

were issued to potential new members (43) and renewing members (13) to a meeting in September 2016. Terms of Reference, which were discussed at the meeting and amended, were issued to 54 people in November 2016. Receipt of a signed copy confirmed membership of the group. A total of 44 members confirmed membership. Since September 2016 they have been involved in a range of activities informing palliative care education, research, policy and practice across both the Republic of Ireland and Northern Ireland.

P-229 **EXPLORING PALLIATIVE CARE NEEDS: A CONSULTATION WITH YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS**

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Background Paediatric palliative care plays an important role in the lives of children and young people with life-limiting conditions and their families. However, the views of young people are rarely sought when improving these services.

Aims This consultation explored the views and experiences of young people, with an aim to inform clinical guidelines.

Methods Qualitative thematic analysis of data collected from 14 young people (aged 12–18) with a life-limiting condition, who took part in focus groups or interviews. Topics explored were information and communication; care planning; place of care; emotional care; and improving services.

Findings Participants were keen to be involved in care planning, although preferences for involvement and information varied and changed over time. Participants emphasised that quality of care was more important than place of care. Aspects that helped them to feel safe and looked after included: access to specialists with knowledge of their condition; being treated as an individual; carers taking time to meet their personalised needs; and continuity of relationships. Participants described a range of negative feelings related to having a serious health condition. Distraction, avoidance, and talking to others were identified as common strategies to manage these. However, some participants expressed unmet needs for emotional care and felt unable to discuss this with others.

Conclusions Providing young people with personalised information and involving them in planning care to the extent they desire can reduce uncertainty about what will happen and when, and minimise disruption to everyday life. This needs to be balanced against their developmental and emotional needs, and the importance to young people of living well rather than focusing on their deteriorating health and end of life.

P-230 **'YOU SAID WE DID': LEARNING FROM SERVICE USERS AT SAINT FRANCIS HOSPICE**

Bridget Moss, Jan Scott, Tracie Brennan, Clare McPartland. *Saint Francis Hospice, Romford, UK*

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Background The Care Quality Commission requires hospices to evidence how views of service users are sought to inform and develop quality of care. Getting constructive comments is

a challenge and can mean a gap in knowledge and understanding.

Aim To gather greater depth on service users' views of the care, using a focus group approach, to generate constructive feedback.

To establish a platform for listening, taking action and informing improvements.

Method Participants were recruited from two support groups and were diverse in age, gender and ethnic origin. All had experienced hospice care. 'You said we did' was emphasised to clarify the purpose. Two key questions guided discussion. Comments were organised into themes of 'What we do well' and 'What can we improve'. Additionally three participants undertook a video recorded interview in an adapted London taxi, provided by Health Watch Essex.

Findings Bereavement support and involvement with the hospice was important to many. Who accessed bereavement services was questioned. Support groups at evenings and weekends were requested. A range of approaches to care and support is needed as one size does not fit all. Extending the opening hours of the hospice shop elicited strong feelings; limited hours had a big impact. Some referral routes were difficult and this caused stress. The video material offers powerful stories.

Conclusion The focus group itself had a big impact on the attendees; being asked for their opinion was highly valued. Some feedback was constructive although further work is needed. Another focus group is planned for October 2017 to feedback on improvements made. The potential for learning from the service users is huge and goes beyond making specific improvements. Funding has been identified to increase bereavement support services. An outcome of the event is recruitment of 12 'Cloud Surfers' who will assist with reviewing marketing material.

P-231 **CREATING OPPORTUNITIES TO EXTEND PATIENT AND CARER INVOLVEMENT IN HOSPICE WORK**

Veronica Mickleburgh. *LOROS Hospice, Leicester, UK*

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Background Our current patient and carer participation group [PCPG] actively engages members with shaping the direction of the hospice whilst simultaneously improving the clinical environment and services.

Aim To create meaningful opportunities for our PCPG members to positively influence our services.

Methods Our three key opportunities are:

- Speaking out – members were invited to explore how we could use their experience in speaking out at LOROS events and to support campaigns involving the local media. Training was provided
- Participating in recruitment of key positions at LOROS
- Increasing the return rate of a comment card scheme – Tell us what you think. Once a month, working with the patient experience lead, members go into clinical areas to engage patients with the scheme.

Results Following training, we now have a programme to utilise their new skills and past experience. So far, our members have attended several events including our annual cathedral concert.

Quote from a PCPG member –