Royal College of Nursing Scotland

RCN Scotland response to
Scottish Government consultation on:

A Draft Palliative Care Strategy

14 January 2025

Introduction

The Royal College of Nursing (RCN) is the world's largest nursing union and professional body. It is the leading national and international authority in representing the nursing profession. We represent over half a million nurses, student nurses, midwives, nursing associates and nursing support workers in the UK and internationally.

The RCN has over 50,000 members in Scotland. We campaign on issues of concern to nursing staff and patients, influence health policy development and implementation, and promote excellence in nursing practice.

Background

This five year strategy (2025-2030) builds on previous Scottish Government palliative care strategies, 'Living and Dying Well: A national action plan for palliative and end of life care in Scotland (2008)' and 'Palliative and end of life care: strategic framework for action (2015)'.

It sets out aims and intended outcomes, with specific actions for each outcome. The Scottish Government believes that through these outcomes and actions, adults and children, as well as their families and carers, should have better experiences of palliative care; care when someone is dying; and bereavement support.

Consultation questions

Section A: Overall Strategy

Question 1. Do you agree with the aims for this strategy?

The aims of the strategy are that, by 2030:

- adults and children in Scotland have more equitable access to well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them, including support for families and carers.
- Scotland is a place where people, families and communities can support each other, take action and talk more openly about planning ahead, serious illnesses or health conditions, dying and bereavement
- adults and children have opportunities to plan for future changes in their life, health and care with their families and carers.

RCN Scotland agrees that there is a real and urgent need to improve access to palliative care across Scotland and that in some parts of the country, there are insufficient services to support people at the end of their lives. With palliative care delivered by a range of organisations and in a range of settings, there is a need to ensure sufficient resourcing and staff are in place to meet the demand for palliative care.

Those in need of palliative care should experience a service which is delivered in a timely and seamless manner, accessing care in a coordinated and compassionate way at the end of life. For this reason, we would question what is meant by "more equitable access" and whether this is an ambitious enough aim? Access which is 'more equitable' is certainly laudably, particularly where we know there are gaps in services particularly for rural and deprived communities, but this aim could be achieved by reducing services to close the gap. RCN Scotland would therefore favour an aim which made it more explicit that access is to be "improved" or "enhanced" across the board rather than a focus on equity.

RCN Scotland is also concerned that the draft strategy does not give sufficient consideration to the resourcing of unmet and future need. Estimates from Marie Curie suggest that approximately 89% of people who died in Scotland between 2017 and 2021 would have benefitted from palliative care, meaning there is a significant unmet need. Furthermore, Scotland has an ageing population meaning more and more people are living longer with multiple, often complex

conditions. Research estimates that by 2040, 10,000 more people will be dying with palliative care needs [How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery. Authors: Anne M. Finucane, Anna E. Bone, Simon Etkind, David Carr, Richard Meade, Rosalia MunozArroyo, Sébastien Moine, Aghimien Iyayi-Igbinovia, Catherine J Evans, Irene J Higginson and Scott A Murray doi:10.1136/bmjopen-2020-041317] Addressing both this unmet need and increasing demand will require significant additional resourcing, in terms of staffing, additional service design, hospice beds and hospital at home capacity.

Hospices rely on charitable donations to run essential services and any ambition to improve access must consider whether this is a sustainable model. Reports are increasing about the financial challenges many charitable organisations who provide palliative and end of life care are facing. Without addressing this, by increased funding, we risk inequality in terms of access to care rising, not falling.

Finally, RCN Scotland is concerned that there is insufficient consideration given to how the success of this plan will be measured. For more on this point, see the response to outcome 3, below.

2. Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?

We used four 'cornerstones' as the foundations for change and improvements in palliative care policy, service delivery and public involvement. These are:

- Working together to provide the care that's right for each adult or child, their family and carers.
- Taking a whole-system population health approach using data and people's experiences
- Ensuring equity and equality of access to palliative care for anyone who needs it.
- Leadership across health and social care systems and with wider delivery partners, including third sector organisations (charities)

RCN Scotland broadly agrees with these cornerstones. The second, on data, is key and must include fully funded workforce planning to determine staffing arrangements needed to deliver services. As discussed above, we know there is significant unmet need and so this needs to be addressed before we can tackle increasing demand. The scale of the challenge is significant.

The Cornerstone on leadership must recognise the important role of nursing in planning and delivery of palliative care. Nurses are seen by the public as being

professional and accessible and are well placed to initiate discussions on bereavement and end of life care. Nurses, particularly specialist nurses, district nurses and practice nurses working in the community and primary care, are very likely to be the people asked to provide the coordinated care of those who can benefit from palliative and end of life care. They are frequently the main link between the GP, local authority and the patient.

In addition to the points raised above about inequality of access for certain populations, there is also a need to look at groups who are at increased risk of digital exclusion. Those commissioning and providing palliative care services need to consider what are the best methods for disseminating information and services while considering factors such as digital literacy, language proficiency and digital access.

Section B: Strategy Outcomes

Question 3. Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?

Outcome 1: People have the understanding, information, skills and confidence to support themselves and others to live well with serious illnesses or health conditions; to plan for the future; and to support each other through dying and bereavement.

Proposed actions:

- Take forward work across relevant policy areas to improve the wider experiences of people receiving palliative care and care around dying; remove barriers to access; and maximise support, including areas related to children and young people, equalities, justice, fair work, housing and tackling poverty.
- Explore ways to promote access to financial benefits for adults or children with serious illnesses or health conditions and increasing health and care needs under the Benefits Assessment for Special Rules in Scotland (BASRiS) application process through improved public information and professional education and guidance.
- Work with agencies, statutory and third sector organisations responsible for housing and services for people who are homeless or vulnerably housed to develop and promote ways to enable adults and children living with serious illnesses or health conditions to access the social, practical and financial assessments and support they need.
- Collaborate with NHS 24 and wider partners to make sure the NHS inform website provides relevant, up to date and accessible public information

about future care planning, palliative care and care around dying for adults and children, families and carers, including links to support organisations and resources for people from diverse groups and communities.

- Support the Scottish Partnership for Palliative Care (SPPC) to provide a sustainable, national infrastructure that enables statutory and third sector organisations, palliative care providers, staff, community groups and individuals to work together to promote understanding and awareness of living and dying with serious or life-threatening illnesses and serious health conditions; and to contribute towards empowering people to be more informed and equipped to plan ahead and support each other through serious illness, dying, death and bereavement.
- In partnership with the third sector, widen access to community-led public education opportunities which provide knowledge, skills, resources and training to help more people be comfortable and confident in supporting family, friends and people in their local community when someone is dying, caring or bereaved.
- Work with Integrated Joint Boards (IJBs) and Health and Social Care Partnerships (HSCPs) to explore options for their strategic plans for palliative care to recognise and work collaboratively with local community groups, networks and projects that offer support for adults with serious illnesses; children and young people with serious health conditions; and their families and carers.

RCN Scotland welcomes the inclusion of clear outcomes in this consultation.

One gap in outcome 1 is the role of training for health, social care and other staff not directly involved in palliative care, in discussing death and services available to those they care for. Staff across a range of social care and community health services in particular, need to feel comfortable and skilled in talking about death. Linked to this is the issue of future care planning and the need for staff in social care and health to be able to have difficult conversations about death and dying at an early stage. Building staff confidence so they are able to explain decisions and options to families needs to be a focus.

In relation to resourcing of services, it should be noted that if outcome 1 is successful, and there is greater awareness and understanding of the role of palliative care, then service demand will increase significantly. This point needs to be acknowledged in the strategy and a proposal for how this will be properly resourced, set out.

Question 4. Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?

Outcome 2: Leaders, stakeholders and delivery partners will work together in partnership, with clear roles and responsibilities, to make sure there is reliable and effective planning, delivery, accountability and improvement of palliative care services and wider support.

Proposed actions:

- Develop guidance with IJBs and Health Boards to support the identification of a clinical and a managerial / executive lead, and to establish a Managed Care Network (MCN), updating previous guidance for Health Boards on MCNs.
- Work with Health Boards to establish new requirements for inclusion of integrated specialist palliative care services within annual delivery plans and performance monitoring.
- Work with HSCPs and adult independent hospice organisations to develop a national guidance framework to support and improve consistency of local planning and commissioning of independent hospice services.
- Work with the Scottish Partnership for Palliative Care to establish a national Palliative Care Innovation Network, where people and teams involved in palliative care delivery; community-led initiatives; improvement and research; or education can come together to share learning and ideas for improvement and innovation.
- Continue to engage with palliative care delivery partners on how the proposed National Care Service Board and the reformed Integration Authorities will improve national and local governance, roles, responsibility, commissioning, monitoring and reporting of specialist palliative care services and general palliative care

Outcome 2 is key to the improvement in access and quality of palliative care and an outcome which almost the whole entire strategy relies on.

RCN Scotland is concerned that the role of Scottish Government is not adequately explained. Integration authorities have a central role in terms of assessing and planning palliative care needs, but the Scottish Government has the power over resourcing, funding and an important role in terms of workforce planning. In relation to nursing, the Health and Care (Staffing) (Scotland) Act 2019 states that the Scottish Government needs to outline the steps they will take in relation to staffing of the health service in response to information received by health boards and integration authorities in terms of staffing levels, which include in palliative care services. The same legislation also requires

Scottish Ministers to take all reasonable steps to ensure there are sufficient number of registered nurses to ensure Health Boards can comply with their duty to ensure appropriate staffing.

RCN Scotland is also concerned by the inclusion of the reference to the NCS in the consultation document in this section (and in others). Firstly, any references will need to reflect plans for a National Care Service as it is now unclear in what form this proposal may or may not progress. However, more fundamentally, RCN Scotland remains to be convinced how and to what extent the National Care Service will improve national and local governance, commissioning or the other points listed in Action 2.5. In some ways, most notably workforce planning, the creation of an National NCS Board could make it more difficult to plan services, which would include palliative care.

Question 5. Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?

Outcome 3: National and local leaders will have access to relevant data to inform planning and delivery of services; and will put in place improved ways to monitor and evaluate the outcomes and experiences of children and adults receiving palliative care, as well as their families and carers.

Proposed actions:

- Work with Public Health Scotland, Health Boards, HSCPs, and other key partners, including paediatric palliative care planners and service providers, across all sectors to improve the quality and range of palliative care data collected, analysed and reported. Such data can be used to inform improvement, experiences, and delivery of palliative care for adults and children, families and carers, and includes:
    - updating and improving the existing adult palliative care population data reporting systems; and providing access for service planners and health and care staff.
    - developing a national approach to data collection on paediatric palliative care services for babies, children and young people (0 -18 years) and developing a new dashboard that can be accessed by paediatric palliative care service planners, and health and care staff.
    - working with HSCPs and Health Boards to develop a data template that supports them to collect, analyse and report high quality data on general palliative care and specialist palliative care services delivered to adults, children and young people for service planning

and improvement, which includes user experiences in all places of care.
    - development of a Scottish minimum data set for all adult specialist palliative care services.
    - development of a Scottish minimum data set for all paediatric and neonatal specialist palliative care services and transitions.
- Explore evidence based and emerging co-design approaches to hearing and measuring people's experiences of palliative care, care around dying and bereavement support in palliative care for all places of care, and establish a consistent national approach to help improve these experiences.

While Outcome 3 seeks to improve data to monitor and evaluate outcomes, there is insufficient clarity on how the success of this plan will be measured. Lived experience and codesign methods have value, they are not sufficient to determine the extent to which improvement is being made systematically. Any measures need to capture unmet need, as well as services which are actually delivered.

The recording of patients' choice of place of care and place of death, as well as a record of whether or not that wish was met, used to be recorded as best practice. This type of information is important in order to meet Outcome 3 in relation to monitoring the experience of patients and carers and needs to be recorded and analysed.

6. Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?

Outcome 4: Adults with serious or life-threatening illnesses will be identified earlier and be able to access general palliative care and specialist palliative care services, whenever and wherever needed.

Proposed actions:

- Work with Healthcare Improvement Scotland (HIS) to improve guidance and promote improvements in use of evidence-based tools to support proactive identification and review of adults with unmet palliative care needs, their families and carers, by staff and teams working across health and social care in all HSCPs and Health Boards.
- Work with NHS National Services Scotland (NSS) and HIS and digital science experts to explore further development and implementation of national health records screening tools to improve identification of adults with serious or life-threatening illnesses for earlier palliative care and future care planning.

- Explore viable options with NHS 24 and other delivery partners to provide a 24/7 national palliative care advice line (via the 111 system) for patients, families and carers that reduces delays in access to urgent primary care and social care and connects with locally delivered palliative care telephone helplines and services.
- Support collaborative working to promote inclusion of palliative care and care around dying in service planning and delivery for people with one or more long term health conditions.
- Support innovative models of care and consider options for service developments and partnership working to increase equity of access to adult specialist palliative care both in-hours and out-of-hours in all Health Boards and HSCPs, including a specific focus on people who have more barriers to accessing the specialist palliative care they need.
- Explore options with Health Boards and HSCPs to make sure there is consistent access at all times (24/7) to specialist clinical care from a consultant in palliative medicine and from senior nurse specialists whenever a person is receiving inpatient hospital or community hospital specialist palliative care, including contractual arrangements to support rural and island Health Boards.
- Work with Health Boards, HSCPs and third sector organisations to improve access to urgent palliative care services in the community that can reduce avoidable hospital admissions and shorten inpatient stays, and provide more effective, timely admission processes for those needing hospital care. This includes improving access to specialist palliative care advice in hospital and at home within wider national and local work on unscheduled care and early hospital discharge.
- Work with Health Boards, HSCPs and third sector organisations to support improved provision of professional-to-professional specialist palliative care clinical advice lines, ensuring these are available 24/7 in all parts of Scotland, so that other health and care staff providing palliative care, including the Scottish Ambulance Service, can access specialist palliative care advice at all times.
- Work with Health Boards, HSCPs, third sector organisations, other delivery partners, and community groups to improve palliative care, care around dying and bereavement support for people from minority communities and other groups who face barriers to accessing palliative care or who need flexible approaches tailored to their health conditions, situation, personal circumstances, values and preferences.

Taken within the current context of palliative care service availability, this outcome is very ambitious. RCN Scotland agrees with the aim of this outcome and that there is a real and urgent need to improve access to palliative care across Scotland. This outcome is essentially seeking to achieve the same

change as the proposed Palliative Care (Scotland) Bill in ensuring those who need palliative care services are abler to access it. However, as we said in response to that consultation, as we see with other legal rights in healthcare (such as diagnosis and treatment waiting time targets), unless there is enforceability, introducing an aim like this may not result in change.

The bigger picture of ensuring that we have sufficient resources to provide the outcome of people being able to access services "whenever and wherever they want" is certainly more important than aspirational outcomes set out in a plan.

As well as ensuring access to services, any draft strategy should aspire to access to high quality services. On this, the importance of continuity of care for people receiving palliative and end of life care is extremely important and something which is not considered in detail by this strategy. In order to achieve continuity of care, resourcing and staffing need to be a central consideration.

As the consultation document correctly points out, the needs of palliative care service users often extend beyond NHS services (to include social work support, as well as financial, respite care, housing etc). These non-clinical needs are largely ignored in the actions and this is therefore a gap which should be addressed.

7. Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?

Outcome 5: Adults living with serious or life-threatening illnesses and children with serious health conditions will be offered person-centred future care planning involving their families and carers, and care plans will be recorded and shared using national digital systems.

Proposed actions:

- Support a national partnership programme for future care planning, overseen by the National Future Care Planning Working Group, that is person-centred, inclusive and takes a 'Once for Scotland' and 'digital' approach to development and delivery for children, young people and adults whose life, health or care may change, and which is suitable for all places of care.
- Continue to work with NHS Education for Scotland (NES) Digital, other national organisations and partners to develop and implement a national electronic urgent and emergency care plan for health and social care accessible to staff working in the community, NHS unscheduled care services and hospitals in all Health Boards, starting with health care staff and extending to social care staff, care homes and independent hospices.

- Continue to work with NES Digital, other national organisations and partners to develop and implement a national electronic hospital urgent care plan to improve treatment and care during a single hospital admission that connects digitally with community urgent and emergency care plans.
- Continue to work with NHS Education for Scotland, other national organisations and partners to develop and deliver national education and implementation resources on future care planning for use across Scotland.
- Promote future care planning across all sectors and involve a wide range of stakeholders in development and delivery including members of the public, adults, young people, families, parents and carers, minority groups, patient support groups and third sector organisations, and to develop accessible and inclusive resources and information about future care planning with them.

RCN Scotland agrees that this outcome is worthwhile.

8. Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?

Outcome 6: Quality and experiences of care around dying and bereavement support are improved for adults, their families and carers, in all places of care.

Proposed actions:

- Oversee an update to the national guidance on *Care around Death* and work with Health Boards and HSCPs to make sure it is implemented as best practice in all places of care in Scotland.
- Work with Health Boards , HSCPs, primary care teams and pharmacy services to promote timely provision and use of 'just in case medicines' for adults dying at home and residents in care homes and improve staff education and public information.
- Work with HSCPs and Health Boards to promote and develop effective models of urgent palliative care able to provide rapid access to coordinated health and social care support for adults dying at home, their families and carers.
- Work with Scottish Ambulance Service and NHS Education for Scotland to ensure palliative care continues to be part of core training and professional development for ambulance clinicians.
- Oversee an update the public information leaflet "*When someone has died – information for you*" with NHS Education for Scotland and other partners, and promote its use along with additional local information

through Health Board Bereavement Leads, HSCPs, and other organisations, including NHS Inform.

- Continue to champion, co-ordinate and work in partnership with key stakeholders to ensure compassionate advice, resources and support are available for people experiencing bereavement, following the death of an adult with a serious or life-threatening illnesses, or with a child who has a serious health condition, and explore improvements to bereavement care.
- Work with NHS Education for Scotland and other partners to develop a new education and training resource on bereavement care for staff across health and social care that includes staff support and spiritual care as part of the Support Around Death resources.

RCN Scotland welcomes the acknowledgment in this section that staff may need emotional support too.

RCN Scotland would also like to take this opportunity to raise a related issue which is of concern to our members. The management and use of controlled drugs, which include a range of palliative care medication, is currently reserved under the Scotland Act 1998 and is governed by the Misuse of Drugs Act 1971 and related regulations. The effect of this regime is that care homes in Scotland are required to apply for licences, for each type of controlled drug, from the Home Office to possess stocks, unless the care home is wholly or mainly maintained by a public authority out of public funds. In Scotland, as there is no legal difference between a care home with nursing and one without, this applies to all care homes in Scotland (unlike in the rest of the UK, where care homes with nursing have to meet fewer requirements to store controlled drugs). The consequence of the current situation is a delay in alleviation of symptoms and access to end of life care for care home residents, where around 20% of all deaths take place across the UK. This poses a risk of unnecessary suffering by the resident and significant distress to families and staff.

9. Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?

Outcome 7: Babies, children and young people living with serious health conditions, and their families and carers, will experience improved support as their distinctive needs are recognised and addressed by paediatric palliative care, including care around dying or as they transition into adult services.

Proposed actions:

- Work with key partners to develop a national approach to service planning for all paediatric palliative care, through a multi-agency steering group, to ensure children and families across Scotland have access to the

services they need, wherever and whenever these are required, and to ensure that these services are equitable.

- Work with CHAS and Health Boards to review current models and develop a national specialist paediatric palliative care service available at all times (24/7) to meet the needs of children, families and staff across Scotland in all places of care.
- Support and develop improved transitions for young people with serious health conditions based on Getting It Right For Everyone (GIRFE) practice model, and the co-designed GIRFE 'team around the person' toolkit for young people in transition from GIRFEC (Getting it Right for Every Child) to GIRFE.
- Draw on best practice models to develop and agree paediatric palliative care standards to children and families across Scotland have equitable access to high quality general and specialist paediatric palliative care services wherever and whenever these are required.
- Explore options for a national approach to providing ethical clinical review of decision making in paediatric palliative care.

RCN Scotland has no detailed comment on this outcome, which is broadly welcome and correctly identifies the need to improve outcomes for young people transitioning to adult services.

Question 10. Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?

Outcome 8: Employers, professional bodies and education providers will make sure that staff who deliver palliative care are trained, skilled and supported.

Proposed actions:

- Work with Healthcare Improvement Scotland (HIS) to ensure there is sustainable management, updating and extension of the Scottish Palliative Care Guidelines as recommended best practice for symptom management across Scotland on the Right Decision Service; and explore options to develop and include Scottish paediatric palliative care guidelines.
- Work with NHS Education Scotland (NES) to develop a designated online learning space readily available to all health and social care staff who deliver palliative care to adults, children and young people that provides a single point of access to relevant training and education resources on palliative care, care around dying and bereavement support.
- Work with NHS Education for Scotland (NES), statutory and third sector organisations, and education providers to support and enable local and national education and training for health and care staff to equip them to

have sensitive and effective person-centred conversations with adults or children, families and carers, that are central to future care planning, palliative care, and care around dying, including NES Having Realistic Conversations resources.

- Work with NHS Education for Scotland (NES) and third sector palliative care education providers to promote and develop online learning opportunities and networks for health and social care staff across Scotland such as Project ECHO.
- Work with universities and further education colleges that provide pre-registration courses and undergraduate education programmes to enable all health and social care staff (including doctors, nurses, pharmacists, allied health care professionals and social workers) and to receive a level of adult or paediatric palliative care education appropriate to their roles.
- Encourage HSCPs and Health Boards to employ palliative care practice educators to support the sustainable delivery of palliative care education and training in line with the NES/SSSC Palliative Care Education Framework and work collaboratively with adult and paediatric palliative care specialists offering education and training.

Professional bodies' are referenced in the outcome, but their role is not explained in any of the commentary or the actions. RCN Scotland, as the professional body for nursing, issues guidance, provides support and some training for members, however it is not our role to train nursing staff. We would welcome clarification on the role of professional bodies in this section.

Questions 11. Please add any further comments you have about the draft strategy outcomes and actions here.

While the strategy correctly identifies an aging population as a factor which will effect future need, there is no reference to the increase in people with no families or relatives nearby and what provision is needed to support them.

Question 12. Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?

Question 13. Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?

Question 14. Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?

No comment on the above questions.

Question 15. Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?

The strategy contains a useful explanation of the above terms. There is certainly a misconception that palliative care is only available in the final weeks or days of life or that it is restricted to cancer care. Education of service users and their families is needed, but a better understanding of what palliative care is, will inevitably lead to an increase in demand for services, which needs to be factored in to this strategy.

One area that could be improved, however is on the definition of the interface between palliative care and community led support. The strategy initially explains the importance of community led support but does not make clear where palliative care ends and community led support begins. This is important as it has implications for both delivery purposes and access to services.

RCN Scotland is of the view that a trend is emerging where community led support is in some cases subsidising or replacing palliative care. One example of this is the No One Dies Alone initiative in Inverclyde, which is a voluntary scheme but one which should be MDT led.

Question 16. Please add any other comments or suggestions you have about the draft Palliative Care Strategy here.

No comment on the above question.