



**Optimising person-centred escalation plans and communication across health and social care systems: experiences of patients, families and practitioners to sustain innovations during and after COVID-19 pandemic.**



## Summary

### Planning for Future Care During the Covid-19 Pandemic:

#### A Qualitative Interview Study

- Data collection completed Sept 2022
- 23 participants recruited (5 in a 1:1 interview; 8 in four dyad interviews, 10 in 3 focus group interviews)
- Participants included patients and a caregiver, palliative care clinicians.
- Data transcription completed December 2022
- Training provided for research assistant and two PCIE members on qualitative research and qualitative data analysis February 2023.
- Data analysis ongoing- Research lead, research assistant and two PCIE members involved in data analysis- using thematic analysis and framework approach.
- Dissemination activities include presentations at:
  - KSS Supportive & Palliative Care Research Event March 1st 2023.
  - NIHR ARC KSS Autumn Research Symposium 2022.

- We will submit an abstract of our findings to the Hospice UK Conference November 6-8 2023.
- We will prepare a manuscript for publication to a peer reviewed journal. Initially we will submit to the Palliative Medicine Journal.

#### Building research capacity:

- Developing hospice research governance capacity at all levels of the organisation.
- Fortnightly research team meetings
- We are actively seeking support and training to strengthen capacity for Research Governance (including regular meetings with the deliverables team at KSS CRN). I am working with the Director of service improvement, research and education to improve our research Governance infrastructure. This includes incorporating research governance responsibilities into the role of a Strategic Projects Manager.
- Supported Director of service improvement, research and education – to present at KSS CRN Research in palliative care event March 2nd 2023. Title of presentation: 'Research at St Barnabas Hospices', with a focus on



- organisational support for research and development of our research governance capacity.
- I am supporting our research assistant to develop research management and delivery knowledge and skills. She has responsibility for day to day management of research studies where we are a recruitment site or a participant identification centre. She is now able to liaise with site teams 3 and has delegated responsibility for managing local site files and local standard operating procedures under the supervision of the research lead and the study PI. She also has delegated day to day responsibility for running our PCIE group. She is involved in writing our new PCIE strategy and is leading on writing information material for new PCIE members.
- Supporting strategic project manager to network with Turning Tides Homelessness Charity, Brighton and Hove LGBTQ Switchboard, Dementia Hub Worthing to complete applications for two UKRI Community Research Network awards. We aim to develop a research network to address health inequalities towards the end of life in underserved coastal communities.

## Public and Community Involvement

### Building PCIE capacity

The PCIE group now has six active members and we have held four PCIE meetings at STBH in this reporting period.

**August 18th, 2022** - Three members attended and provided:

- Oversight over the current research activity at STBH. Members were supportive of
- the range of studies being opened at the hospice.
- Review of research processes for a University of Chichester Speech and Language Therapist's PhD research project
- Support for an application for a UKRI Community Research Network Grant
- application. The applicant's included STBH, Turning Tides Homelessness Charity, 4 Brighton and Hove LGBTQ, Dementia Hub Worthing. The application was unsuccessful, but the applicants are working on future applications.

### February 16th, 24th and March 3rd, 2023

Two PCIE members are involved in analysing data for the Adapting advance care planning studies, as indicated in the grant award and study protocol. We held a training session on qualitative research and qualitative data analysis, and to date, three data analysis sessions. Members were keen to support our participation in a grant application for funding for STBH to join a community research network with partners across our locality.

### NIHR RE-EQUIPP Partnership:

Two of our PCIE members participated in the NIHR Re-EQUIPP Partnership. One member participated and contributed to a Dragon's Den event in November 2022, where research ideas generated by the partnership were presented and critiqued. Both members will be PCIE members on grant applications arising from the partnership alongside PPI members from the Cicely Saunders Institute Public Involvement



Forum and PPI members from the University of Sheffield's palliative care research group. The RE-EQUIPP partnership is providing our PCIE members with a wider range of opportunities for involvement and engagement with national palliative care research studies.

## Widening our membership:

We continue to work to diversify our PCIE group membership. As a result of networking during the Grant Application to form a community research network, we now have PCIE members representing the Homeless Community from the Turning Tides Homelessness Charity and from the Brighton and Hove LGBTQ Switchboard. We are also engaging with members of the local Muslim and Bangladeshi communities.

## Dissemination

- Presented study progress at KSS ARC event – 29 09 22.
- Presented summary of study and PCIE capacity building at KSS CRN palliative care research event March 2023.

## Impact and Implementation

We anticipate that the findings of the Adapting Advance Care Planning Study will impact on the provision of Advance Care planning within the organisation at St Barnabas Hospices. The findings will be presented and discussed across all levels of the organisation, through targeted

communications, service improvement and quality activities. The findings also have the potential to impact on local integrated working across the across ECHO network and lead to improvements in the organisation and delivery of advance care planning processes. To facilitate these improvements, we will hold knowledge exchange to share and discuss the findings with our integrated ECHO hub network partners when data analysis complete.

## Publications

- [How does research inform hospice care? - St Barnabas House \(stbarnabashospice.org.uk\)](https://stbarnabashospice.org.uk)  
The new Research Assistant worked with the external comms team at St Barnabas to write a blog for the St Barnabas House website. The post introduces the research team and explains the contribution research makes to care and peoples' quality of life. This has proved an effective method of communication, as a member of the public contacted the research team to join the PCIE group as a direct result of reading the blog post.
- I am the lead author on A Protocol Paper for the INSPIRE project submitted in early February 2023 to the Palliative and Social Care Journal (currently undergoing peer review).