

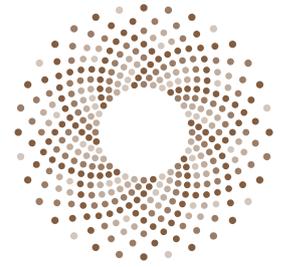
**World Dementia  
Council** Leading the Global Action  
Against Dementia

# Methodology, bibliography and survey data

Presenting a global evidence base for  
dementia friendly initiatives

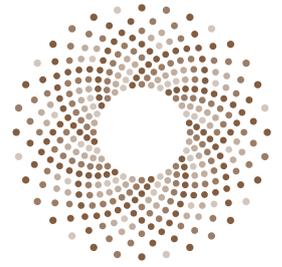


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# Framework and contributors



## The evidence framework

This project aims to understand what impact dementia friendly initiatives may have in improving the quality of life for people with dementia and their caregivers. Improvements to quality of life might include reduced isolation, increased wellbeing, or support for caregivers and their families. Quality of life may also be improved by societal changes such as: reduced stigma; respect; equity and equality within the community; and improved access to the community, services and healthcare.

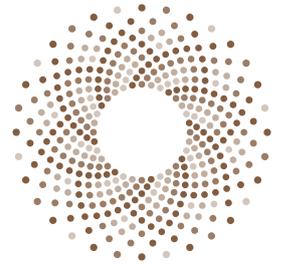
An evidence framework was designed to compare and synthesize a global evidence base. It needed to consider the variety of initiatives designed to have impact, the breadth of evidence likely to be submitted, and the range of voices who would contribute. The framework was developed in consultation with Claire Goodman, professor of health care research at the Centre for Research in Primary and Community Care, University of Hertfordshire (UK), and a lead investigator of the National Evaluation of Dementia Friendly Communities (DEMCOM). DEMCOM is a project funded by the UK's Department of Health and Social Care Policy Research Programme, to undertake a national evaluation of dementia friendly communities.

## Contributors

The project has drawn on a variety of experts. Firstly and most importantly, people with dementia and caregivers were engaged, both to design the survey and for collecting evidence. Through surveys and interviews, these contributors said what is important to them, whether they have been involved in shaping initiatives, what impact they have experienced, as well as what 'dementia friendliness' means to them.

Activists, volunteers and third sector organizations – instrumental in the design, delivery, leadership and evaluation of dementia friendly initiatives – shared their knowledge and submitted evidence.

Academics contributed to the design of the survey and submitted evidence. Policymakers and leaders within the dementia movement were engaged to understand how impact evidence can be used, and how it can influence policy and support the sustainable delivery of initiatives.



# Evidence types

Evidence was collected from several sources to provide a global assessment of dementia friendliness, while also drawing on the expertise of regions who have historically shown leadership in dementia.

## Academic papers and published literature

Papers were selected using the search terms ‘dementia friendly’ and ‘impact’ as well as searching for ‘age friendly’, in cases where the two movements overlapped. Papers developing best practice, assessing provision and discussing the aims and outcomes of initiatives were also included.

A total of 236 papers were reviewed. From those, 39 papers were selected for their relevance to this project and the priorities highlighted by people living with dementia. While the findings do consider information from all 236 papers, citations draw from selected papers.

Systematic reviews completed in 2016 concluded that “isolated dementia friendly environmental changes may improve functional ability, but the impact on quality of life or wellbeing has not been established” (Hebert and Scales 2017, pg 31). Therefore, the selection has focused primarily on publications after 2016.

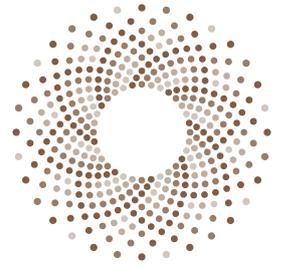
## Roundtables

Two roundtable events were held. The first convened in July 2019 in Los Angeles, United States during the Alzheimer’s Association International Conference (AAIC19) and was organized with the American Association of Retired Persons (AARP). The second convened in September 2019 in Sydney, Australia during the Alzheimer’s Association Satellite Symposium (AASS19) and was organized with Dementia Australia and the Government of Australia.

Participants at both included academics, government representatives, leaders of charities and third sector organizations, people responsible for delivering initiatives and people living with dementia and their caregivers.

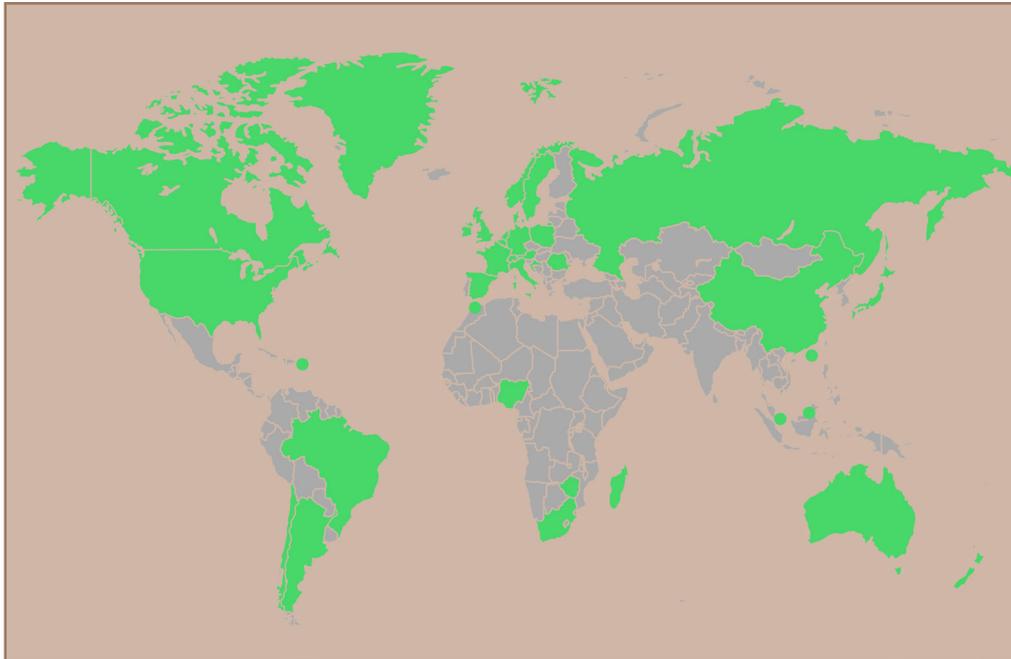
## Surveys

Surveys were designed to capture evidence from people involved in the delivery, evaluation and/or support of dementia friendly initiatives. A separate set of surveys were created for people living with dementia and their caregivers, which focused more on their experiences and were written in a more accessible manner.



## Geographical spread

We collected surveys spanning 37 different countries across all six continents.



 Countries from which a survey submission was received

## Organizational surveys

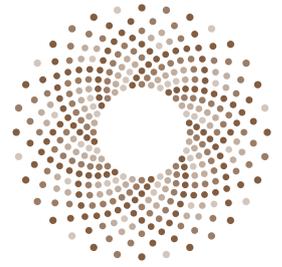
This survey was designed for organizations to respond, and captured regional views on the level of provision, the priorities and outcomes of initiatives, and different leadership structures. The survey also provided the opportunity for respondents to share academic papers, evaluation results, and grey literature. This survey was issued in English, Spanish (Español) and Chinese (中文).

A total of 100 completed surveys were collected, with 4 other additional pieces of evidence submitted in place of a survey. Just under half of all respondents (47) submitted extra evidence beyond a survey itself.

## People living with dementia and their caregivers

Three complementary surveys were designed for people living with dementia and their caregivers, and sought to capture their views in a more accessible way, asking:

1. Whether people living with dementia and their caregivers felt involved in initiatives, and to what extent their experience and knowledge was used to shape initiatives;
2. What impact had been experienced by people living with dementia and their caregivers as a result of taking part in initiatives;
3. What experiences people living with dementia have had within the health sector specifically, such as with general practitioners, hospitals etc.



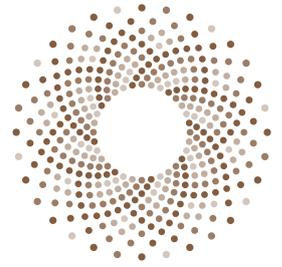
A total of 248 completed surveys were collected across these three surveys designed for people living with dementia and their caregivers. Just over a quarter (70) of all respondents submitted extra comments beyond the survey itself.

## Limitations

Providing evidence alongside survey results was not mandatory. Therefore there was a tendency of people only sharing the positive impact of their own work. While self-selection also affected the responses from people with dementia and their caregivers, a more balanced picture of positive and negative experiences was captured. The number of face-to-face interactions were limited, and written submissions were reliant on electronically submitted responses. While efforts were made to make submissions more accessible with a separate set of surveys, this will have nonetheless presented a barrier for some people with dementia and their caregivers.

Although a global evidence base was collected, most academic papers and survey responses were from high-income countries, and sometimes not in the volumes anticipated. While the project did not expect to reach the majority of global initiatives, the low volume of responses from low- and middle-income countries does give an indication of the realities of delivering ‘dementia friendliness’ in these regions. While the project may not have collected in-depth regional detail, a global picture of dementia friendliness has been achieved.

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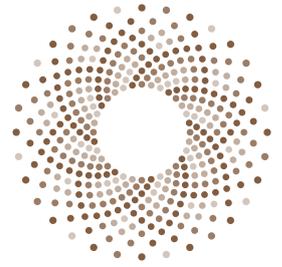
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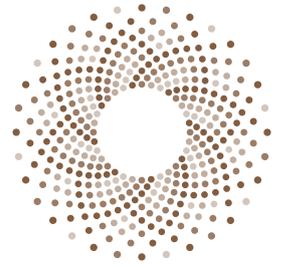
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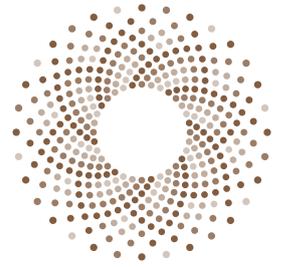
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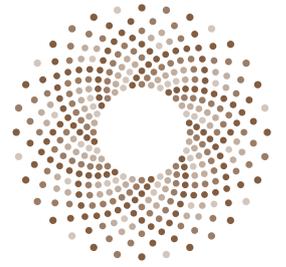
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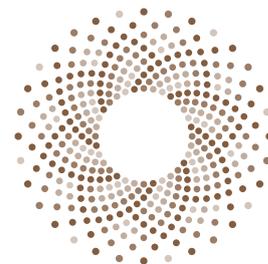
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# Survey data



In 2019 the World Dementia Council launched a project to understand the evidence of impact of dementia friendly initiatives. The Council held a year-long consultation to gather international evidence on the design and delivery of dementia friendly initiatives in order to present a global evidence base for their impact. This is one of a number of papers the World Dementia Council is publishing. They are all available on the Council's website.

The project reviewed a range of evidence. First and foremost, there was a literature review of academic papers. In addition, two roundtable events were convened in July 2019 in Los Angeles, United States and in September 2019 in Sydney, Australia. A separate methodology paper is available for more information on the papers reviewed and the roundtable events.

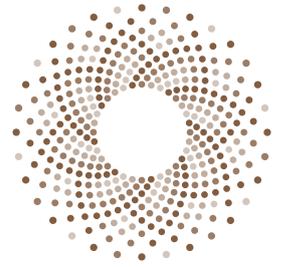
A further element of the evidence gathering was submissions from a number of organizations involved in funding, delivering or review dementia friendly initiatives.

Participants were invited to submit evidence on the evaluation of projects that they delivered or were bring delivered in their region or nation. Alongside the submission of evidence participants were invited to completed a short **survey for organizations and academics**. It was not designed or commissioned to be a representative survey. The data from this survey is presented in this paper.

The organizational survey was designed with input from academic advisers, and provided the opportunity for respondents to share academic or evaluation papers. It was made available in English, Spanish and Chinese, and can be found as an appendix to the back of this paper.

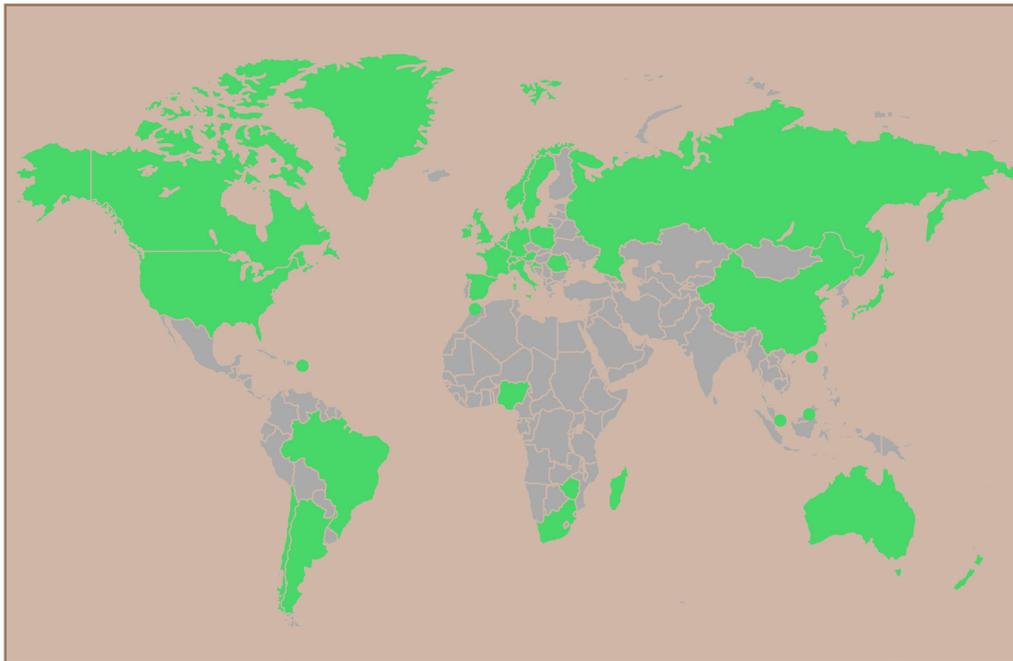
Distribution of the survey was done through the Council's network and through the projects advisory board and through networks of others which expanded over the course of the project. It was also accessible from the Council's website.

A second separate **survey for people living with dementia and their caregivers** was also conducted. The United Kingdom Alzheimer's Society conducted a survey of people living with dementia and their caregivers. The survey was accessible on the Council's website and was completed by a small number of individuals from outside the UK. The data from this survey is also presented in this paper.

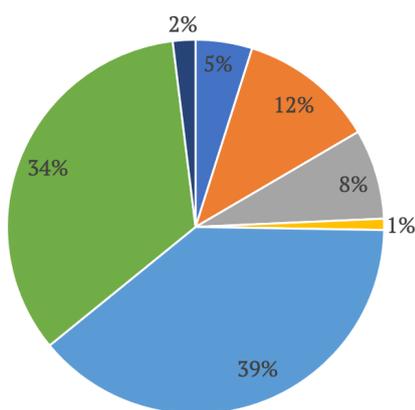


# Survey data: organizations and academics

## Response profile



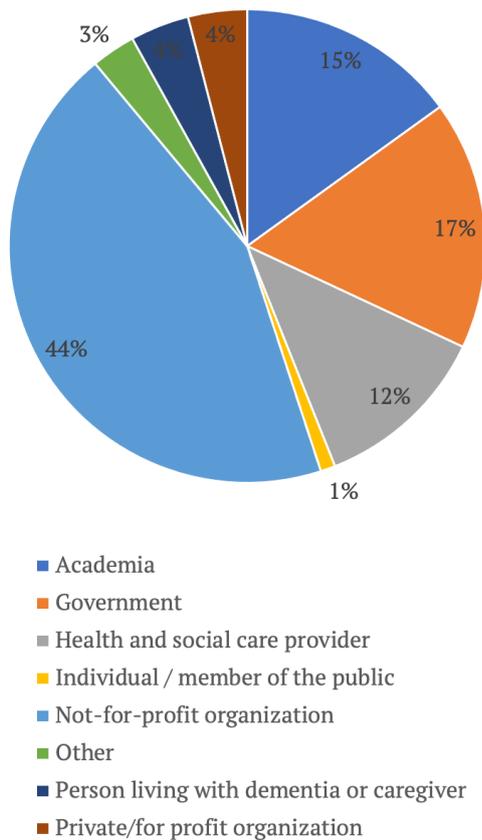
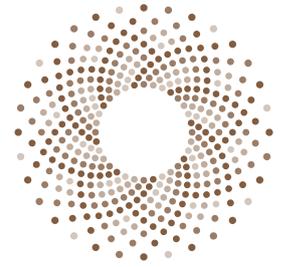
 Countries from which a survey submission was received



- Africa
- Asia
- Australasia
- Central America
- Europe
- North America
- South America

We collected surveys from 37 different countries across all six continents. The respondents were predominately from Europe and North America with significant responses from Asia, particularly from Japan. This is broadly like the geographical distribution of academic papers reviewed as part of the evidence gathering.

104 individuals and organizations responded to the survey. Around half provided additional submissions with half only responding to the survey. The additional submissions included evaluations, academic papers, reports to or by governments and other material on the scope, impact and effectiveness of dementia friendly initiatives.

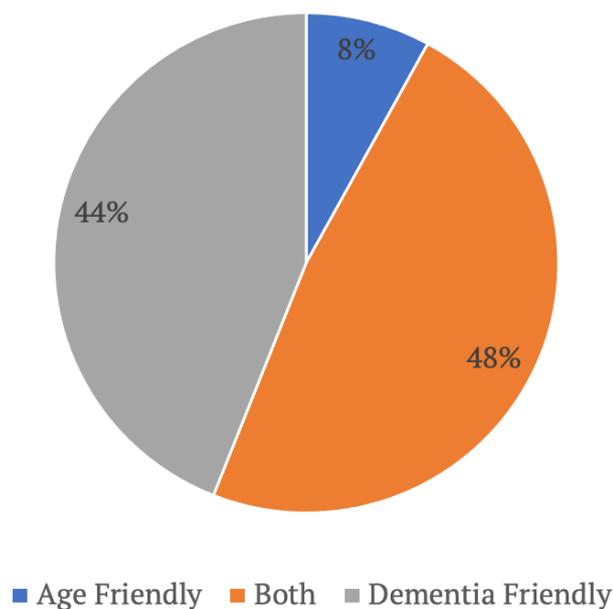


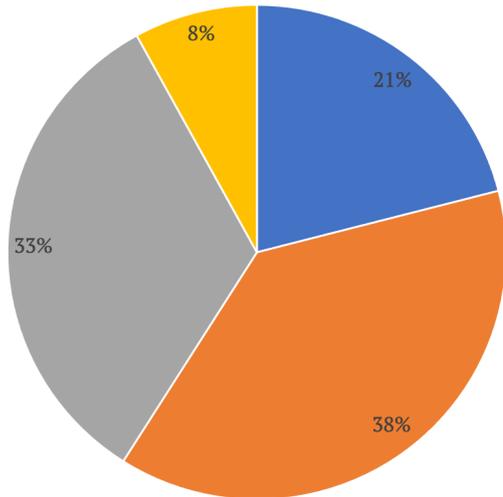
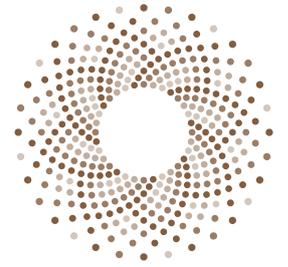
While some respondents fed back on individual initiatives they were delivering, others provided analysis and commentary on initiatives in their region or across their country.

Around half the respondents were from not-for-profits or similar organizations directly delivering projects. Academia consisted mainly of respondents based at higher education institutions providing survey responses and papers assessing the impact of initiatives. Governments were a combination of national and local level governments who primarily provided funding of initiatives, but in some cases also helped coordinate networks for those who ran initiatives.

## Dementia friendly initiatives being delivered

Respondents were asked to select whether “dementia friendly” or “age friendly” more accurately reflected the initiatives was relevant to their involvement. With the option of indicating both. A small number of respondents were involved in age friendly initiatives, but most were either dementia friendly initiatives or both dementia and age friendly.

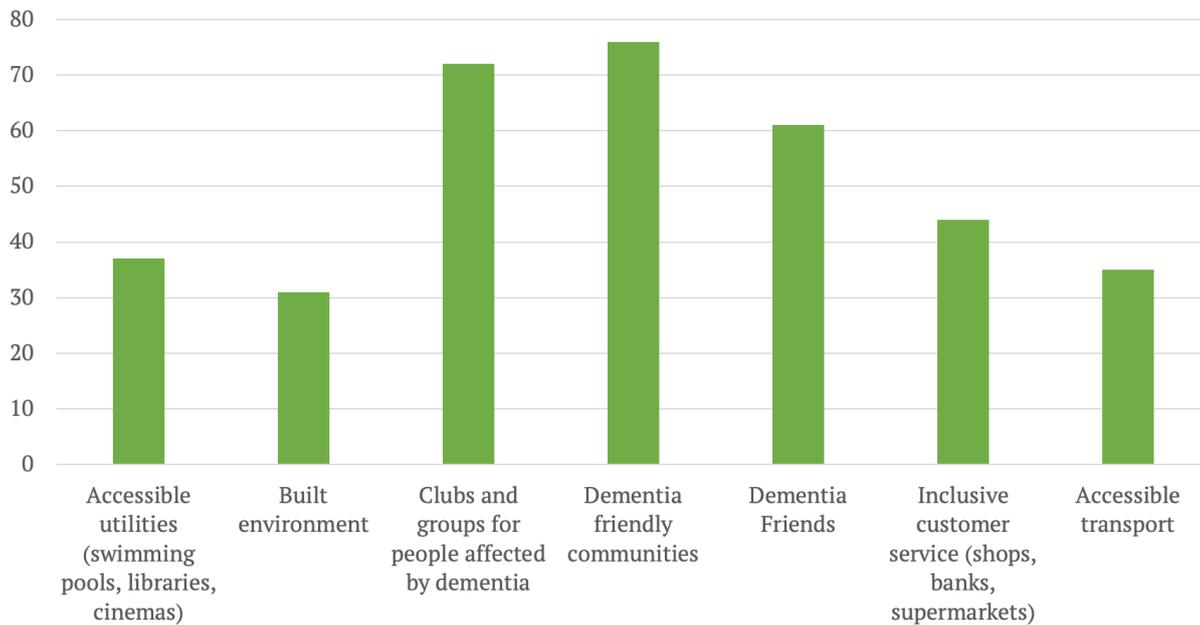


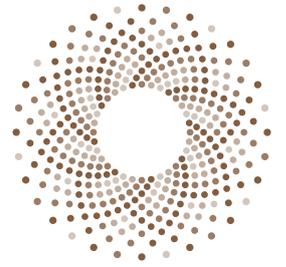


- All three
- Improving quality of life (compassionate)
- Rights based (addressing inequality)
- Meeting need (utilitarian)

Broadly respondents cited in equal proportions improving the quality of life, meeting need or addressing inequality as the motivation for delivering initiatives.

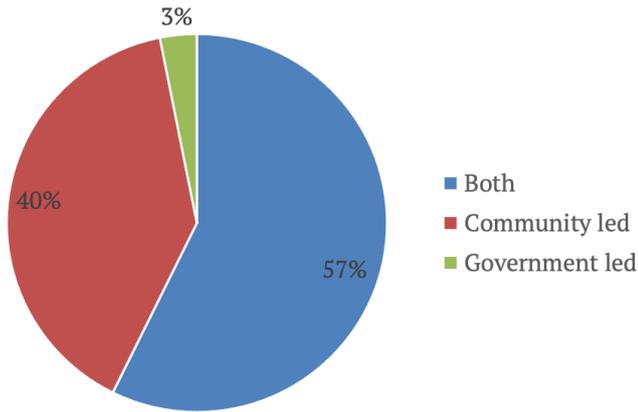
Respondents were asked what types of initiatives they delivered personally or were delivered in their region/country. The most common initiatives were geographically-based dementia friendly communities, clubs and groups for people affected by dementia, and the Dementia Friends programme. The chart reflects that organizations are delivering multiple projects, including around accessibility to enable participation on transport, with public utilities and with the built environment.





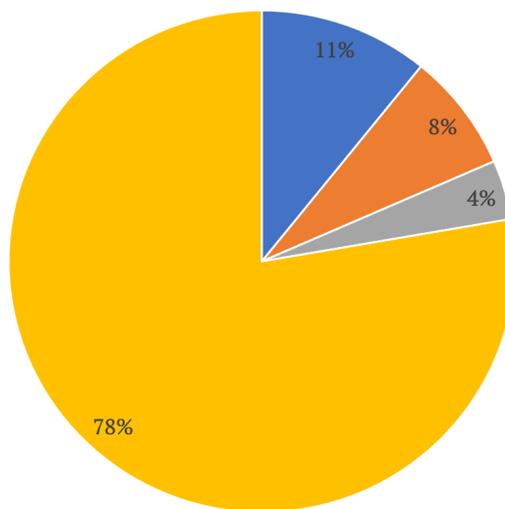
## Management and funding

Very few initiatives were led or managed by government (local, regional or national). Most respondents reported on projects that were led by grassroots organizations or were led through a combination of statutory and non-statutory actors.

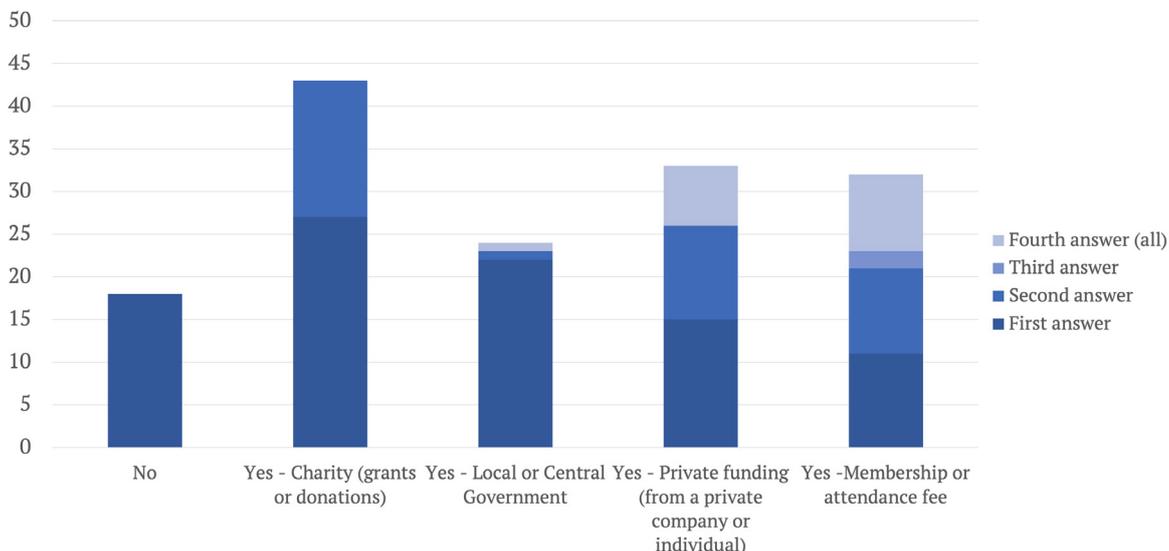


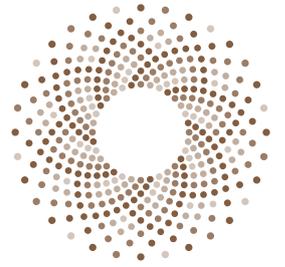
Most initiatives were managed by volunteers. A small proportion were managed by individuals paid for by not-for-profit organizations, local or national governments or for-profit companies.

- People paid by not-for-profit organizations
- People paid for by local or central government
- People paid for by for-profit organizations
- Volunteers from the community

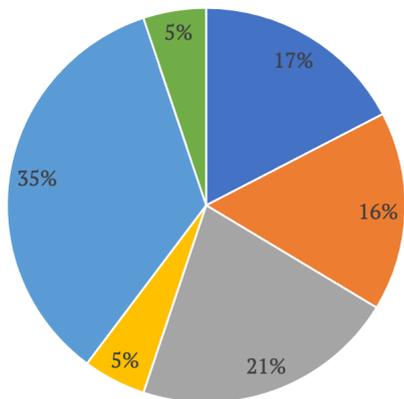


Initiatives were funded through multiple sources relying on a combination of not-for-profit, statutory, for-profit and attendance fees. Respondents had an option to indicate they receive multiple sources of funding (some gave four answers indicating they, or organizations in their area, received funding from all four sources listed).





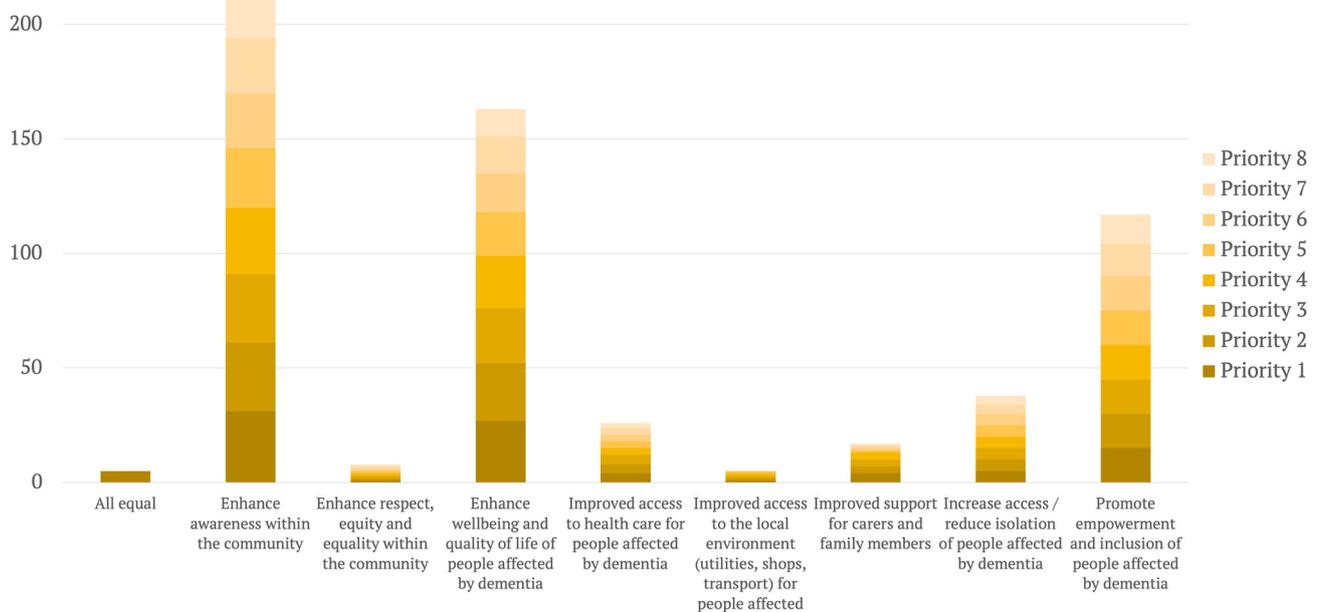
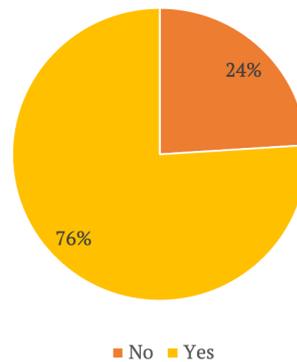
## Impacts and evaluation



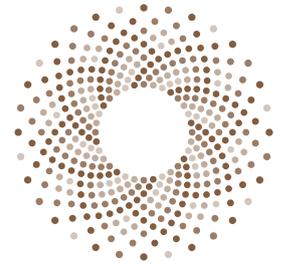
- All
- For society as a whole
- Impact for the individual
- In the organization
- In the community
- On the family

Around half of respondents reported initiatives that were designed to have societal or community level impact with around a fifth being individual focussed. Reflecting earlier responses overall initiatives were aimed primarily at improving awareness with enhancing wellbeing/quality of life and promoting empowerment and inclusion significant desired outcomes.

Around three quarters of initiatives reported some form of evaluation. As part of this project 46 respondents supplied additional papers on the evaluation they had carried out.



# Survey data: people living with dementia and their caregivers

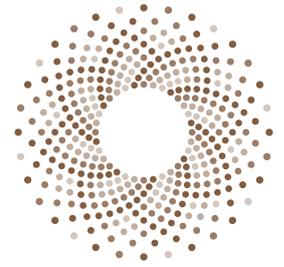


Two surveys aimed at people with dementia and their caregivers was carried out by Alzheimer's Society (UK) as part of the evidence submitted to this review. The need for surveys to be short and accessible required two separate surveys published at different points over the year.

The first survey sought to capture opinions on involvement with dementia friendly initiatives. The second survey invited feedback on experiences and what impact was felt as a result of involvement with initiatives.

Alongside distribution through the Alzheimer's Society network, the surveys were accessible on the Council's website and was completed by a small number of individuals from outside the UK. A total of 172 responses were submitted across these two surveys: 87 responses were received to the survey on involvement, with 85 responses received to the impact survey. These surveys were made available in English only.

An original version of this survey for people with dementia and their caregivers can be found as an appendix to the back of this paper.



## Involvement

Respondents were asked to indicate the country they resided in. As this survey was administered and distributed by the UK Alzheimer's Society, the majority of responses came from the UK.

Country	Number
Australia	5
Brazil	1
Canada	1
Estonia	1
Uganda	1
United Kingdom	71
United States	7
<b><i>N respondents</i></b>	<b>87</b>

From the total number of 87 responses, 76 respondents indicated the dementia friendly initiatives they were involved in. Respondents could select more than one option where they were involved in multiple initiatives.

Initiatives involved in?	Number
Dementia friendly library	22
Accessible swimming pool and sessions	15
Accessible public transport	19
Dementia friendly cinema	23
Support groups	59
Community groups	49
Advisory services	38
Other	32
<b><i>N respondents</i></b>	<b>76</b>

A total of 78 respondents indicated how they had been involved with dementia friendly initiatives, and what their general role in that involvement was from multiple choice options. Some respondents felt they had been involved in more than one way.

Interaction how?	Number
I attend dementia friendly initiatives	39
I support dementia friendly initiatives	48
I run dementia friendly initiatives	27
I evaluate dementia friendly initiatives	18
I research and study dementia friendly initiatives	14
I have no involvement in dementia friendly initiatives	18
Other	11
<b><i>N respondents</i></b>	<b>78</b>

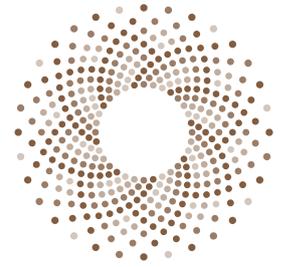
A majority of the 60 people who responded to the question who believed their involvement resulted in a dementia friendly initiative that is meaningful and useful to people affected by dementia.

Meaningful result?	Number
Yes	39
No	7
Don't know	14
<b><i>N respondents</i></b>	<b>60</b>

From the 79 respondents who answered this question, 47 said they had been involved in the design of a dementia friendly initiative through partaking in surveys, focus groups, verbal consultations, community meetings and/or other methods. Some respondents had been involved in the design of initiatives in multiple ways.

Involved in design	Number
Yes	47
No	30
Don't know	2
<b><i>N respondents</i></b>	<b>79</b>

Design of? (if yes)	Number
Survey	18
Focus group	21
Verbal consultation	26
Community meeting	32
Other	24
<b><i>N respondents</i></b>	<b>49</b>



## Impact

Because the respondents to each part of the survey were not the exact same respondents, the geographical profile of each part is slightly different. Again, respondents were asked to indicate the country they resided in, and as this survey was administered and distributed by the UK Alzheimer's Society, the majority of responses came from the UK.

Country	Number
Australia	2
Estonia	1
United Kingdom	79
United States	3
<b><i>N respondents</i></b>	<b><i>85</i></b>

The survey results also illustrated the profile of respondents in terms of how they were affected: either as a person living with dementia, or a carer/ex-carer/family member or friend of somebody with dementia. The majority of respondents were from the latter category.

Affected how?	Number
Diagnosed with dementia	12
Carer, ex-carer, family member or friend of someone living with dementia	69
<b><i>N respondents</i></b>	<b><i>81</i></b>

Asked how they believed dementia friendly initiatives to be helpful, the majority of respondents said they believed impact on the individual, on the family of the person living with dementia, on organizations such as businesses and charities, and on the community and society in general, were all helpful.

Are they helpful?	Number
Impact on the individual affected by dementia	23
Impact on the family of the person affected by dementia	18
Impact on the community	7
Impact on organizations such as businesses, charities or utilities	3
Impact on society as a whole	13
All of the above are equally important	42
Other	4
<b><i>N respondents</i></b>	<b><i>81</i></b>

Respondents said that clubs or groups for people affected by dementia were the most helpful type of initiatives, but broadly agreed that other initiatives were also helpful from the prescribed list offered as answer options.

Initiatives which are helpful	Number
Dementia Friends sessions	32
Clubs or groups for people affected by dementia	56
Accessible transport (buses, taxis, trains)	23
Inclusive customer service (shops, banks, supermarkets)	28
Accessible utilities (swimming pools, libraries, cinema)	24
Public buildings (libraries, doctor's surgery, council)	24
Other	19
<b><i>N respondents</i></b>	<b><i>77</i></b>

The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with a personal dementia diagnosis. The WDC has an executive team based in London, UK.

[worlddementiacouncil.org](http://worlddementiacouncil.org)

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