

Ox-PAQ Update: The quarterly newsletter of the Ox-PAQ Initiative

Welcome to the fifth edition of *Ox-PAQ Update*. News from the last three months is given below:

- A first draft of the Ox-PAQ was finalised at the beginning of May. The draft was subject to significant scrutiny over a number of meetings of the research team and resulted in an initial questionnaire of 24 items.
- This draft has now been reviewed by an expert panel of 11 participants. The panel was made up of a broad range of practitioners and academics and resulted in some minor changes to the wording of items and the addition of 3 new questions. As a result, the Ox-PAQ now stands as a 27 item draft.
- A series of cognitive interviews to pre-test the Ox-PAQ are currently in progress. It is anticipated that approximately 14-16 interviews will be undertaken. The interviews are being conducted with people experiencing the same range of conditions as in the patient interview phase.
- A translatability assessment of the draft Ox-PAQ is currently being arranged. This will be conducted by PharmaQuest during the months of July and August. Proposed languages to be translated include Afrikaans, Arabic, Finnish, French, German, Greek, Hindi, Russian, Chinese and Spanish.
- All of our supporting organisations have now agreed strategies for recruiting participants for the survey phase of the project. These include the use of social media, websites, print and electronic publications, research bulletin boards and invitation by email. We are, as ever, hugely grateful to the following organisations for their support: Floura Health Care, Macmillan Cancer, MND Association, MS Society, Spinal Injuries Association, and Parkinson's UK.
- Our first Ox-PAQ abstract of 2014 was recently presented at the 18th International Congress of Parkinson's Disease & Movement Disorders, which was held in Stockholm, Sweden. The abstract has been published in the journal *Movement Disorders* and can be viewed at the following link:

<http://onlinelibrary.wiley.com/doi/10.1002/mds.v29.S1/issuetoc>

The full reference for the abstract is as follows:

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.

- Our second abstract of 2014 has been accepted for presentation at the 21st Annual Conference of the International Society for Quality of Life Research. This will take place in Berlin, Germany in October. The abstract will be published in the journal *Quality of Life Research* and the full reference and link will be provided in due course.
- Just a reminder that all documentation related to the project can be found at <http://www.dph.ox.ac.uk/research/hsru/OxPAQ>

That completes our fifth newsletter. We would, as always, be grateful for any feedback you might have. The next edition of *Ox-PAQ Update* will be circulated at the end of September.

Please email David (david.morley@dph.ox.ac.uk) or Crispin (crispin.jenkinson@dph.ox.ac.uk) if you have any specific questions or suggestions regarding the project.

Kind regards to all,

The Ox-PAQ Team, 30th June 2014.

