

I am writing to invite you to take part in a consultation, as part of a research project we are supporting through our research partnerships programme.

### **Core Outcomes for Dementia**

The National Institute of Health Research (NIHR) HTA funded project, *Core Outcomes for Dementia*, is led by Prof. Gill Livingston at University College London, and involves a large multi-disciplinary team from around the UK. This is a 6 month project collating data on how results have been measured from all clinical trials over 30 years, looking for disease modifying treatments for dementia. That is, treatments that alter the underlying brain changes rather than the symptoms. The aim of the whole project is to develop a consensus on the 'Core' set of measures that should be used in these trials in the future. This will make it easier to compare or add together the results of different trials.

The research team conducted a systematic literature review to find the different outcome measures that trials have used in dementia research to test whether a therapy or drug was successful. These included cognitive tests, biological tests, behavioural measures and quality of life measures. We then spoke to people affected by dementia to find out if the measures identified by the research were acceptable and feasible. The recommendations made by people affected by dementia are summarised in the attached focus group report. This also gives an overview of the outcome measures we discussed.

The final stage was a consensus conference, which brought together the views of people affected by dementia and research experts to try to decide which measures should be core (used in all future trials). Those present at the conference recommended that cognitive measures should be considered 'core', with others used depending on the aim of each trial. As a secondary measure, researchers suggested that MRI scans should be used only with small groups of people, not for all participants in a trial.

### **How can you be involved?**

To help the production of the final report, we would like to ask for your advice and feedback on the results of the conference, as well as the report on our focus group meetings. We would particularly like to know your thoughts on the following questions:

1. Do you agree that cognitive tests (e.g. memory, language, logic) should be the core measure in dementia research?

2. Researchers suggested that MRI scans are important, but should be optional for trial participants. This would mean that not everyone in a trial would have an MRI - only those who agreed to it. What do you think of this suggestion?
3. Based on your experience, do you agree that a 1.5 hour time limit should be set for completing a set of measures or tests?
4. Do you have any additional comments to add to the discussion summarised in the Focus Group Report? (e.g. on the acceptability of different measures, or the general recommendations for research)

If you would like to take part in this project, please send me your responses by **Monday 25<sup>th</sup> April**. Your feedback will be anonymised and incorporated into the final report sent to the NIHR in June.

I have attached an information sheet on the project to give you some more information on the research. If you have any questions about this project, please don't hesitate to contact me.