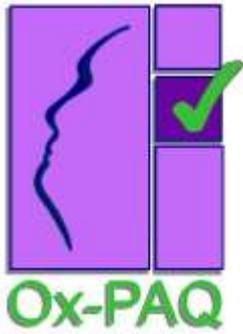


The Oxford Participation & Activities Questionnaire (Ox-PAQ): Abstracts to Date



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 20th 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 21st 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 22nd 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 α .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 α .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 # 8: Presented at the 2nd Congress of the European Academy of Neurology (EAN), Copenhagen, Denmark.

Reference: Morley, D., Kelly, L., Dummett, S., Dawson, J., Fitzpatrick, R., Jenkinson, C. (2016). Comparing the functioning and well-being of people with motor neurone disease, multiple sclerosis and Parkinson's disease. *European Journal of Neurology*, 23 (Suppl. 1), 676.

Background: Comparisons between neurological conditions have the potential to inform service providers by identifying particular areas of difficulty experienced by affected individuals. This study aimed to assess and compare the functioning and well-being of people with motor neurone disease (PwMND), multiple sclerosis (PwMS) and Parkinson's (PwP).

Methods: The Oxford Participation & Activities Questionnaire (Ox-PAQ) and MOS 36-Item Short Form Survey (SF-36) were administered by postal survey to 386 people with a confirmed diagnosis of MS, MND or Parkinson's.

Results: 334 participants completed the survey, a response rate of 86.5%. One-way analysis of variance and Tukey post-hoc tests identified significant differences in all three Ox-PAQ domain scores, with PwMND reporting significantly inferior scores compared to PwMS and PwP. Significant differences were also evident in six of the eight domains of health incorporated in the SF-36. Results for each domain followed a largely similar pattern, with PwMND most affected by their condition, followed by PwMS, with PwP reporting the least impact in comparative terms. Non-significant differences were observed in domains assessing emotional well-being and pain.

Conclusion: Given the clinical characteristics of the three conditions assessed, reported differences follow a largely intuitive pattern and serve to highlight the overwhelming impact of MND. However, that some of the impacts are common to all three conditions may be of most interest to clinicians and service-providers. These results emphasise the severe emotional difficulties and pain experienced by PwMND, PwMS and PwP, and underline the need for their recognition and effective clinical management in all three conditions.

Abstract # 9: Presented at the 23rd Annual Conference of the International Society for Quality of Life Research (ISOQOL), Copenhagen, Denmark.

Reference: Kelly, L., Dummett, S., Dawson, J., Fitzpatrick, R., Jenkinson, C., Morley, D. (2016). Use of the Routine Activities Domain of the Oxford Participation & Activities Questionnaire (Ox-PAQ). *Quality of Life Research*, 25(S1), 106.

Objectives: The Oxford Participation & Activities Questionnaire (Ox-PAQ) is a 23-item patient-reported outcome measure, theoretically grounded in the World Health Organisation International Classification of Functioning, Disability and Health. The measure is specifically designed for the assessment of participation and activity in people experiencing a range of health conditions. Initial validation of the Ox-PAQ identified three domains; Routine Activities (14-items), Emotional Well-Being (5 items) and Social Engagement (4 items). The purpose of the analysis reported here was to assess whether the Ox-PAQ domain of Routine Activities (Ox-PAQ-RA) could be used as a stand-alone measure without compromising its psychometric integrity.

Methods: Data from the 334 respondents of the initial Ox-PAQ validation survey formed the basis of the analysis. The 14 items of the Ox-PAQ-RA were subject to factor analytic techniques using SPSS Version 20.

Results: The fourteen items of the Ox-PAQ-RA loaded onto one single factor with an eigenvalue of 9.41 explaining 67.21% of variance. Factor loadings ranged from .89 to .64. Previous analyses suggest that the Ox-PAQ-RA is highly reliable (Cronbach's alpha .96; intra-class correlation .92) and valid (concurrent and known-groups).

Conclusion: Results indicate that the Ox-PAQ-RA can be legitimately incorporated as a stand-alone measure where researchers wish to focus primarily on the activity component of the Ox-PAQ. It should be emphasised, however, that where a full assessment of all areas of activity and participation highlighted as important to respondents during the development of the Ox-PAQ, all three domains of the measure should be administered.

Abstract # 10: Presented at the 19th Annual European Congress of the International Society for Pharmacoeconomics & Outcomes Research (ISPOR), Vienna, Austria.

Reference: Kelly, L., Dummett, S., Dawson, J., Churchman, D., Fitzpatrick, R., Jenkinson, C., Morley, D. (2016). Pretesting an e-based version of the Oxford Participation and Activities Questionnaire (Ox-PAQ). *Value in Health*, 19 (7), A485.

Objectives: The Oxford Participation & Activities Questionnaire (Ox-PAQ) is a new patient-reported outcome measure, theoretically grounded in the World Health Organisation International Classification of Functioning, Disability and Health. The measure is specifically designed for the assessment of participation and activity in patients experiencing a range of health conditions. Initial validation of the Ox-PAQ was based on a paper-based postal survey. The objective of this study was to pretest an e-based version of the measure for use on a range of electronic devices.

Methods: Cognitive interviews with people with multiple sclerosis (MS) and Parkinson's disease (PD) were conducted to assess the usability and acceptability of the e-based Ox-PAQ. Participants completed the measure in the presence of a researcher who noted any potential difficulties which were discussed both during and after the interview. Participants were recruited via the MS Society and Parkinson's UK.

Results: Six participants, four with MS and two with PD, completed the e-based Ox-PAQ. Two completed the measure on a personal computer, two on an i-pad and two on a laptop. During the interview process two adjustments were made. Firstly, the progress bar that allows respondents to track their survey progress was moved to a more prominent position on the screen. Secondly, font colours were adjusted from red to green to indicate acceptance of information and consent statements. Participant comments were largely positive regarding presentation, ease of completion and time taken to complete the measure.

Conclusion: The e-based Ox-PAQ appears both usable and acceptable to participants on a range of electronic devices. It is currently being incorporated in a large-scale online survey to assess the responsiveness of the measure.

Abstract # 11: Accepted for presentation at the 20th Annual European Congress of the International Society for Pharmacoeconomics & Outcomes Research (ISPOR), Barcelona, Spain.

Reference: Morley, D., Dummett, S., Kelly, L., Jenkinson, C. (2018). Measuring improvement in health-status with the Oxford Participation and Activities Questionnaire. *Value in Health*, In Press.

Objectives: To make a preliminary assessment of the sensitivity to change of the Oxford Participation and Activities Questionnaire (OX-PAQ). The Ox-PAQ is a recently validated 23-item generic patient reported outcome measure that is theoretically grounded in the World Health Organisation International Classification of Functioning, Disability and Health (ICF), as well as fully FDA compliant. The measure is comprised of three domains, Routine Activities (14-items), Emotional Well-Being (5 items) and Social Engagement (4 items), and has been shown to be both valid and reliable.

Methods: Three hundred and seventy three people with chronic pulmonary obstructive disease, motor neurone disease, multiple sclerosis or Parkinson's disease completed the Ox-PAQ electronically on two occasions, six months apart. Participants completed an additional four questions during the second administration of the Ox-PAQ in order to assess any relevant changes since baseline. For each of the three Ox-PAQ domains the minimally important difference (MID) and effect size (ES) was calculated from those participants indicating small, but meaningful positive improvement.

Results: Participants who completed the Ox-PAQ on both occasions and with no missing data for at least one Ox-PAQ domain were entered into the final analysis, equating to two hundred and ninety respondents (77.74% of the original sample). For those indicating 'slight improvement' in Routine Activities (n=19) an MID of 7.51 and an ES of 0.32 was calculated. For Emotional Well-Being (n=26) the MID was 10.77 and the ES 0.44. For Social Engagement (n=16) the MID was 5.47 and the ES 0.28.

Conclusions: Data presented provides MID improvement and effect sizes for Ox-PAQ domains that will act as preliminary guidance for those powering clinical trials assessing activity and participation. Future research with larger samples will provide further sensitivity to change data for the Ox-PAQ.