NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

Involvement Activity Request Form

Name and contact details of researcher (including job title, institution and email address)

Chief Investigator:	Professor Giovanna Mallucci, Associated Director of UKDRI
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Project title

Randomized, double-blind, placebo-controlled study of the Unfolded Protein Response in Dementia (SUPeRD2)

Plain English summary of the study (max 250 words, please include any suitable links to online information about the research)

The most common cause of dementia is Alzheimer's disease, a disease which is characterised by the accumulation of abnormal proteins. One outcome of abnormal protein build-up is that brain cells turn off most protein production, including that of proteins essential for brain cell survival, due to a process called the unfolded protein response (UPR). Insufficient levels of essential protein production leads to brain cell death and progression of the disease. In animal models of disease, reversing this process (the UPR) using the licensed drug trazodone restores protein production and slows disease progression. It is well known that the UPR is active in the brains of people with Alzheimer's disease. We have now established that human patients with Alzheimer's disease have decreased protein production in their brains using brain scans to visualise this. In this study, we will give patients with Alzheimer's disease trazodone or placebo to see if the drug can increase brain cell protein production in patients as it does in mice, using the same brain scanning technique to measure this. If successful, this will confirm that protein production is abnormal in patients with Alzheimer's disease and can be altered using a drug. This would then pave the way for a much larger trial to see if the drug was helpful in improving clinical outcomes in patients.

Purpose of involvement (What are you hoping to achieve through involvement/partnership working? Are there any limitations you need to take into consideration?)

Optimise design in terms of deliverability, acceptability to patients and scientific validity.

At what stage of your research would you like to work with experts by experience?

☐ ~~Identifying and prioritising your research question~~
☐ Designing your study (developing study protocol and relevant documents)
☐ Preparing funding/ethical application
☐ ~~Managing the research (as part of a steering group or advisory committee)~~
☐ ~~Undertaking the research~~
☐ Disseminating the research
☐ ~~Writing up~~
☐ ~~Implementation/Evaluating impact~~
☐ ~~Other (please specify):~~

How would you like to work with experts by experience in your project? (e.g. the tasks, meetings, and activities that people will be getting involved with, when, and how often)

The research group aims to work with experts by experience in the project via face to face meetings if possible as well as email communication. The frequency of meetings and correspondence will depend on the experts' review.

What role will experts by experience have? *(for example, members of a project lived experience advisory group, a steering group or a consultative panel; service user researchers)*

We would appreciate advice on design and developing the protocol further as well as on other relevant documents and execution of the study.
Support with preparing the funding application as well as the submission for ethical committee review. Advice on disseminating the research

Are you looking for people with specific characteristics or experience?

The study group is looking for people with specific experience in caring for people with neurodegenerative disorders or experiencing these conditions themselves.

What will be the expected time commitment for experts by experience?

The time of commitment is expected to be around 2-4 hours depending on the requirements of the panel

What is the deadline or timeline for the request?

At present, no deadline or timeline has been decided for the request