On Tuesday 14th November 2017, the Cicely Saunders Institute (CSI) hosted its fourth full day Patient and Public Involvement (PPI) workshop.

The workshop included presentations and discussion on the theme “Carers in palliative care research”, as well as presentations of new and ongoing palliative care research projects. 12 PPI members attended, and 12 researchers contributed to the day by attending sessions, presenting their research, or asking for PPI feedback on their projects. In addition, four of the 9 themes of CLAHRC South London, and the Department of Adult Nursing were represented at the Workshop. This reflects the interest our PPI work has generated, and our commitment to disseminating good practice in PPI. The workshop was well evaluated, with one participant commenting that “PPI and researchers contributed to each topic. I felt it flowed in a positive way”.

The rest of this report details the content of the workshop and feedback received, concluding with recommendations for future events.

Section 1: Workshop details and costs (page 2)
Section 2: Feedback (page 7)
Section 3: Conclusion & recommendations (page 9)
1. Workshop details

Hosted by: Simon Etkind, Javiera Leniz Martelli, Beth Edwards

Participants in attendance: 12 PPI members

CSI Staff in attendance: India Tunnard, Jonathan Koffman, Mitsunori Miyashita

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Presenter / Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.30</td>
<td>Intro and welcome</td>
<td>Jonathan Koffman</td>
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<tr>
<td>10.45</td>
<td>What it means to be a carer for someone who is ill</td>
<td>Javiera Leniz Martelli</td>
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<tr>
<td>10.45</td>
<td>Short presentation about each attendee, including PPI members and researchers, mentioning their experience as a caregiver and what they expect from the workshop.</td>
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<tr>
<td>11.30</td>
<td>Tea break</td>
<td></td>
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<tr>
<td>11.45</td>
<td>How to best include caregivers in research session</td>
<td>Steve Marshall</td>
</tr>
<tr>
<td>11.45</td>
<td>Current research base – what’s already out there?</td>
<td>Simon Etkind</td>
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<tr>
<td>12.00</td>
<td>Ongoing CSI research projects that explore caregiving – lessons learned from IARE II</td>
<td>(Beth Edwards)</td>
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<tr>
<td>12.15</td>
<td>What's missing and where do we need to go from here?</td>
<td>Beth Edwards</td>
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<tr>
<td>12.15</td>
<td>Idea generation and discussion from PPI members around what to ask carers: when is a good time to approach caregivers for research? What are the barriers to participating?</td>
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<tr>
<td>12.45</td>
<td>Lunch</td>
<td>Beth Edwards</td>
</tr>
<tr>
<td>13.30</td>
<td>Summary - how best to include caregivers in research</td>
<td>Steve Marshall (upcoming bereavement project)</td>
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<tr>
<td>14.00</td>
<td>Dragons’ Den</td>
<td>Deokhee Yi - OptBreathe</td>
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<tr>
<td>15.00</td>
<td>Tea break</td>
<td>Kat Kieslich (new online Commissioning tool)</td>
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<tr>
<td>15.20</td>
<td>Follow up from previous Dragons’ Den – feedback of PPI group’s contribution to research</td>
<td>Joanna Davies</td>
</tr>
<tr>
<td>15.45</td>
<td>Closing remarks / summary</td>
<td>Javiera Leniz Martelli</td>
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</tbody>
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What it means to be a carer for someone who is ill

This opening session allowed PPI members to talk about their own experiences and report what they hope to gain from attending this workshop. Members were keen to talk about their experiences and felt as though the environment was safe enough for them to be very honest in without judgement.

Key points: What is my experience of care giving?
- Being a carer is a mix of love, anxiety and uncertainty
- Pressures of co-ordinating care for someone else with own health and social needs
- Guilt – Predominantly suffered when the carer is struggling to cope with demands. Guilt also arises when carers emotions change towards the care receiver
- Grief – When care receiver passes away, carers can often be left feeling redundant
- Never doing enough – A constant feeling, as a carer, of never being able to do enough
How best to include caregivers in research

Bereaved carers as research subjects: when do we ask? When should we ask?

Steve Marshall discussed the importance of research using bereaved carers and the ethical issues of conducting research in this group. Steve informed the group that it is difficult to judge when it is appropriate to contact a carer bereavement

The group suggested that where possible, researchers should talk to carers prior to the death of the care receiver to determine appropriate timing of contact, though this may often be unfeasible. Sometimes it can be therapeutic for carers to discuss their experiences. Researchers must be aware that responses from carers may differ depending on the time after bereavement and stage of grief.

One member highlighted that National Voices distribute questionnaires 3 months following death. The group agreed that this is a good time frame as it balances sensitivity with likelihood of accurate recall, though this is somewhat sooner than standard practice. One attendee advised that ethics committees will prioritise a thorough consideration of research questions and the approach to attendees over a specific timeline.

Recruiting caregivers to studies in palliative care: Lessons learned from the International Access, Rights and Empowerment (IARE II) study.

Simon Etkind presented on the ongoing IARE II study, and, more specifically, how carers are identified in the project. Simon discussed the challenges of involving carers in this research and how, they have had
issues with identifying the primary carer and organising research visits around the life of the carer. It has highlighted the importance of a flexible approach to recruitment.

PPI members reflected that flexibility may enable inclusion of those less eager to be involved in research. The group suggests that researchers shouldn’t try to establish definite rules as each carer will be different, some will put off giving input to the research others will use it as a distraction. Additionally, the group suggested carers may not engage due to concerns that they are betraying the care receiver by taking part in research.

What’s missing and where do we need to go from here?

Two main areas relating to the participation of carers in research were discussed within the group. These were stigma and recruitment processes. The group came up with several suggestions to improve carer participation relating to these areas:

- **Leaflets**: Allow for choice and control. Can be used for recruitment or dissemination. Needs to be suitable for the target audience too and doesn’t need to be “flashy”.
- **Leaflet distribution**: Placing leaflets in dentist/GP/clinic waiting areas promotes recruitment of those who wouldn’t be advertised to directly normally.
- **Personal approach**: Discussion of research with a professional/researcher increases confidence
- **Forging relationships** with faith, community, and other groups identify those willing to help
- **Using PPI members to recruit** – suggestion that the conversation may improve when the interviewer is a fellow patient/carer rather than a researcher
Dragons Den

Steve Marshall (CSI) – The development of evidence-based good practice guidelines and resources to support children and young people pre-bereavement

Steve outlined his prospective project interviewing people aged ≤ 18 who have lost a parent and those who have a parent with a life-threatening illness, to explore their experiences.

PPI members recommended the lower age limit of the children to be 6 years old. They also suggested the researchers could use a toy to aid interviewing children under the age of 10. Video recording the interviews was also discussed as much can be taken from the body language of children. There was also a brief discussion on whether interviews should have a parent present, particularly with younger children, and the positive and negative effects this could have.

Deokhee Yi and Anna Johnston (CSI) – Optimising cost-effective support for older patients with refractory breathlessness and their carers

Deokhee and Anna discussed their OPTBreathe project with the group which aims to determine the most cost-effective models of breathlessness support services, including factors that influence uptake and economic costs, using a Discrete Choice Experiment design. They asked for a PPI member to join their project advisory group.

Deokhee answered questions from the group around the use of the Quality Adjusted Life Year to measure cost effectiveness and various other tools used to measure carers burden. The researchers were encouraged to record sexual orientation as standard on research, as they would gender and age.

Kat Kieslich (Public Health theme of CLAHRC South London) – Decision-making audit tool (DMAT)

Kat informed the group about the DMAT, which allows the public to voice their opinions on health services, and is designed to enable greater service user input to the commissioning process. The tool can be found at: www.priorities4health.com. Kat asked for feedback as to usability and comprehensibility. The group felt the tool was well designed, and asked questions about confidentiality, Kat confirmed that commissioning boards will be able to see the group output data and only individuals will be able to see their personal responses.

Follow up from previous Dragons’ Den – feedback on PPI contribution to research

Joanna Davies (CSI), and Margaret Ogden– Understanding social inequality at the end of life

Joanna gave an update after presenting to the group earlier this year, and Margaret described her experience of working on this project, which aims to understand why people living on lower incomes, in poorer quality housing, or in more socially deprived neighbourhoods tend to receive poorer quality care. Margaret talked about the complexities of this study and how these are being handled.

Joanna discussed the need for a project advisory group (PAG) once the data has been analysed. The PAG will contribute to interpretation and dissemination of the findings. A discussion around the role of PAG or PPI members in dissemination concluded that training is needed so that PPI members can understand all the aspects of the research, and answer questions confidently.
2. PPI feedback

The following graph and tables summarise evaluation responses from PPI representatives. All twelve attendees returned evaluation forms.

*Graph 1: How useful was each session* (Please note that not all respondents replied to every question.)

Overall, the majority of respondents found the sessions to be either “very useful” or “useful”. The only session to receive two “not useful” responses was the *What it means to be a caregiver* session. The *How best to include caregivers in research* received the highest number of “very useful” responses, however *What it means to be a caregiver, Where do we go from here* and *Dragon’s Den* all received high “useful” response numbers.

*Table 1. Comments: What did you like most about the workshop?*

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1. Positive and active engagement by everyone in room. 2. Everyone listened and respected each other’s contributions. 3. Very informative re: CSI's aims to engage more PPI members and disseminate - new members. 4. Learnt from presentations. Gained more knowledge about research processes and parameters you need to work in. 5. PPI and researchers contributed to each topic. I felt it flowed in a positive way. 6. Positive atmosphere. good, upbeat intro to role of carers.</td>
</tr>
<tr>
<td>2</td>
<td>Meeting staff/other PPI reps and the learning experience</td>
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<tr>
<td>3</td>
<td>The dragons den session - good to put faces to the names of researchers and hear about their updates</td>
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<tr>
<td>4</td>
<td>Stimulation from group. Getting excited and wanting to add my voice</td>
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<tr>
<td>5</td>
<td>The sessions dealing with what it means to be a carer, Dragons den and follow up</td>
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<tr>
<td>6</td>
<td>Warm and engaging. Useful listening to various viewpoints about the subject. Better understanding of what is involved in the research currently</td>
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<tr>
<td>7</td>
<td>Opportunities to share ideas and get involved</td>
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<tr>
<td>8</td>
<td>Listening to people’s views</td>
</tr>
<tr>
<td>9</td>
<td>Good discussions all day long</td>
</tr>
<tr>
<td>10</td>
<td>Openness. Decision making tool. Financial measure (qually)</td>
</tr>
<tr>
<td>11</td>
<td>A very useful and helpful workshop from everyone. A pity no one from government</td>
</tr>
<tr>
<td>12</td>
<td>Research presentations (dragons den)</td>
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</tbody>
</table>
### Table 2. Comments: What did you like least about the workshop?

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Comment</th>
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<tbody>
<tr>
<td>1</td>
<td>Intro/start of the day: Always think it's important to go around the table and let everyone introduce themselves, so we know each other’s names? Do know some people helps to have reminders of name (&amp; their background or why here?) (not sure if last part obligatory)</td>
</tr>
<tr>
<td>2</td>
<td>Intro session - didn’t really work for me</td>
</tr>
<tr>
<td>3</td>
<td>Nothing it was great though I missed having a patient/carer presentation at the beginning</td>
</tr>
<tr>
<td>4</td>
<td>None, all the sessions were relevant and good</td>
</tr>
<tr>
<td>5</td>
<td>My first workshop experience, so just absorbing the process. Useful and productive day</td>
</tr>
<tr>
<td>6</td>
<td>Could have been a bit of introductions with expectations/experiences exercise</td>
</tr>
</tbody>
</table>
| 7          | 1. Not sure we spent enough time teasing out the barriers.  
2. Do you have a close relationship with a number of hospices, care agencies (these are being used a lot in BILT and CHINS). Healthwatch could also help if you approached them - there is one per borough/county - they are the independent voice of patients/public etc.  
3. I am very unclear what motivated this specific topic - maybe I arrived too late - was it in the introduction? |
| 8          | Nothing springs to mind |
| 9          | Domination of teddy bears |
| 10         | Make sure enough leaflets to hand out at Dragons Den |
| 11         | I felt some of the topics were too generalised for example "my experience of being a carer" and "when it would be appropriate to involve bereaved carers in research". It seemed to me that it was considered a carer to be caring mainly at home. My experience was being a carer in hospital at the end of life. Which raises a lot of questions about how much on is allowed to "care" in this kind of setting |

### Table 3. Comments: Please provide any further thoughts, or suggestions about the workshop

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Really useful and informative day. Learnt from both sides - CSI researchers and other PPI members. Real need to find a route to contact with other social groups whose voices will serve both CSI and their own community. Main connection is trust because of sharing.</td>
</tr>
<tr>
<td>2</td>
<td>Well organised, kept to time and lunch was lovely. Well done</td>
</tr>
<tr>
<td>3</td>
<td>It was good to have interaction with the researchers and sharing information and experience with each them and PPI members</td>
</tr>
<tr>
<td>4</td>
<td>Regarding the discussion at the end of the day - as usual the NHSE indicating PPI had forgotten that people do need training in a range of issues. It would help ordinary people to know what training is available and where. Volunteers will vary in their range of understanding and knowledge. There is a lot of duplication - any research needs to be different and specific. Involving all levels of volunteers is important as different types of knowledge etc will be given - but in order for the comments to be valuable/effective people need to understand what is going on and what experience they will be expected to have</td>
</tr>
<tr>
<td>5</td>
<td>Crossmatch PPI members actually experience to projects proposed</td>
</tr>
<tr>
<td>6</td>
<td>Always willing to help whilst life in my bodies. Hopefully with more SU’s. Maybe inclusive of deaf patients and carers who struggle badly</td>
</tr>
</tbody>
</table>
3. Conclusion and recommendations

This well-attended, and well-evaluated workshop enabled all attendees to discuss in-depth an important issue in palliative care research. Several research projects received valuable feedback which will influence how they proceed. Conversations started during the workshop are ongoing, with a number of PPI members asking to be put in touch with researchers for longer term involvement in projects.

Feedback received has identified the following areas for improvement:

a) Include a chance for everyone to say their names and introduce themselves at the start of the day.

b) Inclusion of a patient/carer/PPI led presentation in the programme

c) Ensure the topic is focused on the interests of PPI representatives, whilst remaining relevant to research going on within the department.

d) To consider as a priority the training process for new PPI reps, and to ensure we know enough about individuals’ interests to be able to match upcoming opportunities to experience/interest