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Llywodraeth Cymru
Welsh Government

Welsh Government Consultation – Summary of Responses

Dementia Action Plan: 2017-22

Summary of responses and Welsh Government response

Date of issue: 9 January 2017
Action required: Responses by 3 April 2017

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

1. Introduction

On 9 January 2017 the Welsh Government published the proposed '*Dementia Action Plan*' covering the period 2017-22 and sought views on the priority themes and actions enclosed. It was aimed at health boards, local authorities, third sector providers of support services and people with dementia, their carers and families.

The consultation began **9 January 2017** and closed on **3 April 2017**.

2. Context

'Taking Wales Forward' commits the Welsh Government to 'make Wales a dementia friendly nation' through developing and implementing a new, national dementia plan.

'Prosperity for All' also recognises the need to take cross government action to support our ageing population.

This report summarises the responses to each of the consultation document's questions.

3. Structure of the Dementia Action Plan

The plan outlines the key themes which we propose need further action over the next five years. This document will also be reviewed after three years to ensure it remains relevant and appropriately targeted.

Overwhelming feedback from the stakeholders prior to publication of the consultation version of the plan is that they wanted support and services to be delivered with 'a rights based approach' and that action considers all parts of a pathway, starting from a whole population awareness of dementia. Therefore the plan has been structured following a pathway approach.

4. Consultation undertaken.

There has been a significant amount of engagement undertaken to date which fell into three tranches:

- I. Two stakeholder workshops targeted at professionals
 - II. Workshops held with those personally affected by dementia, and;
 - III. Formal consultation.
- i) A total of 85 attendees from a range of organisations, including health boards, local authorities, the inspectorates, Older People's Commissioner office, the Royal Colleges and third sector organisations, attended two workshops organised by the Welsh Government. The themes of these workshops contributed to both the structure and the proposed actions in the consultation version of the document.
 - ii) Dementia Engagement and Empowerment Project (DEEP) and the Alzheimer's Society were commissioned by the Welsh Government to undertake a series of engagement sessions with those that have been

personally affected by dementia. These events ran both before and during the formal consultation period which commenced in January. The themes of the first suite of events were incorporated within the consultation version of the document with the second suite focusing on the content of the 'draft Dementia Action Plan'. This feedback has been incorporated into the final version of the plan. Both the Society and DEEP also used their established mechanisms to engage with their membership in order to get feedback on the plan's priorities. Over 1200 people were engaged through both the events and through social media.

- iii) The formal written consultation attracted a total of 118 responses which were received via a consultation response form which was available on the website. A breakdown of the responses by organisation is included below:

Individuals	17
Third Sector	15
NHS organisations	35
Local Authority	12
Other public body / education / business / service user representative bodies	39

A full list of respondents is included at Annex A (minus individuals and those respondents choosing to keep their response confidential).

Not all respondents answered the questions directly; some chose not to answer a particular question and others sent a summary of their views instead of the web-based form. The Welsh Government is grateful to all those who took the time to respond to the consultation.

5. Key themes from the consultation responses

A number of comments were received on the generic structure / language of the plan. From this feedback we have included:

- A strengthening of the rights based approach throughout the document.
- More 'person centred' language, including statements which outline what a person living with dementia and their families and carers can expect from the implementation of the plan.
- Actions and outcomes along each stage of the care pathway.
- The requirement that each action needs to be implemented to consider the needs of supporting people with protected characteristics and specific language needs.
- A broader focus from health and social care to a more 'cross – governmental' approach.
- A section which further clarifies how the ongoing monitoring of the plan will be undertaken. This includes the establishment of a separate 'dementia delivery assurance and implementation group'. This group will encompass people living with dementia, including those with younger onset dementia and their carers. This group will also have a formal role in the review of progress at the three year point.

- Additional references included to cite evidence base throughout the document.

The final plan will also be supported by investment to implement a number of the key actions included within the plan. This will include the development of multi-agency 'teams around the individual' that will provide additional support for people with dementia and their families/carers. The creation of these teams will also deliver against a key action in Prosperity for All.

There were a number of comments received as part of the consultation which were considered out of scope for this piece of work. These fell broadly into three main areas:

- Detail which should be included in operational plans, rather than in the national plan.
- Those which impact on dementia but were considered to fit more appropriately in other work streams.
- Information which has been incorporated into the accompanying notable practice compendium document – this will be published shortly following the launch of this plan.

For those areas which are suggesting improvements for operational practice we will ensure that the relevant stakeholder groups are provided with this information so they can incorporate it into their work plans where appropriate.

It should be noted that the *Together for Mental Health 2016-19* priority area 10, 'Wales is a Dementia Friendly Nation', will be formally superseded with the actions laid down within the dementia action plan once it is published.

6. Consultation questions and summary of responses

The following section shows the main themes emerging from the responses and indicates the action taken since the consultation concluded.

Question 1: Do you feel that any additional themes should be included within the final plan?

There were 103 responses to this question with 27 respondents (26%) stating that they did not feel there were any themes missing. The remaining 76 (74%) respondents said 'yes' (46 respondents) or 'partly' (30 respondents)

From the feedback received, a number of amendments have been made to the themes laid down in the document. These include:

- Emphasis on the importance of considering and meeting the needs of families and carers throughout the document.
- Additional detail in relation to an initial outline proposal for multi-disciplinary teams working around the person with dementia.
- Highlighting the importance of the allied medical professions, such as speech and language therapy, occupational health and physiotherapy in supporting people with dementia and their families / carers.

- Recognising that people who have both sensory impairments and are likely to have additional difficulties with their communication. A separate annex for all protected characteristics has been added to the action plan along with additional actions in the plan.
- A greater emphasis on the role of the allied medical professions, such as speech and language therapy, occupational health and physiotherapy in supporting people with dementia and their families/carers.
- Stating that education and training should involve both people with dementia and their carers in its development.
- Changing the emphasis of 'the need for increased support' theme from within the community to include all settings.

A particular area of the plan, which many respondents commented upon as needing to be addressed within a separate theme, was in relation to palliative care and the need to ensure people had the right information and advice to make choices about their future care. This has not been included as a specific theme as it is felt that the principles of enabling people to have the correct information to make choices needed to be considered across the pathway. However the action in this section makes it explicit that the 'team around the individual' have a role in this provision. The actions within this section also complement the implementation of the End of Life delivery plan, published in March 2017¹.

A number of additional comments raised involved making changes to key actions rather than the priority areas itself and this narrative has been included as part of the response to question 2.

Question 2: Within each theme we have identified a number of proposed actions. Do you feel these are the right ones?

There were 91 responses to this question with 13 respondents (14%) stating that they felt they were the right key actions. The remaining 78 (86%) respondents said the key actions were 'partly' correct (69 respondents) and the remainder said 'no' (9 respondents).

From the feedback received, a number of actions have been amended or moved to a differing section of the plan. There have also been a number of additional actions added to the plan, including:

- Local authorities and health boards to work with local communities and third sector organisations to encourage them to open their services so that people with dementia, their families and carers can participate.
- Work with local authorities, local health boards and Public Health Wales so the needs of people living with dementia are considered as part of planning processes.
- More specific actions on transport, housing and planning (including strengthening collaborative working between social care and housing and requirements for transport planners / operators to consider the needs of people living with dementia).

¹ <http://gov.wales/docs/dhss/publications/170327end-of-lifeen.pdf>

- Encourage GPs to take up the dementia component in the mental health Directed Enhanced Service (DES) introduced in 2017
- Review and update, as needed, the dementia awareness DVD for GPs.
- Develop a consistent clearly understood diagnosis, care and support pathway which incorporates standards of care and outcome measures.
- Agree a common approach to cognitive impairment (other than dementia) assessment and intervention, with support offered to primary care by specialist memory assessment services where required.
- Ensure compliance with the Welsh Government's All-Wales Standards for Accessible Communication and Information for People with Sensory Loss.
- Review the capacity and role of dementia support workers to ensure all individuals with dementia living in the community have a dedicated support worker working to agreed occupational standards.
- Develop an All Wales Dementia Allied Health Practitioner Consultant post who will give advice and support to health boards and local authorities to drive forward service improvements.
- Respond to the recommendations of the Health, Social Care and Sport Committee's Inquiry into the use of anti-psychotic medication
- Ensure that the new "teams around the individual" enable families and carers to access respite care that is able to meet the needs of the carer as well as those of the person living with dementia.
- Ensure that the recommendations from the Royal College of Psychiatrists' National audit of dementia in general hospitals are implemented, including instructing health boards and trusts to adopt the principles of the 'John's Campaign'.
- Expand the use of Dementia Care Mapping™ as an established approach to achieving and embedding person-centred care for people with dementia and ensure health boards implement 'Driver Diagram – Mental Health Inpatient Environments for people with dementia'.
- Ensure older person mental health units have agreed care pathways for accessing regular physical healthcare.
- Ensure that access to advocacy services and support is available to enable individuals to engage and participate when local authorities are exercising their statutory duties towards them.
- Continued roll out of 'Good work – Dementia Learning and Development Framework' - enabling people who work with those living with dementia to have the skills to help them feel confident and competent in supporting them. This will be made available to all sectors including health and social care, substance misuse agencies, learning disabilities, emergency staff and prison staff.

A number of respondents felt that whilst it was positive to see a clear target in relation to improving diagnosis rates, it wasn't ambitious enough. Given the need for targets to be challenging but realistic, we have agreed that the target will remain the same but with a commitment to review it in 3 years, this will coincide with the formal review of the full plan.

Question 3: The strategy describes what services should be available for people and their families and carers to live well in the community for as long as possible. What do you think are the key features of this type of service?

There were 77 responses to this question. The majority of responses were based around a number of common themes including:

- Continuity of care from diagnosis onwards.
- More flexible support/respite for people living with dementia and their carers to enable people to stay at home for as long as possible.
- Support that is both age and ability appropriate.
- Strengthening the role of allied health professionals.
- Equal access to care and support for those with protected characteristics.

Throughout the plan we have strengthened these themes. We will also use the wealth of information provided to us throughout this consultation to work with stakeholders in the development of 'team around the individual' approach.

Question 4: Within the final document we would like to include examples of notable practice. If you have any which you would like to highlight, please do so here. Please explain why you think it is an area of good practice e.g. an evidence base, an achieved accreditation award.

There were 67 responses to this particular question and covered a wealth of notable practice. Therefore alongside this document we will be publishing a compendium of notable practice to assist service planners and commissioners in the implementation of this plan. This document will be updated as required to enable it to remain current and 'fit for purpose'.

Question 5: Within the document we have highlighted the advantages of using telehealth, telecare and assistive technologies to help people live more independently and safely within their own home. What do you think the challenges and barriers are in making this happen and how could you overcome these?

There were 66 responses to this question, with many recognising the significant benefits that assistive technologies can provide. Barriers and challenges raised included the cost of obtaining equipment and training in the effective use of technology / ensuring there was clear guidance available.

Therefore in the final plan we have made enabling access to assistive technology and / or equipment' an explicit role of the 'team around the individual' which should ensure that a person living with dementia (or their family and carer) will be provided with the correct information to enable effective use of the technology.

Also, as outlined above, the development of the 'team around the individual' will be supported by investment. The provision of appropriate telehealth, telecare and assistive technologies will be an eligible cost against this budget.

There is also concern in rural areas where access to fast enough broadband is limited and could prevent or deter individuals from being able to participate in

telehealth opportunities. We expect the broader Welsh Government Superfast Cymru project, which will be rolled out across the 'harder to reach premises' in 2018 will enable us to break down these barriers.

Within the notable practice compendium we have also included examples of where telehealth, telecare and assistive technologies are being used effectively.

Question 6: Do you think the actions will provide a positive impact of the proposals for people with the following protected characteristics:-

- **Disability**
- **Race**
- **Gender and gender reassignment**
- **Age**
- **Religion and belief and non-belief**
- **Sexual orientation**
- **Human Rights**
- **Children and young people**

There were 73 responses to this question with 30 respondents (41%) stating that they felt that the actions would have a positive impact for the protected characteristics listed. The remaining 43 (59%) respondents said the key actions were 'partly' correct (37 respondents) and the remainder said 'no' (6 respondents).

Within the final version of the plan we have explicitly stated that each action will need to be implemented in a way that consider the needs of supporting people with protected characteristics and who have specific language needs. We have also included a separate annex which provides additional detail on what is required to ensure that protected characteristics are considered in all themes and actions across the pathway.

It is also recognised that people who have sensory impairment and dementia are likely to have additional difficulties with their communication therefore we have included an additional two actions into the final version of the plan, these are:

- Ensure compliance with the Welsh Government's All-Wales Standards for Accessible Communication and Information for People with Sensory Loss.
- Scope a programme of work that will capture, record, share and flag the communication needs of service users with sensory loss.

Question 7: Do you think the actions will provide a positive impact on the opportunities for use of the Welsh language?

There were 72 responses to this question with 30 respondents (42%) stating that they felt that the actions would have a positive impact on the opportunities for use of the Welsh language. Of the remaining 42 respondents (58%), one stated that the actions would not have a positive impact, while the remaining 41 respondents said the actions would 'in part' have a positive impact.

Comments received reiterated the importance of Welsh language particularly in supporting older people for whom Welsh is their first language; how we intended to

increase the availability of Welsh language staff; and, that Welsh should be available in various means written/visual.

The importance of these issues is recognised and is reflected in *'More than just words.... Follow-on strategic framework for Welsh language services in health, social services and social care'*. The strategic framework sets out our commitment and actions to support and strengthen the planning and delivery of Welsh language services in health and care, including dementia services.

The *'More than just words....'* strategic framework aims to strengthen Welsh language services in health and social care. At its heart is the idea that being able to use your own language must be a core component of care – not an optional extra. We will continue to work with health and social care providers to make sure Welsh language services are actively offered to people. This active offer commitment will also be strengthened when the Welsh Language Standards for the health sector are introduced in 2018.

Question 7: Additional Comments.

Respondents were also given the opportunity to provide additional comments - 77 people that responded took this opportunity.

A number of respondents also provided detailed editing comments and sources of further information which we have reviewed and amended the final document as appropriate.

Within the consultation version of the document we stated that the action plan will be monitored by an Older Persons' Delivery Assurance Group which reports to the National Mental Health Partnership Board.

A number of respondents expressed concern that this could mean that the needs of younger people with dementia were not fully addressed or that the dementia component could be diluted when considering broader older persons mental health needs. Therefore, there will be a separate Dementia Delivery Assurance and Implementation Group established. The membership of this group will include representation from people with dementia (including those with younger onset dementia) and their families / carers. We will ensure that the membership of this group is routinely reviewed to ensure that it remains fit for purpose.

ANNEX A

List of respondents received for the consultation

In addition to those organisations listed below, there were a number of individuals and organisations who responded and those that wished to remain anonymous.

ADSS Cymru

Alcohol Concern Cymru

Alzheimer's Society

Anglesey County Council

Audiology standing specialist advisory group

BASW

College of Occupational Therapists

Company Chemist's association
Community Pharmacy Wales

Company Chemist's association

Deep

Dementia UK

Gwalia Swansea

Housing Lin

Older Person's Commissioner

Parkinsons UK

Pembrokeshire National Park Wales

Public Health Wales

Royal College of Psychiatrists

Royal college of speech and language

Wales Co-op Centre Caerphilly

WLGA

Young onset dementia service - Cardiff and Vale