Proposal for Scotland’s National Dementia Strategy
2016-19: March 2016
1. **Introduction**

- This paper sets out The Scottish Government’s proposals for the key priorities for Scotland’s third National Dementia Strategy, 2016-19.

- The paper has been prepared following extensive discussion and feedback from the series of Dementia Dialogue events held across Scotland between November 2015-January 2016; and written responses submitted as part of that process. **The paper is not intended to be exhaustive** but a strong signal of what the major elements of dementia policy should be over the next 3 years.

- There was strong support from the dialogue process that we should:-

  - continue to focus on our **national and local human-rights based approach to improving dementia diagnosis rates and services** and supports at all stages of the illness and in all care settings; and that this should continue to be underpinned by the rights-based approach to developing and up-skilling the dementia workforce through implementing *Promoting Excellence* and *The Standards of Care for Dementia in Scotland*

  - **continue our national focus on supporting the roll out and embedding of good quality and consistent post-diagnostic support** for dementia, which should include testing the impact and benefit to individuals, families and
to services of re-locating of post-diagnostic services into Primary Care

- prioritise and design a specific national focus on dementia palliative and end of life care

- support and challenge the new Integrated Joint Boards in re-designing local dementia care systems now and for the future, including by extending and strengthening national service improvement support and by providing evidence on the nature and scale of the challenge of providing safe, effective and person-centred care for people with dementia

- continue national approaches to education and training and to service improvement, complemented by the use of data on outcomes for people with dementia, including the first round of national dementia benchmarking data, published later in 2016

- support local strategic approaches to promote and complement bottom-up, community-led Dementia Friendly Community initiatives and utilise these assets as part of service and support re-design

2. Progress 2013-16

- **Dementia diagnosis rates** have been maintained over the duration of the current Dementia Strategy, at either approximately 50% or 65% - depending on which prevalence model is applied to the numerical dementia diagnosis data. The latest round of national performance data on diagnosis - up to
July 2015 - shows that 43,409 people were recorded as having a formal dementia diagnosis. The national service offer that everyone newly diagnosed with dementia is entitled to receive a minimum of a year’s worth of support from a named Link Worker continues to be implemented. **National performance on the national post-diagnostic LDP Standard will be published in the Autumn of 2016.**

- **As part of implementing *Promoting Excellence*, over 500 Dementia Champions** have been trained to lead improvements at the frontline of NHS care, with 100 more graduating this month; In addition as part of the uptake of *Promoting Excellence* in social services, **over 800 people have been identified as Dementia Ambassadors** to lead dementia training in their workplaces, with 70% of those Ambassadors working in care homes.

- **5 areas of Scotland** – Glasgow City, North Lanarkshire, Moray, Midlothian and Highland – **have piloted Alzheimer Scotland’s “8 Pillar” model for integrated, intensive, home-based coordinated care for people with mid-stage dementia**, providing enhanced services to individuals and families; and the applicability of the service model in these areas is being independently evaluated, with the evaluation to report later this year.

- **Bespoke national and local NHS Board action plans have been taken forward for dementia in acute and in specialist dementia mental health settings**, the former supported by the Alzheimer Scotland Dementia Nurse and AHP Consultants. The role and initial impact of the Nurse Consultants, AHPs and
Dementia Champions has been positively evaluated. Healthcare Improvement Scotland’s inspections of care for older people in acute hospitals, its older people in acute care improvement programme and the *Focus on Dementia* improvement programme, have helped drive a culture of continuous improvement and the sharing of good practice.

3. **Challenges**

- **We need to continue to support improvements in all areas of dementia care and at all stages of the illness** – it is vital that people who may be more disempowered because of the progress of their illness or because of where they are being cared for do not experience unintended discrimination or poorer access to services and supports because of their circumstances.

- **We need to do more to prevent avoidable hospitalisation** of people with dementia – this still results too often in poorer outcomes for people with dementia and avoidable costs and pressures on the care system.

- **We need to do more through the new Integrated Joint Board infrastructure to support locality planning and re-design of dementia services**, including through targeted improvement support and the harvesting and use of data on dementia to build and sustain the case for change, re-structuring and improvement. As part of this, we need to do more to increase the accessibility and uptake of Self-Directed Support by people with dementia.
• We need to do more to **nurture approaches whereby local and national community assets and grass-roots initiatives are capitalised on** to complement the change and improvement in dementia services and supports and contribute to better experiences for people with dementia and their families.

4. **Priority proposals**

• **Making further improvements in dementia diagnosis rates and in the quality and consistency of post-diagnostic support**

This will include doing more to identify the right volume of post-diagnostic services required; supporting the further personalisation of services; testing of the re-locating of post-diagnostic services into Primary Care with the aim of making the prospect of getting a diagnosis and accessing post-diagnostic support easier and less daunting for individuals and families; and utilising the Primary Care Transformation Fund to pilot this change.

We will also do more to improve the consistency of post-diagnostic services and work to formally segment the beneficiary group so that people get the right service response reflecting the stage of the illness at which they get a diagnosis.
• Working collaboratively with the new Integrated Joint Boards to support locality planning and re-design of dementia services

This will include a particular focus on integrated and coordinated intensive home care. This will involve the spread of and engagement around the independent evaluation of the applicability of Alzheimer Scotland’s “8 Pillars” model once it is published later this year; and broader attention to the needs of the large percentage of people with dementia who also live at home with a range of other conditions.

It will also include the further promotion of telecare and aids and adaptations for people with dementia; attention to the broader housing and accommodation needs of people with dementia; enhancing a multi-disciplinary approach to care at home, including the promotion of the therapeutic and enabling role of AHPs for people with dementia; more work to increase access to Self-Directed Support for people with dementia; and attention to supporting social inclusion including issues around transport.

• Prioritising policy around dementia palliative and end of life care

In recognition of greater understanding of the proportion of the overall palliative and end of life group who have dementia. This will involve a significant focus on: promoting and supporting care and support planning (also known as “planning anticipatory care”); joining up effectively planned care and emergency care; and the reciprocal and mutually beneficial
development of the specialist dementia workforce and the specialist and generalist palliative and end of life workforce.

This will involve working in partnership with the national programme to support implementation of the Scottish Government Strategic Framework for Action on Palliative and End of Life Care to ensure synergy with Promoting Excellence; taking a national improvement approach to palliative and end of life care, with a specific focus on dementia; testing and evaluating of Alzheimer Scotland’s proposed Advanced Care service model; identifying and spreading knowledge of current good practice; and working collaboratively with Integrated Joint Boards to support the design of effective services in this areas of care, including expanding hospice care to help reduce inappropriate long stays of people with dementia in hospitals.

- **Implementing a further Promoting Excellence dementia health and social services training and education plan for the next 3 years**

To continue to work with NES/SSSC to further embed and sustain improvements in the knowledge and skills of staff working in health and social services against Promoting Excellence through a national workforce development plan to help enable workers to provide the best possible quality of care for people with dementia and implement the human-rights based Standards of Care for Dementia in Scotland; and promoting and supporting the uptake and use of Promoting Excellence training and resources in other areas of public life and by families and communities.
• **Continuing the national focus on improvement in acute and specialist dementia mental health settings**

Building on bespoke national action already in train on dementia in acute and specialist dementia mental health settings, including a key focus on involving families as key partners in care.

• **Continuing to identify and promote the specific issues and needs of the dementia client group as part of the process of implementing the recommendations of the Task Force for the Future of Residential Care in Scotland**

Enhancing a multi-disciplinary approach to dementia in residential care; continuing to support decreases in the inappropriate use of psychoactive medications in response to stress and distress in care homes and elsewhere, including by continuing to provide training on and promoting a range of therapeutic alternatives.

In addition, The Scottish Government is contributing a significant enhancement in resources to help enable councils to allow for all social care workers in adult settings, including in the independent and third sector, to be paid the Living Wage from October 2016 (initially £8.25 an hour rather than the enhanced minimum wage of £7.20).

• **Continuing to work with service user and carers groups – such as The Scottish Dementia Working Group, Alzheimer Scotland’s National Dementia Carers Action Network and the ALLIANCE’s Dementia Carer Voices project**
In order to facilitate and benefit from the direct involvement and experience of people with dementia and their carers in the implementation of policy and improvements in practice.

- **Supporting the development of and complementing bottom-up, community-led Dementia Friendly Community initiatives**

  Utilising these assets as part of service and support re-design, linking with initiatives and programmes such as The Life Changes Trust and Dementia Friends

- **Working with others to respond to both the Scottish Government’s and NHS Health Scotland’s imminent reports on equalities and dementia issues, such as access to timely diagnosis and services by people including those with early onset dementia; those with learning disabilities and dementia; and those with dementia from LGBT and BME groups and communities**

- **Continuing to support research through funding The Scottish Dementia Clinical Research Network and supporting the work of the Scottish Dementia Research Consortium in its objective to bring together the range of dementia research interests in Scotland and maximise the impact of and funding opportunities for research capacity here**

**Next Steps**

- This paper will form the basis of Scotland’s next three-year National Dementia Strategy which will be published later this year.