Response from the Royal College of Nursing Wales to the Health, Social Care & Sport Committee’s inquiry into the Welsh Government’s draft national dementia strategy

General comments

I. Whilst the Royal College of Nursing Wales welcomes the draft national dementia strategy, which provides an important opportunity for Wales to improve the standard of living and the care received by those living with dementia, we would also like to see the strategy go further to improve patient care, with more detail required in some areas.

II. People with dementia and their carers, family members and friends have the same human rights as every other citizen. However, it is widely recognised that, in addition to the impact of the illness, they face cultural, social and economic barriers to fulfilling these. This includes the right to a proper diagnosis, access to information and support from a range of informed, skilled professionals who are able to provide individualised care.

Diagnosis rates

III. More ambitious diagnosis rates is one area in which the strategy could be improved. The Royal College of Nursing believes that the aim for an annual increase of 3% per year on existing diagnosis rates does not go far enough. Current diagnosis rates in Northern Ireland are 64%, and under the target in the draft strategy, Wales would not achieve this rate until 2021/2022. It is only by improving diagnosis rates that we will be able to get a true picture of the level of services needed to meet patient demand, and improve current workforce planning.

Dementia support workers and dementia specialist nurses

IV. The Royal College of Nursing believe that more clarity and detail is needed around the role of the dementia support worker, and the level of training and qualifications individuals in these roles will be required to have. Whilst we are supportive of the aims to ensure that every newly-diagnosed person with dementia has access to a dementia support worker, the Royal College believes the strategy should also recognise the high level of qualifications of dementia specialist nurses. Both dementia support workers and dementia specialist nurses have an important role to play in providing support for people affected by dementia.

V. The needs of individual patients will vary, and in some cases a dementia support worker (assuming they are trained to a similar level as a health care support worker) will be appropriate. In other cases, an individual may require care and treatment from a dementia specialist nurse who has undertaken in-depth practical and clinical training. The most important factor is to ensure that
the patient receives the highest level of care by appropriately trained personnel to meet their needs.

VI. There is little mention in the draft strategy of specialist training and includes phrases such as “diagnosis of dementia by a suitably competent clinician”. The Royal College of Nursing Wales firmly believes that the strategy should be setting out specific requirements for people with dementia to receive care from staff who have received specialist dementia training at an appropriate level to meet the needs of the patient.

Training and education

I. A survey of people with dementia and carers was carried out at a UK level in 2011 on behalf of the Royal College of Nursing. A range of approaches were identified as necessary in delivering better care for people with dementia and their families/carers while in hospital. The two most frequently mentioned barriers to the delivery of care in the surveys were staff understanding and time. This shows the importance of having appropriately trained staff who have the time and capacity to deliver the best possible care for patients.

II. Those delivering care to people with dementia must have access to regular training and education. Patients with dementia have specific and complex needs, and those with dementia on an older persons ward, or in a care home for instance, are likely to require greater levels of care than other patients in similar settings. As such, it is also important to ensure that not only is staff training available, but that the staff are able to afford the time to undertake this training. Having a well-trained workforce with the appropriate skill-mix to cater for people’s needs is crucial.

III. At present, there is variation between the level of training available for nurses and healthcare support workers who care for those with dementia, and this is particularly the case in the independent and care home sectors. Higher levels of training for all staff working in environments where people with dementia receive care is required, and this includes practice nurses, community nurses and nurses working in the independent sector.

Carers and the Triangle of Care

IV. The Royal College welcomes that the strategy recognises the role of the carer in the dementia care pathway and recognises the need to include them in the process. Attached to this written evidence is a copy of the Triangle of Care, a collaborative effort between the Royal College of Nursing and Carers Trust. The Triangle of Care describes a therapeutic relationship between the person with dementia, staff member and carer that promotes safety, supports communication and sustains wellbeing.

V. This model of care has been successfully implemented in areas across the UK, but it could be much more consistently embedded to ensure that everyone receiving dementia care and their carers benefit from the approach outlined in
the Triangle of Care. While developed with dementia in mind the standards are applicable for anyone caring for or living with someone with a long-term health condition.

**Staffing levels**

VI. Much of what we have mentioned above can be linked to staffing levels, and the need to have the right number of staff available to meet the needs of patients. For wards where the majority of patients have dementia, it is likely that more nurses will be required than on a ward where patients have less complex needs.

**Learning Disabilities**

VII. The Royal College is pleased that the draft strategy recognises the needs of those with learning disabilities. People in this group have specific needs which need to be identified and accommodated throughout their care pathway and it is important that this document recognises this.

**Welsh language**

VIII. The Royal College of Nursing welcomes the recognition in the draft strategy that people with dementia need assessment and care to be available in their preferred language and that health boards need to ensure access to Welsh language diagnostic tools and care. However, given the legal status of the Welsh language as an official language, the Royal College would maintain that this is not only a “clinical need” as stated in the draft strategy, but is both a human right and a legal requirement. The need for improving service provision for Welsh language speakers therefore needs to be given greater prominence and specification in the strategy.

**Older Persons’ Delivery Assurance Group**

IX. The Royal College of Nursing welcomes the proposal to have progress with delivery of the strategy overseen by the Older Persons’ Delivery Assurance Group (DAG). However, we would like to see more detail on exactly what the role of DAG will be and the level of accountability it will have. Setting out Terms of Reference for the Group, including a clear requirement to report back, would go some way to addressing this.

VII. The prevalence of dementia and its nature as a disease means that almost everyone working in health and social care will work with people with dementia. As such, it is vital that once the final dementia strategy is launched, it is truly embedded across all fields and specialties in order to truly enhance the care received by people with dementia and improve their quality of life.
About the Royal College of Nursing

The RCN is the world's largest professional union of nurses, representing over 430,000 nurses, midwives, health visitors and nursing students, including over 25,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing. The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.