Research Matters

Pilgrims Hospices

Spring 2026

Doing research to improve care & practice

Research Reflections from Andrew Thorns

Many years ago not long after I started at Pilgrims, I was told by the then chief executive that “we don’t do research because we are too busy looking after our patients”. But how do we know how best to look after our patients without the research? And what do our patients think about this?

As Charlotte Brigden describes below patients and those close to them value being asked to take part in research.

A previous colleague always held that the consultations we have with patients are in themselves therapeutic. But what is it about the way we work with people that helps? And how can we share these skills with other colleagues? Charlotte Davies (the first person to undertake a PhD at Pilgrims) is planning to tell us in what is truly valuable and groundbreaking research.

Delirium was always the commonest reason I would be woken at night when on call, but more importantly it is a frightening experience for patients and so hard for those close to them to see. So the benefit we will see from the work we are doing on delirium will be hugely beneficial. Great credit to Mandy Timms for her dedication to this important area.

Do have read through the rest of the report and see where our work is being published. And keep an eye out for some truly inspiring work coming soon. Called “Last Breaths”, a journalist Cathy Fitzgerald, is planning to work with patients who are dying under our care.

Finally special thanks have to go to Charlotte Brigden for her knowledge, experience and commitment. Special thanks also to the Trustees and the executive team for their ongoing support of the research work. We aim to embed research and evidence from “board to the bedside”.

Pilgrims Hospices Research Team

Charlotte Brigden
Research Facilitator

Dr Andrew Thorns
Consultant & Research Lead

We also work closely with the research delivery team at the NIHR South East Research Delivery Network (RDN), who support us with the delivery of research studies.

Bethany Jones
Research Practitioner

Pamela Brunning
Research Nurse

Find out more about the RDN here: **rdforum.nhs.uk/wp-content/uploads/2025/10/Research-Delivery-Network-brochure-1.pdf**

We also value the support of hospice volunteers to support our research. Mike Hornsey joined us as a Research Volunteer last year. He is a solicitor and has been retraining as a psychologist, completing training in counselling, psychotherapy, and a MSc in Psychology. He was interested to volunteer to learn about research in healthcare settings and Pilgrims Hospice is particularly important to him:

> *“They cared for both my grandmother and mother in their final days (both over 10 years ago) and I greatly appreciated the warmth and kindness of staff”*

Mike supports us as a committee member on the Pilgrims Hospice Research Facilitation and Governance Forum, helping us to review new research proposals and overseeing current research from a public perspective and from his lived experience. He is also supporting us with the POST study currently.

The POST study is a survey looking to answer the research question: *What do individuals known to palliative care and oncology services think about the terminology used to describe them?*

It is looking to understand cancer patient views on the term “cancer survivor” in particular, as its meaning is not standardised or universally understood. The study, being led by Prof Andrew Davies at Our Lady’s Hospice and Care Services in Dublin, is being undertaken in five countries: Ireland, UK, Australia, Canada and the USA. Dr Temi Oyepitan at PHC is leading the study within Pilgrims.

Charlotte Davies, developing the way for Comprehensive Palliative Care Assessment

Congratulations to Charlotte Davies, ACP at Pilgrims Hospice Ashford who successfully applied to Cicely Saunders Institute, Kings College London, to undertake a part time PhD. She started in June and will focus on research to develop a standardised comprehensive palliative care assessment (CPCA) to improve person-centred assessment and understand what is required to support its implementation into routine hospice care.

How did this all begin?

The project proposed the development of a "comprehensive palliative care assessment" (CPCA) and accompanied training, similar to the 'Comprehensive Geriatric Assessment' pmc.ncbi.nlm.nih.gov/articles/PMC4282277/, but specifically tailored to palliative care. There is good evidence that patients who receive a CGA have better outcomes. Palliative care has not been specifically linked to assessment in the same way as a CGA i.e. as a process, as a live document.

CPCA will provide a framework for how best to guide a consultation and use assessments to meet the needs of patients in a comprehensive way, deploying the right people around the patient, putting the patient and their needs at the centre of how we deliver their care.

The hospice's mission for this work was:

Patients and families, facing life limiting illnesses in the last year of life, will have a comprehensive palliative care assessment of concerns, needs and wishes. The assessment will be holistic, with concerns for spiritual, psychological, social, physical and future needs explored, at the right time, in the right place and by the right person-expert healthcare professionals who provide consistency of assessment and evidence based skills and knowledge.

In 2022 a small working group of Pilgrims Hospices staff first met to explore if:

- we can define a comprehensive palliative care assessment?
- how to do it? – through existing or further research
- introduce the resulting CPCA as a structured approach into practice and evaluate.

Pilgrims Hospices

Comprehensive Palliative Care Assessment:

What does the evidence tell us?

Authors:

Charlotte Brigden[1], Charlotte Davies[1], Debbie Boots[1], Andrew Thorns[1], Rebecca Bright[2], Sophie Van-Walwyk[1], Justine Robinson[1], Laura Bacon[1]

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Background

The Comprehensive Geriatric Assessment (CGA) is a standard assessment in frail people leading to better care and outcomes for patients and their families. Comprehensive Palliative Care Assessment (CPCA) has never been defined or validated in the same way as the CGA. A number of tools assessing unmet palliative care needs exist but do not link directly to clinical intervention, facilitate interaction between clinicians and patients, nor adequately address patient complexity across holistic domains of care [1,2].

Encouraging people to engage earlier with therapeutic services

Aim

To review the evidence on the features defining a CPCA as a structured approach, similar to CGA.

Methods

A literature review in October 2021 (updated September 2024) identified the current evidence base. Findings were reviewed by a hospice multi-disciplinary working group.

Results

The review identified the domains that should be present within a CPCA [2, 3]. There were five over-arching domains. However, evidence that considered these domains did not produce a structured framework that captured the CGA approach i.e. a living document beyond the first assessment, used by the whole multi-disciplinary team. Conversely, literature that did consider a similar approach was not informed by the breadth of domains identified in the literature [5].

5 domains that a CPCA should include:

Quality Improvement Project

The first iteration of the CPCA framework was introduced to a focus group of health professionals (in palliative care and/or familiar with the CGA) for discussion and initial evaluation. This was then tested by four community Palliative Specialist Nurses, looking at the usability of the framework. Results showed a transformation in symptom assessment, especially within pain, nausea and spiritual care, and an appreciation of domains to guide the consultation.

Improving equity, equality and accessibility within palliative care

Discussion

There was good agreement within the palliative care literature about the necessary content of a CPCA. This in turn informed the development of a CPCA framework for use when assessing the needs of patients and their loved ones receiving specialist palliative care. We have taken a person-centred approach, rather than a checklist, to guide conversations with patients about their needs and future care.

The future

A hopeful PhD project, that will further refine the CPCA and assess its implementation.

Listen, empathise, plan together in a structured way

References

1. Schmidt EB, Blum D, Domeisen BF, et al. Tools for guiding interventions to address patient-perceived multidimensional unmet healthcare needs in palliative care: systematic literature review. BMJ Support Palliat Care. 2023 Oct;13(e1):e1-e9. doi: 10.1136/bmjspcare-2020-002495.
2. Bryk A, Roberts G, Hudson P, et al. The concept of holism applied in recent palliative care practice: A scoping review. Palliat Med. 2023 Jan;37(1):26-39. doi: 10.1177/02692163221129999
3. Goni-Fuste B, Crespo I, Monforte-Royo C, et al. What defines the comprehensive assessment of needs in palliative care? An integrative systematic review. Palliative Medicine. 2021;35(4):651-669.
4. National Cancer Action Team (2010) Holistic common assessment: NHS National End of Life Care Programme.
5. Birgisdóttir D, Duarte A, Dahlman A,et al. A novel care guide for personalised palliative care - a national initiative for improved quality of care. BMC Palliat Care. 2021 Nov 11;20(1):176. doi: 10.1186/s12904-021-00874-4.

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Poster 281 April 2025

The working group has identified domains of a CPCA from the existing literature and developed an initial CPCA document. An audit of patient notes was also conducted to see how we are covering these domains in our current practice within consultations. The results for this work have been presented as posters at the Association for Palliative Medicine and European Association for Palliative care conferences in 2025. Abstracts are available here:

spcare.bmj.com/content/15/Suppl_2/A46.1

journals.sagepub.com/doiepub/10.1177/02692163251335482 (p401)

Charlotte Davies then conducted focus groups with health care professionals to review the document and she piloted the document with our community nurses who used it in consultations with patients. The feedback from this work is now being utilised in Charlotte's PhD which will develop the CPCA further, including the involvement of patients views and experiences in its co-design and use. The next step would be a feasibility study of the CPCA in different hospice settings.

Congratulations to Hayley Sherwood for MSc Success

Trainee Advanced Clinical Practitioner, Hayley Sherwood, is Pilgrims first home-grown MSc in Advanced Clinical Practice graduate, who recently completing her studies. She achieved an outstanding 85% (high distinction) for her dissertation research project called "Addressing Sexual Intimacy in Palliative Care: Perspectives of a Hospice's Multidisciplinary Team"Head of Nursing, Kate White said:

> *"Hayley has worked incredibly hard to achieve this milestone, and we are so proud of her"*

The conclusions of Hayley's research are that sexual intimacy remains inconsistently addressed in practice, despite it being increasingly recognised as an important aspect of holistic palliative care. She highlighted a clear gap between recognition and implementation, suggesting the need for clearer role guidance, targeted education, and formal integration within holistic assessment processes to better support patients' needs.

Hayley was encouraged to publish her findings as a journal article by her dissertation markers, and is considering this in the future – well done and well deserved, Hayley.

Lisa Gower Awarded Research Internship

Congratulations and well done to Lisa Gower, Trainee Advanced Clinical Practitioner, who successfully applied to the NIHR, to undertake a research internship. Lisa is one of 23 interns starting the internship in March across Kent, Surrey and Sussex. The purpose of the internship is to support Health and Care Professionals to develop their research skills and capacity.

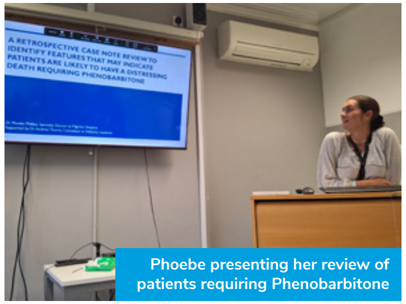
This is a bespoke programme which is tailored to individuals needs and Lisa plans to undertake some academic research modules, networking time with Kings, and develop a research project to help support referral of patients with end stage liver disease to the hospice. The internship will help Lisa to fulfil her research pillar as part for her advanced practice and with future leadership in research.

Study Day Success at Pilgrims

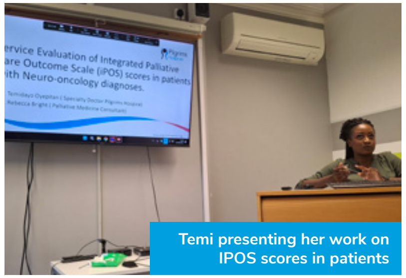
Palliative care medics and clinicians from across the Kent region, including two of our Trustees, joined in us for a medical study day at the Ann Robertson Centre in October. The day was organised and facilitated by Doctors Temi Oyepitan and Phoebe Phillips, and chaired by Dr Andrew Thorns, to share the research and evaluation work by Pilgrims staff and learn from invited guest speakers.

The day featured a presentation by Mandy Timms and Charlotte Brigden on the development and evaluation of the delirium toolkit.

Temi presented her work on IPOS scores in patients with neuro-oncology diagnoses. Phoebe, presented her case note review of patients requiring Phenobarbitone. Charlotte Davies presented her work on comprehensive palliative care assessment.

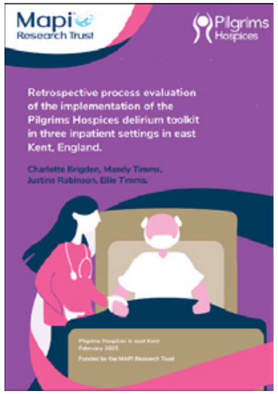


Phoebe presenting her review of patients requiring Phenobarbitone



Temi presenting her work on IPOS scores in patients

Retired palliative care Consultant Dr Victor Pace shared his wisdom on managing seizures in palliative care. The Transition Team from the Demelza Children's Hospice presented their service supporting teenagers and young adults who will be moving from their care to adult services. The day was completed by EKHUFT Psychiatrist who offered a Psychiatry Q+A session, where he answered questions posed by the audience which also made for useful discussion.



Mapi Research Trust

Pilgrims Hospices

Retrospective process evaluation of the implementation of the Pilgrims Hospices delirium toolkit in three inpatient settings in east Kent, England.

Charlotte Brigden, Mandy Timms, Justine Robinson, Ellie Timms.

Pilgrims Hospices in east Kent
February 2025

Funded by the MAPI Research Trust

Feedback on the day was positive, with attendees finding the day informative, interesting and thought provoking with relevant content.

The full report of the delirium toolkit project is available here: **www.pilgrimshospices.org/wp-content/uploads/2025/06/Delirium-toolkit-evaluation-final-report-02Apr2025.pdf**

Temi presented her project at the Society of British Neurological Surgeons Spring meeting and Phoebe and Charlotte presented their projects at the Hospice UK Annual conference in 2025. The published abstracts are available here:

www.tandfonline.com/doi/full/10.1080/02688697.2025.2486652 (p587)

spcare.bmj.com/content/15/Suppl_4/A38.1.abstract

spcare.bmj.com/content/15/Suppl_4/A37.2.abstract

New Research at Pilgrims

Research to Help Improve Delirium Care (DAMPEN II Project)

One-third of people have delirium when they are admitted to a palliative care unit or hospice and a further one-third develop delirium during their stay. It is a common condition that can result in confusion, lack of awareness of surroundings or being withdrawn, which can be very distressing for patients and the loved ones around them. Delirium can also be hard to recognise. Many of you will be familiar with the Delirium Toolkit that was introduced at Pilgrims Hospices, led by Advanced Clinical Practitioner, Mandy Timms, to help prevent, recognise and manage delirium. The toolkit has a step-by-step checklist for staff to follow, which includes patient information gathering, assessments to be completed, delirium is asked about in daily meetings, and a leaflet and poster have been developed to help raise awareness of delirium to patients and their loved ones. The toolkit has now been used in practice for the last 5 years and results from an evaluation showed that the presence of delirium had reduced since the introduction of the toolkit and staff thought it was of benefit.

Despite this success, there is still more that can be done to engage and support staff to recognise and collectively manage delirium to further improve patient care. Pilgrims Hospice Canterbury – led by Mandy - has become a site for a new research project called the Dampen-Delirium II Study. This study, developed by a research team at the Wolfson Palliative Care Research Centre at University of Hull, and funded by the National Institute of Health and Care Research (NIHR 161360), is testing a new workplace learning approach for staff

(see hhtu.hull.ac.uk/dampen-d-ll/).

Pilgrims is one of 20 hospices taking part in the study across the country. The university will compare what happens when 10 hospices test the approach, alongside 10 hospices who continue their normal ways of working. It will look at how it works in the different hospices and what makes it work well, its value for money, and how it can be adapted to work in different settings, such as care homes and people's own homes.

DAMPen-Delirium II

Are you the missing piece?

Raising Awareness and Choice for Eye Donation (the EDiPPPP Project)

Research, funded by the National Institute for Health Research[1] and conducted by the University of Southampton in partnership with the National Health Service Blood and Transplant Organ and Tissue Donation and Transplant (NHSBT OTDT), found that many patients in hospice settings are eligible for eye donation. Many patients who are not able to donate organs or tissues may be able to donate their eyes, but the problem is that that very few patients are asked about this option despite the evidence that patients are willing to have this discussion [1.]

Donating eyes helps restore sight to people who have no or little sight caused by eye disease, injury, or eye conditions present at birth. Currently there is not enough eye tissue available to meet current need. The cornea is the clear outer layer of tissue at the front of the eye which lets in light to help you see. It is used in corneal transplant operations. The sclera (the white of eye) is used in reconstructive surgery.

NHSBT OTDT are now working with Pilgrims Hospices to implement the intervention developed from the EDiPPPP study. The intervention includes resources to

- Support staff to identify eligible patients using an assessment tool,
- increase confidence in discussing the option of eye donation via staff training packages provided by NHSBT OTDT,
- information leaflet for patients and families,
- Access to a Regional Tissue Donation Nurse Specialist who works directly with hospices providing advice and support.

The project is ensuring that those patients who wish to donate eyes to help save and restore the sight of others are asked what their wishes are as part of end-of-life care planning conversations.

To find out more about eye donation and the resources available visit:

www.odt.nhs.uk/deceased-donation/tissue-donation/

Or ask one of the project leads at your site:

PHA: Dr Thurka Parameswaran / Cate Gibson

PHC: Rosie Squire

PHT: Dr Pallavi Singh

1: evidence.nihr.ac.uk/alert/hospice-and-palliative-care-services-could-encourage-eye-donation/

Research Findings

Goal Setting in Palliative Care Rehabilitation

Between 2016-18 our Physiotherapists and Occupational Therapists took part in the GAS Study. The goal attainment scaling tool (GAS) was used with patients to set and review their goals. The researchers from Kings College London looked to understand the characteristics of functional goals in palliative care and the factors associated with achieving them. A journal article was published on the findings of the study in 2025: **link.springer.com/content/pdf/10.1186/s12904-025-01816-0.pdf**

The main findings were that personalised goals using goal attainment setting can be achievable with personalised rehab for palliative care patients, even those with limited function. Goals set tended to be short term. GAS can help to direct and evaluate rehab interventions in hospice settings.

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Priorities for 'out-of-hours' home-based palliative care

Pilgrims supported this national study in 2022-23 by helping to recruit participants to interview about their views and experiences of home-based palliative care out of hours. Nationally, 39 staff and 47 patients, carers or bereaved carers took part.

The study found that it is how care is delivered that matters as well as what is provided. There was both a shared understanding of what constitutes 'good care' between staff and service users. Other themes identified were:

- Care coordination, integration and continuity: professionals emphasised the importance of shared patient records, while for patients and caregivers, feeling known to the service fostered a sense of safety.
- Access to medicines: professionals spoke of the challenges of accessing, prescribing and administering medicines out-of-hours, while caregivers described the hard work of forward planning for out-of-hours.
- Timely, responsive and accessible care within stretched resources.

Stretched resources caused distress to both healthcare professionals and patients and family carers, but also meant that patients and family carers felt concerned about 'bothering' professionals out-of-hours. At times they may avoid contacting services.

A journal article was published on the findings of the study in 2025, which also include recommendations for policy and practice: **www.sciencedirect.com/science/article/pii/S0020748925002032**

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Bereaved carers' experiences of taking part in the Chelsea II Study

The Chelsea II Study was a cluster randomised controlled trial to investigate clinically assisted hydration at the end of life. Ninety-one hospices or hospitals took part between 2022-25, including our three inpatient units. We eagerly await the findings of the trial but findings have been published of the qualitative study that was undertaken alongside the trial with bereaved carers of patients who took part in the trial. Carers of patient participants were invited to take part in a post-bereavement postal survey. Participants who returned this survey and expressed interest to be approached further about their experiences were invited to take part in an interview. Interviewees (n:15) were asked about the impact of the research on the patient / their end-of-life care, the impact of the research on them as an informal carer, and their views on research at the end-of-life.

This study found that research can be undertaken in patients at the end-of-life without negatively impacting the experience of care. Patients and their informal carers wanted to take part in such research, as it provided them with purpose during this time, and gave them the opportunity to help future patients, which was their main motivation for participating.

The findings of this qualitative study mirror those of the related postal survey. However, the qualitative study generated additional information, which can help inform the design of future studies in this cohort of patients.

A journal article was published on the findings of the qualitative study in 2025: **link.springer.com/content/pdf/10.1186/s12904-025-01872-6.pdf**

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ACT sessions on "Exploring the emotional experiences of hospice workers and how they cope" and "Enhancing paramedic care at end of life"

Research was a feature of the hospice ACT sessions in February and March 2026.

On 10th February Lizzie Threlfall who previously undertook a student placement at Pilgrims, presented the findings of her research project as part of her Masters Social Work programme, supported by Pilgrims. The session on the emotional impact of working in a hospice from a social work perspective as well as some key coping strategies, which may be helpful for the wider multi-disciplinary team. Look out for Lizzie's presentation on the hospice Sharepoint.

On the 10th March ACT session Dr Natasha Campling, University of Southampton, presented the findings of the ParAID Study on Paramedic delivery of end of life care. We informed the research by identifying and approaching staff members, patients, carers and bereaved carers to take part in a qualitative study to find out about their views and experiences of paramedic end of life care. Look out for the presentation on Sharepoint

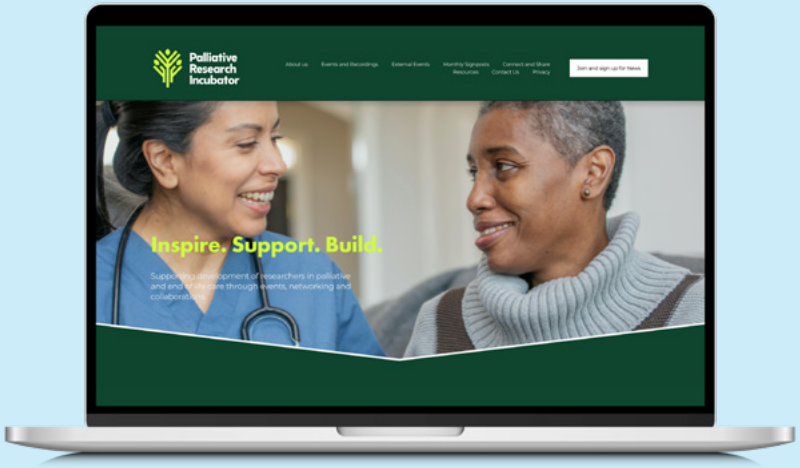
Research Information & Resources

A new forum space has been created in Blue Stream for access to helpful information and resources related to palliative, end of life care and hospice research.

To access, log on to Blue Stream training platform in the usual way. Then select:

- Forum
- Under ‘My forums’ click on ‘Pilgrims Hospice Chat’
- Select ‘Research information and resources’

The most recent post has been about the NIHR Palliative Care Incubator which was setup in 2025 to help support the development of researchers: www.pri.uk.org



Training opportunities

New Good Clinical Practice (GCP) training

Due to the introduction of the new Clinical Trial regulations from April 2026, Good Clinical Practice in research training is being updated. A new GCP E6(R3) Refresher course has officially launched on NIHR Learn, available at: learn.nihr.ac.uk/course/view.php?id=1575. This updated refresher training reflects the latest guidance and best practices, ensuring research teams stay compliant and confident in applying Good Clinical Practice.

The updated version of the Introduction to GCP course was available from February 2026.

A more proportionate approach is now being taken with research training, acknowledging that GCP is most suitable for researchers undertaking clinical trials, and alternative training is being developed that will be more applicable to other types of research.

Other online courses currently available are “Research Practice in Health, Care and Community Settings” and “Research Practice in Clinical Settings” which focus on the correct conduct of research.

All the above courses are freely available by registering and logging on at learn.nihr.ac.uk

Do you have a ‘bright idea’ but not sure about research?

Charlotte Brigden, Research Facilitator is happy to discuss ideas with hospice staff and offers advice and support with project design, ethics approval, funding or training opportunities, and collaboration with colleagues to help take ideas forward.

Charlotte should be informed of any potential research being developed and conducted in the hospice as approval is required from the Hospice Research Facilitation and Governance Forum which meets quarterly.

For further information about any of our research featured in *Research Matters* or to include something in a future issue contact:

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