



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

Welcome to the first edition of *Ox-PAQ Update*. Since we met back in March at the Sofitel Hotel Heathrow Airport, the project has made significant headway as outlined below:

- Full ethical approval for the Ox-PAQ initiative was received from the Medical Sciences Inter Divisional Research Ethics Committee of the University of Oxford on 27-03-13, the very day after our meeting in London in March.
- We now have a dedicated Ox-PAQ link on the Health Services Research Unit website here at Oxford. All documentation related to the project can be found at <http://www.dph.ox.ac.uk/research/hsru/OxPAQ>
- Our interviews with stakeholders are now complete with a total of eighteen having been conducted across Europe. The interviews took place in five different countries, with participants from eight nationalities across eleven areas of expertise. Each interview will now be transcribed with a view to disseminating the results through conference presentations and possibly a short-paper.
- A conference abstract has been accepted for poster presentation at the 21st World Congress of Neurology, which will take place in Vienna, Austria from 21st-26th September 2013. It is anticipated that the abstract will be published in a supplement of the *Journal of the Neurological Sciences*, although this is yet to be confirmed.
- A second conference abstract has been accepted for poster presentation at the 20th Annual Conference of the International Society for Quality of Life Research, which will take place in Miami, USA, from 9th-12th October 2013. The abstract will be published in a supplement of the journal *Quality of Life Research*.
- A protocol manuscript entitled 'Development & Validation of the Oxford Participation & Activities Questionnaire: The Ox-PAQ Initiative' has been drafted and is currently being reviewed by the Oxford team. The manuscript will be submitted to the open access journal *Health & Quality of Life Outcomes* in July.

- The Ox-PAQ team here at Oxford met on 14th June and discussed a number of issues. Most important of these was to confirm those patient groups with whom we intend to develop the items of the Ox-PAQ via patient interviews. Subsequently, recruitment of patients through relevant support groups from the following conditions will begin shortly: arthritis, cancer, diabetes, motor neurone disease, multiple sclerosis, Parkinson's disease and spinal cord injury. Many thanks to those who contributed to deciding on these. It may be that one or two additional conditions might be added during the interview process.
- As you may be aware, our next meeting has been arranged for 21st November with a venue to be confirmed. We very much look forward to seeing you there.

That completes our first newsletter. We would be grateful for any feedback you might have (i.e. content, format), as this will help with future newsletters. The next edition of *Ox-PAQ Update* will be circulated at the end of September.

Please do 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.

Regards to everybody,

The Ox-PAQ Team, 28th June 2013.

