



Health Services Research Unit

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The Oxford Participation & Activities Questionnaire (Ox-PAQ): REQUEST FOR PARTICIPANTS TO TAKE PART IN AN ONLINE SURVEY

Researchers in the Health Services Research Unit (HSRU) at the University of Oxford are looking for people to complete a short e-based survey. Participants will be asked to complete a brief questionnaire related to participation and activity in their daily life, using their PC, laptop, tablet computer or smart phone.

The British Lung Foundation (BLF), Motor Neurone Disease (MND) Association, Multiple Sclerosis (MS) Society and Parkinson's UK have agreed to share information about the survey with their members. We are asking approximately 100 people with COPD, 100 people with MND, 100 people with MS and 100 people with Parkinson's disease (PD) to take part. If having read this information about the survey you wish to participate please follow the link given at the end of this information sheet.

What is the purpose of the study?

The Oxford Participation and Activities Questionnaire (Ox-PAQ) has been developed to measure the effects of health on participation, activities and independence in daily life. An electronic form of the questionnaire has also been developed, and an online survey is being conducted to test the measure with different groups of people.

Why have I been asked to take part in the study?

You are being approached because you are a member of one of the organisations helping to promote the online survey. We are asking approximately 400 English-speaking adults (aged 18 and over) living in the UK, with one of the conditions mentioned above, who use the internet, to complete the questionnaire using their PC, laptop, tablet computer or smart phone.

Do I have to take part?

You do not have to take part in the online survey. Participation is voluntary and it is entirely up to you to choose whether or not to take part. You can contact the research team to ask any questions you have before deciding. You can choose not to take part and are free to withdraw at any point, without giving a reason. There is no penalty associated with withdrawing from the survey.

What will taking part involve?

You will be asked to complete the online questionnaire on two occasions, 6 months apart. To take part in the online survey, click on the link at the end of this information sheet to provide the research team with your email address. You will be sent an email containing a link to access the online questionnaire. Your email address will be retained in order to contact you again in 6 months' time. By providing your email address you agree that it will be retained by the research team for contact in 6 months, after which it will be destroyed. Instructions are given at the start of the questionnaire and it is likely to take you 10-20 minutes to answer the 30 questions. You will answer questions by clicking on the appropriate response button. Two or three additional questions will be included in the second questionnaire that you will complete 6 months later. A

link for this will be emailed to you automatically 6 months after you complete the first questionnaire. This is to help us understand whether or not the questionnaire is able to pick up any apparent changes in your daily activities and participation.

What happens to the research data provided?

If you take part, all the information you give will be anonymised and will be treated in complete confidence. Data will be collected using secure survey software and stored in a secure, password protected file and will only be used as part of this study. It will only be accessed by members of the research team and will be destroyed after a period of 10 years.

What are the benefits of taking part?

By taking part you will be helping the researchers to determine whether or not the Ox-PAQ can assess changes in people's levels of activity and participation.

What are the possible disadvantages or risks of taking part?

We have tried to ensure the questionnaire is as simple as possible so you do not spend more time than necessary completing it. Completing the survey is likely to take around 10 to 20 minutes of your time. There are no risks involved. However, if you feel that issues have been brought up that need to be addressed you should contact your GP or healthcare provider at the earliest possible moment, and in the first instance telephone NHS Direct on 111.

How do I raise concerns or make a complaint?

If you have a concern about any aspect of this project, please speak to the relevant researcher (Dr David Morley, telephone 01865 289432) who will do his best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how he intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner.

Who is organising and funding the project?

The project is co-funded by the European Brain Council and Actelion Pharmaceuticals. It will be organised from the Health Services Research Unit (HSRU), Nuffield Department of Population Health, University of Oxford. The members of the research team at the HSRU are Professor Crispin Jenkinson, Dr David Morley, Dr Laura Kelly, Mrs Sarah Dummett, Dr Jill Dawson and Professor Ray Fitzpatrick.

You will be able to find the results of this research online at <http://www.ndph.ox.ac.uk/research/health-services-research-unit-hsr> in addition to them being published in academic journals. The project has been reviewed by and received clearance through the University of Oxford Central Research Ethics Committee (reference number MS-IDREC- R44281/RE001).

If you wish to discuss this research, please email:

Sarah Dummett, Research Assistant or Dr David Morley, Senior Research Scientist:
oxpaq@dph.ox.ac.uk

TO TAKE PART, [PLEASE CLICK ON THIS LINK](#) AND PROVIDE YOUR EMAIL ADDRESS