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Dear Ms Kinnaird

Consultation on Developing the 8 Pillars Model of Community Support

The Royal College of Nursing (RCN) is the UK's largest professional association and union for nurses with around 420,000 members, of which around 39,000 are in Scotland. Nurses and health care support workers make up the majority of those working in health services and their contribution is vital to delivery of the Scottish Government's health policy objectives.

The RCN welcomes the opportunity to respond to Alzheimer Scotland's advanced dementia consultation. The questions contained within the consultation cover a wide range of issues relevant to dementia care. In order to make the most constructive contribution to the points raised our response to this consultation will focus on a number of themes relevant to our members.

Service design

RCN Scotland supports the need for a joined up and coordinated approach to caring for people living with advanced dementia, which the model outlines.

With the integration of health and social care our entire care system is undergoing a period of significant change. We recognise that the Scottish Government's National Dementia Strategy 2013-16[1] made a commitment to pilot the 8 pillars model across a range of service delivery environments including primary care, local authorities and integrated services. It would be beneficial to have more information on the impact and learning from the five regional pilots[2] to see if any lessons could be learned regarding the model's application for advanced dementia. This could support new integration joint boards to commission dementia services effectively.

[1] Scottish Government's National Dementia Strategy: 2013-16
http://www.gov.scot/Resource/0042/00423472.pdf

[2] http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support

Integrated services must take into account the principles for planning and delivering integrated Health and Social Care[3] contained in the Public Bodies (Joint Working) (Scotland) Act. The principles are "*intended to be the driving force behind the changes in culture and services required to deliver integration reforms successfully and improve outcomes. They explain what people using services and their carers can expect from integrated services. They also explain the behaviours and priorities expected of organisations and people planning and delivering care and support*"[4]. The RCN considers that it would be helpful if the design of the 8 pillars model for advanced dementia included a reference to these principles, which are intended to ensure the quality and safety of care. (See Annex A)

RCN Scotland welcomes the emphasis in the pillars on supporting carers and families as a vital way of supporting people living with dementia. The RCN recently launched the Triangle of Care for Scotland[5] which describes how meaningful involvement and inclusion of carers can lead to better care for people living with dementia. The Triangle of Care has been designed to complement existing policies to improve care for people with dementia in Scotland. In particular, it supports the Scottish Government's commitment to "work as equal partners with families, friends and carers" in the 10-Point National Action Plan, in Scotland's National Dementia Strategy.

The consultation clearly sets out a vision that people living with advanced dementia should experience a care service which is accessed in a timely and seamless manner and is delivered in a coordinated and compassionate way that improves their quality of life.
The RCN agrees with this vision, which aligns clearly to our own Principles for Delivering the Integration of Care[6]. We would hope that this RCN document might support the further development of the 8 Pillars model for advanced dementia.

The care home sector is also faced with meeting the needs of an ageing population with more complex care needs, including dementia. 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[7]. 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.

[3] Principles for Planning and Delivering Integrated Health and Social Care - http://www.gov.scot/Resource/0046/00466005.pdf
[4] Guidance on the principles of planning and delivering integrated health and social care http://www.gov.scot/Resource/0046/00466005.pdf
[5] Triangle of Care for Scotland - http://www.rcn.org.uk/__data/assets/pdf_file/0010/609832/ToC-Scotland-Dementia-Final.pdf
[6] 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
[7] Residential Care Taskforce Report - http://www.gov.scot/Resource/0044/00444581.pdf

- Ensuring that the workforce is adequately trained to respond to higher levels of dementia.

We are therefore keen to see the eight pillars model explicitly demonstrate how it could support the care home sector too.

Support for the workforce

While we welcome the role of a Dementia Practice Coordinator in facilitating holistic care there needs to be further clarity around the position.

It is not clear from the consultation whether this will be a standalone role or if these duties will be in addition to the role of an existing health and social care professional. The latter would require protected time for practitioners to fully carry out the role and meet the needs of people living with dementia.

Anyone providing care to someone with dementia should be suitably trained, in line with the national framework, to manage the conditions and needs of those suffering from advanced dementia. The NES/SSSC Promoting Excellence[8] framework sets out the knowledge and skills all health and social services staff should aspire to when caring for and supporting people with a diagnosis of dementia, their families, and carers. This framework should be reflected in the role of the Dementia Practice Coordinator to ensure the quality of service being provided.

Service pressures

The integration of health and social care is designed to help to improve the coordination of care particularly with the creation of more integrated multi disciplinary teams who work more closely together. Better joined up services will improve the continuity of care, which is of particular relevance to people living with dementia.

However, it is important that the challenges in shifting care into the community are also taken into account when considering the practical implementation of the eight pillars model. Progress in shifting services into the community has been slow. A recent Audit Scotland review of Reshaping Care for Older People[9] found little evidence of money moving 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[10]. Any roll out of the eight pillars model will be done within the context of services under significant resource pressure. It would be helpful to note this directly within the document to support a local discussion among commissioners, practitioners, users of services and carers on how to implement reforms successfully within the realities of current service delivery.

End of Life Care

The Scottish Government has published its guidance and principles of good practice regarding end of life care[11]. NHS boards and social care services are to determine how the guidance will be implemented locally. Health and care providers must apply the principles across all settings with an understanding that all people are different and must receive person-centred end of life care. It would be helpful to clarify,

[8] Promoting Excellence Framework - http://www.gov.scot/resource/doc/350174/0117211.pdf
[9] Audit Scotland – Reshaping care for older people - http://www.audit-scotland.gov.uk/docs/central/2014/nr_140206_reshaping_care.pdf
[10] Audit Scotland NHS Financial Performance 2013/14 http://www.audit-scotland.gov.uk/docs/health/2014/nr_141030_nhs_finances.pdf
[11] Caring for people in the last days and hours of life – Guidance – http://www.scotland.gov.uk/Publications/2014/12/6639

explicitly, how the 8 pillar model aligns with the fundamental elements of end of life care, as written in this guidance.

It will be important for practitioners, people with dementia and their carers to understand clearly what is meant by "end of life care" within the context of this model, For example, in the recent guidance[12] 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[13] a patient is classed as being in end of life care if they are likely to die within the next 12 months. Where this model addresses end of life care for those with advanced dementia, it should clearly set out the expectations set around definitions of the timeframes involved.

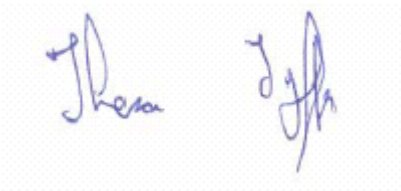
RCN Scotland believes that, where possible, the patient and their family should be involved in decisions about their end of life care, whatever their condition. Evidence shows this improves the quality and person-centredness of their care. For example, work carried out in NHS Shetland[14] has shown that patients with advanced care plans who were seen out of hours were cared for according to their plan without introducing alternatives which may have resulted in an inappropriate admission to hospital.

Early planning with patients who have advanced dementia will ensure that they are making choices about their end of life care while they still have cognitive ability. There should be a more explicit reference to advance care planning and starting end of life care conversations with the patient as early as possible within the proposed model. Robust and early planning for end of life care could provide a foundation for the two proposed pillars on personalised support and support for carers.

We welcome the opportunity to respond to Alzheimer Scotland's consultation and support the approach taken within the model. We would be happy to support Alzheimer Scotland as it further develops its approach to improving care for people living with advanced dementia.

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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[12] Caring for people in the last days and hours of life – Guidance – http://www.scotland.gov.uk/Publications/2014/12/6639

[13] 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

[14] NHS Shetland case study - http://www.jitscotland.org.uk/example-of-practice/247-community-nursing-service-model

Annex A

Integration planning and delivery principles

The integration planning and delivery principles are—

(a) that the main purpose of services which are provided in pursuance of integration functions is to improve the wellbeing of service-users,

(b) that, in so far as consistent with the main purpose, those services should be provided in a way which, so far as possible—

(i) is integrated from the point of view of service-users,

(ii) takes account of the particular needs of different service-users,

(iii) takes account of the particular needs of service-users in different parts of the area in which the service is being provided,

(iv) takes account of the particular characteristics and circumstances of different service-users,

(v) respects the rights of service-users,

(vi) takes account of the dignity of service-users,

(vii) takes account of the participation by service-users in the community in which service-users live,

(viii) protects and improves the safety of service-users,

(ix) improves the quality of the service,

(x) is planned and led locally in a way which is engaged with the community (including in particular service-users, those who look after service-users and those who are involved in the provision of health or social care),

(xi) best anticipates needs and prevents them arising, and

(xii) makes the best use of the available facilities, people and other resources