

Do you have an interest in Palliative Care?

Would you describe yourself as someone with experience of using prescription medications for symptom control or helping others to do so?

We are looking for 9 people to join a patient & public involvement research group for a study funded by Marie Curie. People without prior experience of patient and public involvement are particularly encouraged to apply. We are keen to create as diverse a group as possible and will endeavour to support people to take part. Please contact us to discuss further if you are unsure.

Palliative care is the care of people with progressive and potentially life-limiting illness who experience physical, psychological, social and spiritual needs. Common symptoms that might need medicines to control include pain, breathlessness, nausea or vomiting, anxiety and agitation.

The group will help guide a study that will map out the differences between 'what happens on paper' (the ideal process) and 'what happens in real life' (people's experiences) at all stages of managing prescription medicines in palliative care, from when a decision to prescribe a medicine is made to someone using it. The study will look at who does what when a patient is in their own home, in a hospice, and in a hospital.

This will help us to understand the challenges faced by patients, carers and professionals and volunteers as they try to get good symptom control. Looking at the gaps between what is needed or should happen and what does happen will help to identify how to improve.

Work for the study has already started and the Plain English Summary can be found here:

<https://www.mariecurie.org.uk/globalassets/media/documents/research/grants/sarah-yardley-lay-summary.pdf>

We plan to hold at least two meetings of the group (remotely via video conferencing or face-to-face in London depending on pandemic restrictions and members' preferences) during the study. We anticipate the PPI engagement group activities may also include:

- Feedback on: Scoping review methods and analysis, Ethical issues
- Co-developing process model
- Advising on public updates, recommendations and dissemination using Plain English
- Evaluating the study including evaluation of the PPI impact

Members of the group will need to be:

- able to participate in English and attend London-based meetings or use remote technology (e.g. teleconferencing, email)
- willing to work to confidentially, honour agreements and meet reasonable deadlines.

If you would like to discuss this opportunity further you can contact:

Dr Sarah Yardley (lead researcher) or Margaret Ogden (PPI Co-Investigator) via sarah.yardley@ucl.ac.uk

To apply to be part of the group please email Dr Sarah Yardley sarah.yardley@ucl.ac.uk with a brief summary of your background, any experience of palliative care (including prescription medicines for symptom control), any previous PPI experience, any training or support needs (if applicable) and how you think you could contribute to the group.