


# Exploring English policymakers' attitudes towards dementia risk reduction: A qualitative study

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## Abstract

**Aim:** A growing evidence-base indicates that dementia occurrence can be changed. This has been linked to potentially modifiable risk factors. Risk reduction and primary prevention strategies are increasingly recognized as needing to include population-level policies to tackle the social and commercial determinants of health. How this knowledge can influence policymaking on dementia prevention is unknown. Understanding attitudes of policymakers is an important step in translating evidence into practice, helping to gauge system readiness for implementation, and potential barriers and enablers for influencing policy. The aim of this qualitative study is to explore the understanding of, and attitudes to, dementia risk reduction and population-level prevention strategies amongst English policymakers at national, regional, and local level.

**Methods:** Semi-structured interviews were undertaken with a range of dementia and prevention policymakers, with purposive sampling of national and local policymakers, including politicians, government officials, health system leaders, academics, and dementia charity directors. Analysis of interview transcripts was undertaken by thematic analysis.

**Results:** 14 policymakers were interviewed between November 2021 and February 2022. Three main themes were identified (1) Preventability of dementia, (2) Prevention approach, (3) Barriers and facilitators to improving the approach.

**Discussion:** Policymakers generally held dementia to be partially preventable. Policymakers recognised that both individual- and population-level approaches to primary prevention of dementia are required – with some policymakers perceiving that population-level approaches are under-utilised. Key barriers to implementing more population-level approaches were identified as the complexity and coordination required to effectively tackle upstream determinants of health.

## KEYWORDS

dementia, health policy, population-level interventions, primary prevention, risk reduction

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### Key points

- Adoption of policies to address the upstream, social and commercial determinants of brain health are required to significantly reduce the prevalence of dementia and reduce inequalities, but these policies can only be implemented by coordinated action between various policymakers.
- We interviewed 14 policymakers related to national and local prevention policy and dementia policy.
- Policymakers generally held dementia to be preventable, and suggested the need for both individual-level and population-level interventions.
- Further work is needed to equip policymakers with the knowledge, resources, and structures required to successfully implement more population-level dementia risk reduction policies.

## 1 | INTRODUCTION

Dementia, a syndrome characterised by progressive cognitive decline, is the leading cause of mortality in England.<sup>1</sup> Recent studies from high income countries,<sup>2</sup> including England,<sup>3</sup> have reported reductions in age-specific prevalence, which has challenged the previously held view that dementia cases would inevitably rise with population ageing. In parallel, reviews of observational literature show consistent relationships of dementia occurrence with many potentially modifiable risk and protective factors, including education, hypertension, and air pollution.<sup>4</sup> Primary prevention of dementia – action to reduce the risk factors – could therefore become an attractive option for policymakers. Primary prevention approaches can utilise individualised, clinical approaches – which identify those at increased risk and support them to reduce risk; or population-level approaches – which change societal conditions to reduce risk exposure for the whole population.<sup>5,6</sup> Existing approaches to dementia risk reduction have heavily favoured individual-level approaches,<sup>7</sup> which typically widen inequalities and cannot significantly reduce disease prevalence.<sup>5</sup> The World Health Organization have recognised that redressing this imbalance is a public health research priority.<sup>8</sup> Dementia risk reduction is recognised as a key research priority in the World Health Organization's (WHO) blueprint for dementia research.<sup>8</sup> The balance of prevention approaches is a political choice, as it is ultimately policymakers who decide which research is funded, which interventions are piloted, and which policies are supported. It is therefore imperative to explore policymakers' views on dementia risk reduction, including the balance between individual-level and population-level approaches.

Much of the existing qualitative literature on dementia risk reduction reports the views of older people, with or without memory impairments, and their caregivers, exploring motivators and barriers to individual-level lifestyle change to reduce dementia risk.<sup>9–12</sup> Notably, despite being explicitly focused on individual-level behaviour change, these studies identified some key motivators and barriers that were beyond an individual's control, such as social acceptability (of smoking),<sup>9</sup> workplace and family support,<sup>9</sup> and social disengagement.<sup>12</sup>

To our knowledge, only one study<sup>13</sup> has sought explicitly to identify views on population-level dementia risk reduction. Rohr et al. (2022) interviewed community-dwelling older people and expert stakeholders, such as public health experts and architects, in Germany, exploring how the urban environment could support dementia risk reduction. Key themes were: (a) promotion of social participation and inclusion; (b) proximity and accessibility of services for example, public toilets, cultural events; and (c) prioritising population wellbeing in local town planning.<sup>13</sup> The sub-themes identified the importance of many of the 'social determinants of health',<sup>14,15</sup> such as housing quality, health service access, and high-quality green space availability.

A 2017 paper<sup>16</sup> from Alzheimer's Research UK reported a stakeholder workshop, involving clinical academics and policymakers, aimed at understanding why dementia risk reduction had been underfunded. The authors predominantly identified academic barriers such as scientific uncertainty about the biology of dementia, and the long duration of pathology accumulation before disease onset. They also identified several population-level barriers to research such as the complex interplay of risk factors, cumulative acquisition of risk over the lifecourse, and stigma around receiving a dementia diagnosis.<sup>16</sup>

Finally, a recent study<sup>17</sup> reported interviews with state treasury and ministry of health officers in Australia, exploring decision-making processes regarding allocation of (general) preventive health budgets. The interviews with treasury personnel found that economic evidence was generally favoured; whilst ministry of health personnel reported using economic evidence only to influence other decision-makers, rather than guide their own preferences. This demonstrates the importance of engaging directly with policymakers, in order to produce usable evidence to inform policy change. This is particularly important for population-level approaches, because the social conditions that they seek to modify extend substantially beyond the remit of health departments.<sup>15</sup>

In this study, we explored English policymakers views on dementia risk reduction – and specifically the balance between individual-level and population-level policies.

## 2 | METHODS

### 2.1 | Study design and approach

We conducted semi-structured interviews with policymakers related to dementia and/or prevention. We took a contextualist theoretical perspective,<sup>18</sup> a midpoint between positivist and constructionist perspectives, which acknowledges the importance of social context on how individuals make meaning, whilst also acknowledging some degree of shared social reality.<sup>18</sup>

### 2.2 | Ethics

This study was approved by the Cambridge Psychology Research Ethics Committee (reference PRE.2021.064).

### 2.3 | Study setting and participants

We used purposive sampling to invite national, regional, and local policymakers to be interviewed. We invited national policymakers from England and, in order to explore the role of local context, we used a case study area for more localised policymakers. We selected Stevenage, a town in Hertfordshire, East of England, to be our population of interest (i.e. we invited local policymakers from Stevenage, county-level policymakers from Hertfordshire, regional policymakers from East of England). We chose Stevenage because it is an area with significant health inequalities and a historic lack of applied health research.<sup>19</sup>

We defined 'policymaker' broadly, as someone who drafted ('policy professionals' e.g. local government officials), approved ('politicians' e.g. local councillors), or influenced ('policy influencers' e.g. dementia charity policy lead) policy relevant to dementia risk reduction.

Policymakers were identified using researchers' knowledge of the local and national dementia prevention policy landscape. Policymakers were invited by email. Informed consent was obtained.

### 2.4 | Data collection

The interviews were conducted by two public health specialty registrars, who had completed placements in the local government public health team, or an NHS organisation in Hertfordshire. Both researchers were familiar with major local and national health policies of relevance. A minority of interviewees had previously worked with the researcher conducting the interview.

The semi-structured interview template (Appendix A) was developed by SW, HR, and CB. Questions explored to what extent policymakers consider dementia preventable, what balance of

individual- and population- level approaches should be aimed for, whether current approaches are broadly on the right track, what the barriers and facilitators to improving approaches are, and what terminology should be used when talking about dementia risk reduction.

The first interview was conducted by SW and HR together, and subsequent interviews were conducted by either SW or HR. SW and HR de-briefed after each interview by email, including sharing notes captured by the interviewer immediately after each interview.

The interviews were conducted virtually, on Microsoft Teams, and audio files were professionally transcribed.

### 2.5 | Data analysis

Analysis was conducted using NVivo software version 1.7. Analysis was undertaken by SW and HR, using a thematic analysis approach following the codebook method.<sup>20,21</sup>

An initial high-level, descriptive coding structure was drafted deductively from the interview template. This structure was applied to two interviews by both HR and SW coding together, refining the coding structure, and identifying emergent sub-themes, by discussion. The remaining interviews were coded by either HR or SW, with a subset checked by the other researcher. Inductive codes were added in discussion with the other coder, and recorded using a codebook method.<sup>20</sup>

Final themes and sub-themes relevant to this research question were identified, reviewed, and agreed in discussion between both coders. Disconfirming examples were sought, and where relevant reported, for all themes.

Participants were assigned a unique ID, and quotes were labelled with the participant ID and job role.

## 3 | RESULTS

### 3.1 | Study participants

Of 36 invited policymakers, 14 (39%) agreed to participate and were interviewed between November 2021 and February 2022. This included four local government officials (public health ( $n = 1$ ), social care ( $n = 1$ ), communities team ( $n = 2$ )); four health leaders (executives ( $n = 2$ ), commissioner ( $n = 1$ ), senior clinician ( $n = 1$ )); two local councillors; one academic; and three charity directors/policy leads. All were established in their roles. Table 1 shows the split of policymaker category, and whether they were national or local. Half of the policymakers were female.

Policymakers who agreed to take part and those who did not were comparable regarding gender (50% and 55% male, respectively) and national/local background (21% and 27% national, respectively). There was a higher proportion of politicians amongst the refusal group (41%, compared to 14% amongst interviewees).

TABLE 1 Study participants policymaking category and area.

Area represented	Policy professionals	Politicians	Policy influencers
Local (Stevenage, Hertfordshire, or East of England)	8	2	1
National (England)	0	0	3

## 4 | MAIN THEMES

Three main themes were identified and are discussed below: (1) Preventability of dementia, (2) Prevention approach, (3) Barriers and facilitators to improving dementia prevention approaches. These main themes were identified deductively, having been key sections of the interview template, though several of the sub-themes were identified or refined inductively during the data collection and analysis stage.

### 4.1 | Preventability of dementia

Almost all policymakers expressed a view that dementia is preventable, though confidence in this assertion varied, and the proportion of dementia that they thought could be prevented varied. This theme also summarises policymakers' conceptualisation of dementia prevention, their knowledge of risk factors, and how they view the evidence base.

#### 4.1.1 | Healthy lifestyles and dementia risk

The notion that dementia risk would be reduced by living a healthy lifestyle was generally offered as being obvious and uncontroversial across all policymaker categories.

*"I'm not sure to what degree we can prevent dementia except by improving people's lifestyles and keeping them active and involved."*

(ID:1, Local Councillor)

Several policymakers suggested potential risk factors without prompting. Those related to cardiovascular disease (e.g. physical inactivity, smoking, obesity, hypercholesterolaemia, and hypertension), and excess alcohol consumption,<sup>4</sup> were discussed by more than half of the policymakers. More 'dementia-specific' risk factors such as social isolation, head injury, pollution, and hearing loss<sup>4</sup> were mentioned less frequently.

#### 4.1.2 | Some forms of dementia less amenable to prevention

Several policymakers referenced different diseases that cause the dementia syndrome. Prevention or treatment of cardiovascular

disease (CVD), and promotion of a healthy lifestyle, were described as appropriate prevention approaches for vascular-related dementias. Views were more mixed on other types of dementia. Two policy professionals indicated a view that Alzheimer's disease is less preventable than vascular dementia, whilst two policy influencers felt that the focus on vascular prevention, particularly in the NHS Long Term Plan,<sup>22</sup> acted as a blocker to effective prevention targeting other non-vascular risk factors.

*"...Alzheimer's type dementia...has got a huge genetic element... Moving away from Alzheimer's type dementia, then you're talking about dementias due to circulation and other bits where prevention have a significant impact."*

(ID:7, Local NHS trust medical director)

*"Well, I think if you're going to have an NHS long-term plan that's committing to reducing dementia deaths, to only look at cardiovascular dementia when ... Alzheimer's Disease probably is associated with between 60% and 70% of cases. To only look at vascular dementia means you are immediately reducing the number of people that it might be relevant for...we're not looking at some of the unique or other risk factors which go beyond cardiovascular health."*

(ID:12, Dementia charity head of policy)

#### 4.1.3 | Range of information sources

The two most common sources of prevention information reported were peer-reviewed literature – in particular the Lancet commissions on dementia<sup>4,23</sup> and the Cognitive Function and Ageing Studies (CFAS)<sup>3</sup> – and the dementia charities, in particular Alzheimer's Society and Alzheimer's Research UK. The dementia charities were used by policymakers to stay up to date, but also to signpost members of the public towards. Other common sources of information reported were: colleagues from inside policymakers' own organisations (e.g. local government public health team), and reports from agencies such as Public Health England, the National Institute for Health and Social Care Research, and the National Institute for Health and Care Excellence. One politician reported using dementia charities as sources of knowledge, and the other reported using council officers, council reports, and newspapers (The Times and The Economist).

#### 4.1.4 | Evidence base incomplete but maturing

Several policymakers commented that the evidence base which underpins dementia prevention is relatively weak, and some described that this limited the scope for policy impact.

*"when you look up the evidence base, I have to say I've been a bit disappointed... a lot of comes down to, you know, expert opinions. The grade of evidence is quite low."*

(ID:8, Local senior consultant psychiatrist)

*"We can look at smoking and go, wow, they've got all the data, they can make the case really strongly. And we don't have that in this space, which is more challenging from a policy perspective."*

(ID:12, Dementia charity head of policy)

Whilst a minority pointed to the evidence base maturing and reflected on how much further on the evidence base has come in recent years.

*"I think on a population level there is a significantly more evidence than there was a decade ago that lifestyle impacts on changes to the brain later in life... There is clearly a lifestyle impact on the number of people living with dementia...So, it's there and you'd be much more confident now about it than you would be in 2013..."*

(ID:14, Dementia charity director)

#### 4.1.5 | Primary prevention a secondary issue

The participant information sheet (Appendix B) referred to 'dementia prevention' as the topic of the interview, and the semi-structured interview template (Appendix A) was specifically designed to explore policymaker perspectives on primary prevention. Despite this, several policymakers conceptualised 'dementia prevention' in the context of secondary and tertiary prevention (i.e. intervening early in people who have dementia in order to delay progression, loss of independence, and institutionalisation) – a few policymakers continued to return to perspectives on secondary and tertiary prevention despite repeated prompting towards primary prevention. This association between 'dementia prevention' and post-diagnostic interventions occurred in interviews with all policymaker categories.

*"So, you have to think, I guess, around prevention at each of the stages of how people go through dementia. And that is prevention, also about diagnosis and assessment. But also putting things in place at that time to prevent further deterioration."*

(ID:7, Local NHS trust medical director)

## 4.2 | Prevention approach

Policymakers were asked for their views on what balance of individual-level and population-level dementia prevention interventions there should be, and reasons for these views were

explored. Explanations of these policy approaches were provided by the researchers as necessary.

### 4.2.1 | Individual-level or population-level approaches

#### *A combined approach*

The majority of policymakers expressed a view that both individual-level and population-level interventions were required, in roughly equal measure.

*"I think it's probably an argument for doing both, isn't it. It's about getting a universal offer... like cycling provision... or sugar tax, that sort of stuff. And targeting. I think it's probably a both discussion."*

(ID:4, Local government director of social care)

Two policymakers expressed a firm and consistent view that population-level interventions were relatively under-utilised compared to individual-level approaches, and should receive much greater attention for dementia prevention.

*"[I think it's better] to take a population approach, and that an individualised approach for those most at risk just needs to be a much smaller part of the equation."*

(ID:11, Local university senior academic)

Several of the remaining policymakers gave inconsistent responses through the course of the interview, as to whether individual- or population-level interventions were preferable – indicating a lack of understanding of the difference between individual- and population-level prevention, and in some cases, policymakers were explicit that they had not thought about this choice before.

*"I think in all reality individuals have a responsibility to think for themselves but if they've never been shown how it's exceedingly difficult without something coming down from government but at the same time we don't want to have a nanny state telling everybody what to do and how to do it."*

(ID:1, Local councillor)

*"I'm not sure what our position is...It's not something that I have really considered myself."*

(ID:13, Dementia charity head of policy)

#### *Individual-level approaches allow targeting of resources and support*

Several different reasons were given for supporting individual-level approaches. Targeting resources, towards specific groups (e.g. those at high-risk, those with learning disabilities, those living in

socioeconomically deprived areas) to reduce inequalities, or simply because they are too limited to try and support everyone, was the most common reason given. Other reasons included: increased knowledge of risk factors may give those seeking advice hope and motivation for behaviour change, a political belief that individuals should take personal responsibility for their own health, and that individual-level interventions are easier to implement.

*"Because us and our partners have only got a limited resource and you have to target the areas where the biggest problem is."*

(ID:1, Local councillor)

*"I think the individual side has a very important sort of... therapeutic side. Instilling hope's important."*

(ID:8, Local senior consultant psychiatrist)

*"If I said I would like [local area] to eat a bit less saturated fat I wouldn't know how to start. Whereas, if the GPs in [local area] want to be able to refer to exercise, we know how to negotiate that, you know, the individualised- that tends to be how health works."*

(ID:8, Local senior consultant psychiatrist)

*"There will be many people who don't want to get dementia because they've seen a grandparent or parent have it. And I think giving people just that knowledge is actually really crucial, so that they can make an informed choice."*

(ID:12, Dementia charity head of policy)

#### *Population-approaches create societal conditions that drive larger scale risk reduction*

Policymakers from all three categories asserted that action on the social determinants of health is needed to ensure that societal conditions support people to adopt healthier behaviours. Policy professionals and policy influencers also argued that population-level approaches reach more people, can provide better value for money, and that some risk factors can only be targeted at the population-level (e.g. air pollution).

*"I haven't seen any government do a particularly good job of addressing some of the wider determinants of health because they're too big and too knotty. ...If you could sort out good housing for everybody, those broader determinants, I think would probably the best thing you could do for public health, dementia, and everything else... how can you expect someone to change their eating habits and do more exercise if they've got other much more pressing [needs]. You're not going to worry about your dementia risk if you've not got any electricity and your kids need their dinner on the table."*

(ID:12, Dementia charity head of policy)

*"I just think that given the number of people who are at risk of dementia, it's much greater benefit and value for money, if you want to look at it like that, or return on investment, to take a population approach"*

(ID:11, Local university senior academic)

#### 4.2.2 | Risk accumulates across the lifecourse

Several policymakers, from all policymaker categories, referenced the need to consider dementia prevention from a lifecourse perspective, rather than just acting in later life.

*"If we can instil certain behaviours in children in primary school, be it through their diet, nutritional education as well as physical activity."*

(ID:3, Local government health strategy manager)

*"How can we get dementia into the younger person's health-check, the 40-plus one, to start people thinking about the potential risk factors at that age, because actually, by the time you get to the older age health check...the underlying causes and symptoms may have already been happening for some years"*

(ID:13, Dementia charity head of policy)

#### 4.2.3 | Unequal clustering of dementia risk in certain communities

There was broad recognition across many policymakers that dementia, and its modifiable risk factors, are more prevalent in some groups than others – in particular those from low socioeconomic backgrounds.

*"Many of the risk factors of dementia are obviously associated with wider determinants of health... areas where you've got people with lower socioeconomic status...some of the types of roles they do are less likely to offer some of the mental cognitive stimulation you might get with other roles, as well as the higher risk of smoking, diabetes, and hypertension. And I would also then also be interested in looking at some of the differences with different ethnic groups."*

(ID:12, Dementia charity head of policy)

Further, several policymakers identified that those individuals with less resources and/or less agency would be less likely to successfully adopt healthier lifestyles without changes to the environments around them (without linking this to the need for population-level approaches).

*"ID:2: Stevenage has probably got one of the greatest cycle networks of any town in the country and I'm going to bet*

you that is the most underutilised cycle network of any town in the country”.

INT: Why do you think that is?

“ID:2: ...there's socio-economic reasons for that...And I think in our more deprived communities we have to make even more effort...we've almost got to knock on people's doors and say, “There's a cycleway.” ...to change the culture of a whole community that is inured to, entirely isolated from, exercise, good nutrition, great education, aspiration...you've got to give people the opportunity to stick their head above the parapet...change the housing mix, change the employment proximity, upgrade the shops, stick a health hub in the middle of it...a whole bunch of stuff that could make a bigger difference.”

(ID:2, Local councillor)

#### 4.2.4 | Integration of dementia prevention with broader prevention agendas

Opinions varied considerably on the topic of whether dementia risk reduction efforts should be integrated into broader prevention agendas, such as CVD prevention and healthy ageing, or whether dementia should aim to be a standalone prevention area more akin to cancer prevention. Some policymakers contradicted themselves.

Some policymakers recognised that the modifiable risk factors linked to dementia, particularly those overlapping with CVD, are already the subject of major public health policy endeavours, and the public are already aware they are bad for health. In this regard, it was questioned whether adding dementia to a long list of other diseases associated with a risk factor was likely to make much difference; particularly when dementia is often a distal endpoint to CVD on this pathway. Others suggested that this overlap between risk factors could be a good thing as it allows for pooling of resources and health messaging.

“The extent to which...you will change people's behaviour by talking about dementia. I am unpersuaded, like you know, people start off by saying it's the most feared condition over 50. Which is true, but you know, if you're smoking at 50, it's not dementia you should be worried about”.

In public policy terms, you probably don't want to be disease-specific. It will just be yet another thing where people go around and say, can we take a small bit of your public health budget, and can we spend it on this initiative? It will just be like chucking a pebble into a pond... There are very common things across all diseases that we know are probably beneficial... Actually, that should be central to public policy making and

that's the bit that we never do because we like the advocacy movement says, “oh can we talk about dementia please?”

(ID:14, Dementia charity director)

Conversely, others argued that dementia prevention should aim to stand alongside other prevention agendas, rather than being a footnote within them. It was noted that this view is likely to be held by dementia-specific policymakers, particularly those in dementia charities, given the inherent relationship between dementia's profile and the funding models of their organisations; however, this view was also expressed by other policymakers. For example, a local government social care director (ID:4) suggested that, due to the high social care costs associated with dementia, dementia prevention would be a stronger policy lever in that sector than more generic health promotion language. Others argued that, for some individuals and policymakers, dementia may be the disease they have a particular emotional connection to, and being able to link lifestyle change directly to reduced dementia risk could therefore be a key motivator in behaviour or policy change. Finally, some suggested that agendas like CVD prevention are ‘old news’, whilst dementia prevention and risk factors like air pollution feels fresh and exciting.

“It is perfectly possible that you will come across some political leaders or some, you know, system leaders who for some reason get their eyes brighten at the mention of dementia and they think yes and no because that, like fundamentally, that's how individuals work.”

(ID:14, Dementia charity director)

Further, several policymakers reflected that public mental health has been rising in prominence in public policy, both at local and national levels, and presented this as an opportunity to raise the profile of dementia prevention.

“I think one of the things that's come out, having had Covid, is the mental health of people and the stress of being on your own and not being able to have contact with people during all the isolation we have had and the Lock-downs etc. So, I suspect that that would be a major part of what we would be looking at. Because in the past I mean we still have it to a degree... I very much think mental health will be one of them [future priorities] and that would include dementia.”

(ID:1, Local councillor)

#### 4.2.5 | Tailor messaging to the target audience

‘Dementia prevention’, ‘dementia risk reduction’, and ‘brain health’ are all commonly used to describe this research agenda. Policymakers were asked which they thought was the best term to engage policymakers and the public, and to encourage policy change. There

was support and criticisms for all terms, without a clear pattern according to policymaker category. Several policymakers described the need to tailor messaging to the target audience.

Dementia prevention was considered a definitive, absolute term. For some policymakers this was positive because it conveys a clear potential health benefit; others found this absolutism too strong in the context of the evidence base and considered dementia risk reduction a more honest term. Brain health was considered “wishy-washy” and “nebulous” by some; but accessible by others, particularly for engaging younger people. One policymaker pointed to research<sup>24</sup> that reported only a 1/3 of people felt they could reduce their dementia risk, whilst 2/3 perceived an ability to increase their brain health.

### 4.3 | Specific barriers and facilitators

Perceived barriers and facilitators to achieving the optimum prevention approach described by the policymakers were explored.

#### 4.3.1 | The system favours reactivity over prevention

Almost every policymaker, with the exception of the politicians, said that prevention lacks the priority status of reactive treatments in the minds of the public and policymakers, and that making the case for prevention is difficult. Several suggested that this is because the outcome is a future event that we are avoiding, rather than a present crisis which creates an emotional case for change – particularly for population-level change measured by aggregated disease rates. Others noted that primary prevention interventions, particularly population-level interventions, are harder to evaluate. Some felt the immature evidence base (see 1.4) for dementia primary prevention is a barrier to engaging policymakers. Others highlighted the decades-long gap between intervention and realising benefits, by which time politicians move on and budgets are refreshed.

*“The individual story will always hook people in, so that is kind of a good marketing aspect to it. But the upstream—All of this will keep you from these different conditions, would be a really good public-health, population approach. But it is a harder sell, isn't it?”*

(ID:6, Local government public health consultant)

*“You are basically saying that if you take political heat today for doing something, you will get benefits in 50 years' time, and it's like, that doesn't work for politics.”*

(ID:14, Dementia charity director)

#### 4.3.2 | Lack of funding

Another barrier reported by almost every policymaker was a lack of funding for local government, public health, and prevention agendas

more generally. Several policymakers said Covid-19 had compounded existing financial challenges, by creating a backlog for existing services, diverting resources, and increasing population need for preventive services.

*“Public health generally has had massive cuts... and councils in themselves have had massive funding cuts. So, I'm really mindful that in the scheme of things there are many priorities and that this is quite a low one.”*

(ID:12, Dementia charity head of policy)

#### 4.3.3 | Lack of public knowledge and agency

Several policymakers reported that major barriers to improving the success of individual-level interventions such as NHS Health Checks included a lack of knowledge, motivation, time, money, or trust amongst recipients.

*“When we look at people certainly from black African Caribbean communities there's a huge trust barrier there because of historical, I guess, injustice that have taken place on that community where medical practices are concerned... So, I think, along with sort of cost, time, motivation, I think trust as well.”*

(ID:3, Local government health strategy manager)

#### 4.3.4 | Public health approaches could expand morbidity

Finally, two policy professionals expressed the view that public health interventions may inadvertently cause an expansion of morbidity – with increases in life expectancy not matched by increases in dementia-free life expectancy, therefore causing an increase in the total prevalence of dementia. This was seen as a disincentive to advancing prevention interventions.

*“You don't really want to do an intervention for dementia that delays dementia, but it delays death by even more because then you'll get more dementia. You ideally want an intervention that delays dementia and not death and that's a very tall order.”*

(ID:8, Local senior consultant psychiatrist)

#### 4.3.5 | Strength of local partnerships and assets

Several local policymakers identified the strength of local partnerships, collaborations, and the people working within them, as facilitators to improving dementia prevention. Positive agents for change included the leaders of the county council and the Director for Public Health. It was noted that stable relationships were more important



than political alignment at the local government level, as constructive, long-term partnerships were relatively bigger drivers of achieving policy action than ideology.

*"Nobody's saying, look, we don't want to do this. My own experience is you don't need to drag people. Our local authority partners are very keen to talk about general health and healthy lifestyles."*

(ID:8, Local senior consultant psychiatrist)

Several local policymakers also referenced aspects of the built environment in Stevenage as being assets to build from, with the challenge being less about provision of physical activity infrastructure, and more about getting people to use it.

*"ID:1: We certainly are a town that is well supplied with green spaces, we have lots of community centres where people can do different classes, our Leisure Centre is in the Town Centre"*

*INT: So accessibility isn't a big issue?*

*"ID:1: No, I think it's more likely to be money and inclination."*

(ID:1, Local councillor)

#### 4.3.6 | Value of high-impact academic publications

One policy influencer pointed to high-profile academic endeavours, for example, the Blackfriars consensus,<sup>25</sup> and Mukadam et al.<sup>26</sup> on ethnicity and dementia incidence, which garner a lot of media attention and raise the profile of dementia risk reduction.

## 5 | DISCUSSION

Policymakers expressed the view that both population- and individual-level approaches to dementia prevention should be adopted, and some policymakers considered population-level approaches underutilised. Reasons for recommending inclusion of a population-level approach were that social environments drive individual lifestyle choices, and that approaches targeting these conditions reach more people, provide better value for money, and are the only feasible way to tackle some proposed risk factors. Individual-level approaches were felt to better enable targeting, particularly of limited resources.

Dementia, and even dementia prevention, were commonly conceptualised in the context of care and interventions for people with the disease. However, the view that dementia is, to some degree, preventable was expressed by all policymakers - though some, including politicians, expressed this view tentatively. Some policy professionals

felt the proportion of dementia that could be prevented is likely to be relatively small, and that the evidence base is immature. Of the proposed modifiable risk factors for dementia,<sup>4</sup> the cardiovascular-related risk factors were best known, with the phrase 'what's good for your heart is good for your head'<sup>25</sup> described by several policymakers. There was no consistent preference between policymakers for 'dementia prevention', 'dementia risk reduction', or 'brain health'; and several policymakers felt that different terms should be used when engaging different groups - brain health for younger people, dementia prevention for the older public and lay policymakers, and dementia risk reduction for academics and policy professionals.

Most policymakers felt that dementia prevention should be integrated into broader prevention agendas, such as CVD, mental health, and healthy ageing - owing to the commonality of risk factors.<sup>27</sup> It was specifically noted that in order to tackle complex problems, such as the social determinants of obesity and physical inactivity, pooling of resources and policy attention is needed, rather than current approaches which divide resources into multiple low-cost but superficial and siloed interventions.<sup>15</sup> Others argued that dementia prevention should be a standalone prevention agenda, to encourage action on 'dementia-specific' risk factors such as hearing loss,<sup>4</sup> and because dementia may be a specific, emotional motivator for some individuals and policymakers.

## 5.1 | Findings in context

In keeping with previous literature,<sup>7,9-12</sup> policymakers tended towards individual-level prevention interventions when describing current and future dementia prevention policies. However, several recognised that societal level conditions drive many of the lifestyle choices that individuals make.<sup>15</sup> Population-level interventions were sometimes considered too complex, or the role of national government; whilst individual-level interventions, were considered easier to implement, particularly given shrinking budgets.

Policymakers' recognition of social determinants, and the need for a lifecourse approach, suggests that there is a political will to implement more population-level policy for dementia prevention, but that this would require support to make this feel achievable, and possibly structural reform to better enable pooling of resources. Further work is needed to understand how best to equip policymakers with the knowledge and tools required to successfully implement population-level dementia risk reduction policy.

## 6 | STRENGTHS AND LIMITATIONS

The interviews with local policymakers were specific to one English area, Stevenage and Hertfordshire, and some findings may not be generalisable to, for example, areas with a single-tier of local government, or a more dynamic party political situation. On the other hand, the views expressed by local policymakers were often matched

by the national- and internationally-focused policymakers, indicating important areas of consensus.

Given the relatively low response rate, it is possible that those who agreed to participate were more likely to consider the topic relevant and interesting. The response rate amongst politicians was lower than for other policymaker types (40.9% of non-responders were politicians, compared to 14.3% of interviewees), reflecting challenges engaging this cohort. The sample size was relatively small ( $n = 14$ ), but a variety of views were obtained, as well as important areas of convergence around the central themes described, suggesting that the sample provided sufficient depth and breadth of data.

The interviews were conducted by two public health specialty registrars from the region. Advantages of this were good knowledge of local policymakers to invite, good engagement from local policymakers, ability to contextualise points made about local policy, and being comfortable discussing health policy across the system (local and national government, health and social care, third sector and academia). This also meant there were some pre-existing relationships between interviewer and policymaker ( $n = 4$  interviews), and some policymakers had prior knowledge of researchers' hypothesis that population-level dementia risk reduction approaches are underutilised. This was mitigated by explicitly encouraging policymakers to express their own views.

## 7 | CONCLUSION

Policymakers generally held dementia to be preventable to some degree, and felt both individual-level and population-level approaches to primary prevention of dementia are required – with some policymakers perceiving that population-level approaches are under-utilised. Barriers to implementing more population-level approaches were the complexity and co-ordination required to effectively tackle upstream determinants of health.

### AUTHOR CONTRIBUTION

Sebastian Walsh and Carol Brayne conceived the study. Sebastian Walsh, Hannah Roscoe, Lindsay Wallace, and Carol Brayne designed the study. All authors were involved in interpretation of the findings. All authors edited and agreed the final manuscript.

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### CONFLICT OF INTEREST STATEMENT

The authors declare no interests.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### ETHICS STATEMENT

This research was approved by the Cambridge Psychology Research Ethics Committee, application reference PRE.2021.064.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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## APPENDIX A: SEMI-STRUCTURED INTERVIEW TEMPLATE

### Introduction

I am conducting interviews with key policymakers, stakeholders, and community leaders involved in shaping the policies aimed at preventing dementia amongst the people of Stevenage, Hertfordshire, and further afield. I am interested in your perception of: how preventable dementia is, and what actions we should be taking to prevent it.

I will be writing up my findings for publication in a scientific journal, and using the data to inform further research into this topic. I will anonymise transcripts as far as possible, without losing the detail of what kind of policymaker/stakeholder you are (e.g. "A local councillor said..." or "A local health leader reported").

I expect the interview to last between 45 min and an hour, but we can stop at any point, should you wish.

### Consent

1. Are you happy you have enough information to decide whether to take part in this interview?
2. Are you happy to go ahead with the interview?
3. Are you happy for me to record this interview, and for it to contribute towards a published scientific article?
4. Could you please confirm your name and job title?

### Introductory Questions

1. Please describe your role, and how it relates to dementia

For patient/public participants, this question will be phrased: please describe your experiences of dementia prevention

2. Can you tell me about what work your organisation is currently doing in relation to dementia?
  - a. Is there anything your organisation is doing that you would specifically consider to be prevention?

### Key Questions

We're now going to think a bit more specifically about dementia prevention.

3. To what extent do you think dementia is preventable?

If positive, follow up questions could include:

- What's informed your thinking? Where do you typically get information on dementia prevention from (what data sources)?
- Awareness of the NICE Guidance, Lancet Commission, WHO guidance and which risk factors they include?

If negative – where would you go to get the most up-to-date information about this?

4. Do you think we currently have the right policies in place to prevent dementia?
  - If yes, ask them to elaborate – which policies are particularly good. What's the mechanism?
  - If no, what are the big gaps? What could/should we be doing differently? Why haven't we done this before?
  - They may say they don't know much about the policy landscape, in which case move on to the next question.
5. (If not covered above) **Are there other things you think we should be doing to prevent dementia?**
  - Why haven't we been doing them before?
  - **Who should be responsible for dementia prevention (national government, local government etc.)?**
6. Do you think it is better to target prevention policies at individuals who are at high-risk of dementia, or at trying to get everyone (regardless of their risk) to reduce their risk?

Rewording of question in case someone is struggling:

We could either spend our energy and resources trying to work out who has the most risk factors, and is most likely to develop dementia. Then target our dementia prevention interventions at those people

Or we could look to reduce the risk factors for everyone in the population, regardless of how high or low risk they are as individuals.

Do you have a view on which would be the best way to go about this?

- If high-risk, who should we target? How do we work out who is high-risk?
- If whole population, what kind of policies would these include? Is it fair and realistic to encourage people to change their behaviour even if their risk is low?
- Lifecourse perspective Versus midlife or older groups only

If person has expressed lack of knowledge, could prompt them on Lancet commission factors:

- *Blood pressure, smoking, alcohol, hypertension, diabetes, physical inactivity*

- *Education, hearing impairment, loneliness, social isolation, traumatic brain injury*

- *Air pollution*

7. Do you think there are any particular population groups for whom it might be more difficult to achieve risk reduction?
  - Who are they and what can we do about that?
8. Do you think this research and policy area should be called dementia 'prevention' or dementia 'risk reduction'? Would either term change the way you engage with this area of work?

Close

9. Is there anything else it would be useful for me to know?

Thank you for your time today.

The recording of today's discussion will now be sent for transcription. I can share the transcript with you if you would like.

Once I have completed all of my interviews, I will write up the findings for publication in a scientific journal, and use the findings to inform work to develop dementia prevention policies.

## APPENDIX B: PARTICIPANT INFORMATION SHEET AND CONSENT FORM

### Understanding policymakers' views towards dementia prevention Introduction

Thank you for considering the invitation to take part in this research study. The study aims to explore the views of policymakers and commissioners towards dementia prevention – with a specific focus on the population of Stevenage, Hertfordshire. You have been invited to take part as somebody who directly develops or influences policy related to the prevention of dementia, and applicable to this population. This document sets out the key information about the research. At the end of the document, you will be asked to sign if you feel you understand your role and would like to participate in this study. If at any time you choose to no longer be part of the study, please inform the lead researcher. If you would like to discuss anything in this document further before deciding, please email me via [sjw261@medschl.cam.ac.uk](mailto:sjw261@medschl.cam.ac.uk).

### Research Objective

Dementia is a disease with a very high human and socioeconomic cost. The available treatments are minimally effective at best. It is therefore imperative to prevent as many cases of dementia as possible.

Future research is planned to analyse the current policies and consider whether they are as effective as they could be. It will be important to review this research in the context of how policymakers and commissioners perceive the evidence and current policy approach. This piece of work is therefore intended to explore the views and attitudes towards dementia prevention policies of the

people responsible for writing them. It is expected that around 20 policymakers will take part.

### Research Process

Together with a colleague from the University of Cambridge, Hannah Roscoe, we are conducting interviews with key policymakers, stakeholders, and community leaders involved in shaping the policies aimed at preventing dementia amongst the people of Stevenage, Hertfordshire, and further afield. We will be asking questions that explore your perception of how preventable dementia is, and what actions we should be taking to prevent it.

The interviews you will participate in will be 'semi-structured'. That means there are some set questions we will ask - in order to standardise the process somewhat and ensure we broadly stay on track. It also means that there is flexibility around those questions to explore specific views in more detail should that be appropriate. It should feel as much like a conversation as it does an interview.

The interview is expected to last between 45 min and an hour, but we can stop at any point, should you wish. The interview will be (audio) recorded, and the recordings will then be sent to a professional transcription service. The interview transcripts will then be analysed by the research team.

### Intended Research Outputs

The interview findings of the research will be written up for publication in a scientific journal and into a research poster. I will share these outputs with you, but you will not be invited to comment on them or edit them.

Following this research, there is further planned research to analyse current policies and consider whether they are as effective as they could be. This work is intended to be completed by 2024. If you are still in your current post at that point, I will present the findings of those pieces of work to you and ask you to partake in some focus groups, to understand how your view/attitudes have changed. The views expressed in those focus groups will be compared to the view expressed in this work.

### Data Governance and Anonymity

During the interview process and the analysis, we will use data pertaining to your name, job role and organisation. This is so that we can understand how the views of policymakers are different between different organisations and sectors. These data will not be shared outside of the research team. The transcription service is a professional service that abides by relevant GDPR regulation.

When writing up the findings of the research for publication, the views and attitudes of individual policymakers will be anonymised as far as possible, without losing the detail of what sector you represent (e.g. "A local councillor said..."; "A local health leader reported..."; "A representative of a dementia charity").

General information about how the University uses personal data can be found here: <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>.

### Funding

The researchers are undertaking this work as part of their training to be academic public health consultants, this training is funded by the NHS, and the National Institute for Health Research (the training is based at Hertfordshire County Council and the University of Cambridge).

The transcription of the interviews will be funded by a research grant from Alzheimer's Research UK (ARUK).

### Ethical Review

This project has been reviewed by the Cambridge Psychology Research Committee.

### Consent

Please read the statements and tick the boxes if you agree. If you would like to discuss anything further before deciding please email me via [sjw261@medschl.cam.ac.uk](mailto:sjw261@medschl.cam.ac.uk).

- I confirm that I have read and understand this Participant Information Sheet
- I have had the opportunity to ask questions and had them answered should I wish
- I understand that in the research paper produced from this research my views may be identifiable from the use of descriptors like "a local councillor said...", but that no participants names will be disclosed
- I agree that data gathered in this study may be stored securely, and may be used for future research
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason
- I agree to take part in this study: To partake in the interview, for the interview to be recorded and sent for transcription, and for it to contribute towards a published scientific article

Signature: \_\_\_\_\_

Name: \_\_\_\_\_

Date: \_\_\_\_\_