

Question 1

How much do you agree or disagree that the following statement sets out an overall vision that is right for Wales?

Wales will be a nation where people living with dementia are respected, supported, and empowered to live independently and with dignity in their communities. We envision a society where stigma is not accepted and an increased awareness of dementia, supports people living with dementia and their families to live and socialise in inclusive and compassionate communities, that will empower people to live independently and with dignity in their communities through diagnosis, care, and treatment. Achieving this vision requires a united, cross-government and multi-agency effort, grounded in the voices and experiences of those living with dementia. Together, we will build a future where rights are upheld, support is person-centred, and no one faces dementia alone.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 1.a

Please explain your reasons for your answer to Q1.

We consider this vision is a positive one and one that therefore should be supported. We also recognise that achieving this vision in reality and in all instances will be a very significant challenge and will depend on having health and social care services that are appropriately staffed and resourced, for example with an increased number of geriatricians and trainees entering medicine for the elderly both in the hospital and community sectors to support the ageing population.

The vision will have to be implemented when resource restraints are likely to remain in place and will take very substantial political will to deliver.

Members of the College's Lay Advisory Committee (LAC) highlighted the need for change in societal attitudes toward people with dementia as well as investment in the care and support of people with dementia and their unpaid carers.

Question 2

2a) What is the single most important change you want to see for people living with dementia in the next 10 years?

Improving the quality, availability and coordination of services and treatments (including new treatments) to support people living with dementia, their families and carers as well as changing societal attitudes toward people with dementia.

We also need to see an increase in people involved in clinical trials to ensure there is a robust evidence based for potential new treatments.

2b) How much do you agree or disagree that the strategy is looking to achieve that change?

The strategy appears to be looking to achieve many of these aims but we would want to emphasise that its success depends on the investment in these services, especially in staffing and political will to deliver it. In addition, any investment in service development will need review and refinement to establish a unified approach which can be cascaded more widely.

Question 3

We have set out principles that we think are the building blocks of the new Dementia Strategy. These are:

- Person-centred.
- Rights-based approach.
- Co-production.
- Equity of access, experience and outcomes without stigma and discrimination.
- Recognising intersectionality.
- Timely and accurate diagnosis.
- Taking a preventative approach by focusing on brain health.
- Integrated and coordinated services.
- Providing support for unpaid carers and families.
- Developing our workforce.
- Supporting research and innovation.

How much do you agree or disagree these principles are the right ones?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Question 3.a

Please explain your reasons for your answer to Q3. If you think any principles are missing, include them here.

We consider these to be broadly correct. Some Fellows suggested they preferred the term co-creation rather than co-production and suggested another as the de-implementation of those actions deemed not useful was also recommended.

In questions 4 to 10, we've listed these key areas and provided space for you to share your views on each one.

Question 4

Section A outlines the areas that we will consider under 'Risk Reduction and Prevention in Dementia'.

How much do you agree or disagree that this section identifies the appropriate areas to consider for this key theme?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 4a

Please explain your reasons for your answer to Q4.

We welcome the focus on risk reduction and prevention and consider this is of critical importance. With regard to air pollution and its link to dementia, this is something we wish to raise awareness of and have spoken out publicly on (eg [RCPE calls for urgent enforcement of air quality standards following major report linking air pollution and dementia.](#))

Question 4b

Is there anything else you think should be included in this section?

Members of the College's LAC said that while lifestyle factors are mentioned here, there appears to be limited consideration of whether structural determinants (housing, poverty, inequalities in access to services) are risk factors and these should also be explored.

They also suggested it is not clear who will deliver the prevention activity (Public Health Wales, LAs, or Health Boards.)

Question 5

Section B outlines the areas that we will consider under 'raise awareness and understanding of dementia.'

How much do you agree or disagree that this section outlines the areas that we should consider for this key area?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 5a

Please explain your reasons for your answer to Q5.

We consider these areas are broadly correct.

One further area for consideration is medications reconciliation and active reduction in polypharmacy in this population.

We also support the expansion of communities to allow those with dementia to congregate and share experiences in the early phases as detailed below.

Question 5b

If there are other population groups that you feel are at greater risk of dementia and should be drawn out here, please include these below.

Question 5c

Is there anything else you think should be included in this section?

Members of the LAC suggested that sometimes it felt that there was little scrutiny of the evidence for some of the interventions suggested. For example, the intervention of social prescribing for people with dementia and their carers. Some recent papers have been published which suggest that while there is some evidence for their benefits, there are still challenges including high implementation costs:

<https://bmjopen.bmj.com/content/14/4/e080551.long>

<https://pubmed.ncbi.nlm.nih.gov/40356285/>

In addition, the role of public libraries in risk reduction and prevention in dementia would be worth acknowledging in the strategy and considering further. Public libraries are a key community asset and are a reliable and trusted source of information. The role they can play in awareness raising is worth acknowledging and exploring further. This applies particularly to this section but could contribute to many areas of this strategy including prevention, supporting carers and supporting dementia pathways.

Question 6

Section C outlines the areas that we will consider under 'dementia diagnosis, treatment, care and support'.

How much do you agree or disagree that this section outlines the areas that we should consider for this key area?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 6a

Please explain your reasons for your answer to Q6.

We support the aims set out here but again would emphasise the need for sustained investment in service provision and workforce to allow these to be realised.

We should be aiming for a system where people with neurodegenerative conditions and their families should have proactive, timely, person-centred access to social care and should not have to wait for a crisis or breakdown of informal care before care options are offered. Patients and families also need a range of more flexible options than are often available now, including day care and links to voluntary and third sector resources.

Question 6b. Below is a list of the key topics in this area. Please let us know if you think more information is needed for any of these

Supporting dementia diagnosis.	
Tackling Inequalities in Dementia Care	Members of the LAC stated that more research was needed in this area.
Assessment and Support for Mild Cognitive Impairment (MCI)	
Young Onset Dementia (Under 65s)	Members of the LAC raised the subject of screening for people with a family history.
Post-Diagnostic Support	Members of the LAC consider that the dementia connectors were a positive idea but more information was needed on who these individuals were and where they fitted in to the support system.
Person-Centred Care and Support	
Dementia Treatment and Disease-Modifying Therapies (DMTs)	Members of the LAC indicated that this is a key part of early diagnosis and management.
Planning for the Future: Advance Care Planning, Palliative and End-of-Life Care	

Question 6c

Is there anything else you think should be included in this section?

No

Question 7

Section D outlines the areas that we will consider under 'support for unpaid carers of people living with dementia'.

How much do you agree or disagree that this section outlines the areas that we should consider for this key area?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>

Question 7a

Please explain your reasons for your answer to Q7

We welcome the focus on unpaid carers in this section as their role is vital and needs to be properly supported. It has been sadly often overlooked in the past.

Question 7b

Is there anything else you think should be included in this section?

Question 8

Section E outlines the areas that we will consider under ‘supporting the workforce.’

How much do you agree or disagree that this section outlines the areas that we should consider for this key area?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 8a

Please explain your reasons for your answer to Q8

Question 8b

Is there anything else you think should be included in this section?

Members of the LAC suggested this section seems to be focused on continuous professional development of workforce rather than initial training at medical school, nursing degrees, other important health care settings etc. They said it might also be helpful to discuss training/support needs of non-clinical staff in the NHS (receptionists etc) and how they are trained in dementia awareness.

With regard to MDTs, we consider that the work of multidisciplinary teams is important but those involved must have adequate planned time for discussion and collaboration.

Question 9

Section F outlines the areas that we will consider under ‘dementia research and innovation’.

How much do you agree or disagree that this section outlines the areas that we should consider for this key area?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 9a

Please explain your reasons for your answer to Q9.

This section seems broadly appropriate.

Question 9b

Is there anything else you think should be included in this section?

Members of the LAC said they would like to see some acknowledgement of how we get people who are losing mental capacity (or who have lost mental capacity) to consent to research. The Welsh Government might like to look at the resources created for NIHR ‘INCLUDE Impaired Capacity to Consent Framework’, which is a tool designed to support researchers. Other resources have been created by Dr Victoria Shepherd from Cardiff University:
<https://www.capacityconsentresearch.com>

Given Dr Shepherd’s work, Wales is leading in this area, and it would be good for the Welsh Strategy document to acknowledge this and provide a commitment to support ways for people with dementia to be involved in research.

Another mechanism might be to commit to provide support to ENRICH Cymru. ENRICH is a national (UK) network supporting research-ready care homes and connecting care homes with researchers. ENRICH Cymru is operating in Wales with support from Health and Care Research Wales. LAC members consider this important network should be acknowledged and further commitment given.

Question 10

Section G outlines the areas that we will consider under 'governance and accountability arrangements that will monitor the impact of the strategy'.

How much do you agree or disagree that this section outlines the areas that we should consider for this key area?

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

Question 10a

Please explain your reasons for your answer to Q10

Again, we consider this section to be broadly appropriate.
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Question 10b When reporting on progress against the strategy, what methods of communication do you think would be helpful so that you can keep track of progress? Choose the three most helpful resources:

Annual written update	X
6 monthly newsletter	
Easy read summaries of updates	
Video updates	
Ministerial written statement	X
Ministerial Oral statement	X
Other (please specify)	

Question 10c

Is there anything else you think should be included in this section?

LAC members indicated that they would like more information on when the KPIs be established and who will set these targets.

The Strategy Overall

Question 11

In this consultation document we are setting out what we want to achieve. The full strategy and supporting delivery plans will set out more detail on how. Are there key areas that you want to see included in how we will achieve these changes?

Section A: Risk reduction and prevention in dementia.	
Section B: Raise awareness and understanding of dementia.	Details of specific public awareness raising campaigns may be useful.
Section C: Improving dementia diagnosis, treatment, care and support.	
Section D: Supporting unpaid carers of people living with dementia.	Support should be able to be easily accessed.
Section E: Supporting the Workforce.	
Section F: Supporting dementia research and innovation.	
Section G: Suitable governance and accountability arrangements to ensure the strategy is delivered.	
Other areas not covered elsewhere.	

Question 12

The new strategy will have a number of measurable targets that will show how much progress has been made. What areas would you focus on developing these targets for?

Progress in tackling workforce challenges in key categories like social care and the geriatrician workforce.

Question 13

We have prepared impact assessments to show how the strategy may affect Wales and its people, considering both positive and negative impacts. Are there any impacts or considerations you think are missing from these assessments? Is there anything specifically you would draw out into an integrated impact assessment?

No

Question 14

We would like your views on how the strategy could affect the Welsh language. How could the strategy give people greater opportunities to use Welsh? How could it ensure that Welsh is treated fairly and equally alongside English?

Question 15

Please use this section to share any other comments or suggestions you think we should consider when finalising the dementia strategy

The College is very aware that people living with dementia frequently suffer from additional comorbid physical conditions and thus use many parts of the health service – not just those directly charged with dementia care. As such, all areas and all staff within our health service must be trained to care for the patients with dementia that they will increasingly encounter.

If the care of people with dementia is to meet the aspiration of equality, all hospital and community staff - in almost all disciplines and specialties - must be trained to cater to the specific needs of this growing patient group.

The College and our LAC have had a considerable focus on delayed discharges in hospitals in recent years and the need for early discussions with family members on the importance of Power of Attorney. We consider it would be useful if the strategy encouraged discussion of these issues with family members of individuals living with dementia.