

Consultation response form: *Together for a Dementia Friendly Wales (2017-22)*

Overview	Proposed <i>Together for a Dementia Friendly Wales (2017-22)</i>
How to respond	Responses should be submitted by 3 April 2017 to: mentalhealthandvulnerablegroups@wales.gsi.gov.uk Or post the completed form to: Mental Health and Vulnerable Groups Health and Social Services 4 th Floor, North Core Welsh Government Cathays Park Cardiff CF10 3NQ
Further information and related documents	Large print, Braille and alternative language versions of this document are available on request.
Contact details	Queries on the consultation should be sent to: mentalhealthandvulnerablegroups@wales.gsi.gov.uk
Data protection	Responses will be seen in full by Welsh Government staff dealing with the issues included in this consultation. It may also be seen by other Welsh Government staff to help them plan future consultations. The Welsh Government intends to publish a summary of the responses to this document. We may also publish responses in full. Normally, the name and address (or part of the address) of the person or organisation who sent the response are published with the response. This helps to show that the consultation was carried out

properly. If you do not want your name or address published, please tick the box further down this page.

Names or addresses we blank out might still get published later, though this does not happen often. The Freedom of Information Act 2000 and the Environmental Information Regulations 2004 allow the public to ask to see information held by many public bodies, including the Welsh Government. This includes information which has not been published. However, the law also allows us to withhold information in some circumstances. If anyone asks to see information we have withheld, we will have to decide whether to release it or not. If someone has asked for their name and address not to be published, that is an important fact we would take into account. However, there might sometimes be important reasons why we would have to reveal someone's name and address, even though they have asked for them not to be published. We would get in touch with the person and ask their views before we finally decided to reveal the information.

Responses to consultations may be made public – on the internet or in a report. If you would prefer your response to be kept confidential, please tick here:

1. Contact Details

Your name:	Helen Davies
Organisation (if applicable):	Alzheimer's Research UK
Email address:	Helen.Davies@alzheimersresearchuk.org
Contact telephone number:	01223 896637
Your address:	3 Riverside Granta Park Cambridge CB21 6AD

2. Are you responding as an individual or on behalf of an organisation?

Please tick box.

Individual	On behalf of an organisation (please tell us which organisation)
	Alzheimer's Research UK

3. Structure of the document

In the Welsh Government's Programme for Government 'Taking Wales Forward 2016-2021' we confirmed we would take further action to make Wales a dementia friendly country through developing and implementing a national dementia plan. This commitment was also highlighted in the 2016-19 delivery plan supporting the Welsh Government's 10 year 'Together for Mental Health' strategy aimed at improving mental health and well-being for the whole population.

This is the first dementia strategy for Wales but builds on previous work. Engagement with people with dementia, their families and carers has been central to drafting this strategy. Feedback from stakeholders has informed the layout of the strategy, including organising actions as part of a pathway and embedding a 'rights based approach' within the document.

Question 1

The strategy follows the following themes:

- Risk reduction and health promotion.
- Recognition and identification.
- Assessment and diagnosis.
- Living as well as possible for as long as possible with dementia.
- The need for increased support in the community.
- More specialist care and support
- Supporting the plan:
 - Training
 - Research.

Do you feel there should be any additional themes included? Please tick the appropriate box below.

Yes

No

Partly

Where you have ticked 'Yes' or 'Partly', please explain what the additional themes should be.

Question 2

Within each theme we have identified a number of proposed key actions. Do you feel these are the right ones? Please tick the appropriate box below.

Yes	No	Partly ✓
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Where you have ticked 'No' or 'Partly', please provide an explanation and any alternative suggested wording below. Please state **which theme** you are commenting on.

1. Many of the key actions are appropriate, however we note there is no commitment to improving uptake on Join Dementia Research to get the right people into research studies.

We suggest this could be one of the high-level performance measures and that information about Join Dementia Research could be made available throughout health care settings in Wales where there is frequent contact with people living with dementia.

2. Alzheimer's Research UK has developed 'A Walk Through Dementia' which is an interactive, virtual reality app designed to put the user in the shoes of someone who has dementia.

We are currently working with partners, including a leading care provider, to develop A Walk Through Dementia as a training tool for medical staff and carers coming into contact with those living with dementia. We suggest as an action, that once this tool is further developed that it be used as a training tool for healthcare staff.

<http://awalkthroughdementia.org/>

3. We would like to see more explicit support for research to understand the causes and mechanisms of dementia in Wales. The new National Dementia Research Institute is a UK wide initiative and as such we would expect the Welsh Government would seek to engage and seek to collaborate.

There is already a research base in Wales - Alzheimer's Research UK has a research network centre covering Swansea, Cardiff and Bangor. The Welsh Government should act to promote Wales as a centre for dementia research, recognising the positive impact research has on our understanding of the condition.

4. We suggest that there is an additional action relating to young onset dementia. Currently the actions for young onset dementia do not address how this group of people can access appropriate services. We recommend there are age appropriate dementia services in Wales and individualised and tailored care plans and support.
5. We would also like the Welsh Government to further support research to develop the evidence base around risk reduction. Alzheimer's Research UK has recently launched a £2m Prevention and Risk Reduction Fund and are looking to other partners to also invest in this area to better understand how to reduce risk of developing dementia.

As this evidence base develops, we would welcome opportunities to collaborate to better communicate the evidence base risk reduction.

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?

Question 4

Within the final *Together for a Dementia Friendly Wales* 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 notable practice e.g. an evidence base, an achieved accreditation award.

Alzheimer's Research UK has developed "A Walk Through Dementia" which is an interactive, virtual reality app designed to put the user in the shoes of someone who has dementia.

This is being developed into a training tool for medical staff and carers coming into contact with those living with dementia.

<http://awalkthroughdementia.org/>

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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?

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Question 6

Do you think the key actions will provide a positive impact for people based on 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

Yes	No	Partly ✓
Where you have ticked 'No' or 'Partly', please explain why.		
<p>The challenge is there is no 'one size fits all' solution to dementia care. We would suggest that individual and tailored care solutions must be available for all based around individual need, regardless of protected characteristics.</p> <p>Given the nature of dementia as a slow-progressing condition, it is also vital that any care programme is regularly reviewed and updated as the condition progresses and care needs change.</p>		

9. Sources of information

The final document will include a list of useful sources of information. If there is anything you feel should be included, please state in the space below:

<http://awalkthroughdementia.org/>

<https://www.joindementiaresearch.nihr.ac.uk/>

<http://www.alzheimersresearchuk.org/supporter-orders/> (We have support material in Welsh on our website)