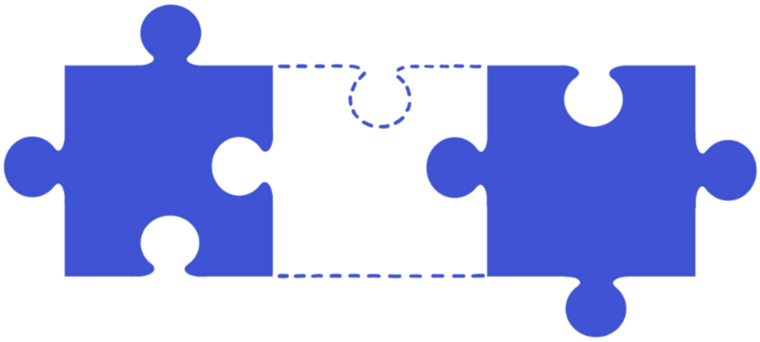
DAMPen-Delirium II



Are you the missing piece?

Public members of the trial steering committee

Information sheet

What is our study about?

One third of people have delirium when they are admitted to a palliative care unit or hospice and a further one third develop delirium during their stay. People with delirium may see or hear things that aren't there, say or do things out of character, and can't 'think straight'. This is distressing for the person, their family, and staff. There is clear national guidance on the actions needed to prevent, detect, assess, and manage delirium. However, it is difficult for hospices to put this guidance into practice because delirium care is complex and involves lots of different people, including family, friends and health professionals.

What have we already done?

We have designed a way for hospices to overcome these difficulties and follow delirium guidelines better. We have tested this on a small scale and shown that we can collect information we need from patient's notes and hospice staff in a reliable and timely way.

We want to:

- Run a major, national trial to test whether this improves delirium care and reduces delirium in hospices.
- find out if this is affordable.
- Look at how our approach works in different hospices and what makes it work well.
- Explore how to adapt our approach for use in different settings, such as care homes and people's own homes.

When does the study begin and end?

The study began on 1st October 2024 and will last for 4 years, ending in September 2028.

What is the role of the public members of the trial steering committee?

This committee will monitor, supervise and advise the study. Your role as a public member of the committee will be to:

- offer the perspective of a potential public participant in the study;
- act as a 'critical friend' when discussing what is practical and acceptable.

What experience are we looking for?

We are looking for people who have personal experience of living with delirium. You might have experienced delirium yourself or have cared for a loved one who has.

You will need some knowledge about clinical trials, and experience of being involved in research studies, and have other relevant experience, such as being a member of a formal committee.

It is helpful if you also have some previous experience of committee work, reading and commenting on written documents, and working as part of a team. We are looking for people who are confident and willing to speak up and ask questions.

Who will you be working with?

You will work alongside senior academics and clinicians, and at least one other public member of the committee.

How often will the group meet and for how long?

We will have a welcome meeting to introduce you to the research team and the other public members. The committee holds 2 meetings a year.

Where or how will meetings be held?

Our meetings will be held online using Teams video-conferencing software. We will share simple instructions for joining each meeting and ground rules for taking part. This means that you will need access to a mobile phone or a computer with internet access.

What will the study steering committee do?

The committee will:

- monitor the progress of the trial;
- monitor adherence to the trial protocol;
- monitor the safety and wellbeing of participants;
- make recommendations to the Trial Management Group;
- make recommendations to the trial sponsor;
- consider new information as it becomes available.

What benefits are we offering?

We will reimburse your expenses for taking part in committee meetings and other activities. More information about the expenses covered is available on request.

We will offer you a fee of **£110 for each steering committee meeting** to thank you for your time and contribution to the study. This will include time spent preparing for, attending and following up meetings, and time spent on separate activities. You will also receive a £5 remote working allowance for each of these meetings. Expenses and fees will be paid as soon as possible after each meeting or activity.

Your fee will cover the following:

- attending a one-hour online meeting;

- reading papers for the meeting;
- any pre-meetings or debriefing meetings;
- any small-scale follow-up activities;
- recognition of the responsibility of the role.

What support will you be offered?

Helen Roberts will be the main point of contact and support for the public members of the committee, with support from Gillian Jackson. Gillian and Helen will meet with you before the first meeting to discuss your role and answer any questions. They will be available to offer one to one support outside of meetings, including support with using video-conferencing software, if you need this. To help you prepare, they will offer you the chance to meet with them before each steering committee to ask any questions.

We will send the papers for each meeting at least 10 days in advance so that you have time to prepare. If you need printed copies, these can be supplied on request. We will share minutes of each meeting.

Gillian reports to the steering committee and will be available to discuss any issues with you, or to reflect on a meeting afterwards. She will be able to explain any complex issues or technical language. She can also speak to the Chair on your behalf if you need support with any issues.

Who is funding this study?

We have received funding from the Health & Social care Delivery Research (HSDR) programme of the National Institute for Health and Care Research (NIHR) (Grant Reference Number NIHR161360).

Any questions?

If you have any questions or are interested in volunteering for this role, please get in touch with:

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