**9th UK PROMS Conference Programme**

“PROMising Future”

University of Birmingham

19th June 2025

******Hosted by the Centre for Patient-Reported Outcomes Research



# Floor plan of the Aston Webb and Great Hall.

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**PROGRAMME OVERVIEW**

09:15 Registration and refreshments

09:45 Welcome – Prof Melanie Calvert & Patient partners, Great Hall

**Plenary 1**

10:00 Prof Devin Peipert, **125th Anniversary Chair & Professor of Health Outcomes Measurement, CPROR, University of Birmingham,** “The Central Role of Patient-Reported Outcomes in Capturing Treatment Tolerability”

**Parallel session 1**

*10:30 Move to parallel session 1*

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| Great Hall | W12 | W5 |
| 1a Clinical conditions | 1b Implementation | 1c Cutting edge methods |

*11:30 Poster viewing and refreshments in the Great Hall*

**Plenary 2**

12:00 Dr Bill Byrom, **VP, Product Intelligence and Positioning Principal, eCOA Science, Signant Health,** “The Patient's Voice Amplified: Five Chapters in the Continued Evolution of PROMs”

*12:30 Lunch, poster viewing & networking with patient partners in the Great Hall*

**Parallel session 2**

*13:30 Move to parallel session 2*

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| Great Hall | W12 | W5 |
| 2a Routine data | 2b Qualitative/Mixed methods | 2c Pilot/Feasibility studies |

**Parallel session 3**

*14:30 Move to parallel session 3*

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| Great Hall | W12 | W5 |
| 3a Patient voice | 3b PROM development | 3c Reviews |

*15:30 Poster viewing and refreshments in the Great Hall*

**Panel discussion**

16:00 **‘Innovation’ in the context of PROMS**, chaired by Assoc. Prof. Kate Absolom. Panel includes Prof. Devin Peipert, Dr. Bill Byrom, Prof. Jill Carlton, Dr Sarah Hughes, Mrs Kathleen Withers, Mr Steve Wilkinson, and Mr Roger Wilson.

16:45 Closing remarks and prize giving in the Great Hall

**PARALLEL SESSIONS**

**Parallel session 1: 10:30 – 11:30**

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| Session 1a: PROMs & clinical conditions  Chair: Konrad Maruszczyk  Room: Great Hall | | |
| 10:30 | **Mollie Price** | Assessing the user acceptability and translatability of the APPRAISE PROM: a patient-reported outcome measure for women who have had surgery for pelvic organ prolapse, stress urinary incontinence or mesh complications (abstract 57) |
| 10:45 | **Georgina Jones** | The impact of endometriosis upon quality of life: findings from two national surveys, across two decades (abstract 61) |
| 11:00 | **Foram Khatsuria** | Development and usability testing of the PRO-CAR-T digital system (abstract 68) |
| Session 1b: Implementation of PROMs  Chair: Nicola Anderson  Room: W12 | | |
| 10:30 | **Scottie Kern** | Building Consensus in the field of Electronic Clinical Outcome Assessment: An Introduction to the Critical Path Institute's eCOA Consortium (abstract 14) |
| 10:45 | **Lorraine Warrington** | MyPath – a digital tool to support the delivery of patient-centred care in oncology (abstract 29) |
| 11:00 | **Katherine Woolley** | Innovative application of patient reported outcome data in palliative and end-of-life care in Wales: a case study (abstract 52) |
| 11:15 | **Manraj Kaur** | Laying the Groundwork: Contextual Determinants of HIT-Assisted PRO Implementation in Community Cancer Centers Serving Black Breast Cancer Patients (abstract 55) |
| Session 1c: Cutting edge methods  Chair: Tim Pickles  Room: W5 | | |
| 10:30 | **Victoria Gale** | Can Young Children Participate in Patient Reported Outcome Measure (PROM) Development? Insights from the PROM Developer’s Perspective (abstract 12) |
| 11:45 | **Jill Carlton** | AI: Artificial Intelligence or Accidental Inaccuracies? The potential pitfalls in applying AI in qualitative research transcription for patient reported outcome measure (PROM) development and/or refinement (abstract 26) |
| 11:00 | **Samantha Sodergren** | Introducing the EORTC QLQ-AYA30: The world's first quality of life questionnaire specific to Adolescents and Young Adults (14-39 years) with cancer (abstract 62) |
| 11:15 | **Tim Benson** | EQ-5D-3L and the Oxford Hip and Knee Scores: Comparative analysis of NHS Arthroplasty PROMs data (abstract 42) |

**Parallel session 2: 13.30 – 14.30**

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| Session 2a: PROs & routine data  Chair: Sarah Hughes  Room: Great Hall | | |
| 13:30 | **Anne Alarilla** | Patient Reported Outcome Measures (PROMs) collected as part of standard care at Great Ormond Street Hospital (abstract 48) |
| 13:45 | **Jessica Penhallow** | myHealthE: A patient-facing digital platform for informing and improving child and adolescent mental health service research and delivery (abstract 56) |
| 14:00 | **Noreen Hopewell-Kelly** | Non-verbal methods used to assess and explore grief, mental health and wellbeing with children and people with additional learning or communication needs, findings from a scoping review (abstract 65) |
| 14:15 | **Bill Byrom** | Advancing PRO integration in Oncology Drug Development and Routine Care: Challenges and Complexities (abstract 39) |
| Session 2b: Qualitative/Mixed methods  Chair: Joe Lanario  Room: W12 | | |
| 13:30 | **Claire Williams** | ‘I got 99 items but “loss of balance” ain’t one’: Assessing the content validity of a novel health-related quality of life (HRQoL) instrument for Amyotrophic Lateral Sclerosis (ALS) (abstract 23) |
| 13:45 | **Nicola Anderson** | Patient-reported outcomes in integrated care settings (ICS-PRO) – a multi-site mixed methods study (abstract 49) |
| 14:00 | **Rhiannon Macefield** | Integrating qualitative work into early-phase studies to optimise PRO measurement in later phase trials: a case study in a Phase II trial of a novel anti-cancer technology (abstract 64) |
| 14:15 | **Megan Pardoe** | Completion of an adapted ICECAP-O capability-wellbeing questionnaire by people living with dementia (PLWD), formal and informal carers. A qualitative interview study (abstract 60) |
| Session 2c: Pilot/Feasibility studies  Chair: Foram Khatsuria  Room: W5 | | |
| 13:30 | **Christina Yiallouridou** | PrEQoL – Pilot feasibility study of prospective socioeconomic and quality of life data collection among haematopoietic stem cell transplant recipients (abstract 19) |
| 13:45 | **Mary Zacaroli** | Using Moodscope cards to measure wellbeing outcomes in third sector organisations: a public-led feasibility study (abstract 37) |
| 14:00 | **Christel McMullan** | Patient Reported Outcomes Research in Trauma (PRiORiTy): A Feasibility Study of using an electronic PRO platform in a traumatic brain injury clinic (abstract 67) |

**Parallel session 3: 14.30 – 15.30**

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| Session 3a: PROs and the patient voice  Chair: Karen Shaw  Room: Great Hall | | |
| 14:30 | **Katherine Broomfield** | Developing in dialogue: Working with people who have communication disability to develop the content for a patient-centred outcome measure (PCOM) and provide insight into meaningful engagement for future implementation (abstract 50) |
| 14:45 | **Victoria Gale** | Co-creating ‘SuperPenguin’: A Mobile App for Caregivers of Children who Stammer (abstract 13) |
| 15:00 | **Sophie Cleanthous** | Insights from Industry III: Principles to Guide the Integration of Patient Expert Input into Mixed Methods Research Protocols in PROM Development (abstract 72) |
| Session 3b: PROM development/Psychometrics  Chair: Devin Peipert  Room: W12 | | |
| 14:30 | **Mike Horton** | Using Rasch analysis to inform the development of The Index of ME Symptoms – TIMES (abstract 21) |
| 14:45 | **Nathan Bray** | MobQoL-7D: Development and validation of a novel PROM for mobility-related quality of life (abstract 32) |
| 15:00 | **Anne Klassen** | Measuring What Matters: Creating a Comprehensive PROM for Gender-Affirming Care Across Borders (abstract 34) |
| 15:15 | **Samantha Sodergren** | International validation of the EORTC QLQ-ANL27, a health-related quality of life measure specific to patients treated with chemoradiotherapy for anal cancer (abstract 63) |
| Session 3c: Reviews  Chair: Lee Aiyegbusi  Room: W5 | | |
| 14:30 | **Rosie Bamber** | Understanding health-related quality of life of informal carers in Amyotrophic Lateral Sclerosis: A conceptual framework (abstract 2) |
| 14:45 | **Victoria Robins** | The impact of age on physical functioning after treatment for breast cancer, as measured by patient-reported outcome measures: A systematic review (abstract 10) |
| 15:00 | **Jack Lawrence** | A targeted review of patient-reported outcome measures used in the treatment and management of endometriosis (abstract 15) |
| 15:15 | **Caroline Dix** | Current practices, challenges and preferences regarding the use of patient-reported outcome measures (PROMs) in measuring the mental health of refugees and people seeking asylum in the UK: a scoping review (abstract 18) |

**POSTER PRESENTATIONS**

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| Poster No | Presenting Author | Abstract Title |
| 1 | **Siobhan Ludlow** | Developing a new patient-reported outcome measure for inducible laryngeal obstruction |
| 3 | **Tim Pickles** | People living with Rheumatoid Arthritis’ thoughts on a weekly Rheumatoid Arthritis disease activity monitoring tool: the PLAN-HERACLES study |
| 4 | **Andrew Lloyd** | Narrative research: An alternative qualitative method for understanding of the burden of rare disease |
| 5 | **Ellie Johnstone** | A Proof-of-Concept study: The development of a Qualitative Tool for people living with Manifest Huntington’s Disease (HD-mQE). |
| 6 | **Rachael Pattinson** | Evaluating the Measurement Properties of Generic Adult Oral Health-Related Quality of Life PROMs: A COSMIN Systematic Review in Progress |
| 7 | **Sally Cox** | Implementation of the OECD PaRIS Study in Wales: A Population Needs Assessment |
| 8 | **Sally Cox** | Expanding the OECD PaRIS Survey in Wales: Insights from the Population Health Survey |
| 9 | **Emily McDool** | Evaluating the validity of the EQ-HWB-S in a large general population sample |
| 11 | **Emma Rowe** | Comparing apples with apples, NHS Wales Patient Reported Outcome Measures (PROMs) Data Standard model. |
| 16 | **Christian Lambert** | Evaluation of a Prehabilitation pathway and understanding the effects of extended knee and hip joint replacement waiting lists |
| 17 | **Chris Bedding** | Developing guidelines for the flexible assessment of patient-reported outcomes in cancer clinical trials and routine care using item libraries. |
| 20 | **Jasmine Rollings** | Confidence to self-manage in Diabetes: An All-Wales cross-sectional population study |
| 23 | **Elena Takasugi** | Translation and cultural adaptation of the FACE-Q Paralysis Module from English to Danish |
| 24 | **Jill Carlton** | Capturing the Impact of Facioscapulohumeral Muscular Dystrophy (FSHD) on Health-related Quality of Life (HRQoL): protocol and preliminary results of a systematic review of existing self-report instruments using COSMIN |
| 25 | **Pongnugoon Kongjaidee** | Patient-reported experience measures in eye care services: A systematic review based on COSMIN guidelines |
| 27 | **Aishwarya Chohan** | Assessing disease impacts via patient-reported outcome measures (PROMs): A case for moving beyond symptoms |
| 28 | **Sarah Copping** | The potential use of Individualised Quality of Life Measures in studies of Multiple Long-Term Conditions: Protocol for a Scoping Review. |
| 30 | **Sarah Evans-John** | Developing and evaluating an electronic questionnaire to capture acne patient-reported outcomes in routine clinical practice (ePAQ-Acne): Establishing content and face validity. |
| 31 | **Monideep Ghosh** | How Useful is the Quality Adjusted Life Year (QALY) in Contemporary Healthcare Decision Making? |
| 33 | **Nathan Bray** | Adaptation and Quality of Life (AdaptQoL): Development and validation of a novel PROM for assistive technology users |
| 35 | **Alan Uren** | The cognitive testing of a non-sex-specific patient reported outcome measure for evaluating lower urinary tract symptoms: The ICIQ-LUTS |
| 36 | **Se Maria Frances** | Recruitment and Engagement in PROM Development: A Reflection on the Methodological Challenges in Recruiting Patients with Idiopathic Multicentric Castleman’s Disease (iMCD) |
| 38 | **Frank Sanders** | Optimisation Of The Daily Living Tasks Dependent On Vision Questionnaire In The Setting Of Patients Being Treated for Macular Diseases |
| 40 | **Tim Benson** | Evaluation of the spread of a data-driven recall system in general practice |
| 41 | **Tim Benson** | Generic PROMs and PREMs: challenges and the case for innovation |
| 43 | **Tim Benson** | The Health Confidence Score: A Brief, Sensitive Measure of Patient Self-Management Capability |
| 44 | **Tim Benson** | QALY vs Load: Valuation of death and illness. |
| 45 | **Tim Benson** | Three Short Generic Measures of Patient Experience |
| 46 | **Hannah Worboys** | Analysing PROMs in clinical trials in the presence of informative dropouts: A comparison of the linear mixed effects model, standard joint and competing risks joint model |
| 47 | **Nova Mathew** | Developing a core outcome set for co-existing dementia and hearing loss: A systematic review of outcomes reported in previous hearing loss and dementia studies. |
| 51 | **Georgie Forshall** | Assessing adverse symptom and health-related quality of life outcomes following treatment for pelvic floor disorders: A content analysis of ePAQ-Pelvic Floor data |
| 53 | **Caroline Potter** | Oxford Brain Health Clinic: health-related quality of life assessment among initial sample |
| 54 | **Jonathan Street** | Development and initial validation of a self-report measure of disease severity for Facioscapulohumeral dystrophy |
| 58 | **Danielle Musson** | Establishing content validity of a novel disease-specific patient-reported outcome measure: The Quality of Life in Antibody Deficiency (QoLiAD) Questionnaire |
| 59 | **Fiona Lerigo** | Understanding care worker-related quality of life in social care: a conceptual basis for measurement |
| 66 | **Noreen Hopewell-Kelly** | Validating the Children’s Attitude to Grief Scale (CAG): A new approach to assessing grief responses in children and young people |
| 69 | **Nancy Bhardwaj** | Usability testing of an electronic patient-reported outcome system linked to an electronic chemotherapy prescribing and patient management system for patients with cancer |
| 70 | **Aviva Gillman** | Insights from Industry I: Methodological Challenges Defining Meaningful Change Using the NSAA and PUL in Duchene Muscular Dystrophy |
| 71 | **Sophie Cleanthous** | Insights from industry II: Methodological Challenges Defining the Meaningfulness of a legacy ClinRO in Parkinson’s Disease |

**ABSTRACTS**

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| **Abstract No** | **Presenting Author** | **Abstract Title** |
| **1** | **Siobhan Ludlow** | **Developing a new patient-reported outcome measure for inducible laryngeal obstruction.** |
| **Background**  A psychometrically robust patient-reported outcome measure (PROM) for inducible laryngeal obstruction (ILO) is required. We previously conducted a scoping review and individual patient interviews that identified items for consideration in such a PROM.  **Aims**  To ascertain what items patients living with ILO and health care professionals (HCPs) working with patients with ILO think are important to include in the new patient reported outcome measure.  **Methods**  An international two-round Delphi study was conducted amongst an expert panel including patients living with ILO and HCPs working with patients with ILO. Participants were asked to rank on a 9-point scale whether the item was relevant for measuring the impact of living with ILO. Consensus was obtained for items when at least 70% of participants felt they were important (rating 7,8 or 9). Participants were given an option to expand the reason for their rating. Qualitative results were presented using a conceptually clustered matrix.  **Results**  Forty-six participants registered for the Delphi survey; response rates to the two rounds were 37/46 (80%) and 29/37 (78%) respectively. 63% of participants were patients living with ILO and the rest HCPs ([respiratory physicians (10%), speech and language therapists (16%), physiotherapists (5%), psychologist (3%) and nurse (3%)]. Of 80 items, consensus was achieved by all participants on 28 items.  **Conclusion**  We have collated information on the importance aspects of ILO that patients and HCPs agree and disagree on. Next, we will conduct discussions with all participants to get agreement on the final items for inclusion in the PROM. | | |
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| **2** | **Rosie Bamber** | **Understanding health-related quality of life of informal carers in Amyotrophic Lateral Sclerosis: A conceptual framework** |
| **Background**  Informal carers of people with Amyotrophic Lateral Sclerosis (ALS) provide extensive and complex care, impacting their health-related quality of life (HRQoL). Nevertheless, the assessment and recognition of this impact remains varied and inconsistent across different person-reported outcome measures (PROMs) and qualitative studies.  **Aim**  To develop a comprehensive conceptual HRQoL framework for ALS carers (Carer-QuALS) and map existing PROM content to the framework.  **Methods**  This study comprised two components. Firstly, a scoping review was conducted in March 2024, to identify primary studies investigating HRQoL in ALS carers, including qualitative, quantitative and mixed-method designs utilising multi-item PROMs. The existing QuALS framework, which conceptualises HRQoL for people with ALS, was used to map the content of eligible articles and PROMs to develop a draft carer-specific framework. Secondly, the draft Carer-QuALS framework was reviewed by ALS carers for validation and ratification.  **Results**  From 715 search results, 82 articles and 44 PROMs met inclusion criteria. Themes and subthemes from articles and PROMs were extracted and mapped to QuALS, with new themes and any existing themes unsupported by the literature noted. One new subtheme (‘physical caring activities’) was added to the draft framework. The draft framework contained three HRQoL domains (physical, psychological and social), seven themes, and 43 subthemes. Carer feedback led to the addition of one subtheme (‘privacy’), removal of six subthemes, and retention of an existing subtheme not identified in the review literature. The final framework consists of 38 subthemes (physical=9, social=6, psychological=23).  **Conclusions**  This study presents a novel comprehensive conceptual framework for HRQoL of informal carers of people with ALS (Carer-QuALS), providing a holistic illustration of the multidimensional impact of ALS caregiving on HRQoL. Carer-QuALS will serve as a vital resource for researchers, clinicians and stakeholders to identify potential instruments for measuring HRQoL and guide future PROM development. | | |
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| **3** | **Tim Pickles** | **People living with Rheumatoid Arthritis’ thoughts on a weekly Rheumatoid Arthritis disease activity monitoring tool: the PLAN-HERACLES study** |
| **Aims**  Regular assessment of disease activity (DA) is important and people living with Rheumatoid Arthritis (plwRA) would benefit from monitoring their DA using patient reported outcome measures (PROMs). Complementing clinical practice with remote DA monitoring between clinic appointments provides better information for plwRA and healthcare professionals to make better decisions on treatments. New evidence shows that a PROM containing five items could be used as the basis for this tool. Ahead of creating a weekly Rheumatoid Arthritis DA monitoring tool, the PLAN-HERACLES study was designed to gather plwRA thoughts on aspects of such a tool.  **Methods**  A survey containing 48 questions covering topics such as usefulness, likelihood of being used, feasibility of a weekly schedule and reminder format was designed. Participants were given a preface to the tool to base their answers on. Participants had to confirm their age as 18 or over and that they had received a diagnosis of RA. This survey was advertised by the National Rheumatoid Arthritis Society (NRAS) opened on 11.06.2024 and closed on 29.07.2024. The survey was available from <https://nras.org.uk/2024/05/14/plan-heracles/> and posted on across NRAS’s social media accounts on facebook, instagram and X.  **Results**  There were 1298 eligible and consented survey participants. From their responses, it was evident that the tool was deemed useful, acceptable, and likely to be used, that the proposed weekly schedule was feasible and that reminders would be required. The NRAS webpage had 159 views and social media posts had 4968 impressions.  **Conclusion**  Given these positive results, we plan to create this tool. An application to the MRC Career Development Award has been submitted and contains a complex intervention development phase with barriers and facilitators work and participatory events, which will involve NRAS and tool developer COHESION Medical Ltd., followed by a feasibility randomised controlled trial of the tool. | | |
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| **4** | **Andrew Lloyd** | **Narrative research: An alternative qualitative method for understanding of the burden of rare disease** |
| **Objectives**  The day to day burden of rare diseases for patients and families is often poorly understood; but this is important information to capture for determining burden and unmet need.  Qualitative research can play an important role here.  However most qualitative research starts with questions and prompts from a researcher which may heavily influence the resultant data.  It also relies on participants joining interviews or focus groups, a barrier which could produce important selection bias.  Here is presented an alternative method, which may be better suited for ultra-rare conditions and a case study.  **Methods**  Narrative research was used to describe the burden of Glycogen storage disorder (Type 1a), GSD1a – an ultra-rare metabolic disorder.  People with GSD1a (and some caregivers) were asked to write down their own experience of GSD1a.  There were no set questions or topics and they were free to write what they wished.  Data were analysed thematically using an inductive approach.  **Results**  Participants (11 people with GSD1a and 8 caregivers) from the UK and US provided narratives which provided many novel insights into the condition.  The analysis of narratives identified many common themes, despite participants being free to write about whatever they wished.  Study participants reported how this method allowed them to write what they wanted, and as much or little as they wanted.  The writing could take place at a time to suit them.  Participation rate was high.  **Conclusions**  Narrative research is an alternative approach to interviews and focus groups for the collection of qualitative data which has a low burden for participants and produced relevant and insightful data.  This methodology helps to address two challenges in ultra-rare disease – namely avoiding researcher bias in questions and prompts and widening access to the research for participants. | | |
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| **5** | **Ellie Johnstone** | **A Proof-of-Concept study: The development of a Qualitative Tool for people living with Manifest Huntington’s Disease (HD-mQE)** |
| **Background:**Huntington’s Disease (HD) is a complex genetic neurodegenerative condition, impacting patients’ quality of life (QoL) (van Lonkhuizen et al., 2023). According to the needs-based model, changes in QoL are attributed to patients’ ability to fulfill their fundamental needs (McKenna, 1994). The HD-mQoL, a new measure for manifest HD patients, is based on this model, as is the HD-Manifest Qualitative Evidence (HD-mQE), a tool for generating qualitative evidence. Whilst the HD-mQoL focuses on quantitative change, the HD-mQE provides qualitative data adding context to these changes. Combined, both can be used to longitudinally assess the effectiveness of clinical and non-clinical interventions using the same theoretical model.  **Aim:**To develop a prototype of the semi-structured interview guide (the HD-mQE).  **Method:**The HD-mQE is composed of ‘areas of relevance’ that arose from a deductive thematic analysis of qualitative interviews with manifest HD patients. These areas of relevance underpin the needs that patients reported to be inhibited. They are representative of a range of disease severities and have been assessed for face and content validity using cognitive debriefing interviews.  **Results:**The HD-mQE adds value to the HD-mQoL by providing qualitative data, contextualising changes in scores in real-life terms. It will be further refined and validated alongside an appropriate intervention.  **Conclusions:**Together, the HD-mQE and HD-mQoL will facilitate extracting mixed methods data under the same theoretical model. This provides an innovative approach to holistically measure patient value. One potential use of this is in evaluating clinical research for Health Technology Assessment. | | |
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| **6** | **Rachael Pattinson** | **Evaluating the Measurement Properties of Generic Adult Oral Health-Related Quality of Life PROMs: A COSMIN Systematic Review in Progress** |
| **Background** Oral health problems can significantly impact oral health-related quality of life (OHRQoL). Patient-reported outcome measures (PROMs) are essential for assessing OHRQoL in research and clinical practice. Numerous generic adult OHRQoL PROMs exist, leading to inconsistencies across studies. Establishing consensus on the most suitable PROM could enhance comparability and evidence synthesis. The COSMIN methodology is the gold standard for evaluating PROMs, yet a comprehensive assessment of generic adult OHRQoL PROMs using these standards is lacking.  **Aim** To evaluate the measurement properties and methodological quality of studies developing or validating generic adult OHRQoL PROMs and provide evidence-based recommendations.  **Methods**  We followed the COSMIN methodology, including assessment of methodological quality using the COSMIN Risk of Bias Checklist and evaluation of measurement properties against COSMIN quality criteria. The protocol is registered on PROSPERO (CRD42024501578).  A systematic search was conducted in MEDLINE (PubMed), EMBASE (Ovid), CINAHL, PsycINFO (Ovid), and Scopus from inception to 10th September 2024. Studies were included if they reported the development or psychometric assessment of generic adult OHRQoL PROMs. Based on the strength of the evidence, measures will be categorised into three recommendation level (A-C).  **Results** The search identified 24,197 articles, of which 219 met the inclusion criteria. Preliminary findings indicate that nine unique original-language PROMs have been identified, with the Oral Health Impact Profile-14 being the most frequently evaluated. Most articles (n=145, 66%) were published after the 2010 COSMIN guidelines. Evaluation of each measurement property per PROM per study is ongoing, with early observations highlighting substantial variability in methodological quality and reported measurement properties.  **Conclusions** This systematic review will evaluate the psychometric quality of generic adult OHRQoL PROMs. It will provide evidence-based recommendations for the selection of robust OHRQoL PROMs for use in both clinical practice and research, including informing the development of core outcome sets in oral health research. | | |
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| **7** | **Sally Cox** | **Implementation of the OECD PaRIS Study in Wales: A Population Needs Assessment** |
| **Background**  The OECD Patient-Reported Indicators Survey (PaRIS) aims to measure and compare health outcomes and experiences reported directly by patients across different countries. It focuses on capturing patient-reported outcomes (PROMs) such as quality of life, physical functioning, psychological well-being, and experiences of healthcare for patients aged 45+ with chronic conditions. Wales was the only UK nation to actively participate in this initiative to improve healthcare quality and support the shift towards more patient-centred healthcare models in clinical practice.  **Aim**  This study describes the implementation process of the OECD PaRIS study in Wales, highlighting the challenges, strategies, outcomes, and lessons learned from this first round.  **Methods**  Two surveys (one for GP practices and one for patients) were conducted from April to October 2023. A large dataset was captured, exceeding OECD requirements. Due to the inability to pre-identify patients with chronic conditions, oversampling was used to ensure adequate numbers. 26,000 patients from 199 practices across Wales responded, with 7,500 meeting OED PaRIS criteria. Data was sent to OECD for analysis, contributing to the Flagship. Report released in February 2020. Key challenges were system awareness and politically sensitive analysis.  Results: The survey collected a novel dataset of over 26,000 patients, including responses to a 122-question survey with validated PROMs and PREMs. This dataset will help the NHS in Wales identify system priorities and support stakeholders in transforming services using person-centred evidence.  **Conclusions**  The implementation of the OECD PaRIS study in Wales demonstrates the potential of PROMs and PREMs to enhance healthcare quality and patient outcomes. Wales is developing analytical outputs and publications with partners, aiming to maximise the dataset's potential for evidence-based policy decisions. Effective communication and stakeholder engagement are crucial for disseminating insights and driving development. | | |
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| **8** | **Sally Cox** | **Expanding the OECD PaRIS Survey in Wales: Insights from the Population Health Survey** |
| **Background**  The OECD Patient-Reported Indicators Survey (PaRIS) aims to benchmark patient-reported health outcomes (PROMs) and experiences (PREMs) across different countries. It focuses on capturing quality of life, physical functioning, psychological well-being, and experiences of healthcare for patients aged 45+ with chronic conditions. To achieve a comprehensive population health needs assessment, Wales broadened the survey, collecting 26,000 patient responses across 199 GP practices, referred to as the ‘Population Health Survey’.  **Aim**  This study describes the initial stages and plans for analysing this novel dataset in Wales following the release of the OECD PaRIS Flagship Report in February 2025.  **Methods**  The analysis began with assessing the representativeness of the data in terms of demographics and chronic condition prevalence. A general data summary was created, followed by linkage to national datasets within NHS Wales and a detailed analysis of diabetes. Multiple publications are being developed with interested partners.  Results: Initial results show the dataset is representative of the Welsh population in terms of age, sex, and chronic condition prevalence, except for epilepsy and arthritis due to definitional differences. Overall, females reported lower quality of life (QOL) than males. In diabetic patients, QOL increased with confidence in managing health, was lower in females, decreased with the number of chronic conditions, and was lower in deprived areas. Higher education levels were associated with higher QOL.  **Conclusions**  Implementing PaRIS as part of NHS Wales’ wider PROMs and value-based health care strategy provides a valuable opportunity to combine population-level analysis with condition-specific insights. Wales is developing analytical outputs focused on health inequalities and the impact of chronic conditions on patient outcomes. Efforts are underway to collaborate with clinical networks, health boards, and academic partners to maximise the impact of the insights. | | |
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| **9** | **Emily McDool** | **Evaluating the validity of the EQ-HWB-S in a large general population sample** |
| **Background**  The EQ Health and Wellbeing Short (EQ-HWB-S) is a new generic preference-based measure for assessing health, social care and informal carer quality of life.  Aim(s): The aim was to assess the psychometric performance of the EQ-HWB-S and to compare it with other measures of health and wellbeing.  **Method(s)**  The Systems science In Public Health and Health Economics Research - Health and Wellbeing Multi-Instrument Comparison (SIPHER-HWMIC) survey (provisional dataset) (UK general population, n=11,383) data was used. Construct validity was assessed based on convergent validity using Spearman correlations of EQ-HWB-S items with selected, conceptually overlapping items from the ICECAP-A (ICEpop CAPability measure for Adults), Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS), Health Utilities Index (HUI3) and Office for National Statistics personal wellbeing questions (ONS4). Pearson correlation was used for utility values. Known group validity was assessed using effect sizes to assess the EQ-HWB-S's ability to distinguish between groups by mental wellbeing, disability and life satisfaction. Known group validity was also compared across all measures in distinguishing groups by caregiving responsibilities, self-reported health and age.  **Results**  Strong associations (rs ≥0.5, P<.001) emerged between conceptually overlapping dimensions of the EQ-HWB-S and the other measures. EQ-HWB-S utility scores were strongly correlated with ICECAP-A, HUI3 and SWEMWBS utilities (rs ≥0.5, P<.001). Effect sizes (≥0.8) demonstrated that the EQ-HWB-S distinguished between groups with ‘low’ and ‘medium’ wellbeing, ‘moderate’ and ‘severe’ disability, ‘very high’ and ‘high’ life satisfaction, and ‘high’ and ‘low’ visual analogue scale (VAS) scores. All measures performed similarly in discriminating between caregiving responsibilities, age groups, and ‘high’ and ‘low’ VAS scores.  **Conclusions**  The EQ-HWB-S shows evidence of psychometric validity in this large general population sample with convergence as expected with conceptually overlapping dimensions from other measures and the ability to distinguish between groups with known differences. | | |
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| **10** | **Victoria Robins** | **The impact of age on physical functioning after treatment for breast cancer, as measured by patient-reported outcome measures: A systematic review** |
| **Background**  Breast cancer is the most frequently diagnosed cancer in England and the incidence increases with older age. Treatment can be multimodal and survival rates for early-stage breast cancer are improving. However, it can have long-term impacts, particularly for older women.  **Aims**  This systematic review aims to explore the impact of age on physical functioning post-treatment for early-stage breast cancer, as measured by patient-reported outcome measures (PROMs), identify PROMs used and variations in physical functioning terms/labels. This is important to aid clinical decision making and provide conceptual and methodological clarity.  Methods: MEDLINE, EmBase, PsycINFO, CINAHL and AMED, relevant key journals and reference lists were searched. Risk of bias (quality) assessment was conducted using a Critical Appraisal Skills Programme checklist. Data was synthesised through tables and narrative.  **Results**  28,207 titles were extracted, resulting in 44 studies with age sub-groups, and 120 without age sub-groups. Of those finding the impact of age, there was variability in the way results were reported and 21% found that age did not have a significant impact. However, 66% of studies found that with older age, physical functioning declined post-treatment. Comorbidities were associated with physical functioning declines. However, findings from sub-groups (breast cancer stage, treatment type and time post-treatment) lacked concordance. Twenty-eight types of PROM were used: the EORTC QLQ-C30 was most common (50.6%), then the SF-36 (32.3%). There were 145 terms/labels for physical functioning: ‘physical functioning/function’ was most common (82.3%), then ‘function/functions/functioning/functionality/functional’, ‘mobility’ and ‘walk/walking’ (11.0%).  **Conclusions**  Findings point towards an older age and comorbidities being associated with more physical functioning declines. However, it was not possible to determine if stage, treatment type and time post-treatment had any influence. More consistent use physical functioning PROMs and terms/labels would aid universal understanding and future comparisons of study results. | | |
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| **11** | **Emma Rowe** | **Comparing apples with apples, NHS Wales Patient Reported Outcome Measures (PROMs) Data Standard model** |
| **Background**  The Welsh Value in Health Centre (WViHC) developed a national standardised approach for the collection and use of PROMs. The PROMs Standard Operating Model (PSOM) defines the processes, data and technical standards to be used across NHS Wales to meet multiple user cases at the micro (patient), meso (service) and macro-level (population).  Data Standards Change Notices (DSCNs) are a critical element of PSOM that mandate data collected locally to flow nationally.    **Aim**  To define the data standards for national PROMs pathways, minimising variation, enabling the development of a comparable national data sets that can support the development of multiple nationally developed analytical tools for both patient-level and population-level insights.    **Method**  DSCNs are created to enable the coding of PROMs across nationally clinically agreed pathways. PSOM requires metadata to be collected alongside each PROM tool. The metadata ensures PROMs can be shared across the system and linked to other data sets, (Ie costing, activity, clinical outcomes and case mix variables).  DSCNs are developed in collaboration between Digital Health and Care Wales (DHCW), WViHC and CEDAR, assured by Wales Information Standards Board (WISB), before issuing to Health Boards (HBs) for implementation.  Pathway Guides are then created for each national PROMs pathway to assist local implementation.   The pathway guide lists all DSCNs associated with the pathway, scoring information, bilingual versions, the schedule of collection and any licence restrictions.    **Results**  49 national PROMs pathways have been agreed in line with PSOM, resulting in 67 DSCNs issued to health boards. HBs have started collection in certain pathways and a national data flow is expected to commence shortly.    **Conclusions**  PSOM defined data standards are crucial to ensure consistency and accuracy in comparisons across HBs. Establishing clear definitions, standardising data collection methods, and using common coding systems will facilitate uniform data collection and enable meaningful comparisons. | | |
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| **12** | **Victoria Gale** | **Can Young Children Participate in Patient Reported Outcome Measure (PROM) Development? Insights from the PROM Developer’s Perspective** |
| **Aims**  Existing recommendations suggest that children aged 8-years-old and above can participate in concept elicitation (CE) and cognitive interviews (CIs) for patient reported outcome measure (PROM) development, yet recent evidence suggests younger children may be enabled to participate. This observational survey study audited opinions of PROM developers regarding the feasibility of including children in CE and CI research.  **Method**  PROM developers recruited from existing networks (e.g., UK PROMs Network, the International Society for Quality of Life Research) participated in an online survey (August-November 2024). Survey questions explored PROM developers’ perspectives on the minimum feasible age that children could be involved in CE/CIs and their previous experience conducting CE/CIs with children. Results were analysed descriptively with exploratory comparisons.  **Results**  Fifty-eight responses were analysed. The mean youngest ages considered feasible for children to participate in CE and CIs were 6.66 years and 7.36 years respectively. The mean youngest ages participants had included in CE and CIs were 7.67 years and 8.13 years respectively. Participants who had experience conducting CIs with children had lower mean perceived feasibility ages compared to those who had not (6.76 years and 7.89 years, respectively). The opposite was true for CE research (6.84 years and 5.82 years respectively).  **Conclusion**  PROM developers followed existing recommendations when including children in CE and CI research, yet in principle considered it feasible to include children younger than 8-years-old. Without direct experience of conducting CE/CI interviews with children, developers considered CE research to be more feasible with younger children, and CI research to be less feasible, than considered by developers with direct experience conducting CE/CI interviews with children. The presentation will discuss practical ways PROM developers can challenge preconceived ideas and adopt a ‘solution-focussed’ approach to enable young children’s participation in qualitative PROM development. | | |
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| **13** | **Victoria Gale** | **Co-creating ‘SuperPenguin’: A Mobile App for Caregivers of Children who Stammer** |
| **Aim**  In the UK, access to speech and language services for children who stammer (CWS) is limited; only 45% of National Health Service trusts provide specialist stammering support and waiting times average 45 weeks. As well as impacting the child, stammering can lead to considerable caregiver anxiety, exacerbated by lack of timely, specialist support. Here we present ‘SuperPenguin’ a novel mobile application designed to empower caregivers in supporting CWS, reduce caregiver anxiety and promote supportive communication environments for children, and facilitate collection of patient reported outcomes (PROs) to enhance delivery of speech and language services.  **Method**  SuperPenguin was co-created through patient and public involvement (PPI) activities with caregivers of CWS (n=25), people who stammer (PWS) (n=3), speech and language therapists (n=62), and stammer charity representatives (n=5). Key collaborators: (1) identified user needs; (2) supported iterative development of app features; (3) identified a PRO instrument to implement in the app; and (4) co-created research projects to further test and refine SuperPenguin.  **Results**  SuperPenguin is grounded in caregiver needs, including addressing anxiety around schooling and providing real-life stories from PWS. Collaborators identified the Pediatric Quality of Life Inventory Family Impact Module as relevant and appropriate for measuring impact of stammering on caregiver quality of life and provided input for incorporating this instrument digitally into the app. A National Institute for Health and Care Research grant has been secured with PPI co-applicants to run a multi-site clinical feasibility trial for SuperPenguin, and collaborators are contributing to ongoing trial design.  **Conclusion**  Involving collaborators is essential to the development of meaningful healthcare services. Co-creation was fundamental during initial development of SuperPenguin and will inform future research to validate use of in-app PRO instruments. This presentation will reflect on challenges and solutions when co-creating a mobile speech and language intervention across research teams and industry partners. | | |
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| **14** | **Scottie Kern** | **Building Consensus in the field of Electronic Clinical Outcome Assessment: An Introduction to the Critical Path Institute's eCOA Consortium** |
| The Critical Path Institute's Electronic Clinical Outcomes Assessment (eCOA) Consortium is a pre-competitive alliance of eCOA and allied service providers that have convened with the key intent of advancing the science of electronic clinical endpoint measurement.  This session will share an overview of eCOA Consortium activities and collaborations past, present and planned, and provide details on a number of the higher impact projects and associated outputs developed for the benefit of the medical product development community. Of specific note, the presentation will discuss the best practices for electronic migration and implementation of PRO measures developed by the eCOA Consortium, and explore other PRO/COA-related initiatives and opportunities. In addition, we will discuss and strategise on how to account for the specific needs of stakeholders in the UK PROM's audience.  Critical Path Institute's Scottie Kern (Executive Director, eCOA Consortium) will be joined by Dr Florence Mowlem (Chief Science Officer, uMotif) | | |
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| **15** | **Jack Lawrence** | **A targeted review of patient-reported outcome measures used in the treatment and management of endometriosis** |
| **Background**  Endometriosis is a chronic gynaecological condition affecting 6-10% of the global female population and is a leading cause of female infertility. Further complicating this condition, approximately 33% of patients develop treatment-resistant chronic pelvic pain (CPP).  **Aim**  This review aimed to identify and categorise the methodologies and patient-reported outcome measures (PROMs) used in studies developing therapies for the effective management and treatment of endometriosis and CPP.  **Methods**  A targeted search of ClinicalTrials.gov was conducted to collate studies assessing the efficacy of interventions for the treatment and management of endometriosis in the last 10 years. Data concerning the studies’ methodologies, eligibility criteria, intervention type and PROMs were extracted and reviewed.  **Results**  This review synthesised data from 17 studies, utilising 36 PROMs to assess critical patient outcomes. Nearly half the interventions were pharmaceutical (24%) or minimally invasive procedures (24%), while non-pharmaceutical interventions included surgery and behavioural changes. PROMs primarily focused on pain, psychological distress, quality of life and patient satisfaction.  The most frequently used PROM was the Endometriosis Health Profile-30 (EHP-30), which featured in 53% (9) of studies. The next most frequently implemented was the numeric rating scale (NRS), a generic PROM used to measure pain severity, utilised in 41% (7) of studies.  12 studies were focused on treating the physiological symptoms of CPP, of which 58% utilised the EHP-30, the only endometriosis-specific PROM available, with other symptoms (such as pain) measured through generic PROMs.    **Conclusions**  The findings from this review validate the EHP-30 as a well-established PROM for assessing the physiological symptoms of endometriosis, particularly CPP. However, the results also highlight a limited selection of endometriosis-specific PROMs, restricting our ability to fully understand the condition’s impact on patients. With data confined to the domains covered by the EHP-30, there is a critical need for the development of more comprehensive endometriosis-specific PROMs. | | |
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| **16** | **Christian Lambert** | **Evaluation of a Prehabilitation pathway and understanding the effects of extended knee and hip joint replacement waiting lists** |
| **Aims**  Patients with severe end stage knee and hip Osteoarthritis (OA) are commonly offered joint replacement surgery. The aim of the surgery is to reduce pain, restore function and improve quality of life. Post Covid-19 waiting lists for elective knee and hip joint replacement have grown exponentially, 2-3 year waits are now common place in the NHS. Longer waiting lists for surgery could cause further deterioration in patient’s joint disease, along with changes in any pre-existing comorbidities. Working collaboratively with technology company Pro-Mapp ltd, a digital platform was configured to collect specific self-reported health PROMs for patients listed for elective knee or hip replacement surgery at a single NHS site. The PROM data allows a cohort study following the health of patients longitudinally as they wait for surgery.  **Methods**  The Pro-Mapp ltd customised digital platform was configured and built to collect agreed patient reported outcome measures (PROMs) at set interval points. Oxford knee and hip score, EQ5D5L, self- reported co morbidity score were the main outcomes used. The PROM data was collected at baseline (first point patient completed a PROM on waiting list) with follow up PROMs at 6 monthly intervals until patient departed waiting list. Patients PROMs separated into knee and hip groups and intervention or no intervention.  The intervention was a supervised 6 week exercise programme designed to improve waiting list patient’s cardiovascular health, muscle strength and joint mobility. Statistical analysis will be used to look for longitudinal changes in PROM scores across all groups.  **Results**  Data collection is ongoing until September 2025.  **Conclusion**  This study uses a novel approach of collecting self-reported PROM data on a digital platform within a clinical setting. Learnings from this research will contribute to how we manage future resources, prioritise and support patients waiting for planned elective Orthopaedic surgery. | | |
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| **17** | **Christopher Bedding** | **Developing guidelines for the flexible assessment of patient-reported outcomes in cancer clinical trials and routine care using item libraries.** |
| **Background**  In recent years, patient-reported outcomes (PROs) have become embedded within clinical trials and routine care. PRO item libraries, such as the European Organisation for Research and Treatment of Cancer (EORTC) Item Library, enable the development of custom PRO item lists which facilitate a more flexible approach to PRO assessment. This innovative approach is often adopted in studies of rare cancers, novel treatments or symptom monitoring. As with traditional PRO assessment, the flexible approach through use of PRO item libraries requires standardised processes and guidelines to ensure that rigour, transparency and scientific integrity are upheld.  **Aim**  To establish international recommendations for the use of PRO item libraries to develop flexible PRO item lists within cancer clinical trials and routine care.  **Method**  A multi-methods approach was adopted. The current  landscape of flexible PRO assessment was explored via a systematic review of the literature. Findings informed a three round multi-partner Delphi survey with the aim of agreeing international consensus guidance on the use of PRO item libraries to develop PRO item lists within cancer clinical trials and clinical care. A series of consensus meetings will enable the development of recommendations based on the results of the Delphi survey.  **Results**  The systematic review identified 33 articles (10 trial/feasibility studies; 23 observational studies) that used flexible PROs. The review helped generate 67 ‘best practice’ statements for the development and implementation of PRO item lists. The Delphi survey is on-going, consisting of 76 international partners. Over two rounds, 62/67 statements reached consensus (70%+ agreement). Following round three, final recommendations will be agreed and published.  **Conclusions**  Flexible PRO assessment is a growing field, therefore, it is important appropriate guidance is available to ensure rigor, transparency and scientific integrity are maintained. | | |
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| **18** | **Caroline Dix** | **Current practices, challenges and preferences regarding the use of patient-reported outcome measures (PROMs) in measuring the mental health of refugees and people seeking asylum in the UK: a scoping review** |
| **Background**  Asylum seekers and refugees (ASR) disproportionately experience mental health challenges. Patient-reported outcome measures (PROMs) are essential tools for mental health assessment, intervention evaluation and informing resource allocation decisions. However, research on their application to ASR populations in the UK is limited. This gap may contribute to suboptimal service delivery and inaccuracies in economic evaluations. This scoping review examines PROM use for measuring ASR mental health in the UK.  **Methods**  Systematic searches were conducted in MEDLINE, PsycInfo, Web of Science and Scopus, with citation tracing and grey literature searches. Studies were included if they focused on adult ASR in the UK, used PROMs to measure mental health, and were published in English after 2005. Data were charted on PROM characteristics, justification for use, psychometric properties, translation, translation validation processes, and acceptability.  **Results**  45 studies using 42 different PROMs spanning twelve mental health constructs were included. The Impact of Event Scale-Revised (IES-R) was the most frequently used PROM. Studies often employed multiple measures and many relied on interpreters or unvalidated translations. Detailed reporting on psychometric properties and acceptability was limited, with participant burden and cultural appropriateness being the most commonly addressed aspects of acceptability. Several studies used amended PROMs or subscales, potentially impacting reliability and comparability of outcomes in economic evaluations.  **Conclusion**  This review reveals a significant evidence gap in PROM use research for ASR mental health in the UK. The heterogeneity of PROMs used complicates cross-study comparisons and synthesis for research allocation decisions. Limited reporting on psychometric properties and acceptability highlights the need for further research to identify culturally appropriate and validated measures that are suitable for use in clinical practice, research and health economic analyses. Future research should focus on validating PROMs and assessing their feasibility and acceptability to ensure accurate measurement, effective intervention evaluation and informed resource allocation. | | |
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| **19** | **Christina Yiallouridou** | **PrEQoL – Pilot feasibility study of prospective socioeconomic and quality of life data collection among haematopoietic stem cell transplant recipients** |
| **Background**  Patient outcomes after haematopoietic cell transplantation (HCT) are influenced by social and demographic factors. Routine collection of demographic and quality-of-life (QoL) data is essential to understanding these effects and addressing care inequities.  **Aim**  To pilot the prospective collection of socioeconomic and QoL data among HCT recipients at UK transplant centres (TCs) using a web-based tool hosted by Anthony Nolan.  **Methods**  Adult (≥18 years) allogeneic HCT patients completed demographic and QoL questionnaires at four timepoints: pre-conditioning, transplant day, and 28 and 100 days post-transplant. Socioeconomic data (housing, income, education, occupation and Index of Multiple Deprivation) were collected using UK ONS census items and the MacArthur Ladder, a subjective measure of social status. QoL data was gathered using the PROMIS-29. Tablets were provided to TCs for recruitment and baseline data collection. REDCap software facilitated digital data collection, enabling e-consent and automatic survey reminders to participants.  **Results**  Sixty participants were enrolled, achieving a 94% recruitment rate. Of 95 eligible patients, 67% (n=64) were approached, and 6% (n=4) declined due to illness, language barriers, or lack of interest. Most participants were male (70%, n=42), White (80%, n=48), with a median age of 56 (range 21–74), had AML (53%, n=32) and received a matched unrelated donor transplant (67%, n=40). Nearly all participants provided e-consent (98%, n=59) and completed baseline measures on tablet (70%, n=42). Completion rates dropped from 97% (n=58) at baseline to 74% (n=42) at day 100, with 95% (n=57) retention. Dropouts were due to transplant withdrawal, disease progression, or relapse. Participant feedback (66%, n=38) showed >90% satisfaction with e-consent, data security information, and completing questionnaires on the digital platform.  **Conclusions**  The PrEQoL study demonstrated the feasibility of using digital tools to collect socioeconomic and QoL data, laying the groundwork to scale data collection in the ongoing SEQoL study across 15+ TCs. | | |
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| **20** | **Jasmine Rollings** | **Confidence to self-manage in Diabetes: An All-Wales cross-sectional population study** |
| **Introduction**  Diabetes is a leading cause of morbidity and mortality in Wales, and concerningly, the prevalence of diabetes and the associated healthcare costs continue to rise. Effective self-management is essential in diabetes care to avoid poor outcomes; however, less is known about how confidence to self-manage impacts outcomes.  **Aims**  This study examines the association between confidence to self-manage and wellbeing in a large sample of people with diabetes in Wales over the age of 45 years (N = 2,941).  **Method**  Multilevel regression modelling was used to assess the impact of confidence to self-manage on wellbeing whilst controlling for potential confounders, and to account for patients being nested within GP practices.  **Results**  After controlling for various individual and situational factors, confidence to self-manage was found to be strongly associated with better wellbeing (B = 12.43-point; 95% [CI: 11.19 – 13.67]). Other individual level factors such as being unable to work (B = -15.51; 95% [CI: -18.66 – -12.36]) and having more chronic conditions (B = -15.80; 95% [CI: -18.32 – -13.29]) were associated with poorer wellbeing. GP practice did not have a large impact on wellbeing, accounting for around 1% of the variance between individuals, suggesting that individual factors are more consequential for wellbeing outcomes.  **Conclusions**  These findings indicate that higher levels of confidence to self-manage was associated with better wellbeing being among diabetic people aged over 45 years in Wales. Therefore, healthcare providers, policymakers, and patients should engage and develop with strategies to enhance confidence and self-management in diabetes. | | |
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| **21** | **Mike Horton** | **Using Rasch analysis to inform the development of The Index of ME Symptoms – TIMES** |
| **Background**  Myalgic encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) is a chronic, fluctuating, disabling condition which affects many body systems and has a wide variety of symptoms. There are currently no PROMs that have been developed specifically for measuring symptom impact in ME/CFS, with most researchers employing PROMs designed for other conditions, or intended to be used generically without ascertaining their suitability for people with ME/CFS.  **Aim**  To develop and psychometrically evaluate a new assessment of symptom impact in people with ME.  **Methods**  An initial list of symptom items was devised from scoping reviews of ME/CFS literature. This was reviewed and revised with patient advisory groups, and refined into a prototype online survey containing 85 items across 8 conceptualised domains, which was then completed by people with ME. In order to assess and refine the scale, Rasch analysis was used to identify measurement anomalies. Each domain was assessed separately for unidimensionality, targeting and internal reliability. All items were individually assessed for model fit and local dependency. In a novel approach, two separate response structures were assessed for all items – one frequency-based and one severity-based.  **Results**  Survey data (n=721) indicated various item anomalies and inter-item dependencies, leading to item re-formatting or removal, where appropriate. The frequency and severity-based levels of patient burden broadly replicated each other, but the functionality of the response categories varied between different domains.  Following Rasch-based scale amendments, a reduced 61-item survey was re-administered to test the functionality of the modifications. Validation data (n=354) showed that the scale modifications led to an improved response structure and functionality across all domains.  **Conclusions**  Rasch analysis provided insightful information of how to modify and restructure the scale items in order to improve the measurement properties of the TIMES, leading to a stable and valid 9-domain scale. | | |
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| **22** | **Elena Takasugi Aagaard** | **Translation and cultural adaptation of the FACE-Q Paralysis Module from English to Danish** |
| **Background**  Facial nerve paralysis involves loss or weakening of facial muscle movement, impacting physical, social, and mental well-being. The FACE-Q Paralysis Module, developed by McMaster University and the Hospital for Sick Children in Canada, is a Patient Reported Outcome Measure designed for individuals aged 8 and older with congenital or acquired facial nerve paralysis. It comprises four scales that assess appearance (n=46), function (n=45), health-related quality of life (n=48), and adverse effects (n=17). These scales can be used individually or in combination, offering flexibility for clinical or research applications. While FACE-Q Paralysis has been translated into several languages, a Danish version is not yet available.  **Aim**  The aim of this project was to translate and culturally adapt the FACE-Q Paralysis Module from English to Danish following internationally recognized best-practice guidelines.  **Method**  The FACE-Q Paralysis Module was translated using a six-step methodology following guidelines from the World Health Organization and the International Society for Pharmacoeconomics and Outcome Research to ensure conceptual equivalence and cultural relevance. Steps include: (1) preparation and approval, (2) forward translation, (3) back translation, (4) expert panel review, (5) cognitive debriefing with patients, and (6) proofreading.  **Results**  The forward translation revealed minor terminological discrepancies, which were discussed to produce a harmonized Danish version 1. The back translation review revealed 12 items requiring re-translation. An expert panel meeting addressed linguistic inconsistencies in 14 items to ensure alignment with the original English meaning. Cognitive interviews are pending to assess patient comprehension.  **Conclusions**  The translation process is ongoing. Forward and back translations are complete, and expert panel revisions have been incorporated. Patient recruitment for cognitive interviews is underway. The translation and cultural adaptation will result in a conceptually equivalent and culturally adapted Danish version of the FACE-Q Paralysis Module, which has the potential to improve treatment for facial nerve paralysis patients. | | |
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| **23** | **Claire Williams** | **‘I got 99 items but “loss of balance” ain’t one’: Assessing the content validity of a novel health-related quality of life (HRQoL) instrument for Amyotrophic Lateral Sclerosis (ALS)** |
| **Background** ALS is a rare, progressive life-limiting condition which impacts individuals’ health and wellbeing. Whilst patient reported outcome measures (PROMs) have been used to quantify the HRQoL impact of ALS, a recent review identified that existing instruments may not fully capture what matters to people living with ALS (plwALS). The PROQuALS instrument is a new PROM designed to comprehensively assess important aspects of HRQoL to plwALS and to quantify HRQoL in terms of subjective impact. This study reports the cognitive interview phase of development.  **Methods** Draft PROM content, informed by an existing conceptual framework (QuALS), was tested across two iterative waves. Interviews were conducted online with purposive sampling to ensure representation across key characteristics. Analysis was informed by best practice methodology to assess relevance, comprehensiveness and comprehensibility of draft PROM content. Reflective of response burden, participants were asked to comment on a maximum of 40 items. Adaptations were made to allow for participation from individuals with impaired speech.   **Results** Ninety-nine draft items across seven themes of HRQoL were tested in Wave 1 (n=21). Potential redundant items and new items for consideration were identified. Interim results were presented to a clinical advisory group with proposed modifications discussed and ratified for formal testing during Wave 2. Wave 2 (n=21) data collection is ongoing with 67 draft items being tested to provide further evidence on the content validity of the draft PROM. Data collection is expected to be complete by summer 2025.  **Conclusions** Cognitive interviews are critical in the PROM development process. In this project adaptations were made for the length of the draft PROM content and needs of the target population to facilitate inclusivity in research. Refinements to the HRQoL framework were made during cognitive interviewing which will help inform the PROQuALS as a comprehensive measure of HRQoL in ALS. | | |
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| **24** | **Jill Carlton** | **Capturing the Impact of Facioscapulohumeral Muscular Dystrophy (FSHD) on Health-related Quality of Life (HRQoL): protocol and preliminary results of a systematic review of existing self-report instruments using COSMIN** |
| **Background** Facioscapulohumeral muscular dystrophy (FSHD) is a rare genetic condition causing progressive muscle weakness. Studies have explored the impact of FSHD on health-related quality of life (HRQoL) using patient reported outcome measures (PROMs). Given that a number of PROMs exist to assess HRQoL in people with FSHD, evidence is needed on their relative validity. This review aims to: 1) identify which PROMs have been used to assess HRQoL in FSHD; and 2) evaluate the strength and quality of evidence for the reliability and validity of PROMs identified.   **Methods** This systematic review employs COSMIN methodology, encompassing four stages. Stage 1: Searches are conducted in key databases (i.e.,  MEDLINE (PudMed), EMBASE, etc.) using a two-stage strategy to identify 1) articles containing PROMs assessing HRQoL in FSHD; and 2) articles reporting the measurement properties of these PROMs. Stage 2: Following a two-stage sifting strategy against pre-specified criteria, data on psychometric properties are extracted from each included article. Stage 3: COSMIN methodology is applied for each measurement property, and the methodological quality of each included article assessed. Stage 4: Results will be summarised qualitatively. A conceptual framework of HRQoL in FSHD will be developed to facilitate the assessment of the content validity of identified PROMs.   **Results** The review is ongoing research. Preliminary searches have been completed, with follow-up searches ongoing. Initial searching identified 496 articles, with n=193 reviewed at full-text, and n=49 retained. 44 potential PROMs were identified and taken forward to Stage 2. The most frequently used PROM was the Epworth Sleepiness Scale (ESS). Further results, including the  conceptual framework of HRQoL for FSHD will be presented at the conference.   **Conclusions** FSHD is a complex condition. This review will provide a recommendation for the most suitable PROM(s) to consider for use in quantifying  HRQoL in FSHD. | | |
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| **25** | **Pongnugoon Kongjaidee** | **Patient-reported experience measures in eye care services: A systematic review based on COSMIN guidelines** |
| **Background**  Patient-Reported Experience Measures (PREMs) have become an essential mechanism for assessing healthcare quality from the perspective of the patient. However, the application of PREMs in the field of eyecare remains relatively underdeveloped, with a limited number of studies or validated tools available to evaluate patient experiences in eyecare.  **Objective**  To critically assess the existing evidence on the measurement properties of PREMs used to capture the experiences reported by individuals using eyecare services.  **Methods**  A systematic search was conducted across multiple databases, including Web of Science, Embase, PubMed, Medline, and Scopus, using a combination of subject headings and keywords. Studies that focused on the development and/or validation of any PREMs designed for use in eyecare services were deemed eligible for inclusion. The extracted measurement properties encompassed information on item development, content validity, structural validity, internal consistency, cross-cultural validity, reliability, hypothesis testing, and responsiveness. Quality assessment, evaluation of measurement properties, evidence synthesis, and grading were performed in accordance with the COSMIN methodology for systematic reviews.  **Results**  A total of 13 studies were included in the review, with 3 of these studies encompassing 10 distinct PREMs. There were PREMs in different settings e.g. low vision and primary/secondary eyecare. These PREMs addressed various aspects of patient experience, including low vision-specific PREMs, General secondary care PREMs, Communication with ophthalmologists, Communication with nurses, Communication about medication, Communication and information, Efficiency, Patient care, Motivation, and Comparisons between research visits and regular clinic visits. Results on the measurement properties will be presented in detail.  **Conclusions**  This systematic review identifies 10 existing PREMs in the field of eyecare and provides a thorough evaluation of their validity and reliability. The findings offer valuable insights that can aid healthcare providers and policymakers in selecting and refining the most suitable PREMs for assessing the quality of eyecare services. | | |
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| **26** | **Jill Carlton** | **AI: Artificial Intelligence or Accidental Inaccuracies? The potential pitfalls in applying AI in qualitative research transcription for patient reported outcome measure (PROM) development and/or refinement** |
| **Background** Artificial intelligence (AI) is becoming increasingly prevalent within all aspects of society. Within research its application appears extensive, with opportunities to improve efficiency in data production, analysis, and dissemination. To date, its use within the qualitative component of patient reported outcome measure (PROM) development and evaluation is sparse. This presentation will outline, through two case studies, the potential advantages and pitfalls of AI applications for transcription in the context of outcomes research.  **Methods** In both case studies Google transcription was used to record and transcribe content of different qualitative methodological approaches commonly used in PROM research. Case Study A: online focus groups of parents of young children. Case Study B: cognitive interviews of individuals with Motor Neuron Disease (MND). All transcripts were checked for accuracy and data familiarisation prior to analysis. Reflective comparisons between typical approaches and AI-assisted data production were considered for (1) speed of transcript generation; (2) transcript accuracy; (3) time taken for transcription checking by the research team; (4) persistent errors post checking within transcripts.  **Results** (1) Transcripts were available for checking approximately 20 minutes post-interview. (2) Errors in AI transcription accuracy were noted in both case studies, with greater inaccuracies observed in Case Study B. Errors were more prevalent if the individual had impaired speech. (3) Time taken for transcription checking of AI-assisted transcripts was significantly greater than typical. (4) Despite transcripts being checked by researcher(s), errors were still present in transcripts identified at the analysis stage, with researchers seemingly influenced by what they read rather than what they heard. Other reflections and observations will be discussed.  **Conclusion** AI has the potential to increase efficiency in some elements of PROM development/evaluation, but it is not without its limitations. Researchers should consider deferred research costs, and mechanisms to ensure data accuracy. | | |
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| **27** | **Aishwarya Chohan** | **Assessing disease impacts via patient-reported outcome measures (PROMs): A case for moving beyond symptoms** |
| Chronic disease patient-reported outcome measures (PROMs) prioritise signs/symptoms over health-related quality of life (HRQoL) for assessing disease burden and treatment benefit. While symptom PROMs are increasingly used by healthcare providers in their routine practice to improve quality of care, HRQoL is often deprioritised and underestimated, yet remains important to patients’ perception of chronic illness burden over time.  To present considerations, challenges and learnings from a study, whereby a HRQoL PROM was developed/validated for use in comparative research and routine practice to assess impacts of a chronic disease.  Study procedures (using Patient-Focused Drug Development guidance as a template) and findings from the development of a HRQoL PROM, which involved a literature review and qualitative concept elicitation and cognitive interviews with N=20 patients, will be used as a case study.  Methodological considerations and learnings from developing a HRQoL PROM for research and practice will be discussed, including:   * **Context of use –**defining this early in development is essential and fundamental to development and validation. * **Concepts of interest**– various methods should be considered for identifying important concepts of interest, including literature review and primary data collection; strengths and limitations of each method will be considered. * **Methods of development, ensuring that key stakeholders are central** – a patient advocate and experienced clinician were part of an advisory committee, who informed development, alongside patient interviews; key considerations will be highlighted. * **Barriers and facilitators to uptake** – instrument appearance and composition (i.e., length, recall period, response options) should be evaluated to ensure the PROM is user-friendly and minimally burdensome.   These learnings demonstrate considerations for future development of HRQoL PROMs and highlight the importance of incorporating the patient voice and PROMs into routine care. This can help close the gap between clinician’s and patient’s views of what is important, ultimately enhancing shared decision making and improving patient-centred care. | | |
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| **28** | **Sarah Copping** | **The potential use of Individualised Quality of Life Measures in studies of Multiple Long-Term Conditions: Protocol for a Scoping Review** |
| **Background**  Patient-reported outcome measures (PROMs) play a crucial role in clinical trials and contribute to the transition toward a more value-based and person-centred healthcare system. In quantitative research, PROMs are used to assess quality of life (QoL), a key outcome in evaluating the impact of illness and treatment effectiveness  QoL is subjective, shaped by personal values and priorities. At the patient level, standardised PROMs may lack relevance and sensitivity where research involves people with multiple long-term conditions (MLTCs). This may be due to differential disease expression and high individual variability.  Individualised QoL measures may be particularly important in research involving people with MLTCs, as the diversity of this group means individuals have unique goals and health challenges. However, they have yet to be widely used in trials assessing interventions for MLTCs.  **Aims**  This scoping review will identify measures of QoL in all areas of disease specialities that allow for some form of individualisation/personalisation, and their validation in adult populations.  **Methods**  MEDLINE, Scopus, CINAHL, CENTRAL, PsycINFO will be searched to identify papers describing the development and/or validation of QoL measures which allow for tailoring to individual needs, preferences, or circumstances in healthcare, social care, or community contexts. Forward citation searching of development studies will ensure that validation studies are identified. Two reviewers will independently screen the identified studies and extract data. A narrative synthesis will summarise individualised QoL measures, focusing on domains, personalisation, validated patient groups, practical use and participant burden.  **Results**  The results of this review will be presented to a PPI group with MLTCs to consider their relevance and identify areas for future research in this field.  **Conclusions**  This review will highlight the strengths, limitations, and gaps in the current body of literature related to individualised QoL assessment and assess their applicability to people with MLTCs. | | |
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| **29** | **Lorraine Warrington** | **MyPath – a digital tool to support the delivery of patient-centred care in oncology** |
| **Background**  Research trials have demonstrated the value of embedding patient-reported outcome measures (PROMs) into practice to improve patient-centred cancer care and outcomes. Despite this evidence, and availability of international guidance, few cancer centres have managed to systematically implement PROMs assessments with patient-centred care recommendations into practice.  **Aim**  MyPath is Horizon Europe funded programme aiming to develop, implement and evaluate digitally supported patient assessments and care pathways for pain, nutrition, physical functioning/fatigue, and emotional/social functioning in 9 European cancer centres.  **Methods:**  The 5-year project began in 2022. Activity is organised through highly interlinked mixed methods work packages (WPs). These include WP1: Creation of content and structure of care pathways (including PROMs, clinical assessment, and care management paths) and WP2: Design of the digital solution/electronic platform. WP3 and WP4 provide social and implementation science expertise to guide the co-creation, implementation, and evaluation of the digital care pathways across participating centres, incorporating ethical/legal/sociocultural requirements.  **Results:**  In WP1 the initial PROMs/patient assessment and pathway content have been developed for pain, nutrition and emotional/social distress pathways. In WP2, a proof-of-concept digital platform has been delivered, guided by information obtained from WP3 and WP4 via clinical observations, interviews and feedback from clinical teams, hospital and IT managers and patients. Participating centres have engaged clinical teams, representing a range of cancer groups and settings.  In Leeds, local clinicians (oncologists, clinical nurse specialists, pharmacist) and patient representatives are supporting ongoing refinement of MyPath for implementation in a prostate oncology clinic with patients with metastatic disease.  **Conclusion:**  MyPath is an innovative and multi-faceted implementation project. Co-creation work is ongoing across all centres to engage clinical teams and local IT services to refine the pathways and digital solution. Implementation is scheduled to commence from Summer 2025 with staggered starts across the 9 centres. | | |
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| **30** | **Sarah Evans-Jones** | **Developing and evaluating an electronic questionnaire to capture acne patient-reported outcomes in routine clinical practice (ePAQ-Acne): Establishing content and face validity.** |
| **Background**  Acne is the most prevalent inflammatory skin disease treated globally, and some patient-reported outcome measures already exist. The Acne Core Outcomes Research Network has identified seven key domains, highlighting the need for a proposed measure aligned with these. The NHS digital strategy aims to integrate health and care services to improve patient outcomes. However, a digital acne assessment platform to capture data that influences treatment while measuring patient-reported outcomes remains absent. This research aimed to develop the content of a new electronic assessment questionnaire for acne (ePAQ-Acne) and evaluate its acceptability to establish its content and face validity.  **Method(s)**  To establish content validity, a qualitative systematic review of 23 papers explored what is important to individuals with acne. Thematic synthesis identified key concerns, which were grouped into questionnaire domains. Interrogation of an acne patient database (n=869) further established the impact of acne. Items were drafted and reviewed by a Patient and Public Involvement Group. Face validity has been assessed using cognitive interviews with patients and healthcare professionals, as well as administering the QQ-10 and QI-10 Clinician questionnaires.  **Results**  The review identified seven domains: Acne and Acne Treatment Assessment, Acne Management, Emotional Impact, Physical Impact, Self-Image and Identity, Social Impact, and Views of the Causes of Acne. Acne database interrogation determined the top five worst aspects of acne according to a range of demographics and allowed for comparison of existing PROM scores with acne location/severity. ePAQ-Acne’s acceptability testing is ongoing, with positive feedback.  **Conclusions**  ePAQ-Acne’s domains have been condensed to five: Treatment and Management, Physical Impact, Self-Image and Identity, Social Impact, and Emotional Impact. Demographic information, health and acne history, and outcome goals are also collated. Suggested changes will be reviewed upon completion of acceptability testing. ePAQ-Acne’s electronic version will be developed, with wider psychometric testing to follow. | | |
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| **31** | **Monideep Ghosh** | **How Useful is the Quality Adjusted Life Year (QALY) in Contemporary Healthcare Decision Making?** |
| In a climate of increasing financial pressure on healthcare systems, tools that quantify health benefits relative to cost are more vital than ever. The Quality Adjusted Life Year (QALY), widely regarded as the gold standard in health economics, offers a common currency to compare disparate health interventions by combining improvements in both quantity and quality of life. Used extensively by bodies such as NICE in the UK, the QALY underpins cost utility analyses and helps guide funding and treatment decisions.  However, this abstract questions whether the QALY remains fit for purpose in 21st century healthcare. While the QALY allows comparisons between interventions with diverse aims such as life prolonging thrombolysis and quality enhancing home care Iit fails to fully capture the broader impacts of treatment, including psychosocial effects, societal benefit, and long term economic savings. Furthermore, its heavy reliance on cost can unintentionally incentivise short term financial decisions at the expense of long term health gains, as demonstrated in analyses of innovative treatments like injectable medicinal heroin for addiction.  Ethical challenges also arise. The QALY's reductionist approach to quality of life can disadvantage vulnerable populations such as disabled individuals, by assigning them inherently lower utility scores, potentially leading to biased resource allocation. Subjective measures of quality of life and the omission of non health related factors further question the robustness of QALY based evaluations.  Despite its widespread adoption, the QALY faces mounting criticism due to methodological, ethical, and practical limitations. This presentation will discuss the uses of this measure and its glaring limitations in modern day healthcare. | | |
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| **32** | **Nathan Bray** | **MobQoL-7D: Development and validation of a novel PROM for mobility-related quality of life** |
| **Background**  An estimated 24% of the UK population (16.1 million people) report having some form of disability. Mobility impairment is the most common cause of disability in the UK, with 48% of disabled people reporting some form of mobility impairment. In England alone an estimated £355million is spent annually by the NHS on wheelchairs and postural seating. However, there is limited robust economic/PROMs data to guide the provision of mobility aids in a cost-effective manner.  **Methods**  The aim of the Mobility and Quality of Life (MobQoL) project was to develop a novel PROM for mobility-related quality of life. Our intention was to develop a holistic measure which was succinct, simple to use in clinical/therapeutic practice and suitable for quality-adjusted life year (QALY) calculations. The project consisted of 3 studies: 1) qualitative outcome measure development, 2) psychometric testing and 3) health state valuation.  **Results**  In study 1 we interviewed n=37 mobility-aid users to understand the relationship between mobility and quality of life. We used their insights to develop the initial version of the MobQoL PROM, which contained 15 dimensions. In study 2 we undertook a psychometric validation study with n=342 mobility aid users to test the validity and reliability of the MobQoL measure. We used factor analysis and Rasch analysis to derive a streamlined 7 dimension version, called the MobQoL-7D. In study 3, we undertook a health state valuation study with n=872 participants to develop a QALY-based scoring system for the MobQoL-7D. We also compared the health state preferences of mobility aid users (n=368) and the general public (n=504).  **Conclusion**  The MobQoL-7D is the first outcome measure designed specifically to measure mobility-related quality of life and QALYs. It has a wide range of applications across academic and clinical settings, and the potential to improve provision of mobility aids. | | |
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| **33** | **Nathan Bray** | **Adaptation and Quality of Life (AdaptQoL): Development and validation of a novel PROM for assistive technology users** |
| **Background**  Almost a quarter of the UK population has some form of disability, equating to 16.1 million people. Many disabled people require assistive technologies and adaptations to maintain independence and undertake activities of daily living. Being unable to perform activities of daily living is associated with a number of negative effects, including poorer physical and mental health, and even increased risk of mortality. At present there is a distinct lack of routinely collected PROMs data in the provision of assistive technology.  **Methods**  The aim of the Adaptation and Quality of Life (AdaptQoL) project is to develop a novel preference-based PROM for assistive technology users. We will specifically design this tool to be succinct and easy to apply in practice. The project will run from 2025-2027, and will be divided into four work packages: firstly we will develop the content of AdaptQoL PROM by interviewing a wide range (n=40) of assistive technology users to understand the relationship between impairment, adaptation and quality of life; secondly we will pilot and validate the PROM in relevant patients groups (n=250), and use Rasch/factor analysis to derive a concise version of the PROM; thirdly we will develop a preference-based QALY scoring system using the Online Elicitation of Personal Utility Functions (OPUF) method, and compare the health state preferences of the general public (n=300) and assistive technology users (n=300); finally, we will develop a Welsh language version of the PROM through linguistic validation and cognitive interviewing (n=10).  **Conclusion**  By the end of this project we aim to launch a finalised version of the AdaptQoL PROM in English and Welsh, as well as a QALY scoring system. The AdaptQoL has the potential to facilitate routine use of PROMs in assistive technology provision, which in turn could enhance service efficiency, patient-centred care and patient outcomes. | | |
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| **34** | **Anne Klassen** | **Measuring What Matters: Creating a Comprehensive PROM for Gender-Affirming Care Across Borders** |
| **Background**  Multiple systematic reviews have called for a gender-affirming care (GAC)-specific PROM. Addressing this gap requires a large-scale effort, as GAC is multi-faceted, encompassing treatments that shape how people, look, sound, feel and function. Capturing these experiences across diverse healthcare systems, cultures, and gender identities requires a PROM that is comprehensive and globally applicable.  **Objective**  To develop and validate a PROM that covers all aspects of GAC and to do this internationally.  **Design**  Our mixed methods study took 5 years (February 2019 - March 2024). Part 1 involved concept elicitation interviews with gender diverse people in Canada, US, Denmark, and the Netherlands. The GENDER-Q was developed and refined iteratively with feedback from patient participants and experts. In part 2, we recruited participants through 21 clinical sites across Canada, US, the Netherlands and Spain, and community groups (e.g., crowdsourcing platform, social media). Rasch and classical test theory analyses were used to examine scale performance.  **Results**  We conducted 84 concept elicitation interviews and formed a conceptual framework with 13 domains: quality of life, sexual, urination, gender practices, voice, hair, face and neck, body, breasts, genital feminization, chest, genital masculinization, and experience of care. Iterative feedback on scales was obtained from clinician experts (4 to 37 experts per scale; response rate, 67%) and 7–14 patient participants (depending on scale). The field test version of GENDER-Q included 55 scales. Collaborators worldwide recruited 5,497 participants who sought or had the following types of GAC: 2,674 (48.6%) masculinizing, 2,271 (41.3%) feminizing, and 552 (10.0%) other. The psychometric analysis provided evidence of reliability and validity for 54 scales and 2 checklists covering a broad range of outcomes and experiences.  **Conclusion**  GENDER-Q sets a new bar for how PROMs can be designed to reflect the full spectrum of patient experiences with a global, patient-centred approach. | | |
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| **35** | **Alan Uren** | **The cognitive testing of a non-sex-specific patient reported outcome measure for evaluating lower urinary tract symptoms: The ICIQ-LUTS** |
| **Background**  The International Consultation on Incontinence Questionnaires (ICIQ) offer a range of patient reported outcome measures for lower urinary tract dysfunction. Lower urinary tract symptoms (LUTS) occur commonly in men and women and are non-sex-specific and non-organ specific. Early detection and assessment can help manage the impact on quality of life. To date, there have been separate questionnaires for evaluating female and male LUTS, the ICIQ-FLUTS and ICIQ-MLUTS. A clinical need was identified for a single questionnaire allowing male and female scores to be assessed without the need for separate questionnaires. The ICIQ-MLUTS and ICIQ-FLUTS were combined into one universally applicable, non-sex-specific questionnaire: the ICIQ-LUTS. Five items were exclusive to either the male or female original questionnaires; these items required further exploration in cognitive interviews.  **Aims**  To test the ICIQ-LUTS questionnaire in cognitive interviews with patients and determine whether all items were understood, relevant and interpreted as intended; to explore whether the 5 items that were only included in either the ICIQ-MLUTS or ICIQ-FLUTS original questionnaires were equally understandable to both male and female patients.  **Method**  Cognitive interviews using the ‘think aloud’ technique were conducted with a purposive sample of patients with LUTS, recruited from the Bristol Urological Institute outpatient clinics.  **Results**  Four rounds of interviews were conducted with n=12 patients. Interview responses and revisions were documented in an item tracking matrix. Items were re-ordered into domains of Storage, Voiding, Post-Micturition. An additional response option of ‘stronger than normal’ was added to one item asking about the strength of urinary stream as some female patients felt there was no appropriate response option available to them.  **Conclusion**  The questionnaire contains items that are understood, clinically relevant, and interpreted as intended by both male and female patients.Psychometric testing is in progress at Southmead Hospital, Bristol and Imperial College Hospital, London. | | |
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| **36** | **Sé Maria Frances** | **Recruitment and Engagement in PROM Development: A Reflection on the Methodological Challenges in Recruiting Patients with Idiopathic Multicentric Castleman’s Disease (iMCD)** |
| **Background**  Idiopathic Multicentric Castleman Disease (iMCD) is a rare, life-threatening disorder characterised by systemic inflammation and lymph node enlargement. Approximately 3.4 new cases per million are diagnosed annually. iMCD imposes a significant symptom burden on patients, profoundly impacting their daily lives.  **Aims**  The “Idiopathic Multicentric Castleman Disease Symptom Burden Study” (ISBUS) aims to develop a novel patient-reported outcome measure (PROM) to quantify symptom burden, track change over time, and provide valuable insights to enhance clinical care.  **Methods**  The study follows four stages:   1. Content Development: Drafting PROM content informed by literature review and expert consultation. 2. Cognitive Debriefing: Conducting patient interviews to explore and refine PROM content. 3. Psychometric Survey: Assessing reliability and validity by quantitative analysis and finalizing PROM content. 4. Estimating Change: Re-administering the PROM  with follow-up interviews to generate preliminary estimates of minimally important change.   Currently in Stage 3, this poster presents researcher’ reflections on ongoing patient recruitment for PROM development in an ultra-rare disease.  **Results/Reflections**  Due to low incidence and geographically dispersed patient population, recruitment challenges were anticipated. To address these, an international recruitment strategy was developed in collaboration with patient advocacy group, the Castleman Disease Collaborative Network (CDCN). Whilst positive, other factors requiring appropriate consideration have emerged. Coordinating interviews for Stage 2 across multiple time zones (e.g., USA, Australia) was challenging, requiring researcher flexibility to accommodate participant availability. The incentivised and online nature of the Stage 3 survey necessary for a hard-to-reach population poses a risk of fraudulent use. As a result, strict screening criteria and vigilant monitoring of data collection have been necessary.  **Conclusion**  International collaboration, flexible protocols, and stringent screening methods are crucial for improving recruitment, retention, and engagement. The ISBUS study recruitment process has highlighted the importance of preparing for potential recruitment challenges when developing meaningful PROMs for rare disease populations | | |
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| **37** | **Mary Zacaroli** | **Using Moodscope cards to measure wellbeing outcomes in third sector organisations: a public-led feasibility study** |
| **Background:** Third sector (charity) organisations play a key role in supporting wellbeing, but they struggle to evidence their impact. Patient-reported outcome measures (PROMs) generate such evidence, but their traditional formats might deter vulnerable individuals with negative experiences of formal services. Moodscope, a validated tool that captures 20 positive and negative mood states, is available online and as physical cards.  **Aim:**In this study we tested the feasibility of using Moodscope cards to collect quantitative outcomes data in a more engaging way within third sector settings.  **Methods:** This study was initiated by a public research partner, who co-led all stages of the project with an academic researcher. Through a partner charity organisation we engaged adult family carers and two staff members during six art sessions. After an introductory online session on using the Moodscope cards, participants recorded their mood scores before and after each art session. Through follow-up qualitative interviews we explored their experiences of the sessions and the Moodscope tool. We independently analysed the data using NVivo software before identifying prominent themes together.  **Results:** Four family carers successfully used Moodscope to track mood changes. Carers and staff found the cards to be simple and useful, especially in recognising positive mood elements even during low overall mood. Most participants showed a consistent mood improvement after sessions. They saw Moodscope as a valuable quantitative tool to complement existing qualitative feedback, offering charities a practical method for evidencing impact. However, staff noted challenges in balancing data collection with running session activities.  **Conclusions:** Moodscope shows promise as a low-barrier, participant-friendly method for gathering quantitative outcomes data in third sector settings. While external factors can influence mood scores, the tool’s simplicity and positive reception suggest potential for broader use. Trust between participants and researchers, and staff capacity for emotional support, were critical to success. | | |
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| **38** | **Francis Sanders** | **Optimisation Of The Daily Living Tasks Dependent On Vision Questionnaire In The Setting Of Patients Being Treated for Macular Diseases** |
| **Background** The Daily Living Tasks Vision questionnaire (DLTV) is an established questionnaires used for assessing patient reported outcome measures (PROMs).    **Aims**  The objective was to ensure accurate response categorisation, eliminate misfitting items, and improve overall psychometric performance of the questionnaire in the context of a range of macular conditions.    **Methods** Rasch analysis was performed iteratively on 2,286 responses from patients with macular conditions undergoing intravitreal anti vascular endothelial growth factor (AntiVEGF) to optimise the 24 item DLTV. Iterative refinements were performed optimising fit statistics (eliminating those >1.2 and those <0.8), reliability indices, and measures of person & item separation. Unidimensionality was examined using principal component analysis of residuals. This study was conducted within the department of ophthalmology in Hywel Dda University Health Board, Wales, UK, examining patients under the care of the macular treatment service.    **Results**.  Category probability curves demonstrated improved category separation and good ordering remained after sequential elimination of misfitting items for the DLTV. The finalised optimised DLTV consisted of 13 items retaining person separation of 3.28 with reliability of 0.92. Subgroup analysis yielded similarly effective abbreviated questionnaires when redundant and unreliable items were removed with 1,077 responses from patients with neovascular age-related macular degeneration (nAMD) resulting in a 6-item questionnaire with excellent person separation (2.7) and reliability (0.88). When this 6-item questionnaire was applied to the entire cohort of 2,286 responses it retained good person separation (2.56), all items demonstrated good fitting and categories remained well ordered, whilst achieving unidimensionality.  **Conclusions**  Rasch analysis successfully refined the DLTV improving measurement precision in patients with a range of macular diseases. The final models exhibited improved psychometric properties, enhancing their utility in assessing functional vision in clinical and research settings. Furthermore, the abbreviated questionnaire provides greater utility in the context of the time-restricted outpatient ophthalmology clinic and busy intravitreal injection services. | | |
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| **39** | **Bill Byrom** | **Advancing PRO integration in Oncology Drug Development and Routine Care: Challenges and Complexities** |
| Patient-reported outcome measures (PROMs) have become essential components of oncology clinical trials, yet significant methodology questions remain unanswered. This presentation examines critical knowledge gaps impacting the effective implementation of PROMs in clinical trials, and potentially in routine care settings.  While evidence consistently demonstrates that clinicians underestimate both the frequency and severity of adverse events compared to direct patient reports, questions remain about optimal collection approaches. The FDA guidance recommends frequent at-home assessments and leveraging subscales as standalone measures, but these introduce methodological challenges that must be addressed to fully realize the value of PROs, and as we bridge from trials to routine care.  First, I'll explore the burden-benefit balance of frequent PRO assessment in oncology patients. I'll present literature evidence to address "how much is too much" with the aim of deriving recommendations on good measurement practice. I'll also examine enhanced completion rates when PROMs are embedded in clinical review, and how this can be implemented in clinical trial operational practice.  Second, I'll examine the measurement properties of subscales when extracted from validated instruments and used standalone. Despite increasing regulatory support, limited research exists on whether context affects response patterns, psychometric properties, and interpretability. I'll explore what we know, whether it's sufficient, and its relevance when transitioning from trials to routine care.  Finally, I'll discuss a forthcoming observational study seeking empirical data to assess PROM completion burden and explore passive sensor data collection for additional treatment impact insights. This research aims to inform more patient-centered PRO strategies across clinical trials and routine oncology practice, ultimately improving how we capture the patient experience throughout the care continuum. | | |
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| **40** | **Tim Benson** | **Evaluation of the spread of a data-driven recall system in general practice** |
| **Aim**  Target Health Solutions (THS) has developed software that improves patient recall for long term conditions such as diabetes and hypertension. This project evaluated its spread to seven other practices.  **Method**  A comprehensive staff survey was conducted before and after implementation of THS. The baseline survey included 9 measures (comprising 36 questions) assessing work well-being, job confidence, digital competence, innovation readiness, team dynamics, patient safety, service quality, patient confidence, and recall systems. After implementation, staff also completed four additional measures focused on the innovation process, behaviour change, training effectiveness, and user satisfaction. All responses were anonymous.  Practices were grouped based on how they adopted THS. Group 1 (2 practices, 5 sites, 29,500 patients) implemented THS as expected, fully replacing previous recall methods. Group 2 (5 practices, 6 sites, 47,000 patients) used THS alongside their existing systems.  **Results**  Recall performance was higher in Group 1. In these practices, 93% of pre-diabetic patients had HbA1c tested, 77% of diabetic patients received over eight care processes, and 80% of hypertensive patients under 80 achieved target blood pressure. By contrast, Group 2 practices achieved 78%, 56%, and 70%, respectively.  Survey results indicated improved confidence in recall systems in both groups, though this improvement was confined to administrative and management staff, not GPs. Other survey measures showed minimal change.  **Conclusions**  Adopting innovation in a busy primary care practice is hard. Where income is linked to recall processes, there is often resistance to replacing these with more efficient but unproven alternatives. Successful change requires strong leadership from GP partners and targeted training, which were found in Group 1 practices.  **Reference**  Benson T, Benson A. Evaluation of the spread of a data-driven recall system in English General Practice. Submitted for publication 2025. | | |
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| **41** | **Tim Benson** | **Generic PROMs and PREMs: challenges and the case for innovation** |
| **Aim**  Generic patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are designed to evaluate how healthcare services affect patients' health outcomes and their experience of care. Unlike condition-specific tools, generic measures can be used across diverse healthcare settings, including when patients have multiple conditions or an unclear diagnosis.  **Method**  Generic PROMs and PREMs provide a system-wide view of patient outcomes and experience. However, their adoption across health services remains limited. This paper considers the barriers to their wider use and identifies opportunities for improvement.  **Results**  Two challenges limit the effectiveness and impact of generic PROMs and PREMs.  First, patient response rates are low and falling (typically under 30%). Many patients find PROMs and PREMs to be long, complex, or irrelevant. High reading ages and burdensome formats discourage completion, particularly among disadvantaged and elderly populations.  Second, for data to drive service improvement, healthcare managers must trust and understand the results. Trust is undermined when different measures show conflicting outcomes, inconsistent scales are used, data is from unrepresentative patient samples, and results are received too late to be useful in decision-making.  **Conclusions**  Healthcare professionals are committed to delivering high-quality care, but lack reliable tools to measure their success from the patient’s perspective. A new generation of simpler, faster, and more inclusive generic PROMs and PREMs is needed. These tools must improve patient response rate, enhance data usability, and foster greater trust among service managers, so as to improve care quality across the board.  **Reference**  Benson T. Patient-reported outcomes and experience: Generic PROMs and PREMs. Cham CZ: Springer 2025 [in press]. | | |
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| **42** | **Tim Benson** | **EQ-5D-3L and the Oxford Hip and Knee Scores: Comparative analysis of NHS Arthroplasty PROMs data** |
| **Aim**  I evaluate the degree of improvement, effect size, and correlation between the EQ-5D-3L and the Oxford Hip and Knee Scores, using data from the NHS Patient Reported Outcome Measures (PROMs) programme. The goal was to assess how well these measures align when scaled to a common 0 (worst) to 100 (best) metric.  **Method**  EQ-5D-3L is a generic PROM consisting of five health dimensions, each with three response levels. It has two scores: the EQ-Index (ranging from -0.594 to +1.0) and a Visual Analogue Scale (EQ-VAS) from 0 (worst imaginable health) to 100 (best). The Oxford Hip Score (OHS) and Oxford Knee Score (OKS) are condition-specific PROMs, comprising 12 items with five response levels, scoring from 0 (best) to 48 (worst).  A total of 40,000 patient records were extracted from the NHS PROMs repository. Scores were linearly scaled to a common 0–100 range. Mean improvement, effect sizes (ES = mean change ÷ baseline SD), and Pearson correlation coefficients were calculated.  **Results**  For hip replacements, mean improvements were OHS 46.8, EQ-Index 28.9, and EQ-VAS 14.1. Corresponding effect sizes were 2.74, 0.50, and 0.64, respectively.  For knee replacements, improvements were OKS 36.1, EQ-Index 21.4, and EQ-VAS 7.9, with effect sizes of 2.23, 0.38, and 0.39.  Correlations between measures for hip replacements were OHS vs. EQ-Index r = 0.64 and OHS vs. EQ-VAS r = 0.35. For knees, OKS vs. EQ-Index r = 0.60 and OKS vs. EQ-VAS r = 0.32.  **Conclusions**  The Oxford Scores and EQ-5D-3L demonstrate only moderate correlation, indicating they measure different constructs. The low effect sizes for EQ-5D suggest it is less responsive to change, raising questions about its reliability in assessing surgical outcomes.  **Reference**  Benson T. Health Status. Chapter 7. In: Patient-Reported Outcomes and Experience: Generic PROMs and PREMs. Cham CZ: Springer 2025 [in press]. | | |
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| **43** | **Tim Benson** | **The Health Confidence Score: A Brief, Sensitive Measure of Patient Self-Management Capability** |
| **Aim**  The Health Confidence Score (HCS), measures patients’ capability manage their own care.  The aim is to assess its reliability, sensitivity and practical application in community settings.  **Methods**  The HCS has four items covering: (1) patients’ opinion of their health knowledge, (2) ability to self-care, (3) confidence in getting help and (4) participation in shared decision-making.  Each item has four options: Strongly agree (3), Agree (2), Neutral (1) and Disagree (0). There is also an aggregate score. For populations, mean scores are scaled from 0 (bad) to 100 (excellent).  Data were analysed from about 5,000 anonymous responses, collected from patients living out of hospital in southern England.  **Results**  The HCS demonstrates strong internal consistency, with inter-item correlations ranging from 0.57 to 0.76 and Cronbach’s alpha of 0.89. It is concise (43 words) and accessible (Flesch-Kincaid reading age of 8.2 years).  The HCS measure is sensitive to clinical change: aggregate scores increased by nearly 20% between referral and follow-up (from 66.4 to 74.7, p < 0.001). Health confidence was highest among patients aged 30–49 and lowest in those aged 50–69. There was no significant difference between sexes. HCS scores were inversely related to the number of medications taken.  Principle components analysis shows that health confidence is a separate concept from health status (howRu) and personal well-being (PWS),with moderate correlations of r = 0.43 and r = 0.53 respectively.  **Conclusion**  Health confidence is an important goal of person-centred care. The HCS offers a brief, validated, and responsive tool for assessing this construct. It is broader and more concise than the 13-item Patient Activation Measure (PAM-13), making it suitable for routine use in diverse healthcare settings.  **Reference**  Benson T. Health Confidence. Chapter 9 in Benson T. Patient-reported Outcomes and Experience: Generic PROMs and PREMs. Cham CZ: Springer 2025 (in press). | | |
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| **44** | **Tim Benson** | **QALY vs Load: Valuation of death and illness.** |
| **Aim**  Two approaches to valuing health outcomes over a person’s lifetime are compared: the well-known Quality-Adjusted Life Year (QALY) model and the newer Load model. The aim is to examine how each model values death and illness and to highlight differences in their assumptions and implications.  **Method**  The QALY model calculates the sum of health states over time, where being in perfect health has a value of one and being dead has a value of zero. Values are multiplied by the duration spent in each state, from birth or from a health event.  The Load model focuses on the burden of illness. It values both death and illness as adverse events and assigns a value of zero to both being well and being dead. It averages the impact of these states over a period (e.g., a lifetime), capturing the disutility of illness and the death event.  An example considers a person who dies at age 75 after three years of illness. The same preference judgement (based on a standard gamble) is used in both models: indifference between a certain outcome (1.5 years of illness followed by death) or a gamble (one year of illness vs. 1.5 years well, both followed by death).  **Results**  The QALY model attributes 99% of the outcome's value to life duration and only 1% to the illness period. In contrast, the Load model attributes equal weight to death (50%) and illness (50%). There is a 50-fold difference in how illness is valued.  **Conclusions**  The QALY model prioritizes extending life over relieving suffering. The Load model offers a more balanced view, potentially reflecting patient values in chronic illness or end-of-life care.  **Reference**  Benson T. QALY and Load. Chapter 17 in Benson T. Patient-reported Outcomes and Experience: Generic PROMs and PREMs. Springer 2025 (in press). | | |
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| **45** | **Tim Benson** | **Three Short Generic Measures of Patient Experience** |
| **Aim**  Three short generic measures of patient experience are described: the Patient Experience (howRwe), the Result Satisfaction and the Service Integration measures. Together, they provide a comprehensive yet concise patient’s view of the administrative, clinical and cross-team aspects of patient experience.  **Method**  Each measure has four items and four response options, scored from 0 (worst) to 3 (best). Aggregate scores can be calculated. For population-level reporting, scores are scaled from 0 to 100, where higher scores indicate better experiences. The measures are designed to be easily understood, with low reading ages.  **Results**  Each measure has four items and four options. Each option has a score 0, 1, 2, 3 (high is good). There is also an aggregate score. For groups the mean scores of each item and the mean aggrgate scores are shown on a 0 - 100 scale (high is good).  The Patient experience measure covers staff compassion, communication with the patient, timeliness and reliability. The length is 28 words and reading age is 7.7 years (as assessed by Flesch-Kincaid).  The Result Satisfaction measure covers the consultation, treatment, practical help and future plan. The length is 40 words and reading age is 9.4 years.  The Service Integration has items for communication with other teams, knowledge of other teams, repetition of story and teamwork. The length is 33 words and reading age is 10.1 years.  **Conclusions**  The three measures offer a practical and accessible approach to capturing patient experience. Their brevity, low reading levels, and common scoring system make them suitable for routine use in varied healthcare settings. They provide a patient-friendly alternative to longer, more complex instruments currently in use in the NHS.  **Reference**  Benson T. Patient Experience. Chapter 6 in Benson T. Patient-reported Outcomes and Experience: Generic PROMs and PREMs. Cham CZ: Springer 2025 (in press). | | |
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| **46** | **Hannah Worboys** | **Analysing PROMs in clinical trials in the presence of informative dropouts: A comparison of the linear mixed effects model, standard joint and competing risks joint model** |
| **Background**  Haemodialysis is a burdensome treatment for people living with end-stage kidney disease (ESKD). As a result, quality of life (QoL) is a key endpoint in clinical trials. The longitudinal aspect of clinical trials and progressive nature of ESKD leads high dropout. The linear mixed effects model performs poorly in the presence of informative dropouts. Joint models are able to model QoL and time-to-dropout simultaneously. A joint model with competing risks of dropout may be more suitable than a standard joint model.  **Aim**  This study aims to investigate in a clinical trial context the consequences of using the frequently used linear mixed effects model (LMM) rather than its corresponding joint (SJM) or competing risks joint model (CRJM) to model QoL in the presence of random and informative dropouts.  **Methods**  We compare a LMM which does not account for the reason for dropout, a SJM that models QoL jointly with time to all-cause dropout, and a CRJM, where two competing risks of dropouts are considered.  **Results**  The methods are compared theoretically and then empirically using data from two previously published nephrology trials The LMM is subject to bias where QoL is significantly associated with risk of dropout. The SJM and CRJM estimates the association between the QoL subscales and risk of dropout. The differences between the LMM, SJM and CRJM will in the presence of both informative and non-informative dropouts and subsequent impact on the HRQoL parameters will be evaluated.  **Conclusion**  We demonstrate the benefits of using a CRJM over an LMM and SJM to minimise bias in the estimation of HRQoL parameters. This model relies on the systematic collection of reasons for dropout in clinical trials, which facilitates the use of CRJMs, and could be a satisfactory approach to analysing longitudinal HRQoL data in the presence of dropouts. | | |
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| **47** | **Nova Mathew** | **Developing a core outcome set for co-existing dementia and hearing loss: A systematic review of outcomes reported in previous hearing loss and dementia studies.** |
| **Background**  Dementia and Hearing Loss (HL) often co-occur, affecting communication, cognition, and well-being. This growing co-morbidity presents unique challenges that differ from experiencing these conditions in isolation, yet guidance on recommended interventions remains limited. Trials are needed to identify effective interventions, but it is currently not known what outcomes should be measured or which outcomes are important to people living with both conditions. This research aims to develop a Core Outcome Set (COS) for trials of interventions for co-existing dementia and HL. Firstly, current outcome measures must be systematically identified.  **Aims**  This review aims to:   1. Identify the outcomes measured in co-existing dementia and HL research, to develop a long list of outcomes. 2. Identify the methods and instruments used to measure these outcomes.     **Methods**  Pre-registered via PROSPERO, this review includes non-pharmacological intervention studies involving adults with both HL and dementia or mild cognitive impairment, alongside studies involving carers. Studies were required to be available in English. No restrictions were imposed regarding publication date, study design or publication status. Searches were performed across seven electronic databases and trial registries during February 2025. Two independent reviewers conducted screening. Data extraction is currently in progress.    **Results**  The findings will include outcomes, definitions, measurement instruments, and trends in outcome reporting across different interventions and populations. Preliminary analysis indicates that outcomes measured include caregiver burden, communication, and health-related quality of life. Instruments used include the Mini-Mental State Exam, and Dementia Quality of Life Instrument.    **Conclusion**  This review will provide a comprehensive overview of outcome measurement in dementia and hearing research. These findings will contribute to the development of a long list of outcomes, progressing towards establishing a COS. With input and guidance from PPI contributors, the next stage of COS development will entail qualitative research with patients, carers and clinicians to identify meaningful outcomes. | | |
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| **48** | **Anne Alarilla** | **Patient Reported Outcome Measures (PROMs) collected as part of standard care at Great Ormond Street Hospital** |
| **Background**  Patient reported outcome measures (PROMs) capture patient’s views of their health status. PROMs may be collected for research but are also increasingly incorporated into standard care. However, little is known about how often PROMs are incorporated as part of standard care at Great Ormond Street Hospital (GOSH), how these data are used, and whether the introduction of electronic health records (EHRs) has influenced this practice.    **Aims**  To explore PROMs collection and use as part of standard clinical care at GOSH and these data can be used for further analysis.    **Methods**  We followed two approaches; firstly, a service evaluation survey of GOSH clinicians which opened on 23 November 2023 with responses extracted on 28 February 2024 (n=33 responses at the time of extraction). Secondly, de-identified PROMs data within the GOSH EHR system (Epic) were extracted and analysed in the GOSH Digital Research Environment (DRE).    **Results**  25 different types of PROMs were collected and used as part of standard care from a range of teams across the different clinical directorates.  Most of these PROMs had been used for ≥ 5 years. The most common uses were for direct clinical care and other purposes such as research, but this varies within and between measures.  There are different methods of collection and storage including within EHRs - this can differ even for a single measure. Some PROMs that were reported to be stored within EHRs were unable to be identified, processed and analysed within the GOSH DRE.    **Conclusion**  A range of teams across different clinical directorates within GOSH have integrated PROMs as part of their standard care. The extent to which these data are integrated into Epic and extractable into the GOSH DRE is highly variable. To optimise the potential value of PROMs data, there are opportunities to standardise the collection, storage and analysis pipelines. | | |
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| **49** | **Nicola Anderson** | **Patient-reported outcomes in integrated care settings (ICS-PRO) – a multi-site mixed methods study** |
| **Background**  Effective care integration requires the right information, at the right time, with care delivered in the right environment to help people better understand their conditions and support needs. Patient-reported outcome measure (PROM) data may offer a mechanism to support collaborative integrated care (IC) to help people to stay well and independent by informing individualised assessments of their needs. At organisational levels, collected alongside Patient-Reported Experience Measures (PREMs), PROMs can monitor provider performance, inform policy, and guide quality improvement. This research explores howPROMs/PREMs can enable organisations to better understand a person’s views about their health and well-being, to develop guidance on optimised use in IC settings.  **Methods** Semi-structured interviews with individuals and carers with past or present lived experience of IC services and professionals working in an IC setting (health/adult social care/voluntary services). Qualitative data analysed using inductive/deductive hybrid approach through codebook thematic analysis using the Consolidated Framework for Implementation Research (CFIR). Online structured survey for IC professionals to further explore potential and current usage of PROMs/PREMs, key contextual and determinant factors for optimised implementation.  **Results**  In depth interviews withprofessionals (n=33) carers (n=2) and patients (n=2). Early findings highlight lack of shared outcomes and harmonisation exacerbated by heterogeneity of populations and settings. Systems are focused on measurement of experience, using PROMs evidence and language largely derived from healthcare settings. Overall understanding of PROMs by some professionals indicated awareness and training needs, and while electronic PROMs may offer digital solutions by supplementing telehealth initiatives, potential unexpected or undesirable consequences of implementation caused by patient health and digital literacy issues need to be addressed. Online survey in progress.  **Conclusion**  PROMs offer an approach to measure outcomes that matter to people and communities. This research investigates PROMs/PREMs use to support integrated multi-disciplinary and cross organisational services. | | |
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| **50** | **Katherine Broomfield** | **Developing in dialogue: Working with people who have communication disability to develop the content for a patient-centred outcome measure (PCOM) and provide insight into meaningful engagement for future implementation** |
| **Background**  Leah McClimans, in 'Patient-centred measurement' (OUP, 2024), argues for a process driven approach to developing patient-centred outcome measures, rooted in an epistemic theory that values experiential knowledge. We applied these principles to developing the content for a patient-centred outcome measure (PCOM) for people who have communication disability and who use augmentative and alternative communication (AAC) devices.  We engaged a public involvement group of AAC users, their family, and carers to initiate dialogue about the project protocol and then to provide critical oversight of the analysis and results.    **Methods and results**  We conducted two stages of qualitative research with people who use AAC; one longitudinal cohort study and one single-interview cross-section study. Using creative, accessible participant engagement and data analysis methods, we accessed rich insights into the experiences of using AAC to support communication, what is important about AAC, and how this evolves over time. We also established the importance of accessible research methods that enable the voices of people who use AAC to be embedded in the PCOM.    **Implications for PCOM development**  Epistemic dialogue with people who use AAC enabled us to co-create a set of 33 items that reflect what is important to people with communication disability about accessing AAC devices. It also provided insights into the dynamic contextual, temporal, and experiential factors that influence how and why people may prioritise certain outcomes over others.  Future development of a PCOM to evaluate AAC needs to consider accessibility, clinical context, and the individuals’ lifeworld. It is also apposite to accommodate the co-constructed meaning-making that is inherent in interactions with people who use AAC in the theoretical basis on which the tool is administered.    **Conclusion**  This study provides a practical example of the application of epistemic dialogue to PCOM development and the subsequent implications for further tool development and implementation. | | |
| **51** | **Georgina Forshall** | **Assessing adverse symptom and health-related quality of life outcomes following treatment for pelvic floor disorders: A content analysis of ePAQ-Pelvic Floor data** |
| **Background/Objectives**:  Patient-reported outcome measures are used in clinical practice and research to better understand the symptoms of pelvic floor disorders and their impact on patients. However, distinguishing between condition-specific outcomes and the effects of treatment can be challenging. In the context of the Cumberledge Review, this is important where treatment may have resulted in adverse outcomes. The electronic Personal Assessment Questionnaire for the Pelvic Floor (ePAQ-PF) is a validated PROM that captures data on female pelvic floor symptoms and health-related quality of life (HRQoL). Using existing ePAQ-PF data, the aim of this study was to analyse adverse symptom and HRQoL outcomes reported by patients who felt that their condition had worsened following treatment.  **Methods**  A multi-site ePAQ-PF dataset, including 5,717 questionnaires from eight participating NHS sites (April 2018 - April 2022), was filtered to produce a sample of patients who had received medical and/or surgical treatment and had reported a worsening of their condition. Content analysis of free-text ePAQ-PF data was undertaken to categorise and count patients’ reports of adverse symptom and HRQoL outcomes.  **Results**  The sample included 420 patients (mean age 54.9, SD=14.6). Ninety-two outcome categories were created and grouped into three themes (‘social and emotional wellbeing,’ ‘experience of symptoms,’ and ‘impact of health interventions’) and 10 sub-themes. Analysis of count data revealed that the most frequently reported outcomes related to the adverse effects (n=324) or failure (n=269) of treatment, urinary symptoms (n=289) and pain and discomfort (n=252). Limitations to patients’ ability to enjoy life (n=208) and impact to intimate relationships (n=121) were also common concerns.  **Conclusions**  The ePAQ-PF is a useful tool that provides comprehensive insights into the impact of pelvic floor symptoms and treatment on patients’ HRQoL. Further research is required on the standardisation of outcomes and development of core-outcome sets to better understand patient experiences. | | |
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| **52** | **Katherine E. Woolley** | **Innovative application of patient reported outcome data in palliative and end-of-life care in Wales: a case study.** |
| **Background**  Collecting patient-reported outcome measures routinely within palliative and end-of-life care has been shown to have positive impacts on patients. Implementation of PROM to routine care is complex, as demonstrated by the PROM healthcare system implementation framework (PROM-HCSIF). This manuscript aims to discuss the opportunities and challenges of the practical implementation of measurement toolkits to generate usable and accessible datasets of PROMs and clinical data for use within palliative and end-of-life care in Wales.  **Methods**  A narrative discussion has been used to explore the opportunities and challenges for the innovative applications of patient reported outcome data in palliative care in Walesbased on the experience of the Programme Board for Palliative and End-of-life Care in Wales and Marie Curie’s Cardiff and Vale’s Hospice. The discussion section has been framed using the PROM-HCSIF framework to summarise focused areas for implementation to ensure system-wide adoption.  **Results**  Opportunities and challenges were identified during implementation at a national and individual level; including identification of toolkits based on the outcome sets, PROM translations and licencing, culture of collection and use and ensuring clinically relevant data collection. Opportunities were also realised with strategic PROM digitisation and digital platform usage, aggregate analysis providing population level insights and patient level data visualisation.  **Conclusions**  Wales is working towards achieving a system-wide approach to PROMs implementation within palliative care. Based on these experiences there are recommendations for generating a culture of PROMs collection, transparent data management and clinically relevant data analysis and uses. | | |
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| **53** | **Caroline Potter** | **Oxford Brain Health Clinic: health-related quality of life assessment among initial sample** |
| **Background**  The Oxford Brain Health Clinic (OBHC) is a novel service that provides detailed assessments for both research and diagnosis of memory problems in later life. It is offered as an alternative step in the usual memory clinic diagnostic pathway and includes an MRI scan, outcome measures reported by patients and carers, and collection of biomarker data.  **Aim**  This study contributes to ongoing analysis of OBHC data. Here we compared health-related quality of life (HRQoL) scores between OBHC patients and patients in the standard memory clinic pathway.  **Methods**  To assess HRQoL, patients following the usual memory clinic pathway completed the full 20-item Long-Term Conditions Questionnaire (LTCQ), while OBHC patients completed the short-form version (LTCQ-8). LTCQ-8 item responses were extracted from the full LTCQ completed by memory clinic patients, and LTCQ-8 scores were compared for the two patient groups using an independent samples t-test.  **Results**  Among memory clinic patients (n=111), LTCQ-8 scores from extracted items correlated very highly with full LTCQ scores (Spearman’s r=0.96, p<0.001) and were used for comparison. OBHC patients (n=194) had significantly higher HRQoL scores than patients following the standard pathway (t(198)=4.79, p<.001, equal variance not assumed). Further analysis of OBHC data showed that 47% of OBHC patients did not yet show clinical signs of dementia, but they nonetheless exhibited burdensome symptoms (e.g. depression, irritability, night-time behaviours) at early stages, with associated caregiver distress.  **Conclusion**  Patients at Oxford Brain Health Clinic had higher health-related quality of life than a comparable memory clinic sample. Further analysis of OBHC data shows symptom burden and carer distress prior to a diagnosis of dementia, indicating unmet support needs. OBHC provides an opportunity to identify and support patients at earlier stages of cognitive decline, with the aim of preventing or delaying progression to dementia. | | |
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| **54** | **Jon Street** | **Development and initial validation of a self-report measure of disease severity for Facioscapulohumeral dystrophy** |
| **Background**  Facioscapulohumeral dystrophy (FSHD) is a progressive, disabling, muscle wasting disease. Understanding clinical severity in FSHD assists in planning patient care and providing appropriate support to people living with FSHD. Measures are also used to help identify potential participants suitable for clinical trials. Currently used severity scales in FSHD require in-person assessment, which may be burdensome for people living with FSHD.    **Aim**  There is a need for a concise measure of disease severity that can be used both in-hospital-clinic, trial settings and for patient registries. We present the development and initial validation of a novel self-complete outcome measure, the Self Report Severity Scale (SRSS).    **Methods**  The SRSS was adapted from an existing measure of disease severity, the Clinical Severity Score (CSS) following expert review elicitation. Thirty adults with genetically confirmed FSHD were assessed using clinical measures of disease severity, function, and strength. These included two regularly used severity scales FSHD Clinical Score (FCS) and Clinical Severity Score (CSS) in-addition to 10 metre walk time, and manual muscle strength testing (MMT). Patient reported measures (SRSS and EQ-5D-5L) were then completed by participants. Analysis was undertaken to determine the convergent validity of SRSS. A subset of participants repeated completion of SRSS and EQ-5D-5L to allow for test-retest reliability.    **Results**  Absolute agreement between the SRSS and CSS was excellent (ICC=0.92). SRSS demonstrated convergent validity with measures of strength, severity and function, with significant correlations seen with FCS (ρ = 0.84, p <0.001), MMT sum score (ρ = -0.71, p <0.001), and 10 metre time (ρ = 0.83, p <0.001). Test-retest reliability was excellent (ICC=0.97).    **Conclusion**  The SRSS is a reliable, valid self-reported severity scale. It can be completed remotely, making it a potentially useful tool to coordinate clinical care, help select potential trial participants, and be utilised in patient registries. | | |
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| **55** | **Manraj Kaur** | **Laying the Groundwork: Contextual Determinants of HIT-Assisted PRO Implementation in Community Cancer Centers Serving Black Breast Cancer Patients** |
| **Background**  Despite strong evidence supporting routine patient-reported outcome (PRO) collection in oncology, implementation remains limited in low resourced settings, such as community cancer centers (CCCs). This study aims to develop flexible, contextually responsive implementation models for health information technology (HIT)-assisted PRO reporting across five CCCs serving high proportions of Black patients. We report findings from site visits and early stakeholder engagement conducted across five CCCs as part of the preparatory phase of PRO implementation.  **Methods**  A structured field observation protocol, rooted in the Consolidated Framework for Implementation Research (CFIR), was applied at five US CCCs. Data collection included in-clinic observations of workflows, staff roles, communication, and patient flow, focus groups with clinic staff, patients and community leaders, and preliminary informational sessions with CCC IT teams. The Health Equity Implementation Framework and Technology Acceptance Model informed qualitative guide development and analysis. Data were triangulated to identify contextual determinants influencing implementation readiness.  **Results**  Field observations and stakeholder input revealed marked variation in clinic workflows, staff responsibilities, patient volume, and digital literacy across CCCs. Despite operating in resource-constrained environments, clinic staff expressed strong enthusiasm for integrating PROs to enhance patient-centered care. Barriers included limited patient health and digital literacy, high levels of unmet social needs (e.g., housing, food insecurity, transportation), and constrained staff capacity. Enablers included the presence of dedicated staff champions, accessible recruitment and training materials, low levels of research fatigue, and alignment with existing electronic health record systems. These early insights informed a Field Observation Toolkit, a replicable resource for PRO implementation and tailoring PRO strategies to diverse community oncology contexts, and site-specific implementation plans.  **Conclusion**  These findings underscore the importance of early field observation and stakeholder engagement in tailoring PRO implementation strategies, and informed the creation of a Field Observation Toolkit and site-specific implementation plans for subsequent phases. | | |
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| **56** | **Jessica Penhallow** | **myHealthE: A patient-facing digital platform for informing and improving child and adolescent mental health service research and delivery** |
| **Background**  With rising referrals to child and adolescent mental health services (CAMHS), there is a need for patient- and caregiver-facing digital platforms to streamline and support service delivery and research. In South London, the CAMHS Digital Lab has worked with South London and Maudsley NHS Foundation Trust and King’s College London to develop and embed myHealthE in CAMHS , providing . myHealthE offers families a virtual waiting room, provides advice and support tool, alongside and collections routine outcome measures and access to trial recruitment from the point of referral.  **Method**  In this study, we provide a cohort profile of n=10,151 families onboarded to myHealthE between 2021 and 2023. To illustrate the clinical and research capabilities of the platform, we provide illustrative examples of how the collection of patient reported outcomes data (PROMS) via myHealthE Strengths and Difficulties Questionnaire (SDQ) data collected via myHealthE can support every stage of the patient journey from referral to discharge. We primarily report descriptive statistics.  **Results**  The most commonly compeleted PROM was the strengths and difficulties questionnaire (SDQ) Of the n=29,906 SDQs completed by the cohort during their referral, the majority were completed via myHealthE (93.2%) rather than traditional pen-and-paper methods (6.8%). myHealthE therefore greatly increased availability of routine outcome measure data, and The resulting sample with available SDQ data was also more representative of the underlying CAMHS cohort. Supplemented with data extracted from the wider electronic health record, SDQ profiles can be used to identify potential sociodemographic biases in care pathways, symptom profiles underlying different diagnoses, and track symptom changes.  **Conclusions**  myHealthE provides a valuable tool for patients, caregivers, clinicians and researchers alike. Such platforms can fulfil multiple functions, including the collection of routine outcome measures. This is advantageous for both informing clinical service delivery, and for research. | | |
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| **57** | **Mollie Price** | **Assessing the user acceptability and translatability of the APPRAISE PROM: a patient-reported outcome measure for women who have had surgery for pelvic organ prolapse, stress urinary incontinence or mesh complications** |
| **Background**  Different surgeries are available to treat pelvic organ prolapse (POP) and stress urinary incontinence (SUI); one of which uses mesh which has led to complications requiring corrective surgery. Addressing a Cumberlege Report recommendation, the NIHR-HRA funded APPRAISE study aims to develop a new surgery-specific patient-reported outcome measure (PROM) to measure the impact of pelvic floor surgery on quality-of-life.  **Aim(s)**  To assess the acceptability and translatability of the prototype version of the APPRAISE-PROM; To ensure the PROM has cross-cultural applicability and can easily be translated into other languages.  **Method**  Cognitive interviews were conducted with 27 women who had surgery for POP, SUI or mesh complications. Participant feedback was recorded in an item-tracking matrix, and reviewed by an expert-steering-group and PPI-panel to make modifications. Nine follow-up interviews were conducted with participants to test the acceptability of the modifications. The PROM was then reviewed by a translation/validation expert and the translatability was assessed by a variety of translators.  **Results**  The APPRAISE-PROM demonstrated high levels of acceptability. Participants reported the items were comprehensive and highly relevant, and could aid communication with healthcare professionals. Most participants approved of the PROM length. The interviews highlighted some items where interpretation was inconsistent among participants, and the need for some additional items. A Concept Elaboration document was produced and modifications were made to item wording to aid translation.  **Conclusion**  The modified APPRAISE-PROM is now being administered to patients in four large national surveys (recruiting via 24 UK NHS sites and social media) to determine its reliability, validity and responsiveness in the context of short- and long-term surgical outcomes, and in a clinical trial. The PROM will be adopted by NHS England and linked to the UK national registry, providing a way that the risks and benefits of surgery can be better measured and compared. | | |
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| **58** | **Danielle Musson** | **Establishing content validity of a novel disease-specific patient-reported outcome measure: The Quality of Life in Antibody Deficiency (QoLiAD) Questionnaire** |
| **Background**  Antibody deficiencies (ADs) are characterised by an impairment in the development or functionality of immunoglobulins, which can result in an increased susceptibility to recurrent infections, often requiring lifelong antibiotic prophylaxis and/or immunoglobulin replacement therapy. Given the negative impact on health-related quality of life (HRQoL), a disease-specific patient-reported outcome measure (PROM) is required which captures the issues of importance to patients with primary and secondary ADs.  **Aim**  This study aimed to (1) identify key concepts, domains, and items for a disease-specific PROM, and (2) use patient input to establish content validity, fulfilling minimum standards outlined by regulatory bodies such as the Food and Drug Administration (FDA) and COSMIN (COnsensus-based Standards for the selection of health Measurement INstruments).  **Method**  In collaboration with the national charity Immunodeficiency UK, three phases were undertaken: (1) a mixed-methods systematic review, (2) concept elicitation interviews (n=27), and (3) cognitive debriefing interviews (n=21 completed). Following each phase, a clinical steering panel and patient and public involvement group were consulted.  **Results**  Acore instrument with 45-items was developed, categorised under eight HRQoL domains (for example, ‘Physical functioning’, ‘Social anxiety’, and ‘Perceived control’). The CORE section is supplemented by four optional modules which may not apply to every AD patient. Cognitive debriefing interviews supported the PROMs acceptability, comprehensibility and relevance. Despite this, high clinical heterogeneity posed challenges in the development and modification of the PROM, for example, during the selection of candidate items and an appropriate recall period.  **Conclusions**  We have developed a novel PROM designed to assess the HRQoL of AD patients. Establishing content validity in rare and heterogenous conditions with varying presentations and treatment pathways can be challenging. Several considerations should be made when establishing content validity of such PROMs against existing guidelines. Further work is in preparation to assess the psychometric properties of the PROM. | | |
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| **59** | **Fiona Lerigo** | **Understanding care worker-related quality of life in social care: a conceptual basis for measurement** |
| **Aim:**  Care-worker related quality-of-life (CWRQL) is adversely impacted by complex working arrangements arising from long-standing challenges, exacerbated by the COVID-19 pandemic.  Although robust measurement has potential to improve CWRQL through more effective monitoring, intervention evaluation, and a stronger research evidence base, few existing measures of CWRQL exist.  Part of this knowledge gap is the absence of a full conceptual framework to understand CWRQL for social care.  Our previous work (Hussein et al. 2022) developed a model partially addressing this issue and identified that CWRQL in social care includes three high level dimensions: Societal Recognition of Care Work, Care Organisation Characteristics, Nature of Care Work.  The current work adds the necessary level of conceptual specificity to support subsequent Rasch-based measurement.  **Methods**  We undertook five online group interviews (n=16) with domiciliary and care-home workers to investigate specific ambiguities, overlaps and gaps in the previous model.  Initial interviews clarified ambiguities and developed concepts.  Later interviews used post-it notes (via “Jamboard”) to understand which components belonged in each domain.  Interviews were recorded and transcribed verbatim.  Thematic coding was undertaken using NVivo. Questionnaire items were mapped to every component of the final conceptual framework.  We used a “think aloud” technique in cognitive interviews (n=20) with a representative sample of care-workers to iteratively revise items.  **Results**  The final conceptual framework comprised 12 domains: physical safety, role autonomy/control, relationships/communication, time pressure, training/development, responsibility, role boundaries, satisfaction/motivation, value/respected, fair pay/benefits, exhaustion, burden.  Cognitive interviews identified changes to item wording, question stem, time frame.  Participants reported no issues with response options and valued the brevity and comprehensiveness.  **Conclusions**  This conceptual framework provides the foundation for a new measure of CWRQL.  Careful investigation and clarification of identified gaps and ambiguities will ensure content validity and potentially better scale-to-sample targeting of the forthcoming measure (ASCK-WELL). | | |
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| **60** | **Megan Pardoe** | **Completion of an adapted ICECAP-O capability-wellbeing questionnaire by people living with dementia (PLWD), formal and informal carers. A qualitative interview study** |
| **Background**  The ICECAP-O is a measure of capability wellbeing for older adults (aged 65+) designed for use in economic evaluations of health and social care interventions. Previous research has found that people living with dementia (PLWD) experience challenges in completing the ICECAP-O questionnaire and PLWD tend to report better wellbeing compared to proxy reports.  **Aim**  An adapted version of the ICECAP-O that is easier to complete for PLWD and their carers is being developed. Using qualitative interviews with PLWD and their carers, we aim to understand how these groups complete the adapted ICECAP-O and how proxy reporting can be improved.  **Methods**  The adapted ICECAP-O is being developed using an iterative, staged approach. First, literature reviews were conducted to identify previously reported challenges PLWD have experienced when completing the ICECAP-O and guidance on adapting existing measures for people living with cognitive impairment. Second, patient and public involvement (PPI) was undertaken to refine a draft adapted measure and interview methodology. Stage three is a cognitive interview study to test the adapted ICECAP-O. Participants include PLWD, formal and informal carers of PLWD. PLWD and informal carer dyads are eligible and enable a comparison between individuals and proxies. In-person interviews are being undertaken using a verbal probing approach. Additional questions include general questionnaire feedback and exploring proxy perspectives.  **Results**  Eighteen interviews have been completed, including seven PLWD, four paid carers and seven informal carers. Providing examples that intend to reduce ambiguity may impact the interpretation of questions, although potentially increase concordance between PLWD and their carers. Despite the questionnaire not being labelled, respondents answer in the context of dementia.  **Conclusion**  This study highlights challenges and opportunities for adapting questionnaires for PLWD and implications for the development of questionnaire versions for proxy completion. How changes could impact the validity of the measure requires further consideration. | | |
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| **61** | **Georgina Jones** | **The impact of endometriosis upon quality of life: findings from two national surveys, across two decades.** |
| **Background**  Endometriosis is a common gynaecological condition affecting 10-15% of reproductive-aged women. The Endometriosis Health Profile 30 (EHP-30) is the first psychometrically established patient-reported outcome measure, designed to evaluate the impact of endometriosis and its associated treatments/interventions, from the woman’s perspective. It is available in 64 languages and is endorsed by national and international professional and regulatory bodies as an outcome measure for this condition.  **Aim**  To compare two datasets collected in 1999-2000 and 2023-2024, in collaboration with the national charity for endometriosis (Endometriosis UK), to explore how the HRQoL of women living with endometriosis has changed during this period.  **Method**  An online survey was conducted which included the EHP-30, a demographic proforma and open-ended questions surrounding patients’ experiences of endometriosis. Analyses included descriptive statistics of demographic and HRQoL scores (domain and item level responses) and thematic analysis of the open-ended questions.  **Results**  In total, 1177 surgically confirmed patients completed the survey. For the EHP-30 core scale, all domain scores (except ‘Control and powerlessness’) had increased since the 1999-2000 survey, indicating a worse HRQoL. The largest increase was the ‘Self-image’ domain (1999-2000, mean = 57.2, SD = 26.7, 2023-2024, mean = 69.0, SD = 25.5). For the modular component, ‘Relationship with children’ and ‘Infertility’ had improved. However, ‘Relationship with the Medical Profession’ had deteriorated (mean = 57.0, SD = 27.6) since the 1999-2000 survey (mean = 41.5, SD = 27.6). Respondents experience of endometriosis was mostly negative, describing debilitating pain, frustration and loneliness. But a number described the sense of community felt by those living with the disease.  **Conclusions**: Despite increasing awareness and the development of interventions designed to support patients with endometriosis, these scores remain at a similar level, or marginally worse, than in the previous survey in 1999-2000. Peer support is critical to those living with endometriosis. | | |
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| **62** | **Samantha Sodergren** | **Introducing the EORTC QLQ-AYA30: The world's first quality of life questionnaire specific to Adolescents and Young Adults (14-39 years) with cancer.** |
| A diagnosis of cancer during adolescence and young adulthood (AYA) disrupts key developmental stages relating to identity formation, peer relationships, development of autonomy, and sexuality, and significantly impacts quality of life (QoL). Available QoL measures for AYAs overlook these important domains. Our objective was to develop a European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group (QLG) questionnaire measuring QoL issues of relevance and importance to AYAs aged 14-39 years with cancer.  The EORTC QLG guidelines for questionnaire development informed our methodology. AYAs receiving treatment or palliative care for cancer completed the draft questionnaire and rated questions according to relevance and importance. AYAs shared their feedback to inform potential omissions, question re-wording and irrelevant or unacceptable questions.The performance of questionnaire items was evaluated according to a priori decision rules and exploratory factor analysis conducted to identify questionnaire sub-scales.  The sample included 253 AYAs from 19 countries, mean (SD) age 25.51 (7.54) years, 51% males, 81% currently on treatment, 79% curative. Questions with highest prevalence included realisation of priorities (89%), lack of energy (84%), and motivation to live life to the full (80%). Fertility and body image questions were identified as high priority questions to include. The resulting questionnaire includes 30 questions with five multi-item sub-scales: Activity limitations, Worry about cancer and the future, Self-esteem, Relationships and Positive outlook, as well as nine single questions. Reliability testing revealed good internal consistency among questions within each subscale (Cronbach’s alpha range between 0.66 and 0.77).  The EORTC QLQ-AYA30 questionnaire was informed by the experiences of AYAs from different countries, representative of different cancer and treatment types and intent. This new measure provides a comprehensive, acceptable, and reliable assessment of QoL for this unique patient group across different cultures, for use in clinical practice, trials, and research. | | |
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| **63** | **Samantha Sodergren** | **International validation of the EORTC QLQ-ANL27, a health-related quality of life measure specific to patients treated with chemoradiotherapy for anal cancer** |
| The European Organisation for Research and Treatment of Cancer (EORTC) health-related quality of life (HRQoL) questionnaire for anal cancer (QLQ-ANL27) was developed to supplement the core EORTC measure to capture the specific concerns of people with anal cancer treated with chemoradiotherapy (CRT). The QLQ-ANL27 incorporates five multi-item scales to assess bowel symptoms (non-stoma), bowel symptoms (stoma), pain/discomfort, stoma care and vaginal symptoms, as well as nine single items assessing urinary frequency, swelling in legs/ankles, need to be close to toilet, clean yourself more often, planning activities, sex life, sexual interest, painful intercourse and erectile problems. The robust and rigorous development process was informed by the EORTC module development guidelines, with input from existing literature, health care professionals, and, most importantly, patients. This final phase of development tests the psychometric properties of the QLQ-ANL27 and is necessary to present the QLQ-ANL27 as a valid measure.  People with anal cancer were recruited from 15 countries to complete the QLQ-C30 and QLQ-ANL27 and provide feedback on the QLQ-ANL27. Item responses, scale structure and sensitivity of the QLQ-ANL27 were evaluated.  Data from 382 people were included in the analyses. The QLQ-ANL27 was acceptable, comprehensive, and easy to complete. Psychometric analyses supported the EORTC QLQ-ANL27 items and reliability (Cronbach’s alpha ranging from 0.71 to 0.93 and test-retest coefficients above 0.7) and validity of the scales (particularly non stoma bowel symptoms and pain/discomfort). Most scales distinguished people according to treatment phase and performance status. Bowel (non-stoma), pain/discomfort and vaginal symptoms were sensitive to deteriorations over time.  The QLQ-ANL27 has good psychometric properties and is available in 16 languages, for people treated with CRT for anal cancer. It is used in clinical trials and has a potential role in clinical practice. | | |
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| **64** | **Rhiannon Macefield** | **Integrating qualitative work into early-phase studies to optimise PRO measurement in later phase trials: a case study in a Phase II trial of a novel anti-cancer technology** |
| **Background**  Selection of appropriate patient-centred outcomes is a key design feature of Phase III RCTs and critical to help patients understand treatment impact and make informed decisions. Identification of appropriate patient-centred outcomes, however, is particularly challenging in clinical areas where the focus is often on clinical endpoints.  Challenges in selecting outcomes are exacerbated when interventions are innovative. Little is known about the impact of new procedures/treatments on patients' symptoms and quality of life(HRQoL). Qualitative methods provide an opportunity to elicit patients’ experiences of their disease/treatment. Whilst often used in the development of patient-reported outcome measures(PROMs), such methods are infrequently used in early-phase research.  This study aims to explore how integrating qualitative work in early-phase studies can inform and optimise PRO selection for definitive Phase III evaluation of novel treatments.  **Methods**  We present our methodology embedded within a surgical case study of a Phase II trial of a novel anti-cancer technology(Pressurised IntraPeritoneal Aerosolised Chemotherapy; PIPAC). In-depth interviews will explore patients’ symptoms and HRQoL as they undergo PIPAC. Purposeful sampling will ensure insights from a range of patients are explored. Discussions will be led by topic guides, adapted as interviews and analyses progress to enable exploration of emerging findings.  We will investigate if there are unique HRQoL issues experienced by patients undergoing the novel treatment compared to those receiving standard care. Identified PROs of importance arising from interviews will be mapped to existing PROMs to determine whether suitable tools/core outcome sets exist for measuring these outcomes in the future Phase III trial.  **Relevance/Impact**  Findings will inform optimal PRO selection for the future definitive RCT. Using qualitative methods in early phase studies to inform Phase III trial design and PRO measurement is generalisable with potential for improved evaluation of innovations across surgical specialties and diseases. | | |
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| **65** | **Noreen Hopewell-Kelly** | **Non-verbal methods used to assess and explore grief, mental health and wellbeing with children and people with additional learning or communication needs, findings from a scoping review.** |
| **Background**  People experiencing bereavement have varying grief experiences and support-needs. The need for tools that can measure and assess grief in clinical practice and research is recognised. However, the evidence for child-specific tools is lacking, particularly in tools which use non-verbal approaches to support bereaved young children and those with Special Education Needs. We conducted a scoping review to examine and map the key components and transferable features of nonverbal methods being used in therapeutic and research settings, with children aged 11 and under, and older children/adults with additional learning or communication needs.  **Methods**  We conducted a literature search following Arksey and O'Malley's (2005) five-stage framework approach. The search included articles published from inception of the databases to 07 December 2023 (time of search) across CINAHL via Ebsco, Medline via Ovid, PsycINFO via Ovid, Cochrane Library (CDSR and CENTRAL) and Scopus. The findings were analysed using a descriptive statistical analysis and a basic content analysis.  **Findings**  We screened 1589 papers with 22 relevant articles being included in the scoping review.  Five main themes were identified in analysis (1) Development of tools and approaches (2) How the tools work (key verbal and non-verbal features) (3) Visual representation and imagery (4) Response options (5) Effectiveness and performance of the tools.  **Conclusion**  The scoping review provides an overview of the range of approaches that are used in therapeutic and support settings to engage with young people and those with Special Education Needs.  Common features, benefits and limitations are identified, as are the diverse range of people that may benefit from the approaches. This review provides an evidence base on which further developments in this field can be made. | | |
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| **66** | **Noreen Hopewell-Kelly** | **Validating the Children’s Attitude to Grief Scale (CAG): A new approach to assessing grief responses in children and young people.** |
| The need for measures which effectively assess grief in bereaved populations is well recognised. However, there is limited evidence for child-specific measures of grief.  The 9-item Children’s Attitude to Grief (CAG) Scale is adapted from the Adult Attitude to Grief Scale (1) both of which are based on the Range of Response to Loss model (2). The model is made up of three primary constructs (‘overwhelmed’ and ‘controlled’ grief reactions and ‘resilient’ coping responses) which explore how a bereaved person experiences and expresses their grief. The CAG is being used with children aged 7-18, by some bereavement services, including Winston’s Wish.  We are carrying out a two-stage mixed-methods validation study to determine suitability of the scale for use in clinical practice and research/evaluation, following COSMIN guidance (3).  This presentation focuses on the results of the first stage, assessing face and content validity qualitatively.  The original CAG scale was discussed in three focus groups; bereaved young people (n=3); parents of bereaved children (n=3); and professional practitioners (n=10).  The CAG was modified and piloted in 1:1 cognitive interviews with 8 bereaved young people and a practitioner focus group (n=10), then revised and discussed in a final focus group with bereaved young people (n=3).  Participants valued the conversational therapeutic approach of the tool, viewing the constructs and corresponding scale items as relevant and comprehensive. Ambiguity was perceived in some items, and the language considered too complex. Wording was simplified and a new response scale introduced. The final focus group confirmed the scale’s comprehensibility, acceptability and validity, with only minor modifications needed.  The revised CAG is being field-tested with c.250 children and young people receiving bereavement support to assess validity and responsiveness. A pictorial version of the scale for use with young children/ young people with additional learning needs is also being developed. | | |
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| **67** | **Christel McMullan** | **Patient Reported Outcomes Research in Trauma (PRiORiTy): A Feasibility Study of using an electronic PRO platform in a traumatic brain injury clinic.** |
| **Background**  Traumatic brain injury (TBI) is a leading cause of death and disability worldwide. Improvements in clinical management of TBI have resulted in improved survival rates, meaning that more people live with life changing injuries and reduced quality of life (QOL). Electronic assessment of patient-reported outcomes (PROs) post-TBI may facilitate early identification of ongoing issues and shared-decision making and help improve long-term outcomes. This study aims to explore the feasibility of using an electronic PRO (ePRO) system (Aparito Atom5TM) in a clinical setting for patients with a TBI.    **Methods**  Fourteen patients were recruited from a TBI clinic in the West Midlands. They completed four ePROs (TBI QOL, PHQ2, GAD2, PCL2) on a provisioned device in the clinic’s waiting room. Their clinician then reviewed their answers before their appointment. Patients and clinicians involved in the study were interviewed. Data was coded and thematically analysed with NVivo.    **Results**  All patients found the app easy to use and did so without external assistance. Two participants felt anxious about making the clinician wait and completed the questionnaires quickly, expressing a preference for completing them at home. All patients, except one said they would be comfortable downloading and using the app at home. Many participants struggled to understand and answer some of the TBI QOL questions. Clinicians found the platform user-friendly and liked the colour coded answers allowing them to quickly identify patients' issues.    **Conclusion**  Our study demonstrates the potential to capture PROs electronically and display findings in real time for routine clinical practice. It is anticipated that this will increase capacity for trauma-specific knowledge and expertise in relation to PROs, as well as inform system development in other areas of trauma research. Further research is needed to test the feasibility of using the Atom5TM app on their own devices and at home. | | |
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| **68** | **Foram Khatsuria** | **Development and usability testing of the PRO-CAR-T digital system.** |
| **Background and Aim**  Chimeric antigen receptor T-cell (CAR-T) therapies have shown remission for relapsed/refractory haematological malignancies. Despite promising results, understanding of its long-term impact is limited. The study aims to develop PRO-CAR-T™ digital system to record and monitor symptoms and side effects from patients receiving CAR-T therapy. The system has 2 components:   1. A digital application to log symptoms and side effects. 2. A clinician dashboard to facilitate monitoring of patient-reported data.   The usability of system was tested by patients and clinicians for its application in real world setting.  **Methods**  Pilot  Conducted online workshop with study’s PPIE group. Participants tested application, provided feedback on user experience. The recommendations to update were shared with the digital partners Aparito Ltd.  Usability testing  Participants were recruited from Anthony Nolan UK and Queen Elizabeth Hospital Birmingham. Contacted via email and provided consent before participating. Online cognitive interviews were conducted using the “Think Aloud” method, encouraging participants to verbalise their thoughts while navigating the system. Qualitative sessions identified usability strengths, challenges, and areas for improvement. All participants completed the System Usability Scale (SUS) to assess user satisfaction.  **Results**  Pilot – Nine participants (aged >50). Feedback including colour enhancements and clearer instructions were incorporated in update. All the participants found system quite easy to use.  Sixteen participants took part in usability testing. Patients evaluated the application and clinicians evaluated clinician dashboard using the user manual. The patient feedback informed the update of application, and clinician feedback refined the user manual. Satisfaction score for dashboard is 89.5/100 and for application is 85/100.  **Conclusion**  Findings indicate that the PRO-CAR-T system effectively captures patient-reported symptoms via the Atom5™ platform, while the clinician dashboard efficiently accessible using manual. Future development might integrate clinical alerts for critical symptoms and has potential to serve as tool to provide support for patients. | | |
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| **69** | **Nancy Bhardwaj** | **Usability testing of an electronic patient-reported outcome system linked to an electronic chemotherapy prescribing and patient management system for patients with cancer** |
| **Background**  People affected by cancer experience symptoms and treatment toxicities that greatly impact their health-related quality of life (HRQoL). This impact is measured through patient-reported outcomes (PROs), which are questionnaires completed by patients themselves.  Patients’ journeys through cancer treatment are increasingly captured with electronic systems, such as ChemoCare®, an electronic chemotherapy prescribing and patient management system. This study aimed to test the usability of an electronic patient-reported outcome (ePRO) smartphone application (ChemoPRO®) with cancer patients to integrate PROs with ChemoCare® clinical records.  **Methods**  ChemoPRO® was designed to be used by cancer patients to report their symptoms and communicate with their clinical team. One-to-one testing sessions were conducted with people with cancer to understand how users interact with the ChemoPRO® system. A number of suggestions to improve the system were recorded. User satisfaction was assessed using a brief satisfaction questionnaire.  **Results**  Ten people with lived experience of cancer took part in the study. Symptoms and HRQoL measures, including the Euroqol EQ5D5L and the PRO-CTCAETM were included in the ePRO system.  Participants had a mean age of 62.3 years. The study identified a number of enhancements that will be incorporated into the product. Participants liked the simplicity and responsiveness of the patient-facing app and highlighted the potential for communicating with their clinical team. They appreciated being able to view their answers to previous questionnaires, and suggested adding graphs. The overall usability and satisfaction score was high (4.5 out of 5) (sd=0.09).  **Conclusion**  People with cancer found the ChemoPRO® app acceptable and easy to use. Key features that should be developed further is the communication between patients and clinicians and visual representations of patients’ previous answers. This will be explored in a feasibility study, commencing soon in an NHS oncology setting, and which will assess the integration of ChemoPRO® into routine care. | | |
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| **70** | **Aviva Gillman** | **Insights from Industry I: Methodological Challenges Defining Meaningful Change Using the NSAA and PUL in Duchene Muscular Dystrophy** |
| **Background**  What counts as clinically meaningful change in rare disease drug development is an increasingly important requirement by regulators, with thresholds typically defined using anchor and/or distribution-based methods. Less often considered, qualitative research methods can offer valuable insights complementing traditional quantitative methods.  **Aims**  To examine and document the methodological challenges in using qualitative research to assess clinically meaningful change from the patient perspective, based on a recent industry-sponsored study.  **Methods**  We conducted 69 semi-structured qualitative interviews involving individuals with Duchenne Muscular Dystrophy (n=18, aged 14+) and caregivers (n=51) across the US, UK, Canada, and Australia—recruited via patient advocacy groups—to explore clinically meaningful change in two clinician-reported outcome measures: the North Star Ambulatory Assessment (NSAA) and the Performance of Upper Limb (PUL).  **Results**  We defined three broad categories of challenge:   1) Terminology   * The term ‘meaningfulness’ is often difficult for participants to understand and express. * Asking about specific point changes can be leading and introduce bias. * Indirect questions may fail to elicit relevant insights.   2) Variability in perceived change   * What is considered a meaningful change differs by severity level, functional ability, and age. * This variability has implications for sample size and recruitment strategies.   3) Maintenance is meaningful   * Patients often view maintenance of function as equally important as improvement or decline. * This perspective may not align with how treatment benefit is traditionally defined.   Learnings included the importance of generating patient-friendly items to ease completion and reduce burden of debriefing items relating to tasks that participants were no longer able to do.  **Conclusions**  When addressing meaningful change using qualitative data, researchers should be conscious of the methodological challenges to minimize burden on participants, ensure the interpretability of results, and reduce bias. | | |
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| **71** | **Sophie Cleanthous** | **Insights from industry II: Methodological Challenges Defining the Meaningfulness of a legacy ClinRO in Parkinson’s Disease** |
| **Background**  Regulatory guidance emphasizes the need to demonstrate the meaningfulness of clinical outcome assessments (including clinician-reported outcome measures; ClinROs) from the patient perspective, beyond traditional measurement properties such as reliability, validity, and responsiveness.  **Aim**  To reflect on methodological challenges in eliciting patient perspectives on the meaningfulness of a legacy ClinRO, the Movement Disorder Society – Unified Parkinson`s Disease Rating Scale (MDS-UPDRS) Part III items (clinician-rated motor signs) in early-stage Parkinson’s.  **Methods**  Interviews were conducted with individuals with early-stage Parkinson`s (n=78) across US, UK, and Netherlands, including participants from an open-label extension study (PD0055; NCT05543252). Participants discussed the relevance of each item and its perceived meaningfulness which was defined as the extent to which an item is linked/has an impact on an individuals` wider daily life.  **Results**  Two broad challenges emerged:  Item Comprehension & Social Desirability Bias   * Reviewing items crafted for a clinical motor exam with patients (e.g., “pronation/supination” or “finger/toe tapping”) can be unclear or abstract. * Participants` responses may reflect perceived importance to clinicians rather than personal meaningfulness.   Terminology & Analytical Complexity   * Participants rarely use the term “meaningfulness” spontaneously, often substituting with “importance” or “relevance.” * Many described potential rather than current impact on their lives, recognizing that any item/concept could be more meaningful as impairment increases.   **Conclusions**  Evaluating meaningfulness of ClinROs from the patient perspective requires careful methodological planning. Key recommendations include (i) using consistent, accessible terminology (ii) applying an analytical framework to distinguish degrees of perceived meaningfulness, and (iii) supporting comprehension through visual aids. These steps are critical for aligning legacy ClinROs with evolving regulatory patient-centred standards. Although; beyond methodology, what remains to be fully understood is the utility of patient input into the use and interpretation of ClinRO data. This will become clearer with an evolving evidence base.  This work was funded by UCB Biopharma | | |
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| **72** | **Sophie Cleanthous** | **Insights from Industry III: Principles to Guide the Integration of Patient Expert Input into Mixed Methods Research Protocols in PROM Development** |
| **Background**  The integration of qualitative and quantitative evidence in the development of fit-for-purpose patient-reported outcome measures (PROMs) is increasingly recognized as best practice. While recent regulatory guidance encourages meaningful patient engagement, the active involvement of patient experts in PROM development remains limited.  **Aim**  To describe the principles underpinning a mixed methods research (MMR) protocol used in the refinement and validation of two novel PROMs in early-stage Parkinson’s disease (5,6), and to highlight the value of embedding patient expert perspectives throughout this process.  **Methods**  The MMR protocol outlined criteria for synthesizing qualitative insights from multinational interviews with patients and quantitative evidence on measurement properties (primarily from Rasch Measurement Theory analyses) using data from clinical trials and observational studies.  **Results**  The MMR protocol established five core principles to structure integration of patient and clinical expert feedback and quantitative findings on item-level:   * Comprehensiveness – Mapping item coverage to conceptual frameworks and identifying content gaps. * Targeting – Evaluating relevance of items based on alignment with patient experience distribution. * Conceptual Uniqueness – Identifying redundant items and local dependency through both qualitative feedback and statistical analysis. * Item Quality – Addressing clarity issues and misfitting items flagged in psychometric testing. * Response Scale Functionality – Reviewing participant feedback and investigating response category performance.   Patient experts played a key role in synthesizing the evidence, particularly in identifying items requiring refinement due to ambiguity or inconsistency.  **Conclusions**  This MMR protocol is an overarching framework that provides a robust, systematic approach to PROM development detailing principles that facilitate meta-inference on an item-level and an ‘action menu’ that enables stakeholder decision making on PROM development. Including patient experts as equal partners on a multidisciplinary steering committee overseeing the PROM development process resulted in a genuine co-creation PROM development process that has been well-documented and can be used in the future.  This work was funded by UCB Biopharma | | |
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