

# Research *newsletter*



## IN THIS ISSUE

- Welcome
- Current research studies
- Conferences
- NIHR ARC Palliative and End of Life national forum
- Research Ready Surrey
- Publications
- Hospice Research Governance Project
- New Wider Care Settings R&D Working Group
- Resources for Hospice Researchers
- Upcoming Research Events

  
Princess Alice  
Hospice

January 2025

For Excellence. For Compassion. For People. For Living.

## Welcome to the Princess Alice Hospice Annual Research Newsletter

During 2024, we have seen some exciting developments in Palliative and End of Life Care (PEoLC) research nationally with Palliative Care now formally recognised by the National Institute for Health and Care research (NIHR) as a stand alone speciality. It is hoped that with this recognition there will be more funding allocated to research in PEoLC to increase our knowledge and evidence base in the specialty. [Dr Amy Gadoud of Lancaster University](#) has been named as the first ever NIHR Research Delivery Network (RDN) National Lead for Palliative Care. Dr Gadoud also works as a consultant at Trinity Hospice, Blackpool, hopefully strengthening the link between hospices and the NIHR.

Hospices have been in the spotlight this past year due to news of deeper financial difficulties facing many hospices following the Chancellor's Autumn 2024 budget in as well as the passing of the second reading of the Terminally Ill Adults (End of Life) Bill in Westminster in November 2024.

In our own news, Princess Alice Hospice continues to support and participate in research. We have also overseen the formation of a new Hospice Research Community of Practice in Kent Surrey and Sussex—further details on this and more below.

### Current research studies at Princess Alice Hospice

#### **CHELsea II: Cluster randomised trial of clinically assisted hydration in patients in the last days of life**

The [CHELseall study](#) team at the University of Surrey, led by Chief Investigator Professor Andrew Davies and Lead Research Nurse Melanie Waghorn, have almost reached their target recruitment of 1600 patients which is an amazing achievement. **Congratulations!** Once recruitment is complete the data can be analysed and published. We will ensure that the results of this important study are shared in this newsletter when they are available.



#### **POST: Palliative care and Oncology Survey on Terminology - What do individuals known to palliative care and oncology services think about the terminology used to describe them?**



Dr Amy Taylor, Specialty Trainee in Palliative Medicine and Clinical Research Fellow at the School of Medicine & Medical Science, University College Dublin is undertaking a study as part of her PhD looking at the terminology commonly used to describe oncology and palliative care patients. **Thank you very much** to the patients under the care of Princess Alice Hospice that have kindly participated in the study so far.

## How do words work? Palliative care patient perceptions of writing for wellbeing.

Helen Stockton is undertaking a PhD through Lancaster University where she is researching palliative care patients' perceptions of writing for wellbeing. She will be interviewing patients participating in our creative writing classes that take place in the Wellbeing Centre at Princess Alice Hospice. **Thank you very much** to our Wellbeing Team for your support and to the patients under the care of Princess Alice Hospice who participate in the study.

## Conferences

## Palliative Care Congress (PCC)

## Online, March 2024

The theme of the 2024 PCC was **World Wide Working – your invitation to an innovative, international MDT**. There was an impressive range of [interesting talks](#) available to attend and [abstracts](#) to read.

A poster authored by our Medical Lead for Research and our Research Lead titled [Attitudes of staff to conducting research in a hospice inpatient unit](#) was accepted for online display at the conference.

The [2025 Palliative Care Congress](#) is being held from 20—21 March 2025 in Belfast.



# Hospice UK Conference

**Glasgow, November 2024**

The theme of the 2024 [Hospice UK Conference](#) was **Hospice care for all, for now, forever**. The conference was opened by HRH The Princess Royal, patron of Strathcarron Hospice in Scotland.

9 colleagues from Princess Alice Hospice, including our CEO Nigel Seymour and our recently appointed Chair of Trustees, [Sally Harris](#), attended the conference.

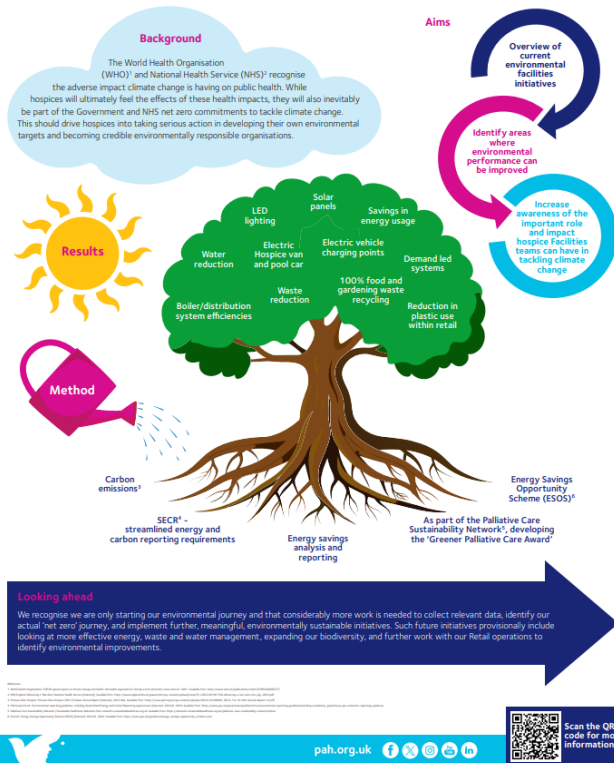


We had a stand in the Conference Hall to share information about the [European Certificate of Essential Palliative Care \(ECEPC\)](#) - a qualification in palliative care founded and co-ordinated by Princess Alice Hospice.

8 posters detailing work by Princess Alice Hospices colleagues were displayed at the conference. These can be found overleaf as well as on our [website](#).

## Becoming an Environmentally Sustainable Hospice

Martin Osborn, Head of Operational Services, Junior Adejpong, Facilities Manager, James Butler, Health, Safety and Environment Officer, Sarah Tullett, Deputy Director Health, Safety, Environment and Business Continuity, Princess Alice Hospice



## Our approach to projects as a methodology

Konstantina Chatziargyriou - Head of Service Design & Continuous Improvement, Lizzie Leigh - Head of Communications, Nigel Seymour - Chief Executive, Princess Alice Hospice

### Background

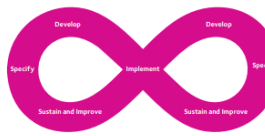
A hospice introduces projects across teams and services that vary in size and scope. Projects enable implementation of beneficial changes set out in our strategic objectives. To deliver on organisational strategic priorities, a scalable framework was required for colleagues to work towards continuous improvements and deliver projects successfully. It was agreed a defined methodology for approaching projects would help achieve this.

### Aims

- Introduce a consistent approach to projects
- Create agile processes to free up staff time
- Create monetary savings and improve service

### Results

- A more consistent approach across:
  - Processes
  - Language
  - Documentation
- More clear roles and responsibilities
- Improved understanding of project justification
- Better time management
- Use of agile techniques
- Empowered team members to lead projects
- Better visibility of projects their progress, and overall capacity



"The approach enabled us to plan and prioritise to keep the things on track, whilst being agile and allowing the project to evolve throughout implementation according to the needs of the team, the wider Hospice and, importantly, our bereaved clients." - Kelly

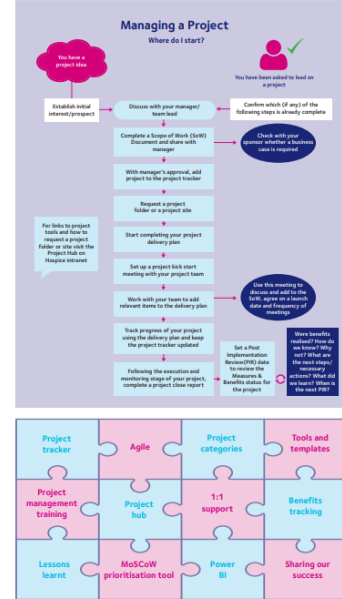
"As this was quite a big project, having a digital project plan in one place, which everyone could access, made a big difference and enabled us to work much more cohesively as a team, managing risks effectively but progressing efficiently." - Sarah

### What's next?

The approach has been used for large strategic and small tactical projects. We have begun work on defining evaluation metrics that will measure the impact of introducing a methodology to all projects within the organisation.

### Method

In 2023, we implemented the new methodology, which was introduced to managers:



## A Service Evaluation of Professional Visitors Rewarding but Requires Resource

Emily Sills - Medical Director, Jane Berg - Director Skills Knowledge & Research, Princess Alice Hospice.

### Background

Hospices have traditionally been seen as experts in end of life care, but we also have expertise in volunteer management, data and digital and managing collaborative relationships with partners such as the NHS. One of our strategic aims is to share our knowledge and expertise.

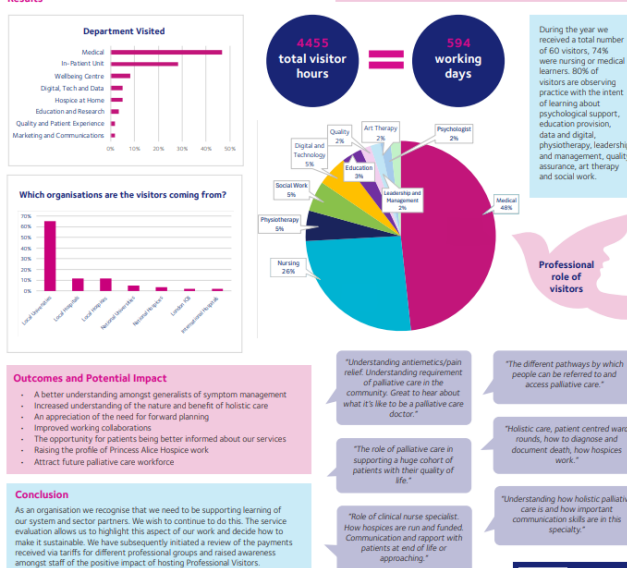
### Aim

The aim of this service evaluation was to quantify the amount and type of professional visits we host, where the visitors are from, how much time they spend at the Hospice and what feedback we receive. The data will be used to inform discussion about how we manage visitors in the future.

### Method

In April 2023 we began collecting data about professional visitors. Professional visitors were defined as people who attend the Hospice with the specific aim of learning from us about an area of our work. They are additional and distinct from the learners who attend our educational events and programmes. We included virtual and face to face attendance. In April 2024 we summarised and analysed the first year of data and presented our results.

### Results



## Research Governance Support for Hospices A Pilot Project

Shannon Milne - Research Lead, Jane Berg - Director of Skills, Knowledge & Research, Emily Sills - Medical Director, Princess Alice Hospice, Becky Dilley - Research Delivery Manager, NIHR CRN Kent Surrey Sussex

### Background

Hospices comply with governance processes as stated in the UK Policy Framework for Health and Social Care Research<sup>1</sup> to ensure delivery of high-quality research. We were awarded a grant from the NIHR to support the pilot of a regional hospice research governance role to support hospices in our region to expand their research activity and enhance governance procedures and practice.

### Aims

- Identify existing research activity and governance processes
- Support development of robust research governance
- Identify mechanisms for ongoing research activity and governance support
- Assess impact of the role

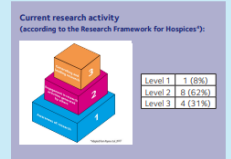
### Methods

- 18 hospices in our region were invited to complete an online questionnaire
- A visit by the Research Lead was offered to discuss governance needs/wish list (virtually/in-person)
- Attendance at NHS R&D Forum: Wider Health and Care Community Working Group
- Develop relevant research governance support and resources based on results

### Results

13 out of 18 hospices responded to the questionnaire:

- Research Capacity**
  - 5 (38%) employ dedicated research staff (0.3 to 0.8 FTE)
  - 2 of these posts currently unfilled
  - 8 hospices include research activity in job role of a clinician (usually consultant, average of 1 hour per week)



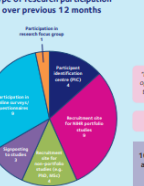
### Conclusion

- Hospices in our region are participating in research but most do not employ dedicated research staff and lack time and resource.
- Governance processes vary between organisations.
- A regional Community of Practice has been established in response.
- Research governance resources including templates have been created for sharing.

### Research governance policies and procedures

- Have a research policy: 9 (69%)
- Have research SOPs: 2 (15%)

### Type of research participation over previous 12 months



### Number of studies hospices participated in over the past 12 months



### What's next?

- Share research governance resources with hospices in our region
- Continued attendance at Wider Health and Care Community Working Group meetings for ongoing collaborative working
- Convene regional Hospice Research Community of Practice meetings twice yearly
- Utilisation of new NIHR Regional Research Governance Lead

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NIHR | National Institute for Health Research

NIHR defines research governance as: "the broad range of regulations, principles and standards of good practice that ensure high quality research."<sup>2</sup>

## Collaborating to Implement a Library Management System in a UK Hospice Library



Marianne Johnson, Library and Learning Resources Coordinator, Shannon Milne, Research Lead, Jane Berg, Director of Skills, Knowledge & Research, Princess Alice Hospice

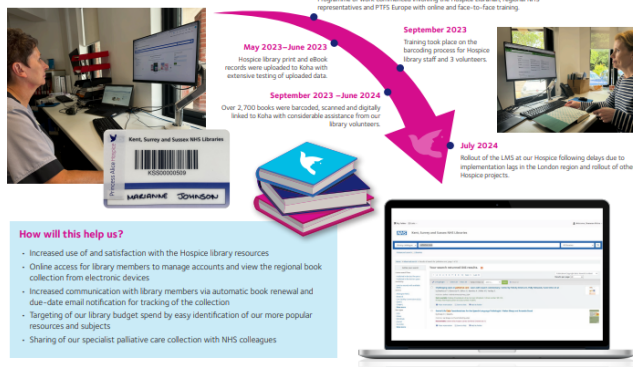
### What is a Library Management System?

In 2020, Health Education England, now NHS England - 'Workforce, Training and Education', unveiled plans to consolidate 91 local NHS library management systems (LMS) and create efficient regional networks. 'Koha' was selected as the LMS platform 'to provide NHS staff with a single, coherent national gateway to their trusted library and knowledge service'. Our Hospice library requested participation and agreed NHS Knowledge and Library Services funding and collaboration with subsequent membership of our local NHS consortium.

### Aims

- To benefit and improve the library experience for staff whereby members can access and borrow items from the substantial regional NHS book collection and download eBooks purchased by the NHS
- To allow NHS colleagues access to our specialist palliative care library collection
- To work closely with the Koha software administrators, PTFS Europe\*, to efficiently deliver the project
- To reflect a drive towards collaboration with healthcare partners, and workforce education in hospices\*

### What did we do?



### How will this help us?

- Increased use of and satisfaction with the Hospice library resources
- Online access for library members to manage accounts and view the regional book collection from electronic devices
- Increased communication with library members via automatic book renewal and due-date email notification for tracking of the collection
- Targeting of our library budget spend by easy identification of our more popular resources and subjects
- Sharing of our specialist palliative care collection with NHS colleagues

### What's next?

- NHS Workforce, Training and Education are rolling out Koha to all NHS healthcare libraries nationally - currently 75% of libraries are on board
- Other non-NHS and hospice libraries will also be encouraged to join Koha in due course
- Mentorship and support for Hospice library staff and volunteers to become more familiar with the new software
- PrintDocs initiative will be added to Koha enabling users to request and share printed journals across the KSS region
- Enabling Single Sign-On (SSO) so that library members will be able to instantly view their library accounts



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## Supporting digital transformation in a UK Hospice



Celia Di Ciccio, Head of Data, Information and Knowledge Management, Jo Hopkins, Head of Digital Platforms and Technology, Julia Russell, Director of Marketing & Comms, Digital and Performance, Princess Alice Hospice.

### Background

In recent years, technological advancements have reshaped how clinical teams operate in the healthcare sector. The 'Topol Review' offers recommendations for using digital skills to transform patient care and explores how to prepare the healthcare workforce through education and training to deliver the digital future.

### The Review advises on:

- Health technology is likely to change the roles of clinical staff over the next two decades to ensure safe, more productive, more effective and more personal care for patients
- What the implications of these changes are for the skills required by the professionals filling these roles
- The consequences for training, development and lifelong learning of current and future healthcare staff
- It is important to the Hospice Digital Team that we invest in digital skills to empower our clinical teams and support the work they do - this is necessary to ensure our digital transformation projects succeed and so that clinical staff can take advantage of digital efficiencies.

It is also important that clinical staff invest in their own digital learning and development so that they are best placed to deliver care in an increasingly digital landscape. Clinical and Digital Teams need to fit together like two pieces of a jigsaw puzzle.



### Aim

- Listen to the clinical workforce to:
- Find out what was working well
- Understand the challenges staff were experiencing
- Associate future needs with regards to digital skills requirements, technology and digital tools.

### Method

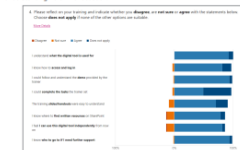
In July 2022, the Hospice on a digital workshop with 20 stakeholders from across the Hospice's clinical workforce. Participants were split into small groups and an appointed facilitator collated discussion ideas. Responses were analysed using thematic analysis.

### Results

Vital insights into the workforce's confidence with digital tools and technology were ascertained indicating that the pace of change was too quick for the clinical workforce with nearly 40 separate comments relating to the digital skills requirements and development of a multi-faceted support programme.

### Impact

Training feedback has been overwhelmingly positive with participants affirming their understanding via online feedback.



- 276 bookings onto the Digital Skills Programme so far, hitting the skills of 113 unique attendees
- 126 one-to-one support sessions delivered via the Embedded IT initiative
- 18 Tech Buddies actively supporting their teams in situ
- Over 3000 tickets resolved by our IT Helpdesk each year

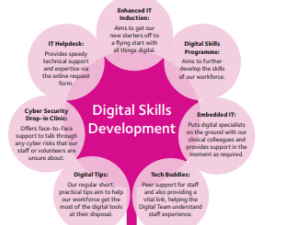
### Conclusion

Virtual feedback on other initiatives, such as the Embedded IT Induction and weekly Digital Tips, affirms the positive aspects of the program. Issue resolution via Embedded IT, Tech Buddies and the IT Helpdesk further demonstrates the reach and impact of this multi-faceted approach.

### Next steps

Engagement and impact of the workstreams is monitored quarterly and data will drive the evolution of each workstream, ensuring we adapt to the changing needs of the Hospice workforce using digital skills to transform patient care and explore how to prepare the healthcare workforce through education and training to deliver the digital future.

### Workshop workstreams designed to address the digital skills gap and support transformation



### Data analysis in Microsoft Power BI tracks the reach and impact of the program's workstreams:



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## Improving Assessment and Management of Delirium in Hospice Patients



Dr Isabel Brewster FY2, Dr Lucy Anson FY2, Dr Rachel Clingan ST6 in Palliative Medicine, Dr Aruni Wijerante Consultant in Palliative Medicine. Contact: aruni.wijerante@pah.org.uk

### Background

Delirium is common in the palliative care population and increases morbidity and mortality. An estimated one third of adults have delirium on admission to palliative care settings\*. Only 13% of UK palliative care teams use a recognised tool to assess for delirium†. The 4AT test is recommended by Scottish Intercollegiate Guidelines Network (SIGN) as a useful screening tool for delirium in hospice patients†. It is used on admission to Princess Alice Hospice as part of the initial medical admission clerk, and entered in the electronic patient record (EMIS). Early identification of delirium is important for treatment and potential reversal to improve patient outcomes.

### Project Stage 1: Audit

#### Aims

- To raise awareness about the prevalence of delirium in hospice settings and the importance of recognising and managing this effectively.
- To audit completion of 4AT as part of the medical admission clerk on the Inpatient Unit (IPU)
- To evaluate identification of causative factors and actions taken to manage these, if 4AT score indicates a possibility of delirium
- To improve documentation of actions if 4AT score significant

#### Methods

- 25 clinical records reviewed for patients admitted to IPU backdated from 31 August 2023 with retrospective data collection

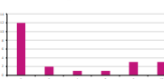
#### Results

- Good engagement and uptake of 4AT completion with a possible delirium identified for over 1/3 of admissions, in line with literature evidence
- However, a cause was not explicitly stated and there was no evidence of specific action taken to manage delirium.

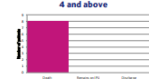
### Was a 4AT assessment completed?



### Scores of completed 4AT Assessments



### Outcome for patients with 4AT score 4 and above



### Outcome for patients with 4AT score < 4



### What is the 4AT?

4AT is an assessment tool to screen for delirium and cognitive impairment (CI), comprised of 4 components:

- Alertness
- Abbreviated Mental Test 4 (AMT4)
- Attention
- Acute change over past 2 weeks

4AT gives a total score out of 12 indicating likelihood of delirium/CI:

- 4 or above possible delirium +/- CI
- 1-3, possible CI
- 0, unlikely

### Project Stage 2: Quality Improvement Project - Plan, Do, Study, Act (PDSA) Methodology

#### Delirium Clinical Guide

##### Screening Cases

| Screening Cases                   | PSDA Cycle 1                                              | PSDA Cycle 2                                              |
|-----------------------------------|-----------------------------------------------------------|-----------------------------------------------------------|
| 1. All new admissions to the IPU  | 1. Exclude medical team                                   | 1. Make further adjustments to 4AT test based on feedback |
| 2. All new admissions to the IPU  | 2. Make changes to 4AT test to make it more user-friendly | 2. 4AT test changes                                       |
| 3. All new admissions to the IPU  | 3. Review current 4AT test                                | 3. 4AT test changes                                       |
| 4. All new admissions to the IPU  | 4. Review current 4AT test                                | 4. 4AT test changes                                       |
| 5. All new admissions to the IPU  | 5. Review current 4AT test                                | 5. 4AT test changes                                       |
| 6. All new admissions to the IPU  | 6. Review current 4AT test                                | 6. 4AT test changes                                       |
| 7. All new admissions to the IPU  | 7. Review current 4AT test                                | 7. 4AT test changes                                       |
| 8. All new admissions to the IPU  | 8. Review current 4AT test                                | 8. 4AT test changes                                       |
| 9. All new admissions to the IPU  | 9. Review current 4AT test                                | 9. 4AT test changes                                       |
| 10. All new admissions to the IPU | 10. Review current 4AT test                               | 10. 4AT test changes                                      |

#### Conclusion

Our audit replicated the evidence that over a third of adults have delirium on admission to a hospice. Ensuring an evidence-based screening tool is embedded within the medical admission clerk is essential for identification. However, this alone is insufficient for optimal management and documentation of actions. We have shown that by including clinical guidelines and facilitating individualised documentation, the medical teams confidence acting on a significant 4AT score has increased, which will improve patient care and create meaningful change to patient outcomes.



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## Introducing an inclusive easy read booklet about our care



Mike Gerrard, Professional Lead, Senior Social Worker; Rosie Noble, Families and Carers Lead; Lizzie Leigh, Head of Communications, Princess Alice Hospice.

### Background

Easy read documents use simple language and images to make information clear and accessible for everyone, including those with learning difficulties. We could not find examples of easy read guides about hospices and felt that the lack of more accessible information was a barrier to some people. In 2022 we set out to create an easy read guide about our Hospice and services.

### Aims

- To create an online and printed visual guide using easy read communication principles to share with carers and potential service users with learning difficulties, to help to:
- Alleviate fears
- Lessen misunderstandings
- Prepare potentially vulnerable service users for hospice care.

### Results

"The easy read booklet is great when we're visiting people in their homes, we've found it an excellent way to start the conversation about Hospice care and what that looks like."

Associate Director, Patient Care and Communities

### Method

A working group was formed, including two colleagues with extensive professional and personal experience of supporting people with learning difficulties.



Easy read principles were studied and adopted<sup>1</sup>.



Incorporating user voice was important.



Two colleagues ran a focus group<sup>2</sup> with seven adults at a learning disabilities day centre, to gain feedback at draft stage, considering practical and emotional needs. Feedback was incredibly valuable and incorporated.



The final guide was made available on our website<sup>3</sup> and in printed form.



### Conclusion

Valuable insights for producing similar easy read literature in the future were generated. The guide has created wider interest around introducing easy read and plain English principles across more of our Hospice literature, as we work to champion equity of access to our care.



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## Sawubona (I see you) Conference – Promoting equity through research in palliative care

The first Sawubona conference was organized by the research team at LOROS Hospice and chaired by Dr Zoebia Islam, Deputy Research Lead at LOROS Hospice and Associate Professor in Palliative Care and Frailty at the University of Leicester. You can listen to the recordings on the [LOROS web-site](#). The [second Sawubona conference](#) will be held online on 6th May 2025, from 9:30am - 3:30pm.

## NIHR ARC Palliative and End of Life national forum

This new [national forum](#) co-led by Professor Irene Higginson, King's College London and Professor Morag Farquhar, University of East Anglia brings together specialist palliative care researchers and clinicians from across England with the aim of driving collaborative work and advancing research and innovation in palliative and end of life care through coordinated activities, sharing best practices, and implementing evidence-based improvements. The group has hosted 2 excellent free webinars so far—joining the webinars is highly recommended!

**NIHR** | Applied Research Collaboration  
South London

## Research Ready Surrey

Research Ready Surrey is an initiative funded by NHS England to help Surrey's healthcare and community partners to prepare for research engagement. Princess Alice Hospice was one of 10 Voluntary, Community, Faith and Social Enterprise (VCFSE) organisations chosen as a case study site to capture information to better understand the interest, awareness, capability and barriers to being involved in health and care research. Further information as well as our case study summary can be found on the [Surrey Heartlands website](#).



## 2024 Publications from studies PAH has supported

1. Understanding and improving community-based palliative care outside of normal working hours study—Alice Firth, Cicely Saunders Institute of Palliative Care Policy & Rehabilitation

- [Community out-of-hours palliative care – ‘It’s a patchwork of services’: A qualitative study exploring care provision](#)

2. ALLIANCE: Enhancing the quality of living and dying with advancing frailty through integrated care partnerships: Building research capacity and capability—Dr Sarah Combes, University of Surrey

- [Building research capacity and capability to enhance the quality of living and dying addressing advancing frailty through integrated care: the ALLIANCE partnership](#)

3. Improving end of life care: supporting workforce and reducing hospitalisations through an implementation study in care homes - Professor Liz Forbat, University of Stirling

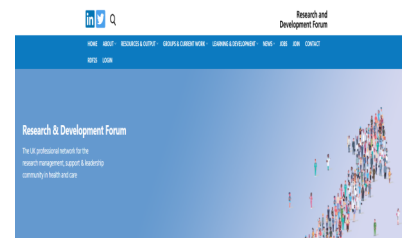
- [Using Palliative Care Needs Rounds in the UK for care home staff and residents: an implementation science study](#)

# Hospice Research Governance project

The pilot project funded by the NIHR to support research active hospices in Kent, Surrey and Sussex with Research Governance procedures and processes was completed in October 2024. As a result of this project, we now have an active, well attended Kent, Surrey and Sussex Research Community of Practice—we meet as a group 2 to 3 times per year and have a dedicated Teams group where we can save resources including the Hospice Research Governance Guide that was developed as part of this project. We are hoping this guide will be available to share more widely in the near future.

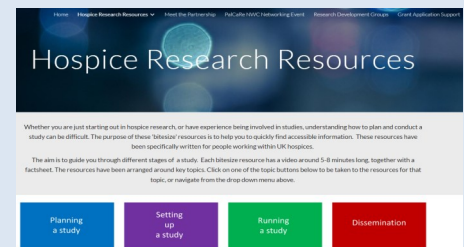
## The New Wider Care Settings R&D Working Group

The recently formed **Wider Care Settings R&D Working Group** is a new working group for colleagues involved in health and care research outside of NHS settings. The purpose of the group is to “*provide peer support, share best practice and solutions, and to form a united voice to advocate where helpful adjustments could be implemented by our partners (e.g. the Department of Health and Social Care (DHSC), NIHR, the Health Research Authority (HRA) the UK Health Security Agency (UKHSA) and Local Authorities).*” If you would like learn more about this group please go to [Groups & Current Work - NHS R&D Forum](#) ([rdforum.nhs.uk](http://rdforum.nhs.uk)) or contact Kimberly Olive, Research Innovation & Improvement Officer, Kent County Council at [phresearch@kent.gov.uk](mailto:phresearch@kent.gov.uk).



## Reminder: Resources for Hospice Researchers

The [Palliative Care Research Partnership North West Coast](#) (PalCaRe NWC) website hosts a number of very helpful new sources specifically written for colleagues undertaking research working within UK hospices.



## Upcoming Events

[Marie Curie Research into Practice Conference 2025](#): 11 - 14 February 2025 | Online | FREE and open to all.

[European Association of Palliative Care Congress 2025](#): 29 – 31 May 2025 | Helsinki, Finland.

[Hospice UK Conference 2025](#): 25—27 November 2025 | Liverpool, UK

**Thank you for your interest in  
research at Princess Alice Hospice**

If you would like to apply to do research with us, please visit our [website](#) for further information or contact our Research Lead at [shannonmilne@pah.org.uk](mailto:shannonmilne@pah.org.uk)

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