

Introduction and background

Evidence suggests that inconsistency in clinical decision making near the end of life adversely affects patient choice regarding preferred place of death (End of Life Care Programme, 2010; General Medical Council, 2010). Evidence also shows that more than 40% of the UK population die in hospital (NEoLCIN, 2012), despite only 7% of people indicating this as their preference (Shucksmith et al., 2013). Advance Care Planning (ACP) tools and resources can improve patient choice (Houben et al., 2014), however uptake of the resources to support ACP is poor (Lund et al, 2015; Lovell and Yates, 2014). Carers and patients identify this as a priority area for research. As a Palliative Care Clinical Nurse Specialist I have a great interest in understanding clinical decision making for patients approaching the end of life. This led to me to conduct a qualitative research study for my Masters dissertation that explored the experiences of senior oncology doctors when faced with difficult clinical decisions for patients approaching death (Charman and Esterhuizen, 2016). One finding was that a lack of documented information about patients' care and treatment preferences was perceived as impacting negatively on the decision making process. This lack of information was despite tools available to ensure ACP decisions could be recorded.

Following on from my Masters research project, I hope to conduct a doctoral study designed to help us understand more about the decision making and implementation processes involved in using Advance Care Planning in a large oncology centre. I have applied to the recent round of NIHR /HEE Integrated Clinical Academic Clinical Doctoral Research Fellowship (CDRF) to enable me to undertake this study. This mixed methods study will focus on patients with advanced lung cancer, their carers and clinicians. Ultimately, I hope this will add to the current knowledge base but also have a real impact on the involvement of patients in planning their own care with clinicians.

Aim

Before progressing further with my proposed doctoral study and CDRF funding application, I wanted to understand what patients and those close to them felt about this area of research and my plans for research design. I wanted to ensure that, if I did undertake this research, it was informed at every step of the way, by what people thought and felt were important issues, rather than just my own perceptions and ideas. I successfully applied for Call 24 round of the RDSYH Public Involvement Grants. I hoped to achieve the following aims:

- Understand from carers and patients, with experience of palliative and end of life care, if this is an area of research they see as valuable and “do-able”
- Understand how best to ensure patients at the end of life and their carers, involved in research, can be supported during and after involvement
- Agree the best way of collaborating throughout the research cycle
- Build partnerships that will ensure PPI involvement is part of every stage of the study, including development of participant information and, ultimately, dissemination.

Method

Initially, I planned to approach two groups based near the proposed research site in Leeds. I approached the coordinator of a patient involvement group based at St Gemmas Hospice in Leeds and the chair of the Yorkshire Cancer Patient Forum to request attendance at their meetings to discuss my research proposal and whether the groups felt they could support ongoing involvement with me for this proposed study. The coordinators of both groups were very supportive, however, the group at St Gemmas was not sustained and, despite posting information on the Yorkshire Cancer Patient forum web page and communicating via the chair, no responses were received.

I had watched the NIHR Webinar on Public Involvement and via, the information links on this presentation, I made contact with two groups based in Sheffield (The Palliative Care Studies Advisory Group (PCSAG) and the Consumer Research Panel (CRP)).

The PCSAG is an established group of patients, carers and bereaved relatives who have a particular interest in supporting research around palliative and end of life care. The CRP is an influential group of patients and carers with an interest in cancer research, who often collaborate closely with researchers.

I made a request, initially via the chair of the PCSAG, Dr Claire Gardiner, for comments on my research proposal, and subsequently was invited to attend a PCSAG meeting to discuss my proposed study in more detail. Claire introduced me to the chair of the CRP, Jacqui Gath. Both kindly supported my approach to group members.

For comments on my research proposal, members of both groups were approached via the respective chairs (to avoid any sense of duress) and sent a covering letter from myself, an electronic copy of the research proposal (as per my CDRF submission) and the Plain English summary. The following questions were asked:

- 1. Do you think this research is of importance and if so why?**
- 2. Do you think that patients and their carers or loved ones will feel able to take part in this sort of research?**
- 3. Are there any words or phrases you don't understand, as this will help me**

write a good summary for others to read.
4.Any other comments are also welcome.

Email response was requested with an offer for telephone contact if this was preferable. A payment of £10 was offered as recompense for time spent. Only one person took up this offer.

I received comments from three members of the PCSAG and 3 members of the CRP. These initial comments led to several email conversations enabling me to gain an insight into their thoughts on, not just the proposal itself, but how to ensure that patient and carer needs were seen as central to the research process. All respondents said they thought this was a valuable piece of research and was an important topic. I was able to amend my research proposal prior to submitting my CDRF application taking account of their thoughts and advice. Because of the positive comments, I was also able to demonstrate that this was an area of research seen as important and essential by these PPI groups. Some contributors sent me links to resources and articles. They were all generous with their time and gave careful consideration to my proposal. Several told me of their own motivation to make a difference and shared stories of their experiences of end of life care. One respondent proof read the documents and made suggestions for complimentary research ideas as well giving their thoughts on a better approach to overall communication within the NHS.

I had also written some vignettes that could be used with PPI groups but had not set up professional focus groups to review these as I wished to ensure there was a forum for discussion to take them to before using time and resources. Palliative care colleagues informally reviewed them and did feel they were fit for purpose. Ultimately I did not use these Vignettes as the groups I engaged with commented by email initially so had gained some insight from reading the plain English summary of my research proposal. I had also planned to have a colleague present when I met with any groups to provide support if the subject matter caused distress. As the meeting I eventually attended was with a group who often consider research about end of life issues this was not deemed necessary.

Comments from contributors

Detailed below are some of the comments from contributors followed by the impact of this on my plans:

1.Do you think this research is of importance and if so why?

"I do feel that this research is of importance, as it should help people providing care an insight into how patients and carers feel about ACP. It may well show that there is a difference between patients' and carers' perceptions of what End of Life care needs to be. It should also allow staff to consider what they think about EoLC and ACP and how this affects them both at work and in their own lives."

This comment made me think about how research is a process that impacts on both patients and professionals.

“Yes I do – I find very little evidence of ACP in practice – it is a difficult subject for people to deal with. I know someone who has done ACP and they are “evangelistic” about it but I think they are in a small minority. Quite recently an organisation I am involved with asked it’s members what issues it should address going forward and “End of Life Care” scored strongly so people are saying give us the opportunity to discuss and we will take it but I suspect few people would initiate discussion themselves – very few would know how. It is an interesting question as to what just might provide the trigger for such a discussion.”

“I think this work is very important, even though only a small part of the whole palliative care experience a patient undergoes.”

This person also acknowledged that ACP is a very individual process but that *“planning is necessary for the sake of family and friends, and their own peace of mind.”*

“this is an important research topic”

These comments reassured me that there is a value in conducting this research and encouraged me to continue in my endeavours to apply for the CDRF fellowship.

2. Do you think that patients and their carers or loved ones will feel able to take part in this sort of research?

“I do think that people will be happy to be included but of course there will be people who would find this to hard to bear, so a measured approach and understanding will need to be at the fore front of this....”

“I don't see any problem here, the main considerations will be ethical and easily overcome with due diligence and planning.”

“I think that you will find patients who are willing to participate but also a bit of reluctance to deal with this subject”

These comments made me reflect more deeply about how to engage potential research participants in the research process without duress. This aspect of was reflected in my research plan in more depth because of these comments.

3. Are there any words or phrases you don't understand, as this will help me write a good summary for others to read.

“The documents are well written and the lay summary very good.”

Contributors made suggestions for word changes to make meaning clear, many of which were incorporated.

4. Any other comments are also welcome.

One person made very helpful suggestions on how to ensure the care and well-being of research participants and also ways to acknowledge their input. I was able to incorporate these into my research plan.

Others reiterated their support for the proposed research and explained their reasons for this.

I was invited to attend both groups, however due to time constraints and other requests to the CRP, it was agreed that I would attend only the PCSAG meeting. I attended on the 4th July 2016 (after CDRF submission) with four members, the Chair and another researcher present. We were able to reflect the proposed research and I shared my motivation for wanting to conduct this study. We had a good discussion about potential sources of bias and how this could be minimised. I was able to ask for their on-going collaboration, if successful in my funding application. I found their insights and input extremely valuable. The PCSAG were keen to hear about my progress over the next few months and agreed I could keep in touch via the chair. We provisionally agreed that, if I was funded and able to start my doctoral study, a member of the PCSAG would attend a 6 monthly advisory group meeting and also be part of separate work to look at Participant information. I was invited to attend future meetings to maintain a collaborative relationship.

At this meeting I explained about some of the current ACP tools such as a Preferred Priorities of Care Document that I had used in practice. I was able to send an electronic copy to the group via Dr Gardiner as those present wanted to consider this for their own use and to take back to other groups.

Evaluation

When I attended the PCSAG, I asked members to complete NIHR RDSYH evaluation forms and provided these and a stamped addressed envelope so people could fill them in and return at their convenience. I only received one returned form, which was a positive review of their involvement. I have since asked via the chair if any other participants would be able to send back the evaluation form. I also received one feedback form from a member of the CRP.

Reflections

This has been a very interesting process for me. I normally meet patients and carers in my clinical role as a palliative care nurse specialist and although I always try to talk to people in a collaborative manner and act as a patient advocate, there was a real difference in this interaction. I feel that building this relationship with the PCSAG will increase my understanding of research participants' perspective and keep the research grounded in the "real world" of patients and carers.

Finding a group to comment or collaborate with in the west Yorkshire region was a real challenge and this reflects other colleagues' (in palliative and end of life care research) experiences. Other researchers in the Leeds region and

myself plan to work both together and with the Sheffield groups to understand how we can build capacity locally.

The eventual public involvement work differed from the approach proposed in my original grant application. This original plan was much more involved because one of the groups was in it's infancy and I was concerned about causing distress by discussing end of life care with those facing their own death or who had suffered a bereavement. It is clear that by approaching through a third party, those who wished to engage were able to do so and those who didn't could decline involvement. I can see that developing approaches to patient and carer contact with the support of a PPI group will give a different perspective to my proposed research study and is to be valued.

Funding spending

Award	£500
Spends Lunch and travel costs for PCSAG attendees on 5 th July 16	£99.70

Award- £500	Costs	Amount	Balance
	Lunch and travel costs for PCSAG members	£99.70	£400.30
	Marks and spencer voucher for contributor remuneration	£10.00 (To claim back)	£390.30 (Once claimed back)

Future Plans

As I hope to continue to meet with the PCSAG, I anticipate future spends will be required against this award. I may need to write to members and provide refreshments or remuneration for meeting time etc. I have also built into my HEE/NIHR CDRF application the costs for on-going PPI work throughout the fellowship. I will discuss with the RDS team how best to utilise the outstanding grant. I will hear the CDRF panel's shortlisting decision by 29th September and, if successful, interviews will be held in mid November.