# Cross-Party Group on Palliative Care
# Hybrid Meeting

Wednesday 04 December, 6.00pm-7.30pm, Scottish Parliament meeting room Q1.04 and on MS Teams

## Approved Minute

**In attendance at parliament:**
Bob Doris MSP
Marie McNair MSP
David Cameron, office of Bob Doris
Anne Finucane, Marie Curie
Mark Hazelwood – SPPC
Helen Malo – Hospice UK
Clare McGowan – Beatson, Glasgow

In attendance remotely:
Bernie Boyd, Health & Social Care, Western General Hospital
Sandra Campbell, Scottish Ambulance Service
Emma Carduff, Marie Curie
Bruce Cleminson, retired Palliative Care Consultant
Pauline Ellison, SPPC
Liz Forbat, Stirling University
Tracy Flynn, Ayrshire Hospice
Erna Haraldsdottir, Queen Margaret University
Donna Hastings, St Columba's Hospice Care
Vicky Hill, St Columba's Hospice Care
Sue Hogg, CHAS
Rachel Kemp, Marie Curie
Till Kroeber, Strathcarron Hospice
Murdina MacDonald, NHS Fife
Marjory Mackay, Strathcarron Hospice
Andrene Maxwell, Scottish Parliament
Colette McDiarmid, MND Scotland
Jude Meryl, Soul Midwives Scotland
Sarah Mills, University of St Andrews
Aileen Morton, Hospice UK
Mandy Murray, St Columba's Hospice Care
Scott Murray, Edinburgh University
Lorna Porteous, NHS Lothian
Neil Ritchie – Scottish Government
Catriona Ross, NHS Forth Valley
Ellie Wagstaff, Marie Curie
Julie Watson, Marie Curie

Apologies:
Jackie Baillie MSP

Miles Briggs MSP
Stephen Kerr MSP
Kirsty Boyd, SG
Fiona Finlay, NHS Lanarkshire
Jacqueline Gray, NHS Shetland
Annabel Howell, CHAS
Lesley Howells, Maggie's
Narmadha Kali Vanan, Ardgowan Hospice
Marie Manzi, Macmillan
Margaret McCarthy, NHS Forth Valley
Clare Murphy, St Margaret of Scotland Hospice
Rami Okasha – Children's Hospices Across Scotland
Dot Partington, St Columba's Hospice Care
Rebecca Patteson SPPC
Jacki Smart, Accord Hospice
Anna Sutherland, NHS Forth Valley
Heather Tonner, Macmillan Cancer Support
Mona Vaghefian, CHAS

**Agenda item 1: Welcome, introduction and apologies**
Bob Doris welcomed attendees to the meeting; everyone introduced themselves either in person or in the MS Teams chat.

**Agenda item 2: Approval of the minute of the previous meeting of 24 September 2024**
The group approved the minute of the meeting of 24 September 2024 as a correct record. Proposed by Sandra Campbell, Seconded by Helen Malo.

**Matter Arising from minute**:
One action from the last meeting:

> *"Bob Doris will work with the speakers and the secretariat to draft a letter to Scottish Government drawing attention to the End of Life Care Together model as something from which learning can be drawn at a Scottish level".*

This has not yet been taken forward. However, this work by Highland is mentioned in the draft strategy. Also, Highland Hospice had an opportunity to discuss their work briefly with the Cabinet Secretary for Health.

**ACTION POINT: Letter (as above) to be drafted before Xmas recess**

**Agenda item 3: Presentations and Discussion**
Tonight's presentation is on the topic of The Scottish Government draft Palliative Care Strategy: *Palliative Care Matters for all.* Due to illness, Kirsty Boyd, National Clinical Lead for Palliative Care is unable to attend tonight. Thanks to Neil Ritchie (SG Policy Unit for Palliative Care Lead) for delivering the presentation in her stead. (Slides available here)

The strategy consultation was launched on 02 October 2024 and closes on 10 January 2025. The aims of the strategy were noted – key to achieving these aims is working in partnership across health and social care, and local authorities; with local communities and wider support networks. It is about partnership activities and maximising synergies between organisations. The delivery plan is looking at tools that are able to support people within these groups and networks.

Leaders at national and local levels need to have whole-system, population based approaches to planning and delivering palliative care and community-led support. SG is currently working at a national level around engagement with Health Boards and Integrated Joint Partnerships to raise their awareness of the opportunities within the strategy.

Next steps: following consultation there will be a much slimmer strategy document focussing on the vision, where we want to go and why – this will be accompanied by a supporting delivery plan which will set out some of the key issues such as the governance of the strategy. SG will not lead on all the actions but will support others to take them forward.

**Discussion and Questions**

The following issues were discussed:

- It is hoped to engage with as many as possible through the online consultation; engagement sessions were not planned due to current financial restrictions, however the SG team has attended numerous meeting sessions with eg SPPC groups, hospices, NES etc and is open to invitation to future meetings.
- There is some concern the ongoing evidence gathering is not representing everyone's needs – members are asked to identify any such gaps in their responses.
- Essential to have a workforce with knowledge skills confidence and is co-ordinated enough to provide quality timely palliative care services – should this be considered as a core aim? Important to have the right staff with the right skill-mix.
- Achieving the equity of service provision that the strategy is aspiring towards is crucial but specific actions are needed to take this forward to ensure localised solutions reflect the population health needs
- The National Partnership Delivery Board was created to harness engagement throughout the Health Boards – would it be useful to see what topics are being considered by the NPDB?
- Consider repurposing existing resources; important to maximise synergies between services to deliver the maximum result.
- Concern around how the outcomes will be achieved – who will lead, support; what is the timescale; how will this happen etc. SG has a strong role to play but cannot lead on everything – there are a lot of groups, organisations and people better placed to drive specifics forward eg Data work is being supported by SG but led by others eg colleagues in the NHS who can better define what is needed, and also Public Health Scotland.
- Encouraging to see outcome 4 relating to early identification for generalist and specialist palliative care - SPICT and other identification tools are helpful.
- MSPs will have a free vote on the on the general principles of the Bill and will be able to make their own decision on the Bill, rather than following party instructions. If the general principles are not agreed to, the Bill will fall and cannot become law
- Outcome 6 Quality and experiences of care around dying and bereavement … we need to address all thinking around pre and post bereavement support and existing services as there are currently postcode lotteries around bereavement right across the country; we need equity around access to available services for all; perhaps a Bereavement Strategy for Scotland should be considered?
- Within SG bereavement is a broad issue; the Palliative Care Policy team works closely with Mental Health colleagues on this topic; NES is currently taking forward work on bereavement – important to highlight specific details of gaps in practice and solutions in any consultation response.

- Interdisciplinary working and training for family doctors and their teams increases their skill levels and can help to contribute to reducing postcode lottery service provision; there is also great value in MDTs supporting patients
- It was noted that as the population ages and there is an increase in the number of people over 85, care homes become increasingly significant as providers of palliative and end of life care for this age group (stats in England 34% of over 85 year olds die in care homes). This needs to be reflected in the actions eg access to palliative care education and support for the care home social care workforce including social care nurses. Also worth flagging that the majority of palliative care is delivered in the community (and not through the hospital Palliative Care specialty) and that urgent/ unscheduled care (GP out of hours, Emergency Department, Scottish Ambulance Service) deliver an enormous amount of palliative care.
- The content of the Strategy is quite complex and dense - would it be possible to add a Summary, making it easier to access for everyone? (Obviously this will depend on who the Strategy is meant to reach.)
- There is potential to make more mention of the additional care needs of those who are dying at home and those who are supporting them. Perhaps part of Outcome 6, along the lines of 'Champion, co-ordinate and work in partnership with key stakeholders to ensure compassionate advice, resources and support are available for people caring for those who are dying at home'.
- Important to have a focus on evidence and data
- The RCN, Marie Curie and Royal Pharmaceutical Society and others will lobby UK Government to Change the Misuse of Controlled Drugs Act 1971 to allow CDs to be stored in care homes outwith a named patient basis to improve access to symptom control; JiC Boxes are stored in care homes but a lot of these will not be used
- Since work around standards would involve regulators, SG is considering corporate reporting from Boards re what they are doing around palliative care
- Within the strategy there are no specific mention of symptoms – possible to note some broad themes from holistic point of view eg spiritual, financial, but especially the emotional impact of people living with life-limiting illness including family, friends and staff too. More scope to mention the importance of broader, cross-cutting emotional needs that touches everyone?
- A challenge is language and making that accessible to all.

There was a brief discussion around the budget statement that £4m is to be allocated to the hospice sector for increasing costs for implementation of Agenda for Change pay awards.

**Agenda item 4: Update on the Right to Palliative Care Bill consultation**
Ellie Wagstaff, Policy and Public Affairs Manager (Scotland), at Marie Curie provided an update on the progress of the Right to Palliative Care Bill.

The independent analysis of consultation responses has been completed which will be shared in the New Year; main themes emerging include ensuring equitable access; upholding human dignity; enhancing quality of life; holistic care; aligning with human rights; preparing for increased demand. Concerns reflected include resource; implementation challenges and system capacity esp in rural areas; some terminology concerns that could potentially exclude some groups conditions specific needs; data.
The right to palliative care has been highlighted at recent broader conferences and engagement is continuing into new year through Marie Curie round table events.

Thanks to Bob Doris MSP, Marie McNair MSP, Miles Briggs MSP and Rhoda Grant MSP for continuing to work together using cross party approach.

**Agenda item 5: Any other business.**
No further business was discussed.

**Agenda item 6: Date of the next Cross Party Group meeting**
The next hybrid meeting of the CPG is on Wednesday 15 January 2025, 6.00pm – 7.30pm and will focus on the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

**UPDATE:** Please note that the 15 January 2025 meeting has had to be postponed due to parliamentary business. It will now take place on **19 February 2025** from **6.00pm – 7.30pm.** This will be a hybrid meeting so attendance is possible on MS Teams or in person (Committee Room 6).
The meeting will aim to explore, understand and discuss issues raised by the provisions of the Assisted Dying for Terminally Ill Adults (Scotland) Bill, with an emphasis on perspectives informed by the practice and provision of palliative care. More details will follow.

There being no further issues the meeting closed at 19.28.