Royal College of Nursing

This response is from the RCN NI Palliative Care network, which consists of registered nurses who work in palliative care or have an interest in the area of practice.

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?

No

The network members would like to establish that palliative and end-of-life care (PEOLC) is supported by nursing staff who work across hospitals, the community, and the independent sector. It is important to define the roles of nursing in the delivery of PEOLC, the palliative care (generalist) workforce, and the specialist palliative care workforce, which supports patients and those important to them along the palliative care journey.

The main barriers to public understanding of PEOLC are

- Identification of PC: Often, professionals lack understanding about PEOLC and don't recognise the benefits of early referral and interventions for the patient.
- Lack of public education awareness/messaging. Failure to implement public health approaches such as advance care planning, even though NI has a comprehensive regional policy.
- The members would suggest a lack of awareness of who provides PEOLC, especially within the community. Our district nursing members commented on the misconception of who is delivering palliative care. Often, patients, and those important to the patients, do not fully understand the role of the DN and GP in providing PEOLC, leading to confusion and often miscommunication. The DN is the PC keyworker in the community, a role that would require an appropriate workforce to support and deliver. DN teams frequently supplement the gaps in social care to support EOLC at home, which puts further pressure on the limited DN workforce.

Access to services

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

No

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

Not all trusts have multidisciplinary Community Specialist Palliative Care teams or HUBS.

Community nursing members have conveyed that regionally, there is an inequity of waiting times overnight in rural areas, which may be due to the geographical coverage the nurses currently support. Furthermore, in some trusts, there is no 24-hour district nursing cover.

Belfast Trust is the only trust offering the vital service of home visits by specialist heart failure nurses in Northern Ireland. Therefore, there is an inequity across the province for patients with advanced heart failure.

A recent SPC workforce review recommended that there is sufficient capacity within the existing training arrangements for SPC Nursing to meet the workforce requirement in 2024.

Members have also advised of frustration due to a lack of a regionally updated strategy in line with the UK and the Republic of Ireland, supported by the commissioning of recurrent funding

The evidence suggests marginalised groups such as people with a learning disability, LGBTQ+, prisoners, those who are homeless, and ethnic minority populations experience significant access issues for PEOLC services.

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

Yes

Within the care home sector, there is no recognition of the increased patient acuity, enhanced skills, training, competencies of staff, and time required to deliver PEOLC services within the regional rate paid to care homes. With the necessary additional training and support in place, care homes could facilitate quicker discharge from the hospital and prevent admissions for PEOLC patients. PEOLC remain not fully funded this has resulted in barriers such as SPC bed availability, Children's Hospice has six beds open out of the ten available due to limited funding.

What additional services could/should be provided?

- Investment in increasing capacity in palliative and SPC nursing
- Palliative Care, Care home nursing support teams
- Specialist palliative care HUBs
- SPC nursing services in the community continue to be a five-day, Monday-to-Friday service, with significant investment needed to enhance the workforce's capacity to deliver anything beyond this
- Community non-malignant Specialist nurses such as heart failure nurses who support PEOLC for patients in their homes
- Increased Nursing education and training in PEOLC both pre and post-registration
- PEOLC public health initiatives, such as Advance Care Planning
- 100% funding for Hospices

Integration of Services

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

There is evidence of some integration, such as the proposed plan to introduce a specialist palliative care HUB in Belfast Trust, which is a collaborative approach to accessing specialist palliative care with support from Marie Curie and Northern Ireland Hospice and Belfast Trust specialist multidisciplinary teams. This work could be resourced and introduced regionally.

Communication could be improved, however with hospices having limited to no access to Encompass that will become even more difficult.

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

Yes

An NI palliative care policy would offer an opportunity to develop the governance, coordination, and delivery of palliative care services across the region.

Palliative care requires a whole systems approach to developing capacity, by developing our workforce, technologies, leadership, education, governance and data systems this would be best achieved from a regional perspective.

What can be done to improve integration?

An NI palliative care policy would offer an opportunity to develop the governance, coordination, and delivery of palliative care services across the region.

- A Policy that is resourced with recurrent funding and commitment
- Increased SPC and generalist nursing workforce capacity
- Palliative care requires 100% statutory funding
- Central HUBs for referrals and communication
- stakeholder involvement, including those who have and are using the services

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?

- Belfast Trust, Care home nursing support team
- Anticipatory care/Advance Care Planning facilitation project in reaching care homes.
- HUB, especially its non-malignancy-focused work in SET.
- Community specialist heart failure nurses in BHSCT who support PEOLC for patients in their homes.
- Advanced nurse practitioners in Trusts and Hospices

- Foyle Hospice 7-day service of community SPC
- Foyle Hospice community SPC nurse involved in a pathfinder project for non-medical prescribing
- Marie Curie and NI Hospice rapid response nursing service, and Marie Curie provides 24-hour services for patients at home commissioned in all 5 trusts

Unfortunately, while there are examples of excellence and pilots to support PEOLC, in most they are in silos, and often short-term funded.

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

No

Patients requiring PEOLC are often supported by family, friends, and their local community, we would suggest this question goes beyond that of a 'family' Accessing services can be problematic for those important to patients, knowing what services are available is difficult. Late support and input from PC professionals can be a concern, also a lack of bereavement services is a regional issue.

Our community nursing members have seen firsthand patients dying at home in poverty. More people died in poverty in 2023 than in 2019. Two thousand people a year died in poverty in Northern Ireland in 2019. Now, that number has risen to 3,300. Both working-age and pension-age people are impacted by poverty at the end of life. Statistics for Northern Ireland show that pensioner poverty has almost doubled from 10% to 19% since 2019, while working-age poverty has seen a slight decrease over the same period.

Two key actions that would significantly impact poverty at EOL are guaranteeing a pension-level income for those of working age living with a terminal illness and introducing a social tariff for energy bills

Funding and Strategy

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

No

Palliative care in NI should have 100% funding. Hospices should not be reliant on charitable funds

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

The current model for funding for hospices is insufficient currently. Against a backdrop of finite SPC inpatient bed capacity and with increasing proportions of people wanting to be

cared for and die at home- investment in the nursing workforce, inclusive of training, education, and clear regional career development pathways, is vital in preparation for meeting the needs of people with palliative care needs. Failure to invest and fully fund this will increase pressure on the current nursing workforce, increasing the risk of burnout and turnover, adversely impacting individual health and well-being and recruitment and retention in the speciality.

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

Fully funded with recurrent funding for services supporting PEOLC

Investment in the nursing workforce, inclusive of training, education, and clear regional career development pathways, is vital in preparation for meeting the needs of people with PEOLC needs

Review of current services, to identify gaps and excellence that could be developed

Robust engagement with stakeholders to develop a strategy

Review specialist palliative care services, creating strong links between acute, community and primary care

Creating a robust public health approach to PEOLC

Improving access to PEOLC services, regardless of where you live

Support the patient and those important to them to navigate and access services

Enabling preferred place of care

Examine and introduce informatics and digital technologies that can support the provision of EOLC and provide data to improve service delivery and demonstrate quality and efficiency

Any other comments

The RCN NI PC Network has highlighted nurses' concerns regarding the delay in the implementation of the Northern Ireland 'For Now and for the Future' Advance Care Planning Policy, which was launched in October 2022, and the supporting Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). Many patients receive treatment and care across organisational boundaries and settings. Patients often have multiple conversations with various professionals about their healthcare wishes and preferred places of end-of-life care. These repeated conversations can cause emotional distress and frustration to patients and those important to them. We need to progress the implementation of ReSPECT as a matter of urgency, and this requires funded resolute post holders to implement this safely.

RCN on 16/1/25 released a report on the current corridor care crisis, hundreds of nurses in NI contributed their experiences. Stories of patients dying in corridors are extremely distressing to everyone involved in their care. In PEOLC we have 'one chance to get it right', expectations of palliative care services should be high, and with the RCN report sadly that is not the case.

The RCN hopes that this information is helpful. We are happy to provide any further details as requested and welcome the opportunity to supplement this by giving oral evidence if that is helpful to the Committee.

Current provision of palliative and hospice care

The RCN NI Palliative Care Network members would like to establish that palliative and end-of-life care (PEOLC) is supported by nursing staff who work across hospitals, the community, and the independent sector. It is important to define the roles of nursing in the delivery of PEOLC, the palliative care (generalist) workforce, and the specialist palliative care workforce, which supports patients and those important to them along the palliative care journey.

Table 1: Nursing roles supporting the current delivery of PEOLC across NI.

Community nursing: District nursing (DN) keyworker	The District Nursing Framework defines the DN as the key worker in PEOLC, citing that most PEOLC is supported in community settings. The most important part of the role of the DN is the therapeutic relationship with the patient and family within the home. The DN is most likely to be the healthcare professional who sees the patient most often in their home and has the most up-to-date information about health and social needs. The 24-hour PEOLC at home by DN, available in some trust areas, is invaluable and makes PEOLC more accessible for patients and those important to them. This highly effective service reassures families that support is available 24 hours a day and underpins that their care is a priority.
Nurses collaborating with community palliative care HUBs.	There are palliative care HUBs in the Southeastern Trust in all three localities, each with a different non-malignancy focus. These services provide care to all patients with PEOLC but in addition, each site provides specialist focus on a different non-malignant condition e.g. respiratory/heart failure.
Community specialist nurses	Within community settings, specialist nurses work in partnership with DN and specialist palliative care nurses to support PEOLC. An example is within the Belfast Trust, where a nurse-led heart failure team supports the delivery of PEOLC to housebound patients in their homes and a nursing/residential home setting.

Care home nursing	PEOLC is provided in all care homes by the members of their nursing teams, and often with in-reach services from trust and hospice nurses.
Specialist palliative care SPC nurses	Nurses across Northern Ireland work within specialist palliative care roles across all trusts and hospices. Most of the community SPC nursing roles are only part statutory funded, with this essential workforce significantly reliant on charitable funding to deliver the palliative and end-of-life care that the people of NI deserve. The specialist palliative care nurse's role includes clinical, education, facilitation, research, leadership, service improvement and operational. It is estimated that 85% of people with SPC needs require access to SPC nursing (Palliative Care in Partnership, Specialist Palliative Care Workforce Planning Report, 2020). Trusts and hospitals have developed Advanced Nurse Practitioners (ANPs); however, this requires further development for palliative care in NI.
Hospice care.	Marie Curie has regional nursing roles across Northern Ireland providing PEOLC. Nurses practice in inpatient, day therapy, community rapid response, nursing 1:1 care in domiciliary settings, education, facilitation, and research. Northern Ireland Hospice provides specialist palliative nursing care and one-to-one care in the community across 3 HSC Trust Localities. Foyle Hospice has nursing staff in its inpatient unit, outpatient clinic, and day therapy. Currently, the hospice provides 7-day service by a community specialist palliative care team in the northern and southern sectors of the WHSCT. This service is subject to funding, which expires in March 2025.
Children's Hospice	Children's palliative care across the region provides diverse delivery of PEOLC services, with nursing staff working with children who require EOLC, but also those who need longer term care for life limited/threatening conditions, from before birth to EOL. Inpatient and community services within the NI Children's Hospice have a regional scope.

The current challenges in the provision of and access to palliative care

Workforce

The members expressed that workforce challenges are currently the most significant concern in providing and accessing PEOLC. Concerns were conveyed regarding the current number of specialists in the palliative care workforce and projected numbers over the next five years. The availability of specialist practice qualifications in palliative care has been reduced, with members advising that they have been unable to avail themselves of educational commissioning to access this post-registration study. In most areas, there has been no investment in increasing capacity in palliative and SPC nursing. Surprisingly, the most recent SPC Workforce review recommended that there is sufficient capacity within the existing training arrangements for SPC Nursing to meet the workforce requirement in 2024.

SPC in the community continues to be a five-day, Monday to Friday service, with significant investment needed to enhance the workforce's capacity to deliver anything beyond this. In the absence of increased sustainable capacity, future increases in demand will outweigh service provision. The same issues are present within hospital settings, with limited access to specialist palliative care services, mainly out-of-hours. Against a backdrop of finite SPC inpatient bed capacity and with increasing proportions of people wanting to be cared for and die at home- investment in the nursing workforce, inclusive of training, education, and clear regional career development pathways, is vital in preparation for meeting the needs of people with palliative care needs. Failure to invest and fully fund this will increase pressure on the current workforce, increasing the risk of burnout and turnover, adversely impacting individual health and well-being and recruitment and retention in the speciality.

Trusts and Hospices have introduced the Advanced Nurse Practitioner role. However, our members know that access to the university training required to develop and expand these roles across Northern Ireland is limited due to commissioning restraints.

Our district nursing members commented on the misconception of who is delivering palliative care. Often, patients, and those important to the patients, do not fully understand the role of the DN and GP in providing PEOLC, leading to confusion and often miscommunication. The DN is the PC keyworker in the community, a role that would require an appropriate workforce to support and deliver. District nursing teams often supplement the gaps in social care to support EOLC at home, which puts further pressure on the limited DN workforce. With only ‘one chance to get it right,’

patients' expectations of palliative care services are understandably high. The paradox of high expectations versus insufficient funding is stark.

The generalist nursing staff require education and support to provide ongoing PEOLC, particularly as specialist nursing support is often limited. A comprehensive, accessible, and responsive education package is needed to maintain the training and competencies of these generalist nursing staff, with access to updated education programmes, such as advanced communication skills and breaking bad news training and guidance.

Across all hospital and community settings, there are other non-palliative care specialist nurses. One example would be Learning Disability (LD) nurses. Often, the bulk of PEOLC within the LD community is provided by LD nurses who do not have specific training in palliative or end-of-life care, and often, care is reactive rather than initiative-taking. Increased liaison with LD nurses within the trust and in the independent sector with specialist PEOLC services would ensure that PEOLC can be supported in a timely and effective manner. Current PEOLC services are not designed for or tailored to meet the needs of people with learning disabilities.

There is a need for an End-of-Life Facilitator post, both in hospitals, as nearly half the deaths occur in acute hospitals, and within district nursing to support the staff providing care in patients' homes.

Advance Care Planning/ReSPECT

The RCN NI Palliative Care Network has previously highlighted nurses' concerns regarding the delay in the implementation of the Northern Ireland 'For Now and for the Future' Advance Care Planning Policy, which was launched in October 2022, and the supporting Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). Many patients receive treatment and care across organisational boundaries and settings. Patients often have multiple conversations with various professionals about their health care wishes and preferred places of end-of-life care. These repeated conversations can cause emotional distress and frustration to patients and those important to them. There is currently no recognised Do Not Attempt Cardiopulmonary Resuscitation form which can be used and transferred across all care settings. It was hoped that implementing the ReSPECT form would resolve this longstanding issue, particularly in the community where no standardised form is used. We need to progress the implementation of ReSPECT as a matter of urgency, and this requires funded resolute post holders to implement this safely.

Regional inequity

Members identified the benefits of the palliative care HUBs in the Southeastern Trust, and we are aware of the pending introduction of the Belfast Trust HUB. However, not all trusts have multidisciplinary Community Specialist Palliative Care teams or HUBS.

Community nursing members have conveyed that regionally, there is an inequity of waiting times overnight in rural areas, which may be due to the geographical coverage the nurses currently support. Furthermore, in some trusts, there is no 24-hour district nursing cover.

Planning for patients' future care within their own homes or care homes often involves anticipatory prescribing and emergency medication boxes for EOL. However, these medications are not accessible in all regions or settings.

Belfast Trust is the only trust offering the vital service of home visits by specialist heart failure nurses in Northern Ireland. Therefore, there is an inequity across the province for patients with advanced heart failure. The PPI group Heart Failure Warriors has raised this issue; they would like to see a change regarding the postcode lottery of the difference of care offered between trusts to patients with heart failure diagnoses; this needs to change for patients with advanced heart failure. It is worth noting that with an ageing population, the need for this type of service will undoubtedly increase, and statistics suggest this also. Services like the Belfast Trust heart failure team need investment to enhance and increase the service within the Belfast Trust, but also in order to replicate throughout NI.

Cost of living/poverty at EOL

Our community nursing members have seen firsthand patients dying at home in poverty. More people died in poverty in 2023 than in 2019. Two thousand people a year died in poverty in Northern Ireland in 2019. Now, that number has risen to 3,300. Both working-age and pension-age people are impacted by poverty at the end of life. Statistics for Northern Ireland show that pensioner poverty has almost doubled from 10% to 19% since 2019, while working-age poverty has seen a slight decrease over the same period.

More than one in four people who died in Northern Ireland in 2022 were in fuel poverty. Among pension-age people, the rate of fuel poverty in the last year of life was higher in Northern Ireland compared to any other part of the UK, where 27.2% were estimated to die in fuel poverty. The increase in energy spending was exceptionally high for people at the end of life in Northern Ireland.

Two key actions that would significantly impact poverty at EOL are guaranteeing a

pension-level income for those of working age living with a terminal illness and introducing a social tariff for energy bills.

Children's PEOLC services

Out-of-home respite for children is part of the definition of paediatric palliative care. Supported short stays for children are extremely limited, at 6 days per year per family. While the children's hospice is located within Belfast, it has a regional reach, supporting children and those important to them across NI.

Children's Hospice has six beds open out of the ten available due to limited funding. Children who require services transitioning to adult care face a complex process. This would often include moving from a community children's nursing service to an adult social care package.

The transition from a children's hospice setting for respite is complex, they often do not go directly to the adult hospice, as adult hospice deals with specialist palliative care and any supported short stays may be offered in a care home environment. On occasion, there has been a referral from children's hospice to adult hospice when the young person is actively deteriorating or dying.

Adult Hospice

Patients requiring hospice care are presenting with progressively complex needs requiring increasing specialist support. Community SPC visits are longer and more frequent and require consulting with other healthcare professionals. Our members who work in hospices have advised that they are identifying a change in the patients they are supporting. They often care for younger or late-diagnosed patients for a shorter period, usually days and weeks, as opposed to months.

Care Homes/Residential units

There is no recognition of the increased patient acuity, enhanced skills, training, competencies of staff, and time required to deliver PEOLC services within the regional rate paid to care homes. With the necessary additional training and support in place, care homes could facilitate quicker discharge from the hospital and prevent admissions for PEOLC patients.

Marginalised groups

The evidence suggests marginalised groups such as people with a learning disability, LGBTQ+, prisoners, those who are homeless, and ethnic minority populations experience significant access issues for PEOLC services.

Access to palliative care for persons living with a serious mental illness is an emerging challenge and a public health priority. Having a serious mental illness puts you at a disadvantage of dying 10-20 years earlier than the general population. Palliative care is recognised as a basic human right to health; healthcare systems must consider this when providing equitable palliative care. Within the LD community, our members have advised that Advance Care Planning is not routinely implemented, alongside ongoing concerns about the application of DNACPR orders with people with learning disabilities. Concerns were raised throughout the COVID pandemic that good practice in DNACPR conversations and documentation was not undertaken. Our members are not aware of any work that has been undertaken to support people with learning disabilities regarding planning for their future care, so we would question whether anything has changed since the pandemic.

Excellence in palliative and hospice care by identifying examples of best practice

Network members have provided examples of excellence and best practice.

- Care home nursing support teams in Belfast Trust provide palliative care clinical input, education, and support to nursing staff in the care home sector. The team has a palliative care nurse facilitator within the service.
- Members working in Northern Trust were advised of the benefits of the GP anticipatory care/Advance Care Planning facilitation project in reaching care homes for patients receiving PEOLC.
- The Southeastern Trust specialist palliative care HUB, especially its non-malignancy-focused work.
- Belfast Trust has a team of specialist heart failure nurses who support PEOLC for patients in their homes.
- Proposed plan to introduce a specialist palliative care HUB on Belfast Trust; a collaborative approach to accessing specialist palliative care with support from Marie Curie and Northern Ireland Hospice and specialist multidisciplinary teams.
- Marie Curie provides palliative nursing services commissioned in all five Northern Ireland Health and Social Care Trusts. These services offer a choice of where the patient wishes to be cared for at the end of life. The services operate over 24 hours, with care delivered by Marie Curie registered nurses and healthcare assistants working alongside the district nurses or the GP out-of-hours Services.
- Marie Curie supports the introduction of nurse-led beds within its eighteen-bedded IPU, led by an advanced nurse practitioner. This initiative will benefit

patients by harnessing the hospice nursing team's existing skills and adding advanced skills in clinical assessment, symptom management, and non-

medical prescribing. In addition, it will maximise the use of our beds and widen access to our beds to reach more people at EOL.

- Marie Curie has introduced the outcome measures Karnofsky, and Phase of illness, within its Hospice. The benefits of using outcome measures can be seen in improving clinical practice, demonstrating the value of palliative care, and improving patient outcomes through person-centred care.
- Foyle Hospice provides a 7-day service of community specialist palliative care in the northern and southern sectors of the Western Trust. The community hospice nurses, and speciality doctors do joint visits and work collaboratively with primary care to ensure timely access to required medicines for symptom control and avoid hospital/A&E admission, not only in the patient's home but also at any place of care.
- Foyle Hospice has an integrative care clinic running 3 days a week for patients who have a life-limiting illness but want to remain independent, and the promotion of self-care is to the fore. Care can be transferred to the community team or inpatient unit, if and when the patient deteriorates.
- Foyle Hospice has an ongoing project with one specialist community palliative care nurse involved in a pathfinder project for non-medical prescribing. This would support the community SPC nurse to prescribe medication for patients in a community setting.
- Northern Ireland Hospice has focused on developing a flexible workforce to meet changing population, patient, and service delivery needs by introducing advanced nurse practitioner roles, both qualified and in-training, alongside newly implemented non-medical prescribing practice.
- Northern Ireland Hospice community SPC nursing teams introduced cross-team working, which has been enhanced to help provide the most responsive care. They also introduced a quality initiative to improve focus on and recording of advance care plans to capture patient wishes.

Summary

In summary, RCN NI members have indicated that workforce is the greatest challenge in providing PEOLC. Investment to increase capacity in palliative and specialist palliative care nursing services to ensure they are available 24/7 is urgently required. For many patients, their preferred place of care for their EOLC journey is at home. Investment in the nursing workforce to provide care at home

needs to include training, education, and clear regional career development pathways to reduce staff turnover and burnout.

Our members have also expressed their concerns and frustration at the lack of implementation of the regional advance care planning policy launched in 2022; we cannot overstate the moral injury and distress the current chasm is causing for our patients, those important to them and the nurses supporting PEOLC. Members have advised of patients having DNACPR conversations multiple times because there is no process or documentation to transfer decisions. There are often difficulties accessing support in care homes to undertake DNACPR discussions, and reports of patients receiving EOLC at home having CPR performed due to no recorded documentation. Implementing the advance care planning policy, which includes DNACPR and ReSPECT, is required as a matter of urgency.

The RCN NI Palliative Care Network views a funded regional strategy for PEOLC as a prerequisite to ensuring meaningful changes to improve the delivery and access to palliative care and provide a blueprint for adapting to the changing and developing population health needs of Northern Ireland.