



Health Services Research Unit Nuffield Department of Population Health

New Richards Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel: +44 (0)1865 289447
email: OXPAQ@dph.ox.ac.uk

The Oxford Participation and Activities Questionnaire (Ox-PAQ): a summary for participants

The Ox-PAQ project commenced in December 2012 at the University of Oxford. The team at Oxford began by reviewing previous research into the area of activity and participation. We also approached a number of potential users of a questionnaire (e.g. health-care professionals and academic researchers) to find out what would be most useful for them. Both of these avenues helped to shape and guide the way in which the project would proceed.

We then conducted 41 interviews with people experiencing one of a number of medical conditions, including Parkinson's disease, multiple sclerosis, motor neurone disease, arthritis, back pain, cancer and diabetes. The purpose of these interviews was to explore how these conditions affect people's ability to engage in activities of daily life. The things people told us in the interviews formed the basis for questions that were subsequently drawn up by the team at Oxford. This resulted in a draft questionnaire containing 24 questions.

The next stage in the process was to ask a number of health professionals and researchers what they thought of our questions. Eleven participants took part in this exercise and following their input we had 28 questions for our draft questionnaire. This was then shown to a number of people who took part in interviews in order to check that all the questions were both relevant and easy to understand. Thirteen people helped with this process.

Now our draft needed to be tested with a large group of people, so that we could establish what the underlying characteristics of the questionnaire were. This was done through a postal survey. You were one of the 365 people to take part in the Ox-PAQ survey. We had an excellent mix of people. For example, there was roughly an even split of men and women, with ages ranging from 24 to 88 years old. Some people had only recently been diagnosed, others had lived with their condition for up to 50 years.

The results from the survey allowed us to do some important data analysis which highlighted broad themes covered by responses to the questions asked. Our analysis also identified five questions that were not particularly helpful. These five questions were therefore dropped from the original 28, resulting in 23 questions being retained in the final questionnaire.

Our next aim is to transfer the questionnaire to an electronic format, so that future surveys can be conducted using technology such as smart phones, computers and tablets. A number of participants in the Ox-PAQ survey explicitly asked if they could complete the survey online, and this next phase will make this option possible.

We would like to thank the hundreds of people who helped us in this research. Without you none of this would have been possible. We would also like to thank our sponsors, the European Brain Council, and the patient support groups who so readily assisted us in advertising this research and finding people to take part.

The Ox-PAQ Team, June 2015