

# The Oxford Participation & Activities Questionnaire (Ox-PAQ): Abstracts to Date



**Abstract # 1:** Presented at the 21st World Congress of Neurology, Vienna, Austria.

**Reference:** Morley, D., Dummett, S., Kelly, L., Dawson, J., Fitzpatrick, R., Jenkinson, C. (2013). Development of the Oxford Participation & Activities Questionnaire: Semi Structured Interviews with Potential Users. *Journal of the Neurological Sciences*, Vol. 333 (Supplement 1), e651.

**Background:** There is growing interest in the management of long term conditions and maximising the cost effectiveness of treatment, in part by keeping people active and participating in the community. The Oxford Participation and Activities Questionnaire (Ox-PAQ) initiative aims to develop and validate a patient reported outcome measure (PROM) for the assessment of participation and activity in patients experiencing a range of health conditions.

**Objective:** To gain the views of a variety of professionals on current PROMs and discuss the challenges and possible future developments that this area might face. Such views would be used to inform the on-going development of the Ox-PAQ.

**Methods:** Fifteen participants from across Europe with a range of expertise including regulation, commissioning, health economics, reimbursement, clinical practice, academic research, government and clinical trials, took part in semi-structured interviews.

**Results:** A range of views were expressed in relation to the appropriate length of PROMs, presentation of PROM data, use of PROM data and utility measurement. There was general agreement that existing measures have a number of limitations, including difficulty in interpretation, poor sensitivity to change and limited coverage across domains of health.

**Conclusion:** There is significant diversity in professionals' views of PROMs. This is largely, but not exclusively, explained by the background of the individual whose views are being expressed. Developing an instrument such as the Ox-PAQ may benefit from such input, whilst at the same time recognising that a 'one size fits all' approach is unlikely to be successful.

**Abstract # 2:** Presented at the 20<sup>th</sup> Annual Conference of the International Society for Quality of Life Research, Miami, USA.

**Reference:** Kelly, L., Dummett, S., Dawson, J., Fitzpatrick, R., Jenkinson, C., Morley, D. (2013). Development & Validation of the Oxford Participation & Activities Questionnaire: Exploring the Views of Relevant Stakeholders. *Quality of Life Research*, 22(S1), 119-120.

**Aims:** There is growing interest in the management of long term conditions and maximising the cost effectiveness of treatment, in part by keeping people active and participating in the community. The Oxford Participation and Activities Questionnaire (Ox-PAQ) initiative aims to develop and validate a patient reported outcome measure (PROM) for the assessment of participation and activity in patients experiencing a range of health conditions. An initial component of the project was to gain the views of a variety of professionals on current PROMs and discuss the challenges and possible future developments that this area might face. Such views would be used to inform the on-going development of the Ox-PAQ.

**Methods:** Fifteen participants from across Europe with a range of expertise including regulation, commissioning, health economics, reimbursement, clinical practice, academic research, government and clinical trials, took part in semi-structured interviews. Interviews were recorded and subsequently transcribed for analysis.

**Results:** A range of views were expressed in relation to the appropriate length of PROMs, presentation of PROM data, use of PROM data and utility measurement. There was general agreement that existing measures have a number of limitations, including difficulty in interpretation, poor sensitivity to change and limited coverage across domains of health.

**Conclusions:** There is significant diversity in professionals' views of PROMs. This is largely, but not exclusively, explained by the background of the individual whose views are being expressed. Developing an instrument such as the Ox-PAQ may benefit from such input, whilst at the same time recognising that a 'one size fits all' approach is unlikely to be successful.

**Abstract # 3:** Presented at the 18th International Congress of Parkinson's Disease & Movement Disorders, Stockholm, Sweden.

**Reference:** Morley, D., Dummett, S., Kelly, L., Dawson, J., Fitzpatrick, R., Jenkinson, C. (2014). Development of the Oxford Participation & Activities Questionnaire: Exploring the Views of Relevant Professionals. *Movement Disorders* 29(Suppl.1), S179.

**Objective:** To gain the views of a variety of professionals on current patient reported outcome measures (PROMs) and discuss the challenges and possible future developments that this area might face. Such views will be used to inform the on-going development of a new measure, the Oxford Participation and Activities Questionnaire (Ox-PAQ).

**Background:** There is growing interest in the management of long term conditions and maximising the cost effectiveness of treatment, in part by keeping people active and participating in daily life. The Ox-PAQ initiative aims to develop and validate a PROM for the assessment of participation and activity in patients experiencing a range of health conditions including Parkinson's disease, multiple sclerosis, motor neurone disease, cancer, diabetes, osteoarthritis, spinal cord injury and chronic back pain.

**Methods:** Eighteen participants from across Europe with a range of expertise including regulation, commissioning, health economics, reimbursement, clinical practice, academic research, government, clinical trials and nursing took part in semi-structured interviews. Interviews were recorded and subsequently transcribed for analysis.

**Results:** A range of views were expressed in relation to the appropriate length of PROMs, presentation of PROM data, use of PROM data and utility measurement. There was general agreement that existing measures have a number of limitations, including difficulty in interpretation, poor sensitivity to change and limited coverage across domains of health.

**Conclusions:** There is significant diversity in professionals' views of PROMs. This is largely, but not exclusively, explained by the background of the individual whose views are being expressed. Developing an instrument such as the Ox-PAQ may benefit from such input, whilst at the same time recognising that a 'one size fits all' approach is unlikely to be successful.

**Abstract # 4:** Presented at the 21<sup>st</sup> Annual Conference of the International Society for Quality of Life Research, Berlin, Germany.

**Reference:** Kelly, L., Dummett, S., Dawson, J., Fitzpatrick, R., Jenkinson, C., Morley, D. (2014). Generating items for the Oxford Participation and Activities Questionnaire (Ox-PAQ). *Quality of Life Research* 23(S1), 81-82.

**Aims:** To generate items for a new patient reported outcome measure: the Oxford Participation and Activities Questionnaire (Ox-PAQ). Grounded in the World Health Organisation International Classification of Functioning, Disability and Health (ICF), the Ox-PAQ is specifically designed for the assessment of participation and activity in patients experiencing a range of health conditions.

**Methods:** Semi-structured interviews were conducted with 41 participants spanning a range of conditions to identify how their condition impacted on their ability and desire to participate in meaningful activities. Participants were recruited via a number of charitable support organisations representing conditions including arthritis, cancer, chronic back pain, diabetes, motor neurone disease, multiple sclerosis, Parkinson's disease and spinal cord injury. Transcripts were analysed using the Framework method.

**Results:** Key themes relevant to participation in everyday life were identified and informed an initial pool of 222 items. This item pool was refined by the research team to retain 95 generic items. Items were mapped onto all nine chapters of the ICF construct detailing activity and participation.

**Conclusions:** Using a clear conceptual basis to inform item generation, 95 candidate items have been produced that are currently undergoing expert and patient review. A large-scale postal survey will follow in order to refine the instrument further and to assess its psychometric properties. The final instrument is intended for use in clinical trials and interventions targeted at maintaining or improving activity and participation.

**Abstract # 5:** Presented at the 19th International Congress of Parkinson's Disease & Movement Disorders, San Diego, USA.

**Reference:** Morley, D., Dummett, S., Kelly, L., Dawson, J., Fitzpatrick, R., Jenkinson, C. (2015). Pretesting the Oxford Participation and Activities Questionnaire: results from an expert review. *Movement Disorders*, 30(S1), S419.

**Objective:** To pretest a new measure, the Oxford Participation and Activities Questionnaire (Ox-PAQ), through views gained from an expert panel on a preliminary 24-item draft.

**Background:** There is growing interest in the management of long term conditions and maximising the cost effectiveness of treatment, in part by keeping people active and participating in daily life. The Ox-PAQ initiative aims to develop and validate a PROM to assess participation and activity in people experiencing a range of health conditions including Parkinson's disease, multiple sclerosis, motor neurone disease, cancer, diabetes, osteoarthritis, spinal cord injury and chronic back pain.

**Methods:** The Ox-PAQ was reviewed by an expert panel of 11 participants with a broad range of expertise, including clinical practice, academia, health economics and health technology assessment. Panel responses were analysed and adjustments based on relevance, concurrence between participants and methodological appropriateness were subsequently made.

**Results:** The review resulted in minor changes to the format and wording of six items. Two new items relating to pain and close relationships (e.g. with parents, carers, spouse, children) were added. One item relating to personal care (washing and dressing) was separated into two items. These adjustments resulted in a 27-item draft questionnaire.

**Conclusions:** Expert review of the Ox-PAQ constitutes an important first phase in pretesting the new measure. This will now be followed by a series of cognitive interviews to further pretest the instrument prior to a large scale validation survey.

**Abstract # 6:** Presented at the 22<sup>nd</sup> World Congress of Neurology, Santiago, Chile

**Reference:** Kelly, L., Dummett, S., Dawson, J., Fitzpatrick, R., Jenkinson, C., Morley, D. (2015). Psychometric evaluation of the Oxford Participation & Activities Questionnaire (Ox-PAQ). *Journal of the Neurological Sciences*, 357(S1), e273.

**Background:** There is growing interest in the management of long term conditions and keeping people active and participating in the community. Testing the effectiveness of interventions which aim to impact upon activities and participation, however, can be challenging without the availability of a well-developed, valid and reliable instrument.

**Objective:** To develop a fully FDA compliant patient reported outcome measure, the Oxford Participation and Activities Questionnaire (Ox-PAQ), theoretically grounded in the World Health Organisation International Classification of Functioning, Disability and Health (ICF).

**Material and Methods:** Questionnaire items generated from patient interviews and based on the nine chapters of the ICF were administered by postal survey to 386 people with three neurological conditions; Parkinson's disease, amyotrophic lateral sclerosis, and multiple sclerosis. Participants also completed the MOS 36-Item Short Form Survey (SF-36) and EQ-5D-5L.

**Results:** 334 participants completed the survey, a response rate of 86.5%. Factor analytic techniques identified 3 Ox-PAQ domains, consisting of 23 items, accounting for 72.8% of variance. Internal reliability for the 3 domains was high (Cronbach's  $\alpha$  .84-.96), as was test-retest reliability (intra-class correlation .81-.96). Concurrent validity was demonstrated through highly significant relationships with relevant domains of the SF-36 and the EQ-5D-5L.

**Conclusion:** Preliminary results suggest that the Ox-PAQ is a short, valid and reliable measure of participation and activity. The measure will now be validated in a range of further conditions and additional properties, such as sensitivity to change and predictive validity, will also be assessed in the next phase of the instrument's development.

**Abstract # 7:** Presented at the 18th Annual European Congress of the International Society for Pharmacoeconomics & Outcomes Research (ISPOR), Milan, Italy.

**Reference:** Morley, D., Dummett, S., Dawson, J., Fitzpatrick, R., Churchman, D.R., Kelly, L., Jenkinson, C. (2015). The Oxford Participation & Activities Questionnaire (Ox-PAQ): Psychometric Analysis. *Value in Health*, 18(7), A742.

**Objectives:** There is growing interest in the management of long term conditions and keeping people active and participating in the community. Testing the effectiveness of interventions which aim to impact upon activities and participation, however, can be challenging without the availability of a well-developed, valid and reliable instrument. The objective of this study was to develop and validate a fully FDA compliant patient reported outcome measure, the Oxford Participation and Activities Questionnaire (Ox-PAQ), theoretically grounded in the World Health Organisation International Classification of Functioning, Disability and Health (ICF).

**Methods:** Questionnaire items generated from patient interviews and based on the nine chapters of the ICF were administered by postal survey to 386 people with three neurological conditions; Parkinson's disease, amyotrophic lateral sclerosis, and multiple sclerosis. Participants also completed the MOS 36-Item Short Form Survey (SF-36) and EQ-5D-5L.

**Results:** 334 participants completed the survey, a response rate of 86.5%. Factor analytic techniques identified 3 domains, consisting of 23 items, accounting for 72.8% of variance. Internal reliability for the 3 domains was high (Cronbach's  $\alpha$  .84-.96), as was test-retest reliability (intra-class correlation .81-.96). Concurrent validity was demonstrated through highly significant relationships with relevant domains of the SF-36 and the EQ-5D-5L.

**Conclusion:** Preliminary results suggest that the Ox-PAQ is a short, valid and reliable measure of participation and activity. The measure will now be validated in a range of further conditions and additional properties, such as sensitivity to change and predictive validity, will also be assessed in the next phase of the instrument's development.