Summary of event

On 25th August 2015, the Cicely Saunders Institute (CSI) hosted the third patient, family and public involvement workshop.

The workshop included a packed program of presentations and interactive sessions. Attendees shared their own views on the overall theme “Videography as a PPI resource”, after listening to an informative session from Sophie Pask from CSI and Luis Carrasqueiro from HealthTalk. A personal account about the experience of creating a video from Naila Hope stimulated much discussion. The afternoon included meeting and net-working with researchers.

Overall feedback from the event was positive. The majority of non-professionals felt that the workshop was valuable and that they had been able to make a contribution. Researchers reported that they appreciated the opportunity to meet patients, carers and members of the public, pitch their projects and discuss potential involvement. Feedback from the event will inform the next workshop on the 1st February 2016.

Thank you to all for attending!

Workshop attendees:

Eight patients, carers and members of the public
Researchers from PhD student to Senior Research Fellow level joined for sessions throughout the day
Special guests included Prof. Diana Rose from the Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC)

The day’s programme

The day included a packed two and a half hour programme of presentations and discussions.

The afternoon started with a speed-dating session, in which small groups of non-professionals met researchers from the CSI. The researchers pitched their upcoming research projects to find PPI involvement in either the long-term or short-term.

Sophie Pask from the CSI and Luis Canasqueiro from HealthTalk informed the participants about researchers’ perspectives of making a video.

The second presentation of the day was led by Mrs Naila Hope, who spoke about her experience of creating a video to inform the public about her involvement in a large research project in palliative care.

Finally, the last session consisted of group discussions around current ideas or issues in research with a focus on composing their message or sharing any experience in advising palliative care researchers by video.
Feedback from non-professionals

Feedback from patients, carers and members of the public was very positive overall, with most attendees saying that content was clear and that the workshop was valuable.

Many also felt that they were able to make a contribution to the workshop and felt that their ideas had been heard.

Non-professionals particularly liked the informal feel of the workshop, as well as the opportunity to network with researchers to gauge the opportunity to become involved in the projects presented during the speed dating session. Participants felt compassionate about composing their message to the public in the experience sharing session.

However, many also felt that some sessions were too packed and the speed dating session needs adjustment in its format. Some also felt that there should be an emphasis on physical conditions, i.e. non-cancer diagnosis, for the next workshop.

Feedback from researchers

Feedback from researchers who attended the event was also positive.

The diversity (age, nationality, patients and carers) of the participants of this workshop was extremely valuable because it matches the range of research projects in the institute that would like to recruit PPIs for advice.

Researchers felt that this time, during and after the speed dating session, the exchange of contacts was warranted.

The researchers felt that the speed-dating forum needs adjustment and refinement in terms of the structure and time.
The skills building session was led by Luis Carrasqueiro from HealthTalk and Sophie Pask, a research assistant from the CSI. This session introduced the HealthTalk concept to the workshop participants. HealthTalk is an online platform where lay members (patients, informal carers, friends) tell their story about their experience of an illness. However, all the accounts are evidence based and are linked to the latest research findings.

This session nicely bridged to the experience sharing session, which was led by Mrs Naila Hope, a lay member on the C-Change project at the CSI. She very kindly gave a personal and reflective account about why a lay production for a video can be a powerful PPI resource. Her main message was that it can raise awareness about the CSI’s research priorities, involvement, and findings amongst policy makers and politicians. She concluded that it can consequently help us to get the evidence-based palliative care we would like to have when we are in need of it.

A lively discussion amongst all participants followed the two presentations. Participants felt that a non-professional production would speak more to the audience’s heart because it would be more authentic, but some professional editing may be commissioned to make the story more fluid. Financial implications need to be considered in relation to the charity and making a video.

There was a consistent opinion amongst the participants that everyone should be given the chance to participate in a video because of the importance of a first hand perspective. There are also different ways of contributing to a video message. For instance, a poem or a piece of writing read by a patient may be a very powerful way to communicate their experience, which can also be supported by a researcher who first talks about the research findings.

If a video is made, there are a large number of dissemination options, and the group had lots of creative ideas for this. The key for any dissemination however would be to extend the collaboration with other organisations. Each member of the CSI PPI group has different contacts to other charities or institutions, for example the charity Age UK, and the message would be spread far and fast. Apart from social media, the group tended to add as much effort in paper leaflets or physical sessions. This would help to allow less computer-literate people access the information and to reach even more of the target groups.

This very fruitful discussion will influence future video productions in the Cicely Saunders Institute as it entails many important considerations when planning and doing a video.

WAYS FORWARD:

- Non-professional take of a video in a homely environment
- Everyone should be given the opportunity
- Collaboration with other organisations
- Disseminate paper leaflets

“You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but to live until you die.”

Dame Cicely Saunders
allow enough time for discussion, whilst researchers agreed that the discussion part should be more focused.

Furthermore, the organisers should continue to invite other professional bodies to the workshop in order to raise awareness and the profile of our patient, family and people from the public group.

### Recommendations for future events

The feedback received at this event has resulted in recommendations for changes that will be considered before the next workshop.

Non-professionals felt passionate that there should be a focus on non-cancer diagnoses, i.e. dementia and palliative care/end of life care, as a main theme for one of the next workshops.

The main part of the improvement will primarily be based around the format of the sessions which allow time for discussions, in particular the speed dating session and the exchange after the experience sharing session. Critique to the existing format from non-professionals included requests to