



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 2,  
November 2023*

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

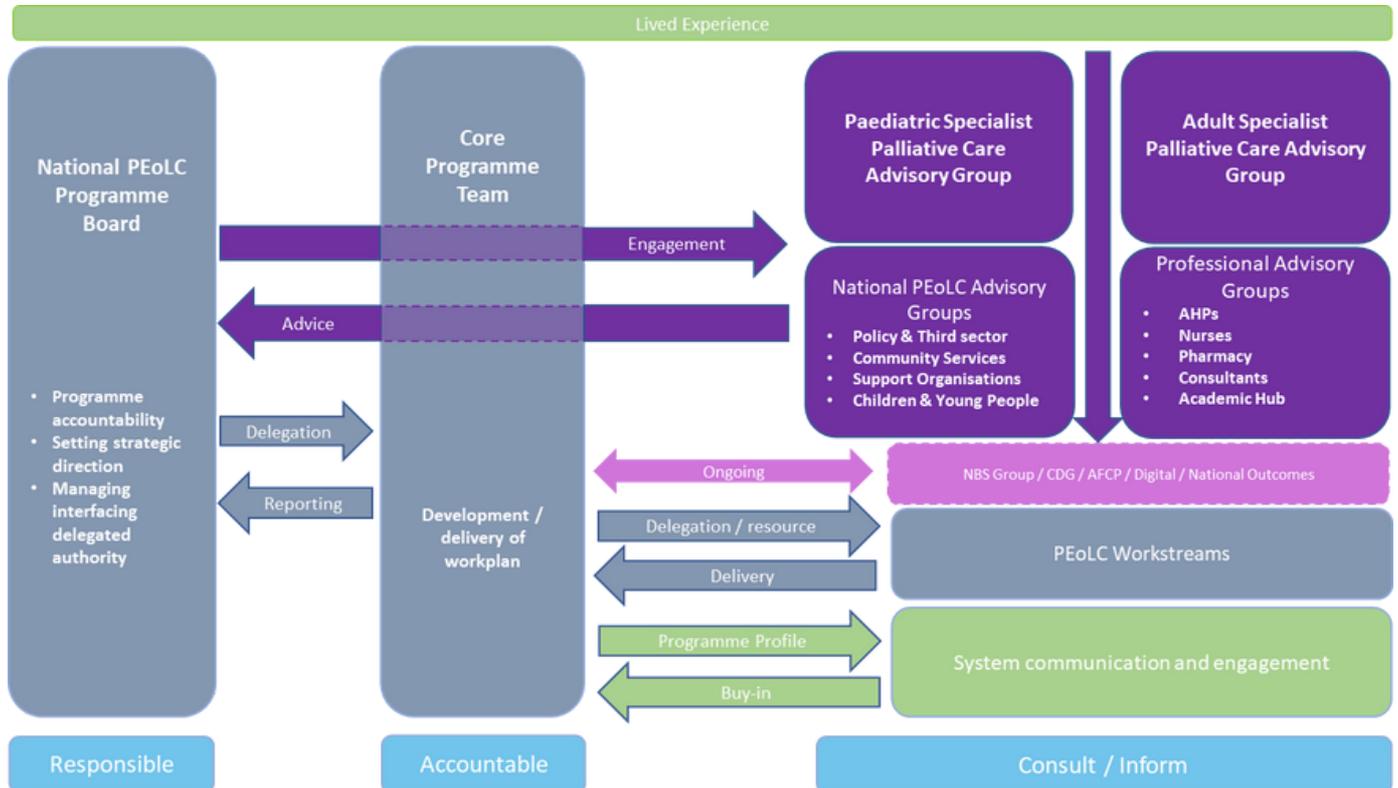
Our efforts this quarter were focused on the stakeholder engagement, the launch of the patient experience survey and progressing Phase 3 recommendations for Welsh Government. We participated at the All Wales Palliative Conference in Gregynog and are excited to announce our upcoming National PEoLC Programme event in March 2024.

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



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

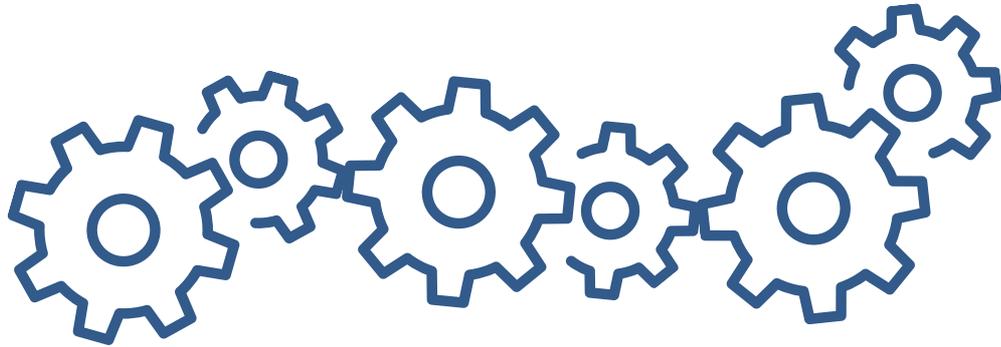
# NATIONAL PEOLC PROGRAMME STRUCTURE



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 Clinical Programme for PEOLC exists to help improve it for everyone in Wales. The Programme encompasses the groups described in this newsletter, 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's going to take all of us working together to get it right, so do think about areas of common interest with your work and do get in touch if you can think of ways to work together.

**Dr Idris Baker - National Clinical Lead**

# OUR GROUPS



## National PEOLC Advisory Groups

*Policy & Third Sector  
Community Services  
Support Organisations  
Children & Young People*

## Professional Advisory Groups

*AHPs  
Nurses  
Pharmacy  
Consultants  
Academic Hub*

*Adult Specialist  
Care Advisory  
Group*

*Paediatric  
Specialist Care  
Advisory Group*

## ADVANCE & FUTURE CARE PLANNING STRATEGIC GROUP

*The Advance & Future Care Planning Strategy Group meets every 2-3 months and has representation from across Wales, including two patient/carer representatives.*



The group keep the deputy Chief Medical Officer briefed on any new developments. For instance, recently we have acquired new members from Muslim Doctors Cymru, hearing about advance & future care planning challenges in Muslim communities in Wales, and the aim will be to deliver talks on this topic in mosques, with the help of Compassionate Cymru.

The chair of the group, Prof. Mark Taubert has recently been elected onto the European Association for Palliative Care (EAPC) board of directors, which will give further opportunities to work with and compare advance & future care planning practice with other countries. Mark was also interviewed by BBC UK News for a piece about the All Wales DNACPR policy which was aired in July.

The group has opened links with the office of the Older People's Commissioner to work on better information campaigns in Wales, and is also engaging with the nosocomial Covid-19 programme Wales, and the learning themes from the pandemic. A letter has been sent to all Medical, Nursing and AHP directors in all health boards and trusts, to disseminate the learning resources on DNACPR and Advance Care Planning that have been created over the last 5 years.

## ADVANCE & FUTURE CARE PLANNING STRATEGIC GROUP

Mark has joined the Executive Board of Directors of the European Association for Palliative Care (EAPC) in May 2023. He has also assumed the role of the Vice-President of the EAPC, with a view to promoting Wales and UK palliative care and Future Care Planning on a wider international footing.

More information on EACP can be found here:  
<https://eapcnet.eu/board-of-directors/>

### DNACPR Framework For Completion of (Section 5) by Registered Health Care Professionals Launched

A competency framework has now been published for holding DNACPR discussions, aimed at, but not exclusive to, nurses and allied healthcare professionals, for signing off section 5 of forms, and this has been compiled via workshops, feedback sessions and an open consultation at the start of 2023. This initiative was led by a dedicated team which included Professor Mark Taubert - National ACP Lead, Alison Foster - National PEOLC Lead Nurse, Ed O'Brian - Clinical PEOLC Lead WAST, Angela Jones - Resus Services Lead nurse and Mel Lewis - National PEOLC Programme Manager.

**You can access the framework via the link below under  
"further resources"**



# NATIONAL BEREAVEMENT FRAMEWORK PROGRAMME

INCLUDING THE NATIONAL BEREAVEMENT STEERING GROUP



*The National Bereavement Steering Group chaired by Dr Idris Baker and managed by John Moss, National Bereavement Framework Programme Manager is well established and includes the Local Health Board Bereavement leads, a wide variety of third sector organisations providing bereavement support to children, young people and adults, those affected by baby loss, sudden death, suicide and all types of bereavement.*

Recognising the key role of funeral directors in providing support to bereaved families the CEOs of the National Association of Funeral Directors and National Society of Allied and Independent Funeral Directors have also accepted our invitation to join the group. The NBSG meets at 2-3 monthly intervals.

The work of the NBSG is currently focused on developing bereavement referral pathways. We have started working on a national bereavement pathway specifically for pregnancy and baby loss, and are in discussion with a number of organisations and experts in this area to help us with this important work. Development of a bereavement pathway for children, young people and adults up to 25 years of age has commenced and is progressing well, with engagement from a wide variety of stakeholders.

# NATIONAL BEREAVEMENT FRAMEWORK PROGRAMME

INCLUDING THE NATIONAL BEREAVEMENT STEERING GROUP



JOIN OUR UPCOMING EVENT!

A special learning and network event on the theme of 'Supporting minoritised ethnic communities across Wales with grief and bereavement' will be taking place on 6th December at Cardiff City Stadium. This one-day event will bring together stakeholders from diverse backgrounds across Wales to discuss successes, challenges and goals for the future in supporting people from minoritised ethnic communities in Wales with death, dying and grief. Throughout the day there will be speakers from community organisations, time to network, and an opportunity to participate in research. Good Grief Connects, Action in Caerau & Ely (ACE) and Compassionate Cymru will be hosting the day.

Please see the poster with more details in our [News & Events](#) section below.

## HOSPICE VISITS 2023



*I have been fortunate to accompany Dr Baker to all of the hospice visits and would like to thank them for their hospitality. I personally found the conversations informative and I look forward to further visits in the coming weeks.*

**Lisa Wooler, Senior Project Manager for the National PEOLC Programme**

The Core PEOLC Programme Team recently embarked on a series of visits to voluntary hospices and statutory specialist services in Wales. Actively engaging with staff and stakeholders to gain deeper insights into their ideas, concerns, and needs within the service.

The aim of the visits is to foster a collaborative environment, encouraging a shared focus on value within the National Programme for Palliative and End of Life Care (PEoLC). The visits will help inform the development of the phase 3 review, ensuring that the perspectives of hospices are effectively incorporated into the recommendations for the Welsh Government.

## HOSPICE VISITS 2023

If any hospices would like for the PEO LC Programme to visit,  
you are welcome to get in touch.



*Ty Gobaith Children's Hospice*

# PALLIATIVE CARE PATIENT EXPERIENCE SURVEY LAUNCH



*We are thrilled to announce the launch of the National PEOLC Patient Experience Survey, which aims to gather feedback from patients about their experiences with PEOLC services. By listening to their voices, we hope to identify areas for improvement and develop a more patient-centered approach to care.*

The Service User Feedback Working Group of voluntary and statutory sector representatives assisted in developing the survey and in collaboration with the Welsh Risk Pool and Health Board Patient Experience Teams the survey is now available to patients of Specialist Palliative Care teams within all Health Boards in Wales.

Cardiff and Vale UHB and Velindre Cancer Centre reported first feedback received on 1st August 2023. Work continues to enable

Voluntary Hospices and wider health care providers to invite patients receiving Palliative Care from their teams to complete the survey and contribute to the national picture of palliative care in Wales.

# MEET OUR PEOLC PROGRAMME BOARD

ALISON FOSTER

NATIONAL PEOLC LEAD NURSE

ANDY GOLDSMITH

HOPE HOUSE & TY GOBAITH CEO

BETHAN DAVIES

SENIOR MANAGER, WELSH  
GOVERNMENT

CHRIS DUNN

DIVERSE CYMRU CEO

DR CLIFFORD JONES

PRIMARY CARE LEAD, ANEURIN  
BEVAN UHB

DR IDRIS BAKER

NATIONAL CLINICAL LEAD FOR  
THE PEOLC PROGRAMME

DR RICHARD HAIN

PAEDIATRIC CLINICAL LEAD EOLC

GARETH HEWITT

HEAD OF CLINICAL CONDITIONS  
AND PATHWAYS, WELSH  
GOVERNMENT

JACQUELINE POTTLE

NATIONAL PEOLC AHP LEAD

JENNIFER WINSLADE

EXECUTIVE DIRECTOR NURSING,  
ANEURIN BEVAN UHB

JOANNE OLIVER

NHS EXECUTIVE SENIOR TEAM

## MEET OUR PEOLC PROGRAMME BOARD

JON ANTONIAZZI

AD FOR POLICY & PUBLIC AFFAIRS  
FOR WALES, MARIE CURIE

KRISTINA KUNSTEINAITE

PROJECT SUPPORT, PEOLC  
PROGRAMME

LISA WOOLER

SENIOR PROJECT MANAGER,  
PEOLC PROGRAMME

LIZ BOOYSE

CEO, HOSPICE CYMRU

MELANIE LEWIS

PROGRAMME MANAGER, PEOLC  
PROGRAMME

MARIA PARRY

PROGRAMME MANAGER, PEOLC  
PROGRAMME

PAUL LABOURNE

NURSING OFFICER, WELSH  
GOVERNMENT

STEVE HAM - CHAIR

CHIEF EXECUTIVE, VELINDRE

## NEWS AND EVENTS

### 21st Annual All Wales Palliative Care Conference

The conference took place on 12-13th October at the Gregynog Conference Centre in Powys.

This was a great opportunity to network with colleagues from across Wales and share about innovations in palliative and end of life care.



*From left to right, Jackie Pottle, Maria Parry, and Lisa Wooler representing All Wales Palliative and End of Life Care Programme*



*Gregynog Conference Centre*



*What Matters Most: A Lived Experience  
Visual Storytelling Exhibition*



*Jackie Pottle and  
Erica Thornton*



*Alison Foster, organiser of  
the Gregynog conference*



*Dr Idris Baker presenting at the conference*

## NEWS AND EVENTS

Please save the date!



### National PEOLC Programme Event

**Date: Friday, 1st March 2024**

**Venue: All Nations Cardiff, CF14 3NY**

The intention of the event is to bring together the PEOLC Programme advisory groups in Wales alongside essential stakeholders. The event promises ample opportunity to connect with colleagues in the PEOLC field, gain insights into the undertakings of the advisory groups and the PEOLC Programme work in Wales, and actively participate by sharing your valuable ideas and suggestions.

A detailed agenda will be shared closer to the event.





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of Life Care Programme

- *Expand /share your AHP knowledge and skills in the PEOLC field*
- *Learn about the National PEOLC Programme's work*
- *Connect with AHP peers working in PEOLC across Wales*

ALL STAFF ARE WELCOME

# Open Network Meeting for AHPs in PEoLC

*Join an inclusive and  
supportive discussion  
facilitated by the National  
AHP Advisory Group led by  
Jackie Pottle, National  
AHP Lead*

**Thursday  
18th January 2024  
10am-12pm**

## JOIN US ON TEAMS

[Click here to join the meeting](#)

Meeting ID: 397 736 936 108

Passcode: Sq3PZy

For any enquiries, please email:  
[nhswe.nationalpeoleprogramme@wales.nhs.uk](mailto:nhswe.nationalpeoleprogramme@wales.nhs.uk)



## You're invited to a learning and network event

### *Supporting minoritised ethnic communities across Wales with grief and bereavement*

Representatives from organisations across Wales are invited to a free event.

Join us in sharing your experiences of supporting bereaved people from ethnic minority groups. Highlight your successes, talk about your challenges, and learn from others.

Good Grief Connects, ACE and Compassionate Cymru will be hosting the day. Tell others about the fantastic work you do. Take part in research during the day and help identify approaches that work best.

**Weds 6th December**  
**9.30am - 4.30pm**



**Cardiff City Stadium,**  
**Leckwith Road,**  
**Cardiff,**  
**CF11 8AZ**

#### *Celebrate*

**Tell people about your successes**

#### *Showcase*

**Bring leaflets and resources to share information about your work**

#### *Network*

**Meet other people & organisations who support minoritised ethnic communities in Wales**

#### *Learn*

**Talk about your challenges. Hear from presenters about examples of good practice in the community**

#### *Free*

**No charge for attendance. Lunch & refreshments provided**

***For more information***  
Please contact  
[healthy@aceplace.org](mailto:healthy@aceplace.org)



**Please scan the QR code or click here to register**

## NHS EXECUTIVE UPDATE



As most of you will know, the NHS Executive was established on the 1st April 2023. The key purpose of the Executive is to drive improvements in the quality and safety of care to achieve better, fairer healthcare outcomes for the people of Wales. This body is comprised of several organisations, including the Delivery Unit, Finance Delivery Unit, Improvement Cymru, and Health Collaborative.

As a result of this new arrangement, the National All Wales PEoLC Programme is now hosted by the NHS Executive, offering better visibility and access to support to continue advancing the Programme's work.

For more information on the NHS Executive, please visit their website.

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

## CONTACT US

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



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



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