On 1st February 2016, the Cicely Saunders Institute (CSI) hosted its fourth patient, family and public involvement workshop. The workshop included a packed programme of presentations and interactive sessions. Attendees shared their experiences and thoughts with researchers on the overall theme “Difference through involvement” in the experience sharing and skills building sessions.

The aim of this workshop was to learn from each other and exchange experiences from collaborations between CSI researchers and Patient and Public Involvement (PPI) members.

Overall feedback from the event was positive. The majority of PPI members felt that the workshop was valuable and that they had been able to make a meaningful contribution. Researchers reported that they appreciated the opportunity to meet patients, carers and members of the public, and to pitch their projects and answer questions in the new “Dragons Den” session.

The subsequent discussion session, which focused on improving involvement within the CSI, was kept short due to previous sections running over time.

The next PPI workshop will be held as a whole day event on the 14th June 2016 and will be informed by the feedback from this workshop.

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

The afternoon started with a combined experience sharing and skills building session looking at “The difference through involvement”. Researchers and PPI members presented and reported together about their experiences of collaborating on research projects. The following discussion session focused on the lessons learned and areas of improvement to foster the collaboration between PPI members and researchers.

The new “Dragon’s Den” format was introduced in the second part of the afternoon to share ideas and interests amongst service users and researchers, and to allow attendees to network and get to know each other better for potential future collaboration.

The day closed with inspiring ideas from everyone, which will be followed up in the next workshops.

Thank you to all for your contribution!
Feedback from PPI members

Feedback from patients, family, carers and members of the public was very positive overall, with most attendees saying that the different sessions were useful and met their expectations. For the Dragon's Den session, expectations were exceeded.

The PPI members particularly liked the “Dragon’s Den” session as it gave them the opportunity to get up to speed with the latest research projects and hear about future opportunities to become involved with projects presented.

PPI members felt compassionate about composing their message to their fellow participants in the experience sharing session.

However, many also felt that all the sessions were too packed, which hindered the discussion sessions.

There was a mutual agreement that the next workshop should be a whole day event to allow for longer and more meaningful discussion.

Feedback from researchers

Feedback from researchers who attended the event was also positive.

Researchers enjoyed hearing from different projects about methods how PPI involvement was done, which they felt was inspiring.

Some felt strongly that we should open the workshop and opportunity to share our experience with external PPI groups.

Researchers felt that the Dragon’s Den needs adjustment and refinement in terms of the structure and time.
In the skills building session, researchers presented together with PPI members about their experiences of working collaboratively on their project, and on their methods of involvement.

Lisa Brighton, together with Sylvia Baily and Colleen Ewart, discussed their collaboration on the Transforming End of Life Care Project. They highlighted that they felt challenged by the emotional nature of the project, but felt empowered through the collaboration.

Alice Firth & Ping Guo presented with Victoria Nnatuanya. They reported on their experience from collaborating on the C-CHANGE project. The project has benefited from critical input from the PPI members, resulting in patient questionnaires and information leaflets, and refined recruitment strategies.

Nilay Hepgul and Sanjay Chadha are collaborating together in the OPTCARE Neuro trial, a randomised controlled trial, where punctual trial documents as well as participant related documents (i.e. ethics, patient information sheet) have been reviewed by Sanjay and others in order for the trial to keep to schedule.

Caty Pannell shared her experience as a research nurse conducting research with patients, who are not able to leave to house due to their illness and symptoms (i.e. breathlessness). She visits patients at home when they would like to be involved in a PPI capacity.

The two questions focusing on lessons learned and improvement in future lead the discussion session of the workshop.

The need and requirements from people in the community in terms of palliative care was very close to the participants heart. Most felt strongly about the provision of excellent palliative care towards the end of life for those people in need.

Some felt it was important to address this through research and that it would not be a problem to recruit patients towards the end of life into studies as many felt the legacy argument was a strong motivator.

Participants felt however very protective towards vulnerable patient groups in palliative care and were thinking about institutional guidelines for this.

The session was left with the question about the national research plan and how the Institute is feeding into this.

WAYS FORWARD:

SHARING AND FEEDING BACK THE EXPERIENCE AND ACHIEVEMENT OF INVOLVEMENT TO THE NHS

DEVELOPMENT OF INSTITUTIONAL GUIDELINES CONCERNING RECRUITMENT OF VULNERABLE PATIENTS

COLLABORATION WITH OTHER ORGANISATIONS

CONTRIBUTING TO THE DEVELOPMENT OF A NATIONAL RESEARCH PLAN AS SOON AS THE OPPORTUNITY COMES UP

"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
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 involvement group.

On the whole, the feedback shows that there is continued support from both researcher and PPI members in continuing with this series of workshops. It is evident that the workshop needs to allow more time for discussion in order to benefit from the breadth of experience and knowledge from all participants involved. Therefore, the next workshop will be a whole day event.

The Dragon’s Den format, to allow for new collaborations and engagement between service-users and developing research projects, was held for the first time with great success.

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 involvement group.

Visit us on the web:
www.kcl.ac.uk/palliative

Conclusion and Recommendations for future events

The Cicely Saunders Institute is the first purpose built institute for research into palliative care and rehabilitation. We offer palliative care courses and other resources relevant to palliative care and rehabilitation.

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. The goal is the best possible quality of life for patients and their families, and includes control of pain and other symptoms, as well as attention to psychological, social and spiritual problems.

The Institute brings together academics, healthcare professionals, community organisations, patients and carers in one centre and acts as the hub for a network of international research. It offers high quality palliative care solutions to patients, as well as providing education, patient information and support.