



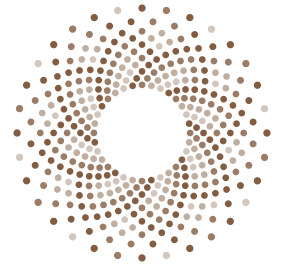
**World Dementia  
Council** Leading the Global Action  
Against Dementia

# Methodology and bibliography

Presenting a global evidence base for  
dementia friendly initiatives

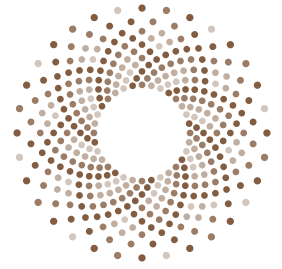


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# Framework and contributors



## 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.

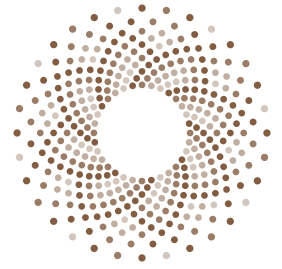
An evidence framework was designed to compare and synthesize a global evidence base. It needed to consider the variety of initiatives designed to have impact, the breadth of evidence likely to be submitted, and the range of voices who would contribute. The framework was developed in consultation with 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.

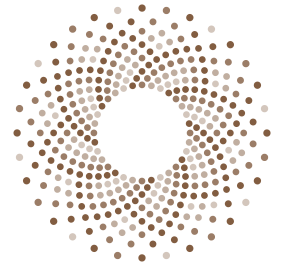
## Roundtables

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.

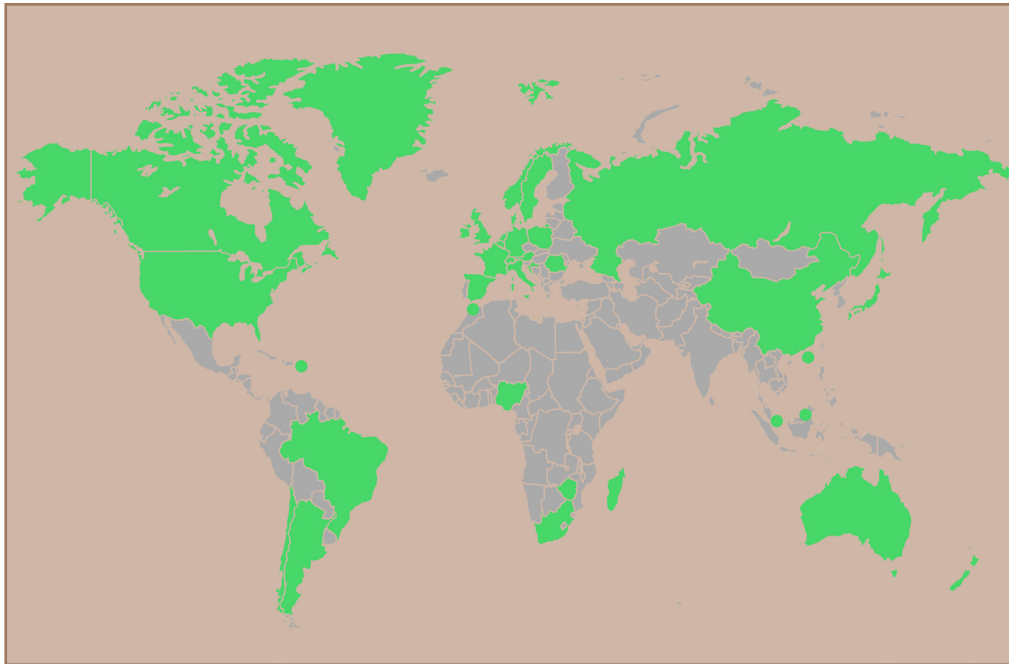
## Surveys


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

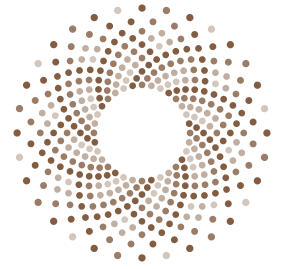
This survey was designed for organizations to respond, and captured regional views on the level of provision, the priorities and outcomes of initiatives, and different leadership structures. The survey also provided the opportunity for respondents to share academic papers, evaluation results, and grey 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.



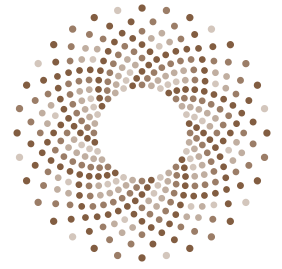
A total of 248 completed surveys were collected across these three surveys designed for people living with dementia and their caregivers. Just over a quarter (70) of all respondents submitted extra comments beyond the survey itself.

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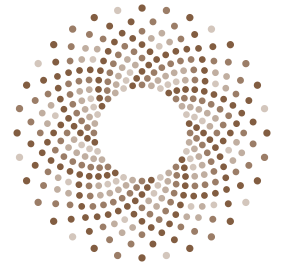
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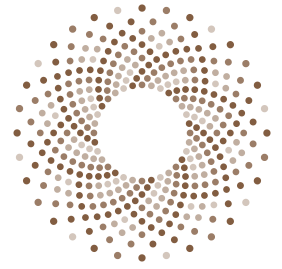
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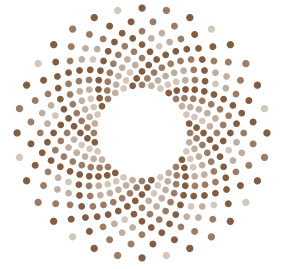
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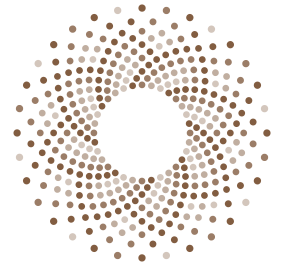
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The World Dementia Council (WDC) is an international charity. It consists of senior experts and leaders drawn from research, academia, industry, governments and NGOs in both high-income and low- and middle-income countries, including two leaders with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

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