

## **DELPHI CLINICAL PROFESSIONALS RESEARCH INVITATION (DELPHI-PRO)**

### **The Angela Project: Improving diagnosis and post-diagnostic support for younger people living with dementia and their caregivers**

Hello, my name is Mary O'Malley; I am a Research Assistant at the University of Northampton. We are currently running an Alzheimer's Society funded research project between four universities to improve diagnostic accuracy and post diagnostic support for people living with young onset dementia (YOD). This project is supervised and led by Dr Janet Carter - University College, London (Division of Psychiatry), Professor Jan Oyebode – University of Bradford, Professor Jacqueline Parkes – University of Northampton and Professor Heather Gage - University of Surrey.

We would welcome your participation in a Delphi consensus with regard to key decision making and clinical assessment of YOD. The goal is to obtain consensus about quality indicators for diagnosis of YOD. These indicators will then act as a set of 'rules' to guide doctors through the correct steps in making an accurate and timely diagnosis of YOD. **We would greatly appreciate your involvement because of your expertise as a clinical leader and experience in diagnosing YOD.**

As a Delphi panel member, you will be asked to complete a series of questionnaires (a minimum of three rounds) using an online survey. Questions will include information about all the complicated features of the diseases that cause dementia in younger people and advise on the best tests to use. It is envisaged that the first round should take approximately 30-60 minutes to complete. This time will be reduced to 10-20 minutes in the second and the following rounds. In these future rounds you would receive a summary of the group's responses and be asked to assess your agreement with the responses and modify your answers should you wish through a further brief online questionnaire. This process would continue until a group consensus is achieved. In order to allow timely conclusion of the study we

would respectfully request a response time of 3-4 weeks for completion of the first round and 2 weeks for the following rounds.

Considering the nature of the Delphi study and the small number of panellists participating it is impractical for responses not to be identifiable by the researcher; however, all responses received in the project will be strictly confidential, and your identity will not be divulged in any publication. Direct quotes to free-text answers may be used as part of the study report or later Delphi iterations, but these will not be traceable back to you. Please note that this study may also be published in academic journals. You will be asked to provide your e-mail address to link your first response to the following ones in order to analyse them. Personal data will be kept for 12 months in a password-protected directory on an external hard drive to which only the lead investigator has access, while anonymous study data will be kept for 5 years after the end of the study. After this, the data will be deleted securely.

You have the right to withdraw from participation at any time; however your commitment to complete the survey would be truly appreciated due to your critical expertise in diagnosing YOD.

**Thank you for reading this information sheet and for considering participation in this research. If you are happy to proceed please consider that you have implicitly given consent by completing the survey.** If you have any questions or concerns, please do not hesitate to contact me.

Thank you very much for your time.

Please direct any queries to Mary O'Malley ([mary.o'malley@northampton.ac.uk](mailto:mary.o'malley@northampton.ac.uk)).  
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Boughton Green Road, Northampton, NN2 7AL, UK. Tel: 01604 892168

If you would like to additionally speak with the work stream lead or project lead, please find their details below.

## Appendix A1

### Work Stream Leads:

Prof. Jacqueline Parkes ([Jacqueline.Parkes@northampton.ac.uk](mailto:Jacqueline.Parkes@northampton.ac.uk)) and Dr Janet Carter ([j.carter@ucl.ac.uk](mailto:j.carter@ucl.ac.uk))

Project Lead: Dr Janet Carter ([j.carter@ucl.ac.uk](mailto:j.carter@ucl.ac.uk))