

UNIVERSITY OF
BIRMINGHAM



CENTRE FOR PATIENT REPORTED OUTCOMES RESEARCH



MAKING PATIENT CENTRED CARE A REALITY

Find out more:

www.birmingham.ac.uk/cpror

Training:

www.birmingham.ac.uk/prolearn

Keep in touch:

CPROR@contacts.bham.ac.uk

 [@CPROR_UoB](https://twitter.com/CPROR_UoB)

FOREWORD FROM CENTRE DIRECTOR PROFESSOR MELANIE CALVERT



At the University of Birmingham Centre for Patient Reported Outcomes Research (CPROR), we believe in putting the patient perspective at the heart of health research and NHS decision-making.

Patient reported outcomes (PROs) provide a systematic way of measuring patients' views about their health and well-being. These data are valued by patients and have potential for many uses within the NHS: at an individual level they may inform patient choice regarding treatment; facilitate cooperation between healthcare teams to provide tailored individual care; and identify those most in need of intervention. At a macro-level PRO data may be used: for audit and quality assurance, to provide long-term safety and effectiveness data for treatments, in pay-for-performance initiatives, in prognostic modeling and to inform health-policy.

Working with international partners CPROR aims to deliver world-class research and education to:

- Optimise the use of PROs in clinical trials and routine care
- Improve service delivery
- Enhance patient care and outcomes

I am delighted to be leading this world-class centre for PROs research on behalf of Birmingham Health Partners, which will make patient centred care a reality.

A handwritten signature in black ink that reads "MJ Calvert".

Melanie Calvert PhD
Professor of Outcomes Methodology
Director Centre for Patient Reported
Outcomes Research

FOREWORD BY **PATIENT PARTNER GARY PRICE**



Four years ago I was diagnosed with a serious illness, in the late stages, with a very low chance of surviving; a long and very intense course of treatment was my only option. So I decided to complete PROs to help me understand how the treatment would affect me. Looking back I know the monitoring really made a difference to my recovery, my healthcare practitioners were able to use my PROs to assess accurately my condition (physically and mentally), thus make the right decisions to keep on with the intense treatment and I could reassure myself that I was doing ok. I'm very pleased and excited to be a member of the CPROR executive and inputting to research that can make a real impact on patient lives.

RESEARCH: 'PROMOTING EXCELLENCE IN PROs RESEARCH'



APPLIED PROs RESEARCH

CPROR members provide methodological expertise across a range of applied health research including:

- Burns, plastics and trauma
- Heart conditions
- Oncology
- Mental health
- Kidney disease

PROs IN TRIALS

- Working with international collaborators to develop best practice for PROs in clinical trials
- Selection of PROs, trial design, minimising missing data, managing PRO Alerts
- Transparent reporting of PRO data to maximise impact and patient benefit

PROs IN ROUTINE PRACTICE

Leading research to develop electronic patient-reported outcome measures (ePROM) systems that:

- Tailor care to individual patient needs
- Aid patient-provider communication and support shared decision-making
- Improve patient activation
- Enhance patient care and outcomes

APPLIED PROs RESEARCH

CPROR members contribute to national and international clinical trials and provide methodological expertise across a wide range of clinical areas within the Birmingham Health Partners (BHP) Institute of Translational Medicine and NIHR infrastructure, such as the NIHR Biomedical Research Centre for Inflammatory Disease and the NIHR Surgical Reconstruction and Microbiology Research Centre.

www.birminghamhealthpartners.co.uk



**LEADING
RESEARCH INTO
BEST PRACTICE
FOR PROs IN
CLINICAL TRIALS
AND HEALTHCARE
RESEARCH**

PROs IN TRIALS

CPROR is working with international collaborators to develop best practice for PROs in clinical trials. This includes PRO selection, trial design (including leading the development of the SPIRIT-PRO extension), minimising missing data, managing PRO alerts, analysis of PRO data (contributing to the EORTC led SISAQOL project) and the transparent reporting of PRO data using CONSORT-PRO to maximise impact and patient benefit.

Selection of
measures

Trial design:
SPIRIT-PRO

In-trial
practices:
PRO Alerts

Analysis
of PRO data:
SISAQOL



BUILDING CAPACITY
‘FOR APPLIED
AND METHODOLOGICAL
RESEARCH TO EVALUATE
PROs USE IN CLINICAL
TRIALS, ROUTINE CARE
AND AS PART OF
“BIG-DATA”.’

Reporting:
CONSORT-PRO
Extension

Clinical
and policy
guidelines

High quality
evidence to
inform patient-
centred care

PROs IN ROUTINE PRACTICE

CPROR members are leading research in collaboration with the award-winning health informatics team at University Hospitals Birmingham NHS Foundation Trust and the Institute of Transitional Medicine to develop groundbreaking electronic patient reported outcome measure (ePROM) systems. ePROMs will improve communication between patients and their doctors, facilitate shared decision-making and help clinicians to more accurately tailor care to individual patient needs.






CASE STUDY

Dr Derek Kyte (NIHR Fellow) and Dr Olalekan Aiyegbusi (Health Foundation-funded Doctoral Researcher) are currently conducting a groundbreaking £0.75m translational research project, which will embed an ePROM system, designed in collaboration with patient partners, into the care pathway of patients with advanced chronic kidney disease.

'INTEGRATING PROs INTO ROUTINE CLINICAL CARE'

TRAINING AND EDUCATION

CPROR provides PRO education and training for clinicians, patients and researchers through online learning resources, CPD workshops and supervision of undergraduate and postgraduate students.



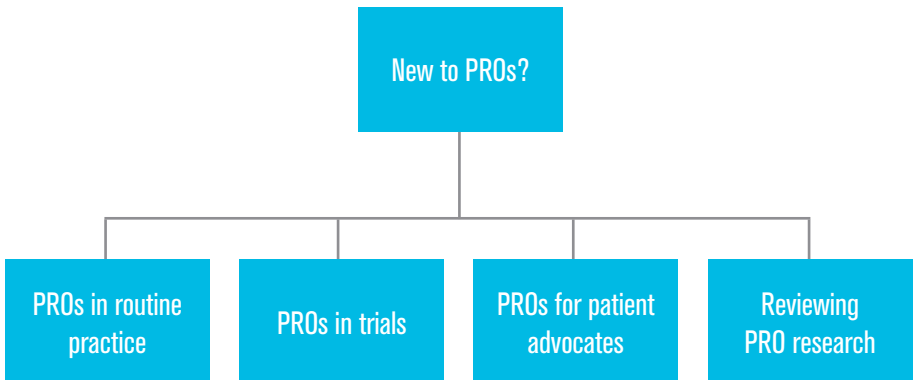
**PROVIDING
PRO TRAINING TO
ENSURE THE PATIENTS
VOICE IS AT THE HEART
OF RESEARCH AND
CLINICAL PRACTICE**



**PROLEARN IS
OUR FREELY ACCESSIBLE
INFORMATION RESOURCE
FOR PATIENTS, CLINICIANS
AND RESEARCHERS
WISHING TO FIND OUT
MORE ABOUT PROs**

Funded by
NIHR Clinical Research Network:
West Midlands

Topics covered



PROLEARNING FOR THE FUTURE
BIRMINGHAM.AC.UK/PROLEARN

GLOBAL COLLABORATION WITH:

- Patient partners
- Clinicians
- Journal editors
- Funders
- Charities
- Trials units
- Regulators
- Ethicists
- Methodologists
- International societies
- Industry

MULTIDISCIPLINARY TEAM COMPRISING MEMBERS FROM BIRMINGHAM HEALTH PARTNERS (BHP) A STRATEGIC ALLIANCE BETWEEN:

- University of Birmingham (UoB)
- University Hospitals Birmingham NHS Foundation Trust (UHB)
- Birmingham Children's Hospital (BCH)
- Birmingham Women's Hospital (BWH)

In collaboration with primary and social care

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