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St Barnabas
House
{Hospice
Care}

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Chestnut
Tree House
{Children's
Hospice Care}



Research Newsletter from St Barnabas Hospices

Issue 1, Autumn/Winter 2023

Welcome to the first issue of the St Barnabas Hospices Research Newsletter. Newsletters will be written biannually to share our highlights and milestones with you as we expand our research activities at both our hospices, St Barnabas House and Chestnut Tree House. We welcome your feedback and questions, so if you would like to see something added to the newsletter, please let us know via research@stbh.org.uk or on 01903 706300 ext. 6086

Reflecting on Our Progress and Planning for Future Research



St Barnabas House Hospice



Chestnut Tree House Hospice

Before sharing an update on our research activities, we wanted to provide some background information on the history of our research team and detail our plans for research going forward.

In 2019, Monica Oancea, a Clinical Nurse Specialist at St Barnabas Hospices, was awarded a Florence Nightingale Research Scholarship. The main goal of the scholarship was to build research capability and capacity at St Barnabas Hospices. As a result of Monica's scholarship, Dr Jo Bayly joined the hospices as Research Lead in 2020 (on secondment from the Cicely Saunders Institute, King's College London) and Phoebe Cooper later joined as Research Assistant in 2021. Dr Tabitha Baker joined the hospices in the role of Strategic Projects Manager in 2022.

Although Monica recently left the hospices to work elsewhere in the local community, she leaves a lasting legacy as the hospices' research capacity continues to grow. We have recently developed a new Research Strategy, aligned with our Care Strategy, to direct our research activities over the next three years. Our key priorities for the 2023/24 period will be to continue to participate in portfolio studies, aiming to recruit patients from all our service areas and across both hospices.

Building and extending our research capacity will be prioritised throughout 2023/24, and our work with the Sussex Hospices Research Collaborative will widen our network and increase opportunities for collaboration. We will continue to develop our research governance infrastructure and ensure that our research governance activities are underpinned by the requisite training and skills. Finally, we will continue to seek and apply for competitive external funding to ensure the sustainability of our research, develop links with academic partners, and to ensure that palliative and end of life care in Sussex continues to be informed by excellent research.

Meet the Research Team



Dr Jo Bayly, Research Lead - [Jo Bayly | LinkedIn](#)

Prior to starting her career in research, Jo was a Specialist Physiotherapist in Palliative Care at a hospice in Liverpool. She completed a PhD in Health Services Research at the Cicely Saunders Institute, King's College London (KCL) in 2020. She is now a Research Fellow at KCL and is seconded to work at St Barnabas Hospices two days per week. She leads on research at St Barnabas Hospices, building research capacity and capability, to ensure people accessing our services have opportunities to participate in research. At KCL, she is the Scientific Project Manager for the Inspire Randomised Controlled Trial. [INSPIRE - Integrated short-term palliative rehabilitation \(palliativeprojects.eu\)](#)



Dr Tabitha Baker, Strategic Projects Manager - [Tabitha Baker | LinkedIn](#)

Tabitha joined St Barnabas Hospices in 2022 following a career in research management at the University of Oxford. Prior to this, Tabitha completed a PhD in History at the University of Warwick and Victoria & Albert Museum. Tabitha supports the Research Team with research governance, ensuring that our research activities are conducted within the appropriate ethical, legal and professional frameworks.



Phoebe Cooper, Research Assistant - [Phoebe Cooper | LinkedIn](#)

Phoebe has just completed a master's in Clinical Neuroscience at UCL and hopes to begin training as a Clinical Psychologist in the near future. Her current focus is on growing the PCIE group and research administration, including managing recruitment to ongoing studies and analysing data for the Planning Future Care During Covid-19 study.

Study Progress: Planning Future Care During Covid-19: An Interview Study

In this study, we interviewed people to find out what it was like to talk about future care plans during the Covid-19 pandemic. It was a time of great uncertainty and rapid change, and decisions were made quickly. To understand peoples' experiences and to learn for potential future pandemics, we interviewed patients, their relatives/carers, hospice nurses and doctors, GPs, community nurses and NHS commissioners. We are currently analysing the interview data and hope to report our findings soon.



Previous research studies at our hospices

During the four years our research team has been assembled, St Barnabas House Hospice and Chestnut Tree House Hospice have participated in a number of national research studies detailed below.

CovPall – ‘Rapid Evaluation of the COVID-19 Pandemic Response in Palliative & End of Life Care’. This project was set up to understand how hospices and palliative care services responded to the COVID-19 pandemic. The results showed the problems faced by patients, families, and services. The study describes some of the challenges in detail along with how services were able to respond. 19 participants were recruited for this study through St Barnabas House. The results of the study can be found here: <https://www.kcl.ac.uk/research/covpall>

DIScOVER (Comparing DISability in activities of daily living OVER time among adults with advanced respiratory disease during the COVID-19 pandemic) – Patients with lung cancer or lung disease took part in this project. It investigated how these illnesses affect peoples’ daily activities such as dressing, walking, shopping, and social events over time. The aim was to understand the difficulties people experience better, and to learn how treatments and services can be modified and improved where needed. 10 participants were recruited for this study through St Barnabas House.

The Out of Hours Project – This study found out how hospices and palliative care services in the UK can provide the best care for patients outside of normal working hours. St Barnabas House took part in two phases of the project. In one phase, participants recruited from St Barnabas told researchers about how we provide care outside of normal working hours in this area of Sussex. In a later phase, patients and their families/carers told the researchers about their experiences of receiving care outside of normal working hours. 10 participants from St Barnabas Hospices participated in total, recruited across two phases of the project. You can find out more information about this project here: <https://www.kcl.ac.uk/research/out-of-hours-community-palliative-care>

SWiCH (Staff Wellbeing in Children’s Hospices) – The term ‘burnout’ refers to mental and/or physical suffering as a result of stress, particularly due to workplace pressures. When healthcare staff experience this it can have many negative consequences for them and others. The SWiCH study sought to find out about burnout in care staff working in UK children’s hospices and what support was in place for them. Staff from Chestnut Tree House completed surveys for this study. Read more about the findings here: <https://spcare.bmj.com/content/early/2023/08/29/spcare-2022-004056>

C-POS Phase 1: Delphi Survey – A questionnaire called the **Children’s Palliative Outcome Scale (C-POS)** is currently being developed by researchers from the Cicely Saunders Institute at King’s College London. The questionnaire is to help healthcare professionals understand children and young people’s needs and feelings, as well as those of their family and/or carers. This phase of the study evaluated which topics were most important to children, young people and their families. Some of the families at Chestnut Tree House took part in this phase. Find out more here: <https://www.kcl.ac.uk/research/c-pos>

C-POS Phase 2: Cognitive Interviews – Children, young people, and their parents/carers at Chestnut Tree House were interviewed for the next phase of C-POS to see whether they interpreted and understood the questions as researchers intended. 7 families were recruited for this study via Chestnut Tree House. <https://www.kcl.ac.uk/research/c-pos>

Ongoing research at our hospices

C-POS (Children's Palliative Outcome Scale) Phase 2: Validation *Mar 2023 – Jan 2024*

Chestnut Tree House was involved in two previous phases of the C-POS study, which is focused on the development of a new questionnaire to help understand children and young people's needs and feelings (as well as those of their family and/or carers). In the current phase of the study, the C-POS team are checking the reliability and validity of the new questionnaire by asking families to complete it and nominate their key workers to complete it too, if they wish. Chestnut Tree House have been asked to recruit 10 families for this phase before December 2023. To date, we have recruited 4 families and 1 healthcare professional to the C-POS study.

CHELsea II (Clinically Assisted Hydration at the End of Life) *Dec 2022 – Oct 2024*

The aim of the CHELsea II trial is to assess whether providing fluids via a drip for people in their last days of life ("clinically-assisted hydration", CAH) prevents them from developing delirium ("terminal agitation"). This problem often occurs at end-of-life, and causes distress to patients (e.g. confusion, restlessness), families, and healthcare professionals. Furthermore, it often means that the patient requires sedating in the last days of life. The trial will also explore if CAH affects other end-of-life problems (e.g. noisy breathing, shortness of breath), causes any side effects, and affects length of survival. The inpatient unit at St Barnabas House is in Arm A of the study which is the control arm. This means that clinically assisted hydration will only be provided if clinically indicated. We have been asked to recruit 20 participants by October 2024 and have recruited 16 participants to date. Find out more here: <https://www.surrey.ac.uk/chelsea-ii-trial>

The MND (Motor Neurone Disease) Register *Ongoing*

MND is a rare disease and there is a need for more effective treatments. This register helps to improve care and treatments for people living with the disease. The information will help healthcare providers to find out which care and support works best for people with MND and could assist in the development of new treatments. We are adding data to the MND Register as new referrals come into the hospice. The MND database continues to grow and has already become a source of useful information for researchers improving care and treatment for people with MND. To date, 19 people have been added to the register from St Barnabas House. Read more about the study here: <https://www.mndassociation.org/research/our-research/research-we-fund/improving-standards-of-care/mnd-register-england-wales-and-northern-ireland>

The Hospice at Home Toolkit *May 2023 – October 2023*

A large number of people now choose to spend their last days of life in their own homes. 'Hospice at Home' teams provide a high level of palliative care for people approaching end of life in the comfort of their home surroundings. Researchers at the University of Kent have developed a new toolkit which provides Hospice at Home services with a structured method to evaluate which elements of service are performing well, as well as revealing areas that can be improved. The St Barnabas House Hospice at Home and Research Teams met with a researcher from the University of Kent and piloted using the toolkit. The St Barnabas Hospice at Home team are now reviewing the findings from our self-evaluation and will let the researchers who created the toolkit know if it leads to any changes in how our service is provided.

Planning Future Care During Covid-19 Study *June 2022 – December 2023*

This qualitative interview study, funded by the Applied Research Collaborative, Kent Surrey Sussex, was set up and conducted by the research team at St Barnabas Hospice to understand what it was like to have conversations about available care and preferences for care during the Covid-19 pandemic. In total, 23 participants participated in interviews. This included patients, family members, healthcare professionals and commissioners from both the hospice and the wider local community. As explained below, data analysis is well under way and members of our PCIE (Public and Community Involvement and Engagement) Group are involved.

Data Analysis with the PCIE Group

Members of our PCIE (Public and Community Involvement and Engagement) group bring a wealth of knowledge and lived experience to our research at the hospices, and we really value their perspectives and feedback. As part of St Barnabas Hospices' own study on Planning Future Care during the Covid-19 pandemic (see section above), we have collected a lot of interview data from a varied group of participants.

After receiving training in data analysis from Jo, two members of the PCIE group analysed some anonymised interview extracts from our study. Additional sessions were held for further analysis and discussing identified themes. Analysis involves finding 'units of meaning' in the text that help us to answer our research question. These meaning units are described as 'codes' and as the analysis progresses, they are combined into meaningful themes. The codes and themes are discussed and interpreted to gain insights and understanding from the interview data. The PCIE group found some meaningful quotes in the interviews and provided some important insights during analysis. We hope to hold more data analysis sessions with PCIE members

Recent presentations, publications & conferences

SimNet Conference – Optimise Simulation

May 2023, Canterbury Christ Church University

Our colleagues Chrissy Goodban (Head of Education) and John Lansdell (Lecturer Practitioner) won 'Best Abstract' at the SimNet Optimise Simulation Conference held at Canterbury Christchurch University in May. The abstract was titled 'The Introduction of simulation-based education in a hospice setting.' Chrissy said:



“The conference workshop was a great opportunity to discuss the work that we are doing to introduce Simulation Based Education into the hospice setting. There was a lot of discussion generated and the importance of an MDT approach was highlighted. Participants gave ideas on priority areas where simulation could be useful such as in supporting the recognition of the clinical signs of dying. Benefits of this approach were shared such as having the ability to try practical skills and communication skills out and having a chance to learn in a ‘safe’ environment. Personally, I was encouraged as the perspectives of the learners aligned with the plans that we have started to implement, and this was a good endorsement of the approach that we are using.”

2023

Policy Brief on
Integrating Rehabilitation
into Palliative Care
(World Health Organisation)



Copenhagen: WHO Regional
Office for Europe; 2023. Licence:
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[WHO-EURO-2023-5825-45590-
68173-eng.pdf](https://www.who.int/publications/i/item/WHO-EURO-2023-5825-45590-68173-eng.pdf)

(Co-written by Jo Bayly)

Recent presentations, publications & conferences (continued)

August 2023

Using volunteers to improve access to community rehabilitation in palliative care: The St Christopher's Living Well at Home Team

Preston et al. (incl. Jo Bayly)
Frontiers in Rehabilitation Sciences
<https://doi.org/10.1183/16000617.0243-2022>

June 2023

Integrated Short-term Palliative Rehabilitation to improve quality of life and equitable care access in incurable cancer (INSPIRE): a multinational European research project

Bayly et al.
Palliative Care & Social Practice
<https://doi.org/10.1177/26323524231179979>

March 2023

Meditative movement for breathlessness in advanced COPD or cancer: a systematic review and meta-analysis

Nolan et al. (incl. Jo Bayly)
European Respiratory Review
<https://doi.org/10.1183/16000617.0243-2022>

December 2021

Understanding the impact of the Covid-19 pandemic on delivery of rehabilitation in specialist palliative care services: An analysis of the CovPall-Rehab survey data

Bayly et al.
Palliative Medicine
<https://doi.org/10.1177/02692163211063397>

Common elements of service delivery models that optimise quality of life and health service use among older people with advanced progressive conditions: a tertiary systematic review

Bayly et al.
BMJ Open
<http://dx.doi.org/10.1136/bmjopen-2020-048417>