	Poster viewing and refreshments	Discovery room 3 & Inox Restaurant
Parallel session 1		
11:15 – 12:15		
1a Room: Inox Suite 1	1b Room: Inox Suite 2	1c Room: Inox Suite 3
12:15 – 13:15	Lunch, poster viewing and networking	Inox Restaurant & Discovery room 3
Plenary session 2		
13:15 – 14:15	<b>The challenges relating to measuring outcomes at the three extremes – in childhood, life limiting conditions and older people</b> , presented by <b>Lucy Coombes</b> , Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King’s College London, <b>Dr James Van Oppen</b> , Clinical Research Fellow in Emergency Medicine, Department of Health Sciences, University of Leicester and <b>Professor Fliss Murtagh</b> , Professor of Palliative Care and Director of the Wolfson Palliative Care Research Centre, University of Hull.	Discovery rooms 1 & 2
Parallel session 2		
14:20 – 15:20		
2a Room: Inox Suite 1	2b Room: Inox Suite 2	2c Room: Inox Suite 3
15:20 – 15:45	Poster viewing and refreshments	Discovery room 3 & Inox Restaurant
Parallel session 3		
15:45 – 16:45		
3a Room: Inox Suite 1	3b Room: Inox Suite 2	3c Room: Inox Suite 3
16:50 – 17:00	Closing remarks and prize presentation	Discovery rooms 1 & 2
17:00	Networking	

# PARALLEL SESSION DETAILS

Thursday 22<sup>nd</sup> June – 11:15-12:15

## Session 1a

Chair: TBC

- |       |   |   |
|-------|---|---|
| 11:15 | <b>Rachael Pattison</b><br>Abstract No.8      | Patient-centred development and validation of the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure  |
| 11:35 | <b>Katherine Broomfield</b><br>Abstract No.23 | Collaborative research methods to develop a patient-reported outcome measure (PROM) for people with communication disability who use augmentative and alternative communication (AAC) |
| 11:55 | <b>Joseph Newman</b><br>Abstract No. 48       | Co-designing and testing an electronic patient reported outcome measure package with patients for use in clinical trials in pulmonary hypertension                                    |

## Session 1b

Chair: TBC

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|-------|--|---|
| 11:15 | <b>Tomos Robinson</b><br>Abstract No. 46 | Generating a UK Value Set for the Weight- Specific Adolescent Instrument for Economic Evaluation (WAITE)  |
| 11:35 | <b>Haode Wang</b><br>Abstract No.54      | Discrete Choice Experiments in Health State Valuation: Progress and New Trends  |
| 11:55 | <b>Philip Powell</b><br>Abstract No.79   | Understanding Public Views on the Normative Decisions Made when Valuing Health-Related Quality of Life Patient Reported Outcome Measures in Children and Young People |

## Session 1c

Chair: TBC

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|-------|--|--|
| 11:15 | <b>Tim Pickles</b><br>Abstract No. 6     | Using cognitive interview and think aloud techniques to assess content validity for a new Patient Reported Outcome Measure for Rheumatoid Arthritis Disease Activity |
| 11:35 | <b>Arabella Baker</b><br>Abstract No. 22 | Is my instrument inclusive and accessible? Checking language variation and age appropriateness of an eczema patient reported outcome measure                         |
| 11:55 | <b>Jill Carlton</b><br>Abstract No.61    | Throwing a fit: exploring tensions between model fit and content validity in PROM development  |

## Thursday 22nd June – 14:20-15:20

### Session 2a

Chair: TBC

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|-------|--|---|
| 14:20 | <b>Victoria AR Gale</b><br>Abstract No. 26 | Including young children in the development and testing of patient reported outcome (PRO) instruments: a systematic review of children's involvement in qualitative methods |
| 14:40 | <b>Raveen Jayasuriya</b><br>Abstract No.13 | Identifying determinants to predict patient adherence to brace treatment in scoliosis: development of a questionnaire based on Protection Motivation Theory                 |
| 15:00 | <b>Sarah Somerset</b><br>Abstract No. 53   | Developing a questionnaire for children with hearing loss – the York Binaural Hearing Related Quality of Life – Youth (YBHRQL-Y)  |

### Session 2b

Chair: TBC

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|-------|--|---|
| 14:20 | <b>Hannah Hussain</b><br>Abstract No. 30 | Recommendations for HRQoL data collection in dementia populations   |
| 14:40 | <b>Joanna Thorn</b><br>Abstract No. 77   | Participant-reported questionnaire modules to measure the use of informal care, social care and personal expenses: development and preliminary validation |
| 15:00 | <b>Rachel Evans</b><br>Abstract No. 31   | The impact of different researchers to capture patient reported Quality of Life measures in a dementia randomised controlled trial                        |

### Session 2c

Chair: TBC

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|-------|---|--|
| 14:20 | <b>Yirui Qian</b><br>Abstract No. 24              | Comparison of statistical methods for the analysis of patient-reported outcomes (PROs) in randomised controlled trials (RCTs): a simulation study                                  |
| 14:40 | <b>Ameeta Retzer</b><br>Abstract No. 83           | Development of core outcome set for use in adult primary glioma phase III interventional trials and identification of those that can be patient-reportable - a mixed methods study |
| 15:00 | <b>Olalekan Lee Airyegbusi</b><br>Abstract No. 39 | Statistical analyses and interpretation of patient-reported outcomes in early phase dose-finding oncology trials: A methodological review  |

## Thursday 22nd June – 15:45 – 16:45

### Session 3a

Chair: TBC

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|-------|---|---|
| 15:45 | <b>Derek Kyte</b><br>Abstract No. 33      | Development and validation of the kidney symptom burden questionnaire (KSB-Q): Rasch Analysis   |
| 16:05 | <b>Mike Horton</b><br>Abstract No. 63     | Assessment and validation of the Modified COVID-19 Yorkshire Rehabilitation Scale (C19-YRSm) patient-reported outcome measure for Long COVID or Post-COVID syndrome |
| 16:25 | <b>Nikita Arumalla</b><br>Abstract No. 78 | A psychometric evaluation of the Musculoskeletal Health Questionnaire (MSK-HQ), assessing validity and sensitivity to change in inflammatory arthritis              |

### Session 3b

Chair: TBC

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|-------|--|--|
| 15:45 | <b>Judith Jade</b><br>Abstract No.7      | Improving the uptake of electronic patient reported outcome measures in a specialised axial spondyloarthritis clinic, Sheffield Teaching Hospitals |
| 16:05 | <b>Frances Varian</b><br>Abstract No. 19 | Design and delivery of remote electronic patient reported outcomes (ePROs) for personalisation of therapy in pulmonary arterial hypertension (PAH) |
| 16:25 | <b>May Bianchim</b><br>Abstract No. 38   | Realist and Social Return on Investment Evaluation of the use of Patient Reported Outcomes in Four Value Based Healthcare Programmes               |

### Session 3c

Chair: TBC

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|-------|---|---|
| 15:45 | <b>Georgina Jones</b><br>Abstract No. 52  | Development of a patient-reported outcome measure for gastrointestinal recovery: The PRO-diGI study.  |
| 16:05 | <b>Nicole O'Connor</b><br>Abstract No. 75 | A scoping review and semi-structured interviews to generate a list of outcome measures used to evaluate the clinical effectiveness of interventions in children with nocturnal enuresis |