



GIG
CYMRU
NHS
WALES

Rhaglen Genedlaethol Gofal
Lliniarol a Diwedd Oes
National Palliative and End
of Life Care Programme

This is our vision for palliative and end of life care delivered in Wales for all who need it by people working closely together, at home when appropriate, determined by what matters to the person and underpinned by what works.

BULLETIN

*Issue 4,
May 2024*

Welcome to the fourth edition of the Palliative and End of Life Care (PEoLC) Programme bulletin.

Our efforts this quarter were focused on progressing the PEoLC service specification, collaborating with the key stakeholders as well as raising the visibility of the Programme. We hosted and attended PEoLC events in the UK and in Europe with more details provided in this issue.

You can access our **Quality Statement** by clicking on the icon below

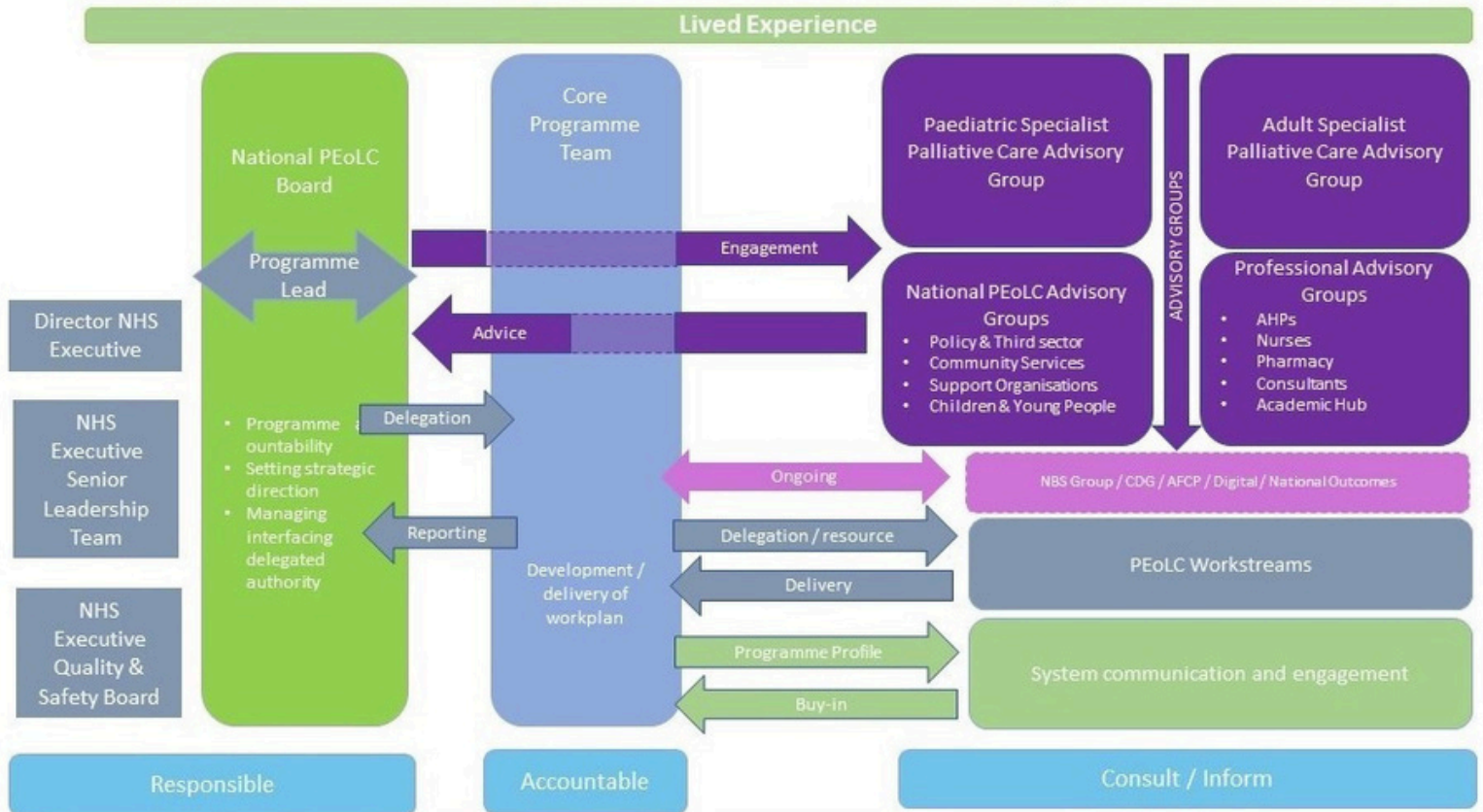


PLEASE NOTE, THE BULLETIN WILL BE MADE AVAILABLE IN WELSH ON REQUEST

TABLE OF CONTENTS

Welcome to the 4th edition	1
Table of contents	2
PEoLC Programme structure	3
Service specification for Wales	4
A rapid review: PEoLC cost effectiveness	5
£4M funding for hospices	7
Further faster funds	8
PEoLC Programme engagement event	9
The Bereavement conference	13
Dying matters awareness week	16
CARiAD - St David award nomination	17
EAPC Barcelona feedback	19
Staffing announcements	22
Contact us	24

NATIONAL PEOLC PROGRAMME STRUCTURE



Whether it's in the community or in hospitals, in the NHS or in voluntary sector services, wherever it is needed, whatever the age or diagnosis or circumstances of people needing it, Palliative & End of Life Care (PEoLC) matters. The National PEoLC Programme exists to help improve the experience for everyone in Wales. The Programme encompasses the groups shown in the Programme structure, and is working with other Networks and Programmes whose work overlaps with ours, and with local teams across Wales, to enact the requirements of the Quality Statement for PEoLC. The need for better palliative & end of life care affects us all, and it is going to take all of us working together to get it right. So do think about areas of common interest with your work and get in touch if you can think of ways to work together.

Dr Idris Baker - National Clinical Lead

SERVICE SPECIFICATION FOR WALES

The core Programme team has been developing the PEOLC Service Specification for Wales. This document is being co-produced with key stakeholders, including the Advisory Groups, the Welsh Government, the Third Sector, and NHS Wales colleagues. Several task and finish groups have been assigned to define the out-of-hours service and the specialist PEOLC service across Wales.

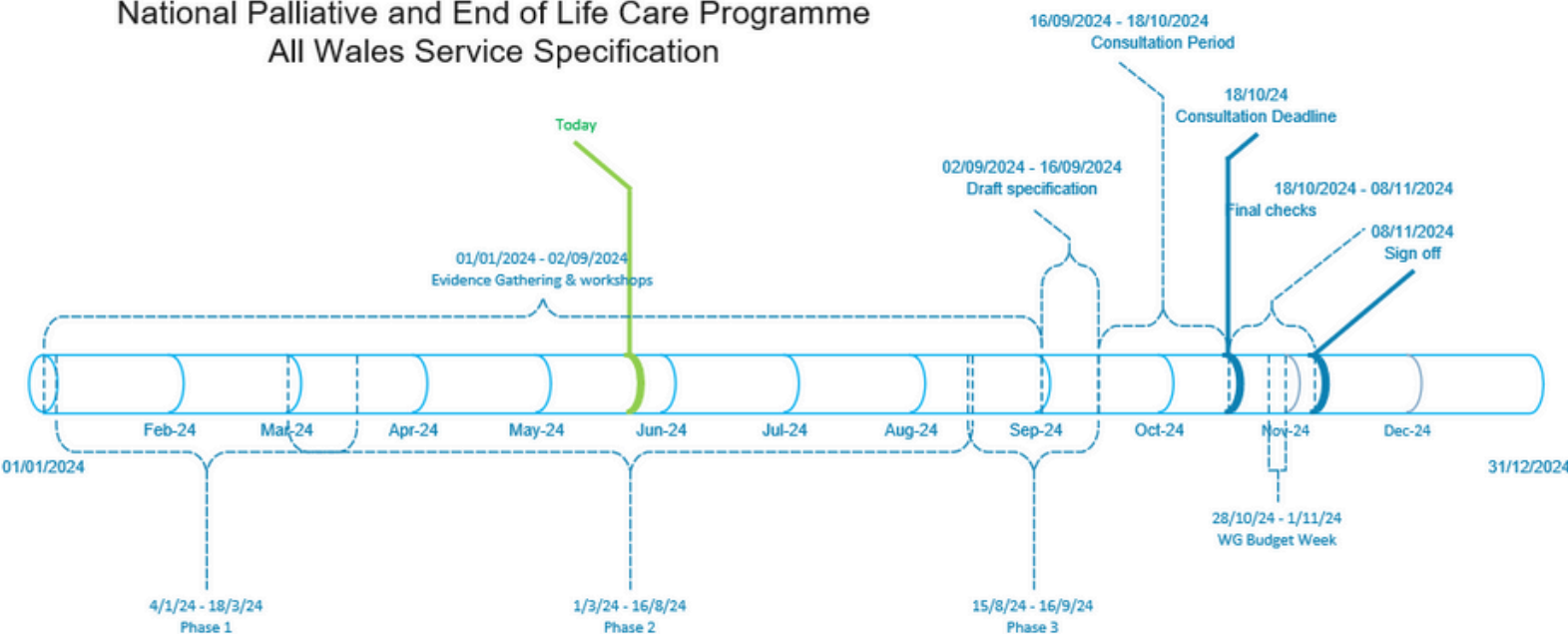
Additionally, a new group is being established to scope the referral criteria across different sectors and health boards. The document will address both adult and paediatric sections, providing guidance for achieving a high standard of PEOLC care in Wales.

The draft specification is scheduled to be ready in September, followed by a month-long consultation with stakeholders until mid-October. The final sign-off is expected in early November 2024.

DELIVERY TIMELINE

A PHASED APPROACH

National Palliative and End of Life Care Programme
All Wales Service Specification



- Phase 1: Review existing frameworks
- Phase 2: Gather stakeholder input
- Phase 3: Draft the core service components



The costs and cost-effectiveness of different service models of palliative care, focusing on end of life care: A rapid review

March 2024

Llinos Haf Spencer, Rhiannon Tudor Edwards, Deborah Fitzsimmons, Dyfrig Hughes, Jayne Noyes, Bethany Anthony, Kalpa Pisavadia, Jacob Davies, Idris Baker, Melanie Lewis, Praveena Pemmasani, Rashmi Kumar, Elizabeth Doe, Ruth Lewis, Alison Cooper, Adrian Edwards

Background

Some people receive **palliative or end of life care** at home, others in hospitals or hospices, or a combination of home and hospice/home and hospital models.

This review aims to determine the **costs and cost-effectiveness of different service models** of palliative care or end of life care.



These studies are mostly **conducted from the perspective of the healthcare system**, disregarding costs related to patients'/caregivers' economic burden (Perea-Bello et al., 2023).

Evidence Base

Studies published between 2003 and 2023.

48 primary studies were reviewed in total, including:

39

Cost
analyses

1

Social Return
on Investment
(SROI)

5

Full
economic
evaluations

3

Markov
modelling
studies

Cost analyses were reported for **hospital, hospice, home-based, and community-based palliative care models**, as well as primary care focussed and mixed models of palliative care.

Key Findings

- **Hospital end of life care costs tend to be higher than hospice end of life care.**
Home-based palliative care is the least costly model in many studies (Duncan et al., 2019; Saygili & Çelik, 2019; Yi et al., 2020).
- The evidence suggests that **home-based palliative care should be available to all patients** in a recognisable end of life phase who desire to remain and die at home.
- Healthcare planners should aim to **reduce hospitalisation** at the end of life but only if access to quality home care at the end of life is guaranteed.
- Patients **should have a choice** about where they prefer to die **without moving the costs from the healthcare system** to the home caregivers, rendering the costs invisible.

Research Implications and Evidence Gaps

Cost Impacts of New Services

More UK research is needed on cost impacts of new services such as Enhanced Supported Care (ESC).

Appropriate Methodology

Future research should consider which methods are most appropriate to evaluate palliative care models. Standard methodology, such as the calculation of quality-adjusted life years (QALYs), may not be most appropriate for this end of life population. Improving QALYs may not be the intended aim of palliative care or end of life interventions, and prolonging death may be inconsistent with patient preferences and wishes.

Quality of Evidence and Perspective

The quality and applicability of the evidence found was **variable** and **uncertainty remains**, especially when the perspective of analysis was not stated clearly. Therefore, it was difficult to ascertain whether all relevant costs were considered.

[The full report is available to view here](#)

£4M ADDITIONAL FUNDING FOR HOSPICES FOR 2024-2025



Hospices in Wales will receive £4 million from the Welsh Government, as announced by Health Secretary Eluned Morgan in April 2024. This funding is part of a review into end-of-life care in Wales conducted by the National PEoLC Programme.

The funds will be distributed among 12 commissioned adult and children's hospices to help maintain services, cover staffing costs, and enhance the quality of end-of-life care.

You can read more by clicking on the icon above or the picture below.



WALES' HEALTH SECRETARY ELUNED MORGAN

WELSH GOVERNMENT FURTHER & FASTER FUNDING



The National PEoLC Programme Phase 2 Review for Government 2023, highlighted the need for urgent additional funding and fed into the Further and Faster WG workstream.

We are pleased that the WG Further and Faster funding has resulted in investment in palliative and end of life care in some Health Boards already. We hope this continues to make a difference to the services that patients and families can expect to receive. We will continue to monitor its impact going forward.

[Read more here](#)

PEOLC PROGRAMME ENGAGEMENT EVENT

1ST MARCH 2024
CARDIFF CITY STADIUM PREMIER LOUNGE



DR IDRIS BAKER, CLINICAL LEAD FOR THE PEOLC PROGRAMME, PRESENTING AT THE EVENT

PEOLC PROGRAMME ENGAGEMENT EVENT

This gathering brought PEOLC stakeholders together to network, share valuable insights, and facilitate the co-production of the All Wales service specification through group sessions.

Dr. Kathryn Mannix opened the event with an excellent talk on improving conversations around death and dying. Emily Holmes followed with a presentation on Health Economics. We were honoured to have guests with lived experiences share their stories, highlighting what is at the heart of our programme's work. Gareth Hewitt presented an overview of the WG role in relation to the Programme.

The advisory groups also presented their key work priorities, providing opportunities for co-production with other groups.

Following positive feedback from attendees, we intend to hold more events like this in the future.



PEOLC PROGRAMME ENGAGEMENT EVENT

YOU CAN ACCESS PRESENTATIONS FROM THE
DAY [HERE](#)



The Wall of Remembrance

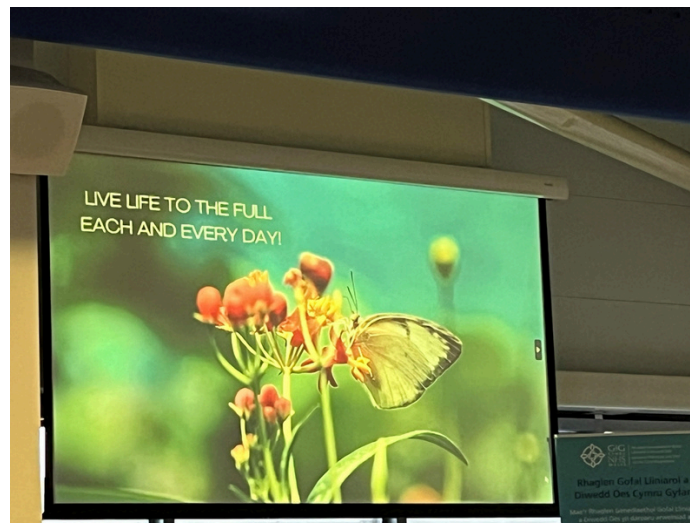
Marie Curie curated a lovely space for a remembrance wall at the event, encouraging attendees to write messages to their loved ones on special paper petals.



PEOLC PROGRAMME ENGAGEMENT EVENT

The Bucket List Video

During the event registration, we asked all attendees to share an item from their bucket list, and we compiled the main themes into a video. The response has been very positive, and we hope you will also find it enjoyable. Simply click on the image below to view the video.



THE BIG CONVERSATION - BEREAVEMENT CONFERENCE

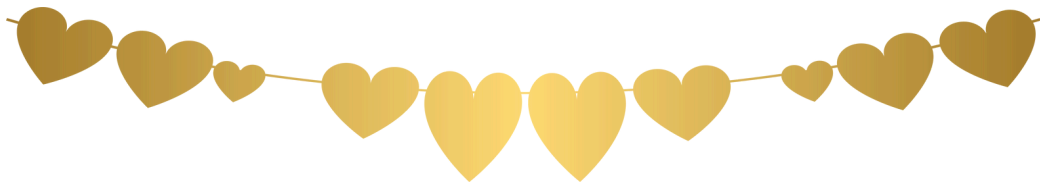
20TH MARCH 2024
THE CHRISTCHURCH CENTRE - NEWPORT



The Aneurin Bevan University Health Board's Patient Experience and Involvement team held a Big Conversation event in the Christchurch Centre, Newport on 20 March 2024. Its purpose was to co-produce their new bereavement model by working in partnership with the local community, developing a better understanding of their experiences of bereavement care, what "good" looks like and what would have made their experience better.

THE BIG CONVERSATION - BEREAVEMENT CONFERENCE

Over 170 people were present on the day with all attendees sent the National Bereavement Framework prior to the event. The morning session contained a series of presentations that outlined the national bereavement priorities and considerations on the circumstances of loss, with opening addresses from Nicola Prygodzicz CEO and Jenny Winslade, Executive Director of Nursing / Executive Lead for EoLC and Bereavement, third sector organisations, support for people with sensory loss and the importance of religion, spirituality and pastoral care. Attendees were provided with a paper heart and asked, if they so wished, to write messages to loved ones they have lost and hang them on a Tree of Hope at the venue. These messages were used in the evaluation report.



The afternoon programme centred around a series of nine round table conversations on loss and bereavement support, including support for people whose loved ones have died in hospital, in the community, under traumatic circumstances, people who have lost a child or young person, bereavement support for people with protected characteristics, advance and future care planning and the importance of making your wishes known. The conversations were emotional at times with attendees very generously sharing their own personal experiences and their insights into what they would like to see in the new bereavement model. The Health Board also sought views on 'branding' their new bereavement model GRACE (grief, respect, advice, compassion and empathy).

THE BIG CONVERSATION - BEREAVEMENT CONFERENCE

All of the feedback has been collated into an Evaluation Report and AB plan to hold further Big Conversation events throughout Gwent between May and July 2024, and to use all feedback to help inform their new bereavement offer.

EXPLORE FURTHER



NATIONAL
BEREAVEMENT
FRAMEWORK



NATIONAL
BEREAVEMENT CARE
PATHWAY

DYING MATTERS AWARENESS WEEK

6-12TH MAY 2024

Dying Matters Awareness Week reminds us to encourage open conversations within our communities using diverse approaches.

Visit our PEoLC Programme website where a dedicated page is now available, offering resources to help guide discussions about death and dying.

Feel free to browse through useful links, listen to engaging podcasts, and find out about upcoming events in Wales during the Dying Matters week. You can access these resources by clicking on the image below.



ST DAVID AWARDS

11TH APRIL 2024
THE ROYAL WELSH COLLEGE
OF MUSIC AND DRAMA



We are excited to announce that the CARIAD team based at North Wales Centre for Primary Care were Nominated for Innovation, Science and Technology award.



CARIAD Team at the St David Awards

ST DAVID AWARDS

Seriously ill people often want to spend their last days of life at home being cared for by family or friends.

Family or friends, if willing, can be taught how to recognise symptoms and give 'no-needle' medicines when their dying loved one is too weak to swallow. This means not having to wait for a doctor or nurse to arrive to give such medicines. This practice has been successfully used in Australia for many years.

The North Wales-based team of researchers and clinicians led UK research on the practice, developed All-Wales policy for it, and put the CARIAD (CARer ADministration) package into clinical use in North Wales in 2020. Their work is helping to spread this practice across the UK.

The outcomes of the innovation are excellent: dying people's symptoms are treated much quicker, with waits down from 105 to 10 minutes. Family and friends feel well-supported and empowered: they value the opportunity to support a loved one's wish to be at home in this way.

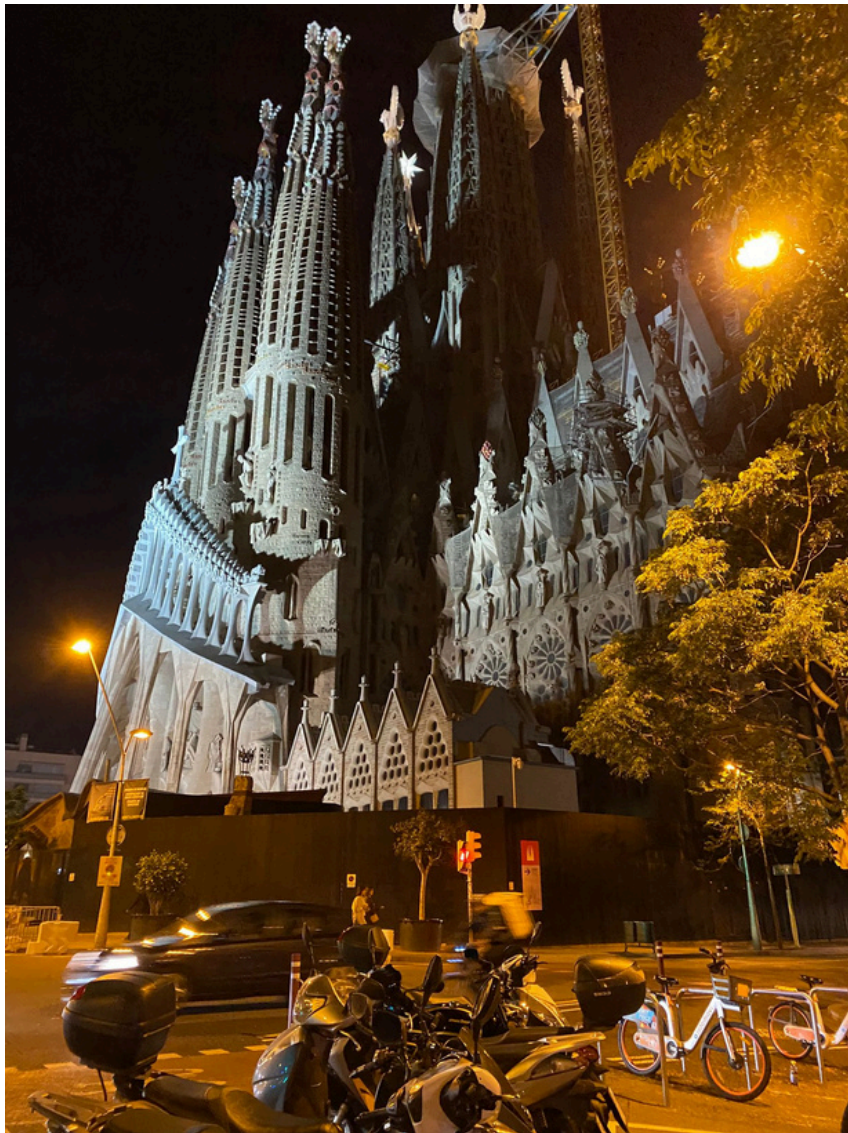
This evidence-based approach is responding to changing priorities and needs within society, supporting choice at the very end of life.



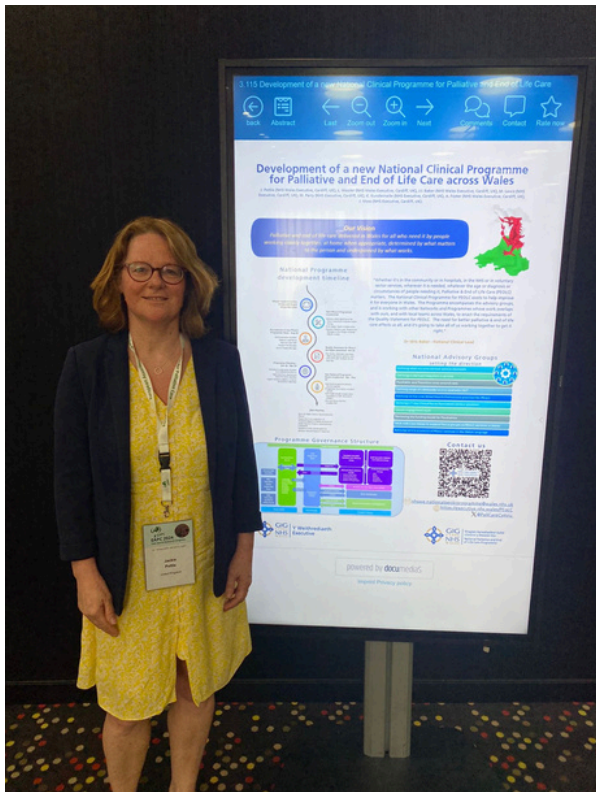
Cariad Team at St David Awards

EUROPEAN ASSOCIATION FOR
PALLIATIVE CARE WORLD RESEARCH
CONGRESS 2024

16-18TH MAY, 2024
BARCELONA - SPAIN



EAPC 2024



**JACKIE POTTLE,
NATIONAL PEOLC AHP
LEAD, REPRESENTING
THE PEOLC
PROGRAMME IN
BARCELONA**

I had the privilege of attending the Research Conference in Barcelona to represent the National Programme team and support the accepted poster submitted by Consultant Dr. Baker, titled "Development of a New National Programme for Palliative and End of Life Care across Wales" (acknowledgment to Lisa Wooler for the poster design).

It was an amazing experience, and I encourage everyone to attend if given the opportunity. You will return inspired, motivated, and energised with new ideas and connections for future work, plus the added bonus of experiencing new places, food, and cultures!

Topics included Innovation & New Technologies, Artificial Intelligence, Communication, Development and Organisation of Services, Education & Advocacy, Identification, Outcomes and Assessment, Carer Support, Bereavement, and research skills development.

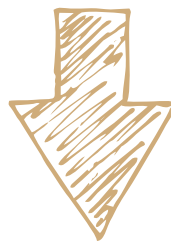
EAPC 2024

It was wonderful to see our Professor Mark Taubert chairing sessions and Mala Mann from Cardiff sharing the collaboration between clinical, policy, and academic partnerships. This collaboration supports the "Availability of Competency Framework Palliative and End of Life Care Education: A Rapid Evidence Map," highlighting the close work between academia and the Wales PEoLC Programme to support future education in Wales.

[please visit our website](#)
[for takeaway messages](#)

CHALLENGE TO ALL

Showcase some of the brilliant work we are completing across Wales and submit to the next World Congress



19th World Congress of the European Association for Palliative Care

29 - 31 May 2025 | Helsinki, Finland

Ready for the Future



RETIREMENT ANNOUNCEMENT AND BEST WISHES FOR STEVE HAM



We would like to take a moment to acknowledge the upcoming retirement of Steve Ham, our esteemed Chair of the Palliative and End of Life Care (PEoLC) Programme Board. Steve is retiring from his main role as Chief Executive of Velindre at the end of June 2024.

Steve has been a cornerstone of our programme, leading with dedication, vision, and an unwavering commitment to improving palliative and end-of-life care across Wales. His leadership and contributions have been instrumental in advancing our mission and achieving significant milestones.

We wish Steve all the best in his retirement. Thank you, Steve, for your remarkable dedication and impact on the PEoLC Programme and the broader healthcare community.

Warmest wishes,

Palliative and End of Life Care Programme Team

WARM WELCOME TO THE PEOLC PROGRAMME LEAD



We are excited to announce that Lynda Kenway will join us as the new Programme Lead, starting on June 3, 2024. Lynda brings extensive experience from her work with the Stroke Implementation Group at the NHS Executive and will strategically lead the PEOLC Programme.

HEARTFELT THANK YOU TO OUR MANAGER



We extend our heartfelt appreciation to Joanne Oliver for her exceptional support and leadership managing our team in the last couple of years. Joanne, thank you for not only guiding us through the transition to the NHS Executive but also for providing a platform for collaboration with the wider Networks and Planning team. Your unwavering support has been invaluable.

CONTACT US

Let us know if you would like to be on our mailing list



<https://executive.nhs.wales/PEoLC>



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