

Regional Specialist Palliative Care Nursing Group (RSPCNG)

This is a collective response on behalf of the Regional Specialist Palliative Care Nursing Group (RSPCNG). This group is a collection of Nursing Leaders who are involved in the delivery of specialist palliative care. They provide a regional collective leadership voice for Specialist Palliative Care Nursing, from across all care settings, and a continued Nursing reference group for the Palliative Care in Partnership Clinical Engagement group. This supports two-way communication between the Group and the Regional Palliative Care Clinical Engagement Group. This group actively seek opportunities to progress and support the development and monitoring of Specialist Palliative & End of Life Care nursing services.

The group collate information or data on occasions to provide all members of the group with the necessary intelligence to inform decision making in relation to the SPC nursing workforce. Examples of this may be collating/updating SPC workforce census, SPC Nursing NMP census etc. All members of the RSPCNG currently reflect those responsible regionally for the management of Trust and Voluntary specialist palliative care nursing services.

Each Trust and Voluntary Organisation has one identified Nursing lead contributing to the group, with further contribution given by the Palliative Care Nurse Consultant BHSCT/Marie Curie/Queens. In addition to this there is Nursing leads from the three university providers in Northern Ireland and the Royal College of Nursing (RCN).

Membership is extended to Clinical Nurse Specialist and Advanced Nursing Practitioners within these organisations to facilitate professional leadership development. On occasions it is necessary to co-opt other Nursing Leads/ PC Service Improvement Leads or Clinical Nurse Specialist's within these organisations to facilitate a more comprehensive discussion of other matters which arise impacting on specialist palliative care nursing.

Current state of palliative care services

In your view what is the current state of palliative care services in Northern Ireland?

Poor

Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?

Not sure

The public knowledge of palliative care is varied, and it is difficult to accurately gauge the level of public knowledge without a robust scoping exercise to inform this. It is the experience of the group that public knowledge is poor, many people still believe palliative care is only for the last few weeks of life. Many do not understand it can be beneficial much earlier in the disease trajectory or the difference between generalist and specialist palliative care. Generalist palliative care can be provided by multidisciplinary staff in the acute and community setting however many people believe it can only be provided by those who work in specialist palliative care. One of the main barriers is that professionals have a lack of

understanding about palliative care and fail to recognise the benefits it can bring much earlier in the person disease trajectory. Also, some professionals do not recognise that they are delivering generalist palliative care and fail to recognise when they should refer on to Specialist Palliative Care. Professionals and public education and information has not been standardised and there has not been a public messaging campaign to ensure delivery in a structured way. Consequently, the public and some professionals are not fully aware of the services or support that is available. The ACP policy was launched in 2022 this needs to be implemented in particular the ReSPECT document.

Access to services

Are palliative care services equally accessible to all who need them?

Not sure

From your experience where are the gaps in the provision of service?

It is difficult to identify all the gaps without a robust analysis of the current provision and lack of funding often prevents services being developed to their full potential. Below are some of the obvious gaps

No structured implementation of ACP and the ReSPECT document to proactively manage peoples palliative care needs whilst respecting their wishes

Lack of a regionally agreed model supported by commissioning

Lack of integration and standardisation between different palliative care services

Lack of an updated strategy that aligns to the rest of the United Kingdom and the Republic of Ireland

Lack of multidisciplinary specialist workforce planning

Lack of intelligence to identify the gaps in service delivery

Lack of coordination and sustainable services as funding is often non recurrent

Lack of care packages to support patients and families 24/7 in the community

Lack of the ability to rapidly respond to symptom management when a patient returns home – need outreach community services to provide additional support during period of crisis this could potentially prevent the patient needing to attend acute services such as A/E

Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes

Lack of awareness between professionals and the public about the support palliative care can provide to people with a palliative condition which in turn prevents access to services.

Inequitable access to palliative care services depending on the persons postcode.

Lack of understanding of need for palliative care services in areas of social deprivation, prisons, homeless, learning disability, mental health etc. We need to be better informed about the strengths and weakness of different communities so we can meet the needs of those in our most deprived areas. Those who need more should get more.

Lack of trained and supported Domiciliary Care Workers, to help support people to remain in their own homes (which may be their preferred place for EOLC) or facilitate discharge home from hospital.

We need full implementation of ACP policy to support timely identification of patient needs.

What additional services could/should be provided?

This is difficult to quantify without a robust needs assessment to evidence the service gaps.

Standardised education and training in palliative care for all disciplines both pre and post registration. Including domiciliary care workers. This should be mandatory similar to DNACPR training.

Standardised education and public messaging to support self-management and reduce over reliance on services were possible

Palliative care Hubs should be available within an appropriate geographical distance from the patient. People living in rural areas often must travel long distances to access inpatient services and they not well supported by public transport to access or visit relatives in inpatient beds. They also have distances to travel to access palliative care hubs however these are not available in all areas.

There is a need for standardised 24/7 service provision in community. Outreach services need to be progressed in a standardised manner to support integration and equitable palliative care services across all sectors.

There is an inability to rapidly respond to the need for symptom management in community during the out of hours period this is often a barrier to a patient returning home especially in rural areas.

Integration of Services

How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

There are multiple providers of palliative care and whilst integration exists it is not standardised and needs to be improved. Specialist palliative care services are often influencing without authority in care settings outside specialist palliative care units. Quality

indicators need to be developed for acute services similar to community services to monitor the delivery of care. Communication between services need to be improved to improve coordination and efficiency of service delivery. Hospices and G.Ps need to have greater access to Encompass, at present this is limited and therefore is a barrier to full integration and communication.

Should palliative care be a regional service? Please outline your reasons in the box provided.

Not sure

If established a regional service may support equitable access to services and enhance governance structures. This initiative is likely to aid SPC workforce planning, boost efficiency, and attract investment. Additionally, it could improve response times and facilitate resource sharing. By integrating care pathways that connect hospitals, hospices, and community services, the coordination of acute and community care would be enhanced, leading to more seamless transitions of care. Currently, there are significant disparities across Northern Ireland for patients in long-term care facilities. Regional services allow for the consolidation of specialised resources such as palliative Medicine consultants, AHP's, Counsellors, Nursing (ANP's / Consultant Nurses etc). A regional structure would act as a hub for regional education, training and research. Regions could tailor services to the specific cultural demographic and health needs of their population to ensure people receive the required level of palliative care depending on their level of need. The Northern Ireland Statistics and Research Agency reported that the older population in Northern Ireland has grown by nearly 25% in the past decade, mirroring the trend across the UK. As the ageing population continues to rise rapidly, the demand for PC services will increase, but the workforce cannot keep up with the growing caseloads.

What can be done to improve integration?

To improve integration, a structured and standardised model with sustained investment is essential. This model should include education and public awareness campaigns, supported by an up-to-date policy that prioritises palliative care within regional healthcare planning. A regional framework with robust governance structures is necessary to ensure accurate monitoring, accountability and coordination of palliative care services. Service design should be informed by the voices of service users and key stakeholders. Enhanced communication systems and centralised data, such as the Encompass system, should support this integration, with improved access for hospices and GPs. Needs-based funding is crucial to ensure underserved areas receive adequate support. Deploying outreach multidisciplinary palliative care services in order to reach rural communities. Quality indicators should be used across all care settings (generalist and specialist) to assess performance and measure patient outcomes. The Palliative Care in Partnership programme has provided a good structure which brings all partners involved in the delivery of palliative care together. However, any funding is limited to support this and the number of staff leading on this is insufficient. Its impact needs accessed, and the structure strengthened to ensure items on the workplan are delivered timely to improve patient care.

Best Practice

Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

There are numerous examples of good practice and pilot programs in PC that endeavour to effectively meet the needs of patients and their families. There needs to be a standardised approach to ensure consistency and quality across the board. Currently, there is still a tendency towards siloed working, which can hinder the widespread adoption of best practices across NI

This list is not exhaustive

- Just in Case boxes – ensuring required medication for end of life care is available
- Belfast Hub, single point of access – pilot to bring all partners together to deliver appropriate care efficiently and effectively to patients
- Foyle Hospice 7-day community specialist palliative care service
- Healing Hearts service, in Foyle hospice, provides pre and post bereavement support to children and young people
- Marie Curie is supporting the introduction of nurse-led beds within their IPU, led by an Advanced Nurse Practitioner
- SET Specialist Palliative Care Hub
- NHSCT – G.P in reach to care homes this supports ACP discussions
- Southern Area Hospice – Consultant Nurse in training, MD Community Outreach Team, Facilitation of 'The Bereavement Journey' course, monthly family nights, and carer support services. Pilot of OOHrs End of Life Nursing Service.
- SHSCT – Southern PEARL - Palliative Education And Resource Library an interactive learning & education resource that covers key areas related to palliative and EOL care in adults.

Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

No

No, the current funding for palliative care is not sufficient. Palliative care services in Northern Ireland have largely relied on support from charitable trust funds. While there is occasional investment, it tends to be on a non-recurrent basis, which does not provide the stable and consistent funding necessary for sustainable and comprehensive palliative care services. The RSPCNG undertook an exercise in 2023 to review data collated in 2017 regarding SPC nursing workforce predictions. This found there had been a 44.5% turnover of staff either retiring or leaving the service. This loss of knowledge and skills is difficult to replace without appropriate proactive workforce planning.

The current funding model makes it challenging to sustain an adequate workforce across all disciplines. There is an urgency to workforce plan to ensure there continues to be a

workforce with the adequate knowledge and skills required to continue to deliver care. There is also a potential for workforce movement to southern Ireland as these positions are more attractive due to the investment being made following the launch of the new National Adult Palliative care policy by Slainte care.

Funding and Strategy

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

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Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

No

No, the current model for funding hospices, including hospice at home, community care, and rapid response support, is neither sustainable nor sufficient to meet current and future needs. Palliative care should be recognised as an essential service within the overall healthcare provision, and funding should reflect this to support true integration with other healthcare services. The funding model for hospices needs to be increased to 100%, as essential palliative care services should not rely on charitable funds for service delivery. Securing funding is challenging, making it difficult to attract and retain a skilled workforce. Additionally, regional evidence is needed to identify current gaps and future needs in services, ensuring a comprehensive career pathway for those working in the palliative care sector.

Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided

Yes

Yes, there is a need for a new Palliative Care Strategy for Northern Ireland with sustainable funding to support service development and meet the needs of the population. This strategy should include a comprehensive review of palliative care services to identify current gaps and evidence future improvements. It is important to understand the needs of different populations as we are to deliver the care required in those areas of social deprivation.

Some community staff report the struggle of delivering care to people dying in poverty at home. Public and patient involvement should be integral at all levels of strategy development and implementation. The strategy should emphasise robust governance structures to monitor both generalist and specialist palliative care, ensuring it is forward-thinking, inclusive, and adaptable. It should prioritise equitable access for all, regardless of condition, and gather intelligence on the current workforce to support its development and sustainability through proactive education and training. The strategy should aim to improve service integration through enhanced communication and performance indicators, optimise the use of technology for better service provision and efficiency, and raise public awareness and engagement. Ultimately, a new strategy will help Northern Ireland improve the coordination of palliative care services, ensuring high-quality care that aligns with standards in other parts of the UK and the Republic of Ireland.

Any other comments

The Advance Care Planning: For Now, and For the Future policy, along with the associated ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) document, was launched on October 19, 2022, to provide a comprehensive framework for advance care planning for all adults in Northern Ireland. However, the delay in its implementation has several significant impacts. The absence of the policy and ReSPECT document in Northern Ireland leaves many adults without clear guidance for future care planning, causing uncertainty and stress, especially in emergencies. This delay hinders early advance care planning, leading to decisions that may not reflect individuals' values. Healthcare providers struggle to offer consistent, person-centred care without these documents, increasing pressure on emergency services to make quick decisions without knowing patient preferences. This situation may also worsen healthcare inequities, as those with better resources can still create informal plans, while others lack support. Implementing the Advance Care Planning policy and the ReSPECT document is essential to ensure that all adults in Northern Ireland can make informed decisions about their future care, reducing uncertainty, inequity and improving the quality of care provided