

Project title: Amyloid DuAl-biomarker PeT for DEmEntia diAgnosis and subTyping (ADAPT DEfEAT)

About the project

The term dementia is used to describe symptoms which occur because of declining brain function. The most common cause of dementia is Alzheimer's disease, but it can be caused by a variety of diseases. The specific disease someone has is called the 'subtype', and the severity of the disease is called the 'stage'.

Currently disease subtyping and staging is performed by asking the patient a series of questions to establish their symptoms and to exclude other causes. However, this can still leave the diagnosis uncertain so the patient may be sent for further testing, including brain imaging scans.

The aim of this project is to develop a state-of-the-art artificial intelligence (AI) tool to analyse these brain scans. The AI tool will be combined with a new method to get two scans within one hospital visit. This project is designed to meet the urgent clinical need for increased confidence and accuracy in subtype diagnosis and staging, without greatly increasing the burden on the patient or the cost to the hospital.

About the steering group

The steering group will be made up of patients, carers, and members of the public who will influence and shape the project. The steering group is an essential part of the project to ensure that the research is of high quality and relevance to those living with dementia. There will be up to 8 people in the steering group who will be asked to attend 3 meetings per year for up to 3 years. At each meeting I will present the work that has been completed and the future plans for discussion and feedback. There will also be the opportunity to participate in a workshop to encourage engagement of the wider public and sharing the findings of the project.

We aim to hold at least 1 meeting per year in person, however you may attend remotely if you prefer, either online or over the phone. The

meeting place will depend on the location of the members of the steering group but will most likely be held in London. Each meeting will last between 1-1.5 hours. You are not required to commit to the full 3 years and you may leave the group at any time if you feel that you would not like to continue.

What we would like from you

As a member of the steering group we would ask the following from you:

- To attend and actively participate in the meetings (either remotely or in person)
- To treat all other members of the group with respect and dignity
- To let me know if there is anything that I can do to make the meetings more accessible for you e.g. if you would prefer to receive the information for the next meeting via email beforehand, or if you require a headset to be able to join a remote meeting more easily

What you can expect from us

- That you will be treated with respect and dignity
- That your personal information and the opinions you express will be treated confidentially. No information about you or your opinions will be made public without your permission.
- You will be listened to and I will act on your advice where possible.
- You will be compensated for your time, including caring costs, and for the use of your internet connection as required. Full details of compensation will be discussed with you if you are interested in joining the group as it will depend on your circumstances.
- Support to join meetings remotely if needed

Please note that participation in the steering group will not change your treatment/diagnosis or the treatment/diagnosis of someone that you know. The aim of the project is to produce methods which may improve patient treatment in the future.

Frequently asked questions

I'm interested in joining the group but I'm not sure if I will be able to manage for 3 years- can I still join?

Yes! We understand that circumstances change and you may need to leave the group. If you like, you can opt to continue to receive information about the group even if you are no longer able to participate in meetings.

I am quiet and get nervous speaking in groups, should I still join?

Yes! It is really important that we get feedback from different types of people to do good quality research. All meetings will be chaired by me and I will make sure that everyone who wants to gets a chance to talk. The aim is to create a group where everyone feels comfortable. If you would prefer to write something down and send it to me later, that's also absolutely fine.

I am a carer and would need someone to replace me while I join the meetings, is this possible?

Yes. We have funding to help towards carers costs so please let me know if this is the case I can help to get those costs covered.

I would like my partner/carers to attend with me, is this possible?

Yes. We have funding to help towards carers costs so please let us know if this is the case and we can help to get those costs covered.

I find it easier to read information first so that I have time to process it, is this ok?

Yes, please let me know if there is anything I can do to make it easier for you to participate and I will do my best to help

I disagree with my diagnosis and I would like something to be done about it, can I find this here?

No. The purpose of this group is to get feedback on a project designed to help people in the future but it is not yet ready to be applied to patients. Please contact your doctor to get further assistance for this.

I would like a brain imaging scan, can I have one as part of this project?

No. This project uses brain scans which we already have and we are not acquiring any new data as part of the project.

I'm not sure if I want to be involved in this and would like more information, how do I do this?

Please contact me using the details below and I would be happy to provide more details, and discuss the project further to see whether it suits you.

Contact

Name: Dr Catherine Scott

Email: Catherine.scott25@nhs.net