



Health Services Research Unit

Nuffield Department of Population Health

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The Oxford Participation and Activities Questionnaire Initiative (Ox-PAQ)

YOU ARE INVITED TO TAKE PART IN A SURVEY OF A NEW MEASURE TO ASSESS THE IMPACT OF HEALTH ON PARTICIPATION, ACTIVITIES AND PARTICIPATION IN DAILY LIFE.

What is the purpose of the survey?

Researchers at The Health Services Research Unit (HSRU) at Oxford University are developing a questionnaire that measures the effects of ill-health on participation, activities and level of independence in every day life. We are looking for people to take part in a postal survey. The survey will require you to complete a questionnaire booklet and return it to the researchers in a prepaid envelope.

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

You have been approached because you are a member of a healthcare charity which is helping to promote the research. We are looking for people with a health-related condition (including Parkinson's disease, motor neurone disease, multiple sclerosis, spinal cord injury, back pain, arthritis, and cancer) who live in the UK.

Do I have to take part?

You do not have to take part in the survey. Participation is voluntary and it is entirely up to you to decide whether or not you wish to be involved. Talk about it with friends and relatives if you wish, and ask the researchers any questions you have before making a decision. If you decide to take part, you will be asked to sign a consent form. You can decide not to take part at any point and without giving a reason. You can withdraw from the survey at any stage, without giving a reason and without penalty.

What would happen if I take part?

You will be sent a consent form and a questionnaire booklet by post. We would like you to complete the questionnaire booklet in your own time, in a quiet environment and without the assistance of others. You can choose not to answer any questions that you feel uncomfortable about. Your responses will be used solely for the current study. Any data generated will be anonymised. You will be invited to complete a questionnaire again two weeks later to allow the researchers to conduct some final analyses. A prepaid return envelope will be provided for you to return the completed questionnaire booklet.

How long will it take to complete the questionnaire?

The questionnaire booklet may take up to 30 minutes to complete, but this varies from person to person and it may take less time. It is usually best to complete questionnaires such as this in one sitting, but if you wish to take a break at any time you can do so.

How would the researcher use the answers to the questionnaire?

Your answers will help to establish which items are suitable for inclusion in the questionnaire and those which might not be necessary. Your answers will be kept in a secure place at the Health Services Research Unit at the University of Oxford. No personal information (e.g. names or addresses) will be stored with the answers. Any answers you give will be accessed only by members of the research team and will be destroyed after a period of 10 years.

What if I decide to withdraw from the survey?

You can withdraw from the survey at any point without giving any reason and without penalty. If you withdraw, any data you have provided will be destroyed.

What are the benefits of taking part?

By taking part in a survey of this kind you will be helping the researchers to determine which items to include in the questionnaire.

Are there any risks involved in taking part?

No, 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 funded by the European Brain Council. 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 Jill Dawson, Sarah Dummett, Laura Kelly and Professor Ray Fitzpatrick.

Results will be published online and in academic journals. If you wish to receive a copy of the results please send your name and address to the research team when you return your questionnaire.

The project has been reviewed by and received clearance through the University of Oxford Central Research Ethics Committee (reference number MSD-IDREC-C1-2014-089).

If you wish to take part or discuss this research, please contact:

Sarah Dummett, Research Assistant or Dr David Morley, Senior Research Scientist
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