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24 June 2015

Dear Mark

Consultation on SPPC position paper end of life care in Scotland

We thank you for the opportunity to comment on the initial phase of the development of the SPPC position paper on a proposed strategic framework for palliative care in Scotland.

As you are aware, the RCN, as a UK organisation, have been working with the Leadership Alliance for the Care of Dying People in England which reports directly to Baroness Neuberger. The Neuberger review has produced an approach, One Chance To Get It Right[1] , which we hope that the strategic framework for Scotland will learn from and build on given all of the work already carried out on clinical practice in Neuberger Review. It would be the wish of the RCN that any proposed strategic framework must provide clear guidance and direction for our members who will be delivering end of life care.

In our response we have focussed on the barriers and potential solutions and standards that have been highlighted in your consultation document.

Barriers to good end of life care

Joined up care services

The consultation clearly highlights that those in need of palliative care should experience a service in a timely and seamless manner with the access to care in a coordinated and compassionate way that improves their end of life. The RCN carried out extensive research into this and produced our Principles for Delivering the

[1] One Chance to get it right
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Integration of Care[2]. These principles should also provide a focus for considerations when developing the national strategic framework.

Complex systems run differently by different care providers can lead to confusion in an already stressful situation for patients and their families. The implementation of health and social care integration is designed to bring about a more seamless transition between services for those moving from medical care to palliative care. Locally designed services must be able to meet the palliative care needs for those in their locality who choose, where possible, to die at home. There must be a single point where patients and their families can access these services in a joined up and holistic manner including, but not limited to, community nursing, AHPs, GPs, social work and third sector services. Particularly in health, an enabler to this type of joined up care is a managed clinical network. These networks of linked groups of health professionals and organisations from primary, secondary and tertiary care, work in a co-ordinated manner, unconstrained by existing professional and Health Board boundaries, ensuring equitable provision of high quality clinically effective services throughout Scotland.

Community capacity

It is particularly important that the challenge of more palliative care being delivered in the community is also taken into account when considering the practical implementation of any strategic framework for end of life care. Progress to shifting services into the community has been slow. A recent Audit Scotland review of Reshaping Care for Older People found little evidence of progress in moving money to community-based services. Pressures on budgets are putting the sustainability of services at risk, as Audit Scotland highlighted in its overview of NHS finances published in October 2014. Moving services to the community will increase the activity in these areas and, without sufficient funding, community capacity pressures will increase. It may be helpful for any proposed framework to set out clearly how it will contribute to addressing some of these challenges.

Early proposals around the future of the Scottish GP contract from 2017 suggest, if taken forward, these changes could have a significant impact on clinical responsibility and capacity with regard to palliative care in the community. This must be taken into account as new approaches are developed. Planning a multi-disciplinary workforce of clinical decision makers to deliver truly responsive care 24/7 is required now.

Training

In June 2015, Healthcare Improvement Scotland issued their standards for the care of older people in hospital. The standards are clear that:

Good care requires a holistic, integrated, multidisciplinary approach delivered by a knowledgeable, well-trained, compassionate team of professionals and support staff. Training and education may include, but is not limited to, areas such as palliative and end of life care. Safe care in hospitals can only be delivered when the team has safe staffing levels, supported by the appropriate skills mix for the patient population and the right attitude and approach to care.

All staff who deliver care for older people in hospitals must be trained in and be able to demonstrate the knowledge and skills required to provide safe, effective and person centred palliative and end of life care. These standards are limited to hospital settings. The same expectations and support must be set in the community if we are to ensure palliative care is a central part of the 2020 vision implementation.

[2] RCN in Scotland: Principles for delivering the integration of care - http://www.rcn.org.uk/__data/assets/pdf_file/0016/442132/RCN_in_Scotland_integration_principles.pdf

The RCN has been developing two resources[3] to support staff in providing good end of life care, one with a particular focus on the sensitive issues relating to nutrition and hydration, and the other on the wider issues of end of life care. Both resources are applicable in end of life care across the UK and have been informed by a review commissioned by the RCN and by the results of an RCN survey on end of life care. We hope these resources will inform the elements required in any proposed framework which will provide guidance for staff.

Seven day services

Patients should not have to wait for a weekday to have specialist palliative care assessments carried out. Ensuring that people have timely access to high quality, person-centred, safe and effective palliative care when they need it, regardless of the day of the week, requires a whole system approach. This means focusing on community services, as well as hospital services, and looking at multi-professional models of care that maximise the potential of different professions to meet the needs of patients and improve patient outcomes out with core Monday to Friday services. The proposed framework must ensure that people entering the last stages of life do not experience a poorer service out of hours. The outputs of the out of hours primary care review and the 7 day task force must clearly reflect a commitment to improved palliative care, though they are likely to report before the Scottish Government framework is complete. Influencing of these is required now. The RCN is leading work for the primary care group on models of out of hours care for people requiring palliative care.

Care home sector

In the future the care home sector will also need to adapt to better care for an ageing population with more complex needs including palliative care. The RCN, along with other key stakeholders, joined with the Scottish Government and COSLA to form the Taskforce for the Future of Residential Care in Scotland[4]. Its recent report makes a series of recommendations including:

- *Expansion of the residential sector in three directions: development and expansion of the extra-care housing sector; a focus on rehabilitation and prevention; smaller more specialised residential sector focused on delivering 24 hour care for people with substantial needs.*
- *Person-centred services and development of new accommodation that is more tailored to care needs of residents/tenants.*
- *Better partnership working with volunteering and carers' roles to support people that live in care homes.*
- *For staff working in care homes, In addition to possessing the core qualifications to practice, there are a wide range of training and development requirements needed in a care home setting. Depending on the role, this can include skills and knowledge e.g. administration of medications, falls prevention, nutrition, anticipatory care planning, tissue viability, moving & handling, health & safety.*

It would also be beneficial for any proposed strategic framework to express how it would practically be implemented in this new landscape for the care home sector.

Public perception and understanding

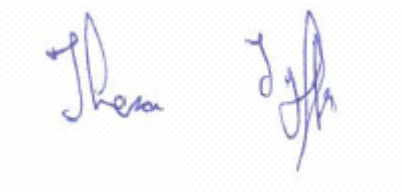
[3] Getting it right every time. Fundamentals of nursing care at the end of life http://www.rcn.org.uk/__data/assets/pdf_file/0011/629858/End-of-Life_RCN.pdf

[4] Residential Care Taskforce Report - http://www.gov.scot/Resource/0044/00444581.pdf

It will be important for practitioners, the dying person and their families/carers to understand clearly what is meant by "end of life care" within the context any proposed strategic framework. For example, in the recent guidance[5] on end of life care, issued by the Scottish Government, end of life is defined as caring for someone in the last days and hours of life, however, in the guidance produced for England[6] a patient is classed as being in end of life care if they are likely to die within the next 12 months. Where any proposed framework addresses end of life care it should clearly set out the expectations set around definitions, the timeframes involved and what good end of life care should look like. It will also be essential that the public understand the clear standards that will be applied to palliative care across all settings throughout Scotland. The new framework and the re-working of the national care standards must go hand in hand to ensure coherence for the public.

We hope the above informs the next iteration of the position paper and we look forward to working with you over the coming months. For further information or to discuss any of the points raised please contact David Liddle on 0131 662 6176 or at david.liddle@rcn.org.uk

Yours sincerely,



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[5] Caring for people in the last days and hours of life – Guidance – http://www.scotland.gov.uk/Publications/2014/12/6639
[6] One Chance To Get It Right - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf