Welcome to the first PPI newsletter from the Cicely Saunders Institute.

PPI input into research is an invaluable resource that researchers can use not only to improve their outputs but also to gain a better understanding of the patient, family and carer perspectives to ensure we ask the ‘right’ research questions. Many researchers have mentioned that their PPI groups have provided them with insights that they would never have considered, and here at the CSI we strongly encourage researchers to incorporate PPI feedback into their projects from inception to dissemination.

In this first issue of our PPI newsletter, we look at the most recent of the PPI workshops held at the CSI. These workshops invite PPI members across all department projects to discuss themes important to them, to review and update and the chance to be involved in the latest research being conducted at the Institute.

In the PPI interview, we talk with a member of our PPI group on her experiences and look at the ways in which PPI input has influenced the C-CHANGE project.

Finally, we would like to introduce you to our PPI Virtual Forum, which was created to allow more flexible discussion between PPI members and researchers outside of formal meetings, and to allow researchers to receive faster feedback from participants.

What is PPI?

Patient and Public Involvement (PPI) can be defined as research being carried out ‘with’ or ‘by’ patients, carers, and members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE, 2017). This could include advising on research through a project advisory group, providing feedback on grant applications or research materials, or helping to set research priorities. PPI therefore allows people’s real life experiences to feed into the research process from developing research questions through to dissemination and impact.

Palliative care and Rehabilitation put patients and their families at the heart of care, and we want the work of the Cicely Saunders Institute (CSI) to reflect this by involving patients, carers and the public at every stage of our research. We aim to facilitate meaningful Patient and Public Involvement (PPI), which will improve the relevance, quality and impact of our research, and ensure that research is focused on the needs and priorities of patients, carers and their families.

There are 3 key principles the Institute aims to follow in our PPI work:

1. Early involvement to improve research relevance, quality and productivity
2. A model that uses a high degree of flexibility to increase involvement through virtual and face-to-face methods
3. Promote the contribution that PPI members make & evaluate how this affects the research process.

1. INVOLVE is the public involvement arm of the National Institute for Health Research (NIHR)
The C-CHANGE Project

What do we do?

C-CHANGE is a five year research project, which aims to improve adult palliative care provision by better matching resources to patient need. This will reliably reflect the complex needs and concerns of patients and families to enable the delivery of better quality care in the last year of life and more efficient use of resources.

How have we involved PPI members?

PPI members have been involved in C-CHANGE from the grant stage, so they have made valuable ongoing contributions throughout the project. Members attend meetings at 3 month intervals where they are given an update and asked for their opinions on aspects of the project, in particular materials that will be given to patients, including information leaflets and questionnaires. PPI members have also helped create videos which document the progress of the project.

What difference have PPI members made to the project?

PPI members have made invaluable suggestions that have helped to shape the research project, including:

· Refining questionnaires and ensuring that the measures chosen reflected the real needs of patients and carers, such as: spiritual care and cultural needs, post-bereavement needs of carers and patients’ goals.

· Enhanced researchers understanding of patient and carers experience to ensure that qualitative interviews were conducted in a sensitive manner (e.g. to take breaks if needed), and ensured that the interviews covered issues of patient safety.

Interview with a PPI member

Colleen joined the CSI PPI group in 2014 and is a regular attendee at the CSI department workshops.

Why did you join the CSI PPI group?

My father died at home as he wished, pain free and with his family around him - I assumed this was the norm as it was my first experience of death. Yet when I helped to care for a terminally ill friend the experience was so different; pain, fear and suffering. Joining the PPI group at CSI has given me the opportunity to share these experiences and help to make a difference.

How do you feel you have made an impact within the PPI group?

Well I keep being asked back so I must be adding something! Living in the East Midlands and being actively involved in PPI there means I can add a regional perspective which can be very different at times. Recently I have been involved in a focus group looking to increase activity with the Online Forum. If a flurry of activity begins I shall claim success for my input!!

Do you feel you have benefitted from being involved?

Absolutely yes. Initially I responded to a call for public involvement in the Transforming End of Life project and was able to utilise my skills as a lay assessor along with my personal experiences. Being part of the group has taught me so much about research; helped develop my confidence / presentation skills and to face my own fears of death.
CSI PPI Workshop—Difficult Conversations

On Monday 10th April 2017, the CSI hosted our seventh patient, family and public involvement workshop. This was a full day event where attendees were invited to hear presentations on both staff and patient and family experiences of having difficult conversations around end of life care.

Attendees were also given the chance to feed back on new research grants that are currently in development during the ‘Dragon’s Den’ session, where researchers looking for PPI participation in their research present their work to the group and ask for feedback and interest. Linking in with this session, researchers who presented at the previous workshop’s Dragon’s Den were invited to return and update the group with how their research had progressed following PPI input.

The next workshop will take place in late Autumn 2017.

Difficult Conversations

‘Difficult Conversations’ was the topic chosen for this workshop as it is an issue that many of the participants of previous workshops have experienced. Service users had reported that some conversations with staff had gone badly, especially when being given bad news or when addressing failures in care. In light of this, the workshop aimed to address what is being done to teach staff to have better conversations with patients, families and carers.

Presentations were given by PPI members and clinicians in order to show perspectives of difficult conversations from both a professional and user experience, and attendees participated in a discussion on what makes for a good conversation when passing on bad news.

The group were introduced to the training programmes designed to help staff develop their skills in dealing with difficult conversations, as well as the challenges that research projects on the topic of difficult conversations have run into.

The day finished by giving attendees the chance to participate in new research projects at the CSI.

Feedback

The feedback for the workshop was overwhelmingly positive. While some attendees felt that the Experiences of Difficult Conversations section was too anecdotal, this session was also praised: ‘I found the experiences of [Difficult Conversations] most powerful and resonant’. Six out of nine respondents said they found the session ‘very useful’ two found it ‘useful’ and the remaining respondent marked ‘not sure’.

Researchers attending the workshop reported that they benefitted greatly from presenting on their projects: ‘I have found it a very helpful first step for engaging with PPI’

However, PPI attendees mentioned that they would like to know more about how PPI involvement is affecting research and what difference their input has made, as they are often not informed by researchers. For future workshops, we will encourage feedback to be more oriented around this rather than a general overview of how projects are progressing.

We would like to thank everyone who attended the session for helping to make it such a thoughtful and engaging workshop.

Workshop attendees:

Ten patients, carers and members of the public travelled to attend the April workshop. This included two PPI members who came to present on their experiences of difficult conversations.

Researchers presenting from the CSI included two PhD students, a senior member of staff and a member of the clinical team.

For this workshop, attendees were also joined by Vicky Robinson, an expert clinical educator.

What did you enjoy most about the workshop?

“Tremendously informative day - very mentally invigorating & so many plans to help PPI further, if I’m allowed to.”

“It was good to hear real life stories around communication and hear what is important to patients and families. This is really relevant to the research project I work on.”
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.