



GIG
CYMRU
NHS
WALES

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

All Wales AHP Professional Advisory Group Meeting for PEOLC

Minutes of meeting:

Date: 26/10/2023

Time: 9:30 – 11:00

Author: [REDACTED]

Version: 0b

Name	Initials	Role	Organisation
[REDACTED]	[REDACTED]	Specialist Palliative Care OT	Cwm Taf UHB
[REDACTED]	[REDACTED]	Clinical Lead Palliative and PEOLC	Welsh Ambulance Service
[REDACTED]	[REDACTED]	[REDACTED]	Cardiff & Vale UHB
[REDACTED]	[REDACTED]	Palliative Occupational Therapist	Hywel Dda UHB – Palliative OT
[REDACTED]	[REDACTED]	[REDACTED]	UHW Heath Hospital Cardiff
[REDACTED]	[REDACTED]	Chair, AHP Lead for Palliative and End of Life Care Programme	NHS Executive
[REDACTED]	[REDACTED]	Clinical Lead Occupational Therapist, Cancer Services	Swansea Bay UHB
[REDACTED]	[REDACTED]	Macmillan Head of Therapies	Velindre
[REDACTED]	[REDACTED]	Senior Project Support Officer for Palliative and End of Life Care Programme	NHS Executive
[REDACTED]	[REDACTED]	Senior Project Manager for Palliative and End of Life Care Programme	NHS Executive
[REDACTED]	[REDACTED]	Consultant Clinical Psychologist	BCUHB
[REDACTED]	[REDACTED]	Occupational Therapy Team Lead	Betsi Cadwaladr UHB
[REDACTED]	[REDACTED]	Post Doctoral Researcher	Bangor University
[REDACTED]	[REDACTED]	Programme Manager for Palliative and End of Life Care Programme	NHS Executive
[REDACTED]	[REDACTED]	Programme Manager for Palliative End of Life Care	NHS Executive
[REDACTED]	[REDACTED]	Macmillan Dietitian	Cwm Taf Morgannwg UHB

██████████	████	Senior Policy & Public Affairs Officer	Hospices UK
██████████	████	Dietitian Team Lead	Powys Teaching HB
██████████ (for taking minutes)	████	Programme Administrator	NHS Executive
██████████	████	AHP Lead for Macmillan Cancer	Aneurin Bevan UHB
██████████	████	Consultant Therapist	BCUHB – Care of the Elderly
Apologies			
██████████	████	Palliative Care Physio Lead	Hywel Dda UHB
██████████	████	Strategic Programme for Primary Care	Hywel Dda UHB
██████████	████	Macmillan All Wales Lead Cancer Allied Health Professional	Cancer Network, NHS Executive
██████████	████	AHP Lead for Macmillan Cancer	Cwm Taf Morgannwg UHB
██████████	████	Specialist Art Therapist	BCUHB
██████████	████	speech and Language Therapy	Swansea Bay UHB
██████████	████	Deputy Head of Therapies	Velindre
██████████	████	Art Psychotherapist in Palliative and End of Life Care	Hywel Dda UHB
1. Welcome and apologies			
████ welcomed the group to the third All Wales AHP professional Advisory Group meeting.			Action
2. Approval of previous minutes / matters arising			
████ is currently in the process of compiling a document aimed at defining the value of AHPs in palliative and end of life care (PEoLC). The compiled document will be shared with the All-Wales AHP professional advisory group prior to the next meeting. The previous minutes were approved as an accurate record by the group. Action log from previous meeting:			Action
DNACPR competency framework – to be shared with Director of Therapy meetings and each HB/ trust to decide how to progress. provisional date in August was cancelled by DoTH – to be rescheduled Nov 23 – █████ to send a summary prior to Nov meeting. Action noted as ongoing. Further update provided on 26.10.2023 █████ scheduled to meet the director of therapies on 10 th of November. █████ mentioned it is a great opportunity to raise awareness of AHP work amongst the directors of therapies and get their support. █████ advised to send an email after the meeting to the head of service to regarding the DNACPR competency section - 5 framework.	████	Ongoing.	
Task & finish group to create a SOP for DNACPR competency framework. Further update provided on 26.10.2023 █████ cannot create a group until the meeting with the Director of therapies.	████/nominations	Ongoing.	

New Action created under this action: add task and finish group to the next meeting's agenda.	■		
Patient reported core ADL measure – to be explored with a view to future development.	■■■■■	Ongoing.	
Share Value based Health care information – invite ■■■■■■ to a future meeting.	■	Ongoing.	

3. Education: Knowledge & skills sharing			Action
<p>■ mentioned that knowledge and skills sharing is important to promote AHP work. ■ updated the group that AHPs had an excellent representation at the All-Wales Palliative Care Conference in Gregynog. A number of presentations were delivered by different individuals on a range of topics. One of the presentations was given by ■ on data collection. Another presentation was led by ■■■■■■, who addressed the issue of palliative rehabilitation. Lastly, ■■■■■■ and ■■■■■■ presented their role in DNACPR section 6 as a senior responsible officer. It was noted by ■ that ■ and ■ are the only consultant therapists with the title of a senior responsible officer Wales.</p> <p>■ informed the group that regarding the DNACPR section 5 and competency framework, the Ceredigion Specialist Palliative Care Team Manager ■■■■■■ is exploring the possibility of establishing a pilot for the Ceredigion Trust. She will discuss this with the Director of Therapies and Head of Services.</p> <p><i>Action: ■ will link ■ with ■ regarding the DNACPR section 5 and competency framework pilot framework in Ceredigion.</i></p>			■

4. I just want to be me – Trans and Gender Diverse Communities Access to and Experiences of Palliative & End of Life Care. Hospice UK Research			Action
<p>■ from Hospices UK presented a report on 'I just want to be me' – exploring trans and gender diverse communities' access to and experiences of palliative & end of life care.</p> <p>Terminology:</p> <p>Trans: People whose gender is not the same they were assigned at birth.</p> <p>Gender Diverse: People whose gender identity, including their gender expression, does not conform to socially defined gender norms.</p> <p>Non-Binary: People whose identity does not sit comfortably with man or woman.</p> <p>Cis gender: People whose identity is same from the birth.</p> <p>Background of Research: In 2021 Hospices UK conducted research on the challenges of inequality in palliative care end of life around 7 different communities and subsequently reached out to organisations of these communities. Following this research, brief research was conducted by Hospices UK to address and mitigate the barriers faced by these communities. The focus on LGBTQ+ communities was driven by its continuous growth, with the aim to improve their experiences around palliative care end of life and create a platform for open communication about their concerns.</p>			

Two surveys were conducted with in collaboration with Gender Identity Research & Education Society (GIRES) for palliative and end of life care.

- One was aimed at trans and gender diverse communities' perspective and experience.
- Second was aimed at working and volunteering in death, dying and bereavement.

It was highlighted by [REDACTED] that several falsified responses were received in the community survey.

Key Findings:

- **Planning for the end of life and funeral care:**
It was mentioned by 68% people in survey being trans diverse had impacted on their plans and wishes for the end of life and after their death.

- **Approaching care providers:**
The majority of people expressed anxiety over approaching end of life care providers because of their negative previous health care experience and fear of discrimination.

Recommendations: Having workplace policies to support trans and gender diverse people against discrimination.

- **Retaining identity and dignity:**
The biggest concern was being addressed with the incorrect title and pronouns. Other concerns included not having access to gender affirming clothing, items, and personal care and access to transition health care.

Recommendations:
All NHS and hospice patients' information should be updated in a timely way. Health care providers should use the correct title and pronouns while addressing trans and gender diverse people.

- **Physical care:**
The biggest concern was lack of medical knowledge around trans people in palliative and end of life care. Concerns over discrimination in physical care were also brought up.

Recommendations:
Providing the required education and information to professionals in palliative and end of life care.

- **Workforce and training**
It was noted that most people working in PEoLC were keen to learn about trans and gender diverse people.

Recommendations:
Education providers should ensure health and social care staff should receive pre - registration training on gender diverse courses.

[REDACTED] suggested to read the report and experiences of trans and gender diverse people.

<p>█ also provided an overview on the 'being ready' project phase two which will be out soon. In this project Hospices UK is conducting one to one interview with transgender people and the palliative care end of life workforce to capture brief information.</p> <p>█ informed the group she was able to share a useful PowerPoint created by a █ to raise awareness around LGBTQ plus.</p> <p><i>Action: █ to share LGBTQ plus awareness PowerPoint with the group.</i></p> <p>█ recommended to read the Marie Curie report 'Hiding Who I Am.' This report contains experiences of people in palliative and end of life care.</p>	<p>█</p>
--	----------

<p>5. Research -proposal development presentation INSPIRE Project- EU RCT (integrated short-term pal rehab for incurable Cancer)</p>

	Action
<p>█ gave a presentation on a proposal for research.</p> <p>Proposed aims of the research:</p> <p>Primary aim: to explore PEoLC care needs for LGBTQ+ adults in Wales with a focus on advance care planning.</p> <p>Secondary aim: to explore Allied Health Professionals understanding and implementation of advance care planning and training support needs.</p> <p>What is ACP (Advance Care Planning)?</p> <p>ACP enables individuals who have decisional capacity to identify their values, to reflect upon the meaning and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health care providers.</p> <p>Benefits of Advance Care Planning:</p> <ul style="list-style-type: none"> ● Allow the person to have more choice and control. ● Improve the quality of end-of-life care. ● Reduce the chance of unwanted treatment. ● Fulfil their wishes, for instance preferred place of death. ● Reduce family burden. ● Reduce anxiety and depression of family and friends after the person's death. ● Allow the person to consider what is important to them and support relationships. <p>Advance and Future care planning and key components in Wales:</p> <ul style="list-style-type: none"> ● Advance decisions or advance decisions to refuse treatment (ADRT) or living wills. ● Advance statements. ● Lasting power of attorney for health and welfare. ● Do not attempt cardiopulmonary resuscitation (DNACPR) decisions and forms. 	

- Record of best interest decision form.
- Hospital treatment escalation plan (TEP) forms.

It was noted that most people do not plan their end-of-life care and have little awareness of this. It is often discussed at an acute situation which is more challenging for both the practitioner and the patient. Additionally, health care professionals also face cultural competency challenges.

LGBTQ+ Action Plan for Wales:

Understand and improve the experiences of LGBTQ+ people in health and social care sectors in Wales. Review existing training for NHS Wales staff to address any gaps. Collaborate with social care Wales to design and evaluate the impact of training for staff in social care setting.

█ shared that they use qualitative and photovoice methods to gather data from LGBTQ+ people and their loved ones who accessed PEOLC care service for her proposed development approach.

It was mentioned in the presentation that █, project lead, is running a training course called “No Barriers Here” to identify challenges and inequalities in PEOLC. It was noted that the No Barrier Here Model is an essential tool in engaging and involving individuals in Advance Care Planning in the community.

█ informed everyone that the late █ led extensive training on advance future care planning for AHPs. Following this, select participants assumed the role of trainers, contributing to subsequent training initiatives. █ noted that, despite thorough training, using advanced care planning documents remained a challenging task.

█ and the team successfully developed an advance care plan for people in the community hospital to clearly document the end of life wishes of patients. However, it was observed that there was a scarcity of participation among patients from the transgender and gender-diverse community.

█ shared a copy of the All-Wales document for cognitive capacity with the group.

█ mentioned all issues are wider than the gender diverse community and recommended to produce meaningful results from any research conducting, which can be used for clinical practices.

█ asked everyone to send feedback to █ to support her research.

█ mentioned about the European Union research project INSPIRE (Integrated short term palliative rehab for incurable cancer). It is a fully funded project with the aim to deliver cost effective palliative rehabilitation intervention and for quality-of-life symptom alleviation for patients with cancer, with focus on equitable access to rehab. Trials are taking place in different countries apart from Wales for this research. █ got in touch with INSPIRE to explore collaborative opportunities.

Action: █ to provide update about the INSPIRE research to group.

Action: To keep ‘research’ as an agenda item for the next meeting.

█
█

6. Programme board / AHP national leads information

<p>■ revisited the survey that was completed around what core skills AHP group can bring to palliative and end of life care. ■ is compiling the discussion and survey findings and will share them with the group once completed. Additionally, ■ is also engaged in AHP workforce scoping in Wales which is proving to be challenging and requires additional efforts to accurately assess the service.</p> <p>Action: ■ to share the report regarding AHP value in PEOLC care with the group prior to the next meeting.</p> <p>■ also mentioned ■ National AHP Lead of Dementia Care, organises a monthly meeting which is open to anyone who works in dementia. The next meeting will be held on 12th of December which is aimed at PEOLC for dementia patients.</p>	<p>■</p>
<p>7. Any Other Business/ Actions</p>	
<p>■ expressed the intention to establish a task and finish group and with the first meeting to take place in early January. Following this, a meeting will be scheduled quarterly. She has asked all the AHP group members to volunteer for this initiative.</p> <p>Action: <i>Everyone to think about an area to progress for the future task and finish group and inform</i> ■</p> <p>■ announced that the first National Palliative and End of Life Care Programme face to face event is planned for 1st of March 2024 at the All Nations Centre in Cardiff and requested the group members to save the date.</p> <p>■ also updated that the some of AHP Lead has developed rehab modelling. ■ would like to explore this model further.</p> <p>Action: <i>Interested AHP group members for volunteering to explore rehab model contact</i> ■.</p>	<p>Everyone</p> <p>Everyone</p>
<p>8. Date of Next meeting</p>	
<p>The next meeting will be held on 7th of December at 09:30- 11:00 via MS Teams.</p>	