

TMRP-HDRUK North Workshop:

What do we need to do to make Patient-Reported Outcomes (PROs) part of routinely collected health data?

Thursday 16th March 2023, 10am-3pm

Via [Zoom](#)

Meeting ID: 964 5472 6032

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Aims and objectives of the workshop

- Consider why and how PROs could be embedded in routine care to improve care and research
- Highlight key areas of research in this field
- Identify opportunities and challenges to implementation
- Identify opportunities to collaborate to drive progress in this area
- Develop a research agenda

Agenda

10.00-10:15 Welcome and introductions – Paula Williamson (MRC/NIHR TMRP), Geoff Hall (HDR UK)

10:15-10:45 Overview of the area and case study – Kate Absolom (University of Leeds)

10:45-11:15 Purposes of collecting PRO data

‘Core outcome sets for routine care and research’ – Anna Kearney (University of Liverpool)

‘PROs collected alongside routine data in clinical trials’ – Alice-Maria Toader (University of Liverpool)

‘PRO monitoring as a healthcare intervention’ – Arabella Baker (University of Nottingham)

11:15-11:30 Refreshment break

11:30-12:00 What PROs/PROMs

‘How to choose a PROM – case study from Long COVID’ – Caroline Terwee (Amsterdam UMC)

12:00-12:30 Engagement of patients and healthcare professionals in PRO data collection

‘What do we know about patient engagement with PROs – a scoping review’ – Rhiannon Macefield (University of Bristol), Lee Aiyegbusi (University of Birmingham)

‘Reflections from HDR UK Public Contributors’ – HDR UK Public Contributors

12:30-1:30 Lunch Break

1:30-1:50 Technical issues

‘The potential technical challenges of linking PRO data with the common EHRs we have in the UK’
- Monica Jones (HDR UK/ University of Leeds)

‘Supplementing registry data with PROM data collected through apps’ – Fred Taylor (UK IBD Registry)

1:50-2:30 Breakout groups - open discussion

2:30-3:00 Feedback from groups and next steps