Technical Report

**Evidence Review of**

**Dementia Friendly**

**Communities**

**European Union Joint Action on**

**Dementia**

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# INTRODUCTION AND OVERVIEW

This technical report supports the findings of an evidence review conducted by Imogen Blood & Associates in partnership with Innovations in Dementia to inform Workpackage 7 of the EU Joint Action on Dementia, which is being led by the English Government (Department of Health). The evidence report aims to:

* Identify evidence-based examples of best practice in key aspects of promoting, nurturing and sustaining dementia friendly communities,
* provide a definition of DFCs,
* Identify the components of an effective DFC: arriving at a model demonstrating the key success factors of a DFC, synthesizing data from interviews, group discussions, online survey feedback, and key components of other existing models; and
* Develop a set of indicators to test the success of the forthcoming pilots within this Workpackage.

The evidence report is based on the following primary and secondary evidence:

* 82 reports and articles identified through a systematic search for international published and ‘grey’ literature;
* Three group discussions with people with dementia, including the European Working Group of People with Dementia and two groups within the Dementia Engagement and Empowerment Project network in England;
* 20 interviews with 25 participants with people involved in DFCs from a total of 10 countries across the EU, including two visits to DFC projects in the UK.
* An online survey, sent out to EU dementia leads and contacts, to which 57 responses were received.

The evidence report is structured around the ‘four cornerstones’ model, which has been used in the evaluation of several DFC initiatives in the UK. The four ‘cornerstones’ are: People, Place, Networks and Resources.

The review team were asked to draw on both secondary and primary data sources to develop a definition of DFCs and to describe the key components of a ‘good’ or ‘effective’ DFC. This was to be informed by a review of published and unpublished information from around the world, with a particular focus on evidence from EU countries.

The methodology for the review might best be described as a ‘rapid evidence assessment’, supplemented with primary data collection and stakeholder engagement. However, given the fairly limited amount of published research which specifically evaluates the effectiveness of DFCs, the team found that it needed to widen search terms, rather than make decisions about the exclusion of certain publications.

# SELECTION OF METHODS

Conscious that we had only three months to complete the whole review, a ‘scoping review’ of the ‘core’ DFC literature specified in the brief was conducted at the outset. Having read this literature and run some initial searches for further literature on DFCs, a short ‘scoping report was produced and shared with the Department of Health at start-up meeting. This document looked at the following topics/ questions:

1. What are the different approaches to defining ‘Dementia Friendly Communities’?
2. Principles of DFCs: what are the core principles according to these documents and what degree of congruence is there in relation to them?
3. How are the different aspects of DFCs categorised in these documents?
4. What forms of evidence have been collated and/or analysed in relation to DFCs?
5. Implications and questions to refine the methodology used and the final output

The initial searches confirmed that, although there was an emerging (English) literature on the effectiveness of DFCs, this was limited. This confirmed the importance of an EU-wide call for evidence, to identify evaluations which were unpublished and/or not available in English, to gather primary data about the state of DFC development in as many EU member states as possible, including examples of (albeit not yet evaluated) practice. The need to gather information in English as quickly as possible from as many EU countries as possible confirmed the importance of a flexible and multi-method approach, involving phone/ Skype interviews, an online survey and supplemented by email correspondence and Google searches for web-based information about DFC initiatives.

Ensuring that the views of people with dementia regarding effective DFCs were gathered by and informed the review was a priority for the team. Arranging to meet with existing groups of people with dementia was selected as both the quickest way of reaching a significant number of people within the timescales, and the best method ethically since people were already comfortable with facilitators and other members. Innovations in Dementia support the DEEP network of groups of people with dementia in the UK and workers from Innovations are already well-known to these groups so it was decided that Steve Milton and Damian Murphy of Innovations would conduct two group discussions with members of the York (North England) and Redditch (Midlands) DEEP groups.

It was the team’s intention to return to these groups at the end of the review and share with them our proposed definition and model for verification, however, the opportunity arose to attend a meeting of the European Working Group of People with Dementia at the start of the report writing phase. A decision was made to share emerging findings with this group instead, given the clear advantage of gathering the views of people with dementia and their care-givers from a range of EU countries.

# LIMITATIONS OF THE REVIEW

There are a number of limitations to this review:

* There was insufficient time and budget to review literature and information which was not in English language. To mitigate this as far as possible, we drew on the findings of the recent EFID review (Williamson 2016) (which had been able to translate primary and secondary data more proactively). Our online survey/ invitations to interview included the offer of translation/ interpretation and this was taken up on several occasions.
* Many of the countries contacted were at too early a stage in their DFC development to provide us with *any* information, let alone formal evaluations, though evaluations are planned or in process. Northern European countries were generally more advanced in terms of the development and evaluation of DFCs, therefore we recognise that the UK, Norway, the Netherlands and Germany are over-represented. The team sought to counter this with practice examples from Spain and Italy and with qualitative feedback from participants from a range of countries where the response to dementia is at a much earlier stage of development (e.g. Bulgaria, Portugal (Madeira), Greece, Czech Republic). These conversations provided a different frame of reference for the interpretation of evidence from elsewhere. This also meant that we looked further afield – to Australia, Japan and the US, where there is a well-established community of DFC practice.
* Given the time constraints of the project:
  + It was only possible to run the survey for 3 weeks, which may have restricted the response – the survey was mailed out to an email circulation list of those with an interest in DFCs drawn from across the EU, however, the team did not have any additional contact or role information so we were dependent on these contacts to act as ‘gatekeepers’, circulating the link to the survey/ completing it.
  + It was not possible to return to participants (including people with dementia) to iteratively test the model and definitions proposed; to mitigate this, we shared the draft report with those who contributed to the review, including circulating the easy read and full versions of the report with the groups of people with dementia we had consulted. We were not able to collect feedback systematically.

# LITERATURE SEARCH

At the initial scoping stage, the team added to the list of existing ‘core’ literature provided in the specification by conducting Google searches using the terms ‘Dementia Friendly Communities’ with various added terms that included geographical areas, and/or ‘evaluation’, ‘report’. The terms ‘Dementia Supportive Communities’ and ‘Dementia-Capable Communities’ were also searched. Since the focus was on identifying ‘evidence-based’ and ‘effective’ practice, the main focus was to find publications which presented the *findings of evaluations* of DFCs.

A number of definitions of DFCs were collated from the core literature and from Open Access academic papers and websites involved with DFC initiatives across the globe (eg Alzheimer’s Disease International, Alzheimer’s Europe, etc). These were reviewed to select four prominent but contrasting definitions on which online survey respondents were asked to feed back.

From the outset, the team used a spreadsheet to record the literature identified, its source and type.

At the next stage of the review, the team continued to use these search terms, and supplemented them with wider searches using the terms ‘dementia’ and ‘community/ies’. Studies which looked at the effectiveness of medical or formal service provision to people with dementia living in community settings were excluded: the focus was on finding evidence related to how people with dementia experienced and accessed communities and how communities respond to and support those with dementia and their care-givers.

Manchester University Library Databases facilitated by the University’s Research Information Management System, ‘Pure’, were searched for limited access publications. Through this system the team accessed several databases listed under the subject areas of:

* **Social Statistics and Social Change;**
* **Social Work; and**
* **Sociology.**

Within these subject areas the team were able to search databases for peer-reviewed journal publications, e-journals, articles and books. Key databases included:

* **Social Policy and Practice; and**
* **SAGE publications online.**

Via Manchester University Library, the team also accessed databases supported by EBSCOHost, (a delivery platform with extensive research content) including:

* **Social Sciences Full Text; and**
* **Sociology Source Ultimate**

In addition to searches through Manchester University Library, the team conducted searches via the following publically accessible search engines and databases:

* **‘BASE’**: the academic search engine operated by Bielefeld University Library. It offers documents from more than 5,000 sources and supports indexed documents under Open Access;
* the UK’s National Institute for Health and Care Excellence **(NICE) Evidence Search**, which provides access to selected and authoritative evidence in health, social care and public health;
* **Social Care Online**, which is the UK’s largest database of information and research on all aspects of social care and social work;
* **Google**, whereby the team performed catch all searches across the world wide web; and
* **Google Scholar**, whereby the team identified abstracts to direct restricted access searches and to derive Open Access sources.

We grouped our searches into two categories:

* A direct relevance to the search term ‘Dementia Friendly Community(ies)’
* A second search to source supporting evidence by using the simpler terms ‘dementia’ and ‘community’.

In total the team collected 82 relevant documents which were made up of peer reviewed journal articles, evaluation and government reports, research updates and overviews, blogs, newspaper articles, books, tools, and synthesis and learning papers. The team also collected 2 papers via internal communications with participants and have listed organisational website sources where relevant.

In Table 1, which outlines identified documents below, the general term ‘Manchester University Library’ is used to describe our searches across several databases, of which key sources are listed above.

The team also searched for and collated relevant ‘grey literature’ looking for practice examples, especially those which had been evaluated. Typically, these searches were targeted following a mention of a practice example in an existing publication or an interview or survey response. For example, the team reviewed the EFID online collection of  dementia-friendly community case studies across Europe**[[1]](#footnote-1)** and the ADI Dementia Friendly Communities: Global Developments report (Alzheimer’s Disease International 2016), conducting online searches (using Google) on those projects which mentioned ‘evaluation’. The team found that many citations of evaluations were planned, in process, or could not be found.

Once identified, all documents were reviewed by the same researcher (Imogen Blood), who made notes on the spreadsheet under the following headings:

**Evidence**: references to/ description of formal evaluation, research questions, methods and sample size, limitations and gaps, evidence of impact

**Context**: outline of the community/ies; organisation/ programme

**Process learning**: Key findings in relation to the effectiveness of structures, partnerships, approaches taken the DFC and how these evolved.

Although some critical appraisal was undertaken, at the time of the review, the evidence base in relation to DFCs was not of the nature, scale and stage of development to support a more structured comparative evaluation of studies. The process was therefore more akin to a synthesis of qualitative data.

Table 2: Documents Identified

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **No.** | **Type** | **Source** | **Topic/Key Feature** | **Reference** |
| 1. | Blog | Google | Reporting on building a DFC | Shafii, S. & Crockett, A. (2012) ‘Building a dementia friendly community in Motherwell Town Centre— Our story so far’, *Alzheimer Scotland* |
| 2. | Book | Aktion Demenz | Comprehensive German perspective on DFCs | Gronemeyer, R., Kreutzner, G., and Rothe, V., (2015) *Im Leben bleiben: Unterwegs zu demenzfreundlichen Kommunen* (German only), Transcript Verlag, Bielefeld. |
| 3. | Book | Manchester University Library | Good Practice | Rahman, S., (2015) *Living Better with Dementia: Good Practice and Innovation for the Future*, Jessica Kingsley Publishers, London |
| 4. | Book | Google Scholar | Included Dementia Friendly pharmacy | Wegleitner, K., Heimerl, K., and Kellehear, A., (eds.) (2016) *Compassionate Communities: Case studies from Britain and Europe*, Routledge, London and New York. |
| 5. | Evaluation  Report | Social Care Online | Comprehensive evaluation and DFC project | IPC, (2015), *Evaluation of Hampshire Dementia Friendly Communities: Final Report*, Hampshire County Council. |
| 6. | Evaluation  Report | Google Scholar | Intergenerational exchange in Schools in support of DFCs | Atkinson, T., and Bray, J., (2013) *Dementia Awareness & Intergenerational Exchange in Schools: A Pioneer Project supporting Dementia Friendly Communities*, University of Worcester Institute of Health and Society. |
| 7. | Evaluation  Report | NICE Evidence Search | Detailed evaluation of Age UK’s Dementia Friendly Programme | Kispeter, E., Alden, S., and Wigfield, A., (2015), *Age UK's Dementia Friendly Programme: Evaluation Report*, CIRCLE, University of Leeds |
| 8. | Evaluation  Report | Google | Evaluation in Scotland | Henderson, J., (2015) *Dementia Friendly Communities: Edinburgh City Initiatives 2014-2015,* A Stitch in Time, Edinburgh. |
| 9. | Evaluation  Report | Google | DFC pharmacy | Plunger, P., et al (2015) 'Dementia-friendly Community Pharmacy: findings from a Participatory project in Austria, Alpen Adria Universitāt |
| 10. | Government Report UK | Google | Evaluation of peer support networks and advisors | Healthbridge (2013) *The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England*, Department of Health, England. |
| 11. | Journal  Article | Google Scholar | Issues around stakeholder engagement | Heward, M., et al, (2016), 'Dementia-friendly communities: challenges and strategies for achieving stakeholder involvement', Health and Social Care in the community. |
| 12. | Journal  Article | Google Scholar | Definitions and concepts | Lin, Shih-Yin., and Lewis, F.M., (2015) 'Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future’, *The Gerontological Society of America*, vol. 55, no. 2, pp. 237 - 244. |
| 13. | Journal  Article | Google Scholar | Evaluation of Alzheimer UK’s Dementia Friends Programme with 1st year nursing graduates | Mitchell, G., et al, (2016) 'Evaluation of “Dementia Friends” programme for undergraduate nursing students: Innovative practice', *Dementia.* |
| 14. | Journal  Article | Social Care Online | Descriptive - project overview in Wales | Chalk, A., (2014), ‘Dementia RED (Respect Empathy Dignity): Collaborating to build dementia supportive communities in North Wales - reporting on a pilot project (innovative practice)’, *Dementia*, 15(2), 2016, pp.257-262. |
| 15. | Journal  Article | BASE | Outside EU | Wright, T. (2014) ‘Reconceptualising dementia friendly communities’, *Diversity and Equality in Health and Care*, 11 (3). pp. 282-283. ISSN 2049-5471. |
| 16. | Journal  Article | Manchester University Library | Concept driven | Bartlett, R. (2016) ‘Scanning the conceptual horizons of citizenship’, *Dementia*, vol. 15(3), 453-461. |
| 17. | Journal  Article | Google | Workplace engagement with successful outcomes | Robertson, J., (2013) ‘Side by Side: A workplace engagement program for people with younger onset dementia’, in *Dementia*, vol. 12 no.5, pp. 666-674. |
| 18. | Journal  Article | Google | Seeks perspectives to develop a toolkit | Smith, K., (2016) *Developing a Dementia-Friendly Christchurch: Perspectives of People with Dementia*, Canterbury District Health Board and Age Concern Canterbury, New Zealand. |
| 19. | Journal  Article | Manchester University Library | Policy | Nedlund, A-C., and Nordh, J. (2015) ‘Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013’, *Journal of Ageing Studies*, 34 (2015) 123-133. |
| 20. | Journal  Article | Manchester University Library | Excellent refocus on PWD being at the centre of DFCs | Swaffer, K. (2014) ‘Dementia: Stigma, Language, and Dementia-friendly’, *Dementia* vol. 13(6), pp. 709-716. |
| 21. | Journal  Article | Google | Peer support, gender, inclusion of PWD | Milligan, C., et al (2015) 'Place and wellbeing: shedding light on activity interventions for older men', *Aging & Society*, 35, 2015, 124-149, Cambridge University Press. |
| 22. | Journal  Article | Manchester University Library | Citizenship | O'Connor, D. and Nedlund, A-C. (2016) ‘Editorial Introduction: Special Issue on Citizenship and Dementia’, *Dementia*, 2016, vol. 15(3), pp. 285-288. |
| 23. | Journal  Article | Manchester University Library | Relational aspects of place | Phillips, R., Evans, B. and Muirhead, S. (2015) ‘Curiosity, place and wellbeing: encouraging place-specific curiosity as a way to wellbeing', *Environment and Planning* A 2015, volume 47, pp. 2339-2354. |
| 24. | Journal  Article | Manchester University Library | Quality of life | O'Rourke, H. M. et al, (2015) ‘Factors that Affect Quality of Life from the Perspective of People with Dementia: A Meta-synthesis’, *Journal of the American Geriatrics Society (JAGS),* 63: 24-38. |
| 25. | Journal  Article | Manchester University Library | Environment and planning | Mitchell, L. et al, (2003) ‘Making the outside world dementia-friendly: design issues and considerations’, *Environment and Planning B: Planning and Design 2003*, volume 30, pp. 605-632. |
| 26. | Journal  Article | Manchester University Library | Environment and planning | Mitchell, L., Burton, E., and Raman, S. (2007) ‘Dementia-friendly cities: designing intelligible neighbourhoods for life’, *Journal of Urban Design*, 9:1, 89-101. |
| 27. | Journal  Article | Manchester University Library | Environment | Mapes, N. (2010) ‘It's a walk in the park: exploring the benefits of green exercise and open spaces for people living with dementia’, *Working with Older People*, Volume 14, Issue 4, December 2010. |
| 28. | Journal  Article | Manchester University Library | Holistic | Kane, R. A. and Cutler, L. J. (2015) ‘Re-Imagining Long-Term Services and Supports: Towards Liveable Environments, Service Capacity, and Enhanced Community Integration, Choice, and Quality of Life for Seniors’, *The Gerontologist*, vol. 55. no. 2, 286-295. |
| 29. | Journal  Article | Manchester University Library | Friendship and community | Hahmann, J. and Adams, R. G., (2015) ‘Friendships and Community in Old Age’, *The Gerontologist*, 2015, vol. 55, no. 3, pp. 506-508. |
| 30. | Journal  Article | Manchester University Library | Community awareness | Friedman, D.B, et al, (2016) ‘Increasing Community Awareness about Alzheimer's Disease in Puerto Rico Through Coffee Shop Education and Social Media’, *Journal of Community Health*, 2016, 41: 1006-1012. |
| 31. | Journal  Article | Manchester University Library | Overview of research based initiatives | Duffin, C. (2014) ‘Dementia- friendly neighbourhoods’, *Nursing Older People*, March 2014, volume 26, Number 2, pp. 16-17. |
| 32. | Journal  Article | Manchester University Library | Technology | Cutler, C., Hicks, B., and Innes, A. (2016) ‘Does Digital Gaming Enable Healthy Aging for Community-Dwelling People with Dementia?’, *Games and Culture*, vol. 11(1-2), pp. 104-129. |
| 33. | Journal  Article | Manchester University Library | Qualitative study | Brorsson, A. et al, (2016) 'Being a pedestrian with dementia: A qualitative study using photo documentation and focus group interviews’, *Dementia*, vol. 15(5), pp.1124-1140. |
| 34. | Journal  Article | Manchester University Library | Housing | Bligh, J. (2016) 'A mainstream social housing response to dementia', *Working with Older People*, Vol. 20 Iss3 pp. 144-150. |
| 35. | Journal  Article | Manchester University Library | Accessibility of public space | Blackman, T. et al, (2003) 'The Accessibility of Public Spaces for People with Dementia: a new priority for the 'open city', *Disability and Society*, Vol. 18, No. 3, pp. 357-371. |
| 36. | Journal  Article | Manchester University Library | Japan and policy | Nakanishi, M. and Nakashima, T. (2014) 'Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health-and-social care systems?' *Alzheimer’s and Dementia*, 10, 468-476. |
| 37. | Journal  Article | Manchester University Library | Technology | Brittain, K., et al (2010) ‘Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments’, *Sociology of Health & Illness*, Vol. 32 No. 2, pp. 272-287. |
| 38. | Journal  Article | Manchester University Library | Place and citizenship | Clarke, C.L. & Bailey, C. (2016) ‘Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places’, *Dementia*, 2016, vol.15 (3), 434-452. |
| 39. | Journal  Article | Manchester University Library | Subjective experiences of PWD | Von Kutzleben, M., Schmid, W. Halek, M., Holle, B., Bartholomeyczik, S. (2012) ‘A systematic review on the subjective experiences of persons with dementia’, *Aging and Mental Health*, 16(3), 378-390. |
| 40. | Journal  Article | Manchester University Library | Enacting citizenship through walking together | Phinney, A, Kelson, E, Baumbusch, J, O’Connor, D, & Purves, B (2016) ‘Walking in the neighbourhood: Performing social citizenship in dementia’, *Dementia*, May 2016, v.15, no.3, 381-394. |
| 41. | Journal  Article | Manchester University Library | Arts and strengths-based approach | Depuis, SL, Kontos, P., Mitchell, G, Jonas-Simpson, C & Gray, J (2016) ‘Re-claiming citizenship through the arts’, *Dementia* 2016 v.15 (3) 358-380. |
| 42. | Journal  Article | Manchester University Library | Case study | ‘DF pharmacies a community based health promotion project’ *BMJ Support Palliative Care* 2015;5:Suppl 1 A17. |
| 43. | Journal  Article | Manchester University Library | Workplace engagement | Robertson, J & Evans, D 2015, 'Evaluation of a workplace engagement project for people with younger onset dementia', *Journal of Clinical Nursing*, vol. 24, no. 15-16, pp. 2331-2339. |
| 44. | Journal  Article | Social Care Online | Outside EU | Wiersma, E. C., and Denton, A., (2013), 'From social network to safety net: Dementia-friendly communities in rural northern Ontario, Dementia, 0(0), 1-18. |
| 45. | Overview  Report | Social Care Online | Skills for Care funded programme of 12 pilot sites with 11 organisations, over a period of 12 months to support the development of DFCs | Henwood, M., (2015), *Living a Normal Life: Supporting the development of Dementia Friendly Communities*, Skills for Care, Leeds. |
| 46. | Report | Social Care Online | Learning on engagement and empowerment | Seydak, E., et al, (2015), *Building a Dementia Friendly Community in Northern Ireland: Learning from the DEED Project in Derry*, Joseph Rowntree Foundation, York. |
| 47. | Report | Social Care Online | Dementia Friendly Cities | Hare, P., and Dean, J., (2015), *How can we make our cities dementia friendly?,* Joseph Rowntree Foundation, York. |
| 48. | Social  Attitudes  Survey  Report | Social Care Online | Attitudes to Dementia in Scotland | Reid, S., Waterton, J., and Wild, A., (2015), *Attitudes to Dementia: Scottish Social Attitudes*, NatCen Social Research, London. |
| 49. | Overview of Evaluation Progress  Report | Google | Factors for developing DFCs | Easton, A., (2014), *Overview of the Dementia Friendly Communities Initiative*, The Alzheimer Society of Ireland, Republic of Ireland. |
| 50. | Research  Report | Alzheimer’s Disease International | Comparison of DFCs and ‘age-friendly communities’ | Turner, N., and Morken, L., (2016) *Better Together: A Comparative Analysis of Age-Friendly and Dementia Friendly Communities*, AARP/WHO International Affairs, Washington DC. |
| 51. | Report | NICE Evidence Search | Evaluation Report on DFCs in Oxfordshire, UK | IPC, (2014), *Oxford Dementia Challenge Group: Evaluation of Dementia Friendly Communities Project*, Oxford-Brookes University, Oxford. |
| 52. | Overview  of Progress Report | Google | Progress report of DFCs in Scotland | Life Changes Trust, (2015), *Dementia Friendly Communities: Report 1 – The First Six Months: April to September 2015, Life Changes Trust*, Glasgow. |
| 53. | Workshop  Report | BASE | Learning event on DFCs | Tippett, Joanne; How, Fraser; Wesslowski, Viktoria (2015) *Living well with dementia, Workshop at the North West Dementia Action Alliance Learning Event: building dementia friendly communities*, Ketso, Manchester. |
| 54. | Report  Findings | Google | National Survey | Alzheimer's Australia, (2014), *Living with Dementia in the Community: Challenges & opportunities: A report of National Survey Findings,* Alzheimer's Australia, Barton. |
| 55. | Research  Update (Overview) | Google | Identifying features of the physical and social service environments that help or hinder people with dementia | Dementia Illawarra Shoalhaven, (2015), *Dementia Friendly Kiama: Research Update*, University of Wollongong; Fight Dementia.org.au, Kiama Municipal Council, Kiama. |
| 56. | Research  Report | Google | Qualitative study using local hosts and forums | Orlando Health, Inc. and Carlin Rogers Consulting LLC, (2010), *Florida Dementia Friendly Transportation Research Project*, Florida Department of Elder Affairs, Florida. |
| 57. | Report | Google | Summary of web searches worldwide for DFCs | Haggarty, M. (2013) *Dementia friendly communities worldwide: A summary of web searches*, Centre for Education and Research on Aging and Health (CERAH), Lakehead University, Thunder Bay. |
| 58. | Review | Social Care Online | Review of progress and achievements of the Dementia Challenge | Henwood, M., Butler, T., and Pollard, K., (2015), *Slaying the Demon: The Dementia Challenge: Progress and Achievements*, University of the West of England, Bristol. |
| 59. | Measurement Tool | Google | Quantitative measurement screening | Kaelen B., and Crey F., (2015) Dementieproof Meter 2015: Inventarisatie van Brabants Gemeentelijk Dementiebeleid, Programmaraad Zorgvernieuwing Psychogeriatrie, Tilburg. |
| 60. | Yearbook | Alzheimer’s Europe | Progress of DFCs across EU to date | Alzheimer Europe (2015), *Dementia in Europe Yearbook 2015: “Is Europe becoming more dementia friendly?” Examples of dementia friendly communities in: Austria, Belgium, Germany, Ireland, Netherlands, Norway and the UK*, Alzheimer Europe, Luxembourg. |
| 61. | Updated dementia  plan | Google | Projected plan to develop a dementia friendly Flanders | Vlaamse Regering, (2016) *Continuing to build a dementia-friendly Flanders together: Updated Dementia Plan for Flanders2016-2019*, Vlaamse Regering, Brussels. |
| 62. | Poster | Google | Methods guide | Barclay, T., Barclay, M., & Mastery, O. (2015) *Building dementia -friendly communities: a collective action approach*, ACT on Alzheimer’s, Minnesota. |
| 63. | Evaluation  Report | Google | Social isolation for men with early-stage dementia | Abbato, S., (2013) *Every Bloke Needs a Shed Project: Newcastle & Hunter Region,* Alzheimer’s Australia, NSW. |
| 64. | Evaluation  Report | Google | Goals to advance the dementia capability of Minnesota | Paone, D., (2015) *Act on Alzheimer’s Evaluation Report 2013-2015,* Act on Alzheimer’s, Minnesota. |
| 65. | Report | Google | Development guide | Alzheimer’s Australia, (2014) *A Guide to Becoming a Dementia-Friendly Community,* Alzheimer’s Australia, NSW. |
| 66. | Report | Internal communications | Workshop report | Bruges and Aalbeke, (2015) *EFIS workshop: Exchange of practice and development of indicators to capture change,* EFID, Belgium. |
| 67. | Publication | Google | Global developments on DFCs | Alzheimer’s Disease International, (2016) *Dementia Friendly Communities: Global Developments,* Alzheimer’s Disease International, London. |
| 68. | Publication | Google | Key principles and resources guide | Alzheimer’s Disease International, (2016) *Dementia Friendly Communities: Key principles,* Alzheimer’s Disease International, London. |
| 69. | Report | Google | Evidence from the perspective of people with dementia | Green, G., and Lakey, l., (2013) *Building dementia-friendly communities: A priority for everyone,* Alzheimer’s Society, London. |
| 70. | Annual  Report | Google | Quality of life for older people with dementia | Kane, M., and Terry, G., (2015) *Dementia 2015: Aiming higher to transform lives,* Alzheimer’s Society, London. |
| 71. | Code of  Practice | Google | Recognition of DFCs | Alzheimer’s Society, (2015) *PAS 1365: 2015 Code of practice for the recognition of dementia-friendly communities in England,* British Standards Institution (BSI), London. |
| 72. | Evaluation  Report | Google | Identifying distinctive features of DFC Programme | Dean, J., Silversides, K., Crampton, J., and Wrigley, J., (2015) *Evaluation of the Bradford Dementia Friendly Communities Programme,* Joseph Rowntree Foundation, York. |
| 73. | Evaluation  report | Google | Identifying distinctive features of DFC programme | Dean, J., Silversides, K., Crampton, J., and Wrigley, J., (2015) *Evaluation of the York Dementia Friendly Communities Programme,* Joseph Rowntree Foundation, York. |
| 74. | Report | Internal Communications | Learning from two pilot local authorities | Innovations in Dementia, (2012) *Developing dementia-friendly communities: Learning and guidance for local authorities,* Local Government Association, London. |
| 75. | Report | Google | Mapping DFCs in Europe | Williamson, T., (2016) *Mapping dementia-friendly communities across Europe: A study commissioned by the European Foundations’ initiative on dementia (EFID),* EFID, Brussels. |
| 76. | Departmental Policy Commitment | Google | UK Government policy priorities on dementia | Department of Health England, (2015) *Prime Minister’s Challenge on Dementia 2020,* Department of Health England, London. |
| 77. | Departmental implementation plan | Google | UK government plan for implementing Prime Minister’s Challenge on Dementia 2020 | Department of Health England, (2016) *Prime Minister’s Challenge on Dementia 2020: Implementation Plan,* Department of Health England, London. |
| 78. | Proceedings from Roundtable | Google | Intellectual disability policy | Wilson, E., (2006) *Defining and measuring the outcomes of inclusive community for people with disability, their families and the communities with whom they engage,* La Trobe University, Melbourne. |
| 79. | Devolved Government Publication | Google | Best practice guidance | The Scottish Government, (2007) *With Inclusion in Mind: The local authority’s role in promoting wellbeing and social development: Mental Health (Care and Treatment)(Scotland) Act 2003 Sections 25-31,* The Scottish Government, Edinburgh. |
| 80. | Grey  Journalism | Google | Japan’s approach to dementia | Yang, J., (2015) ‘How Japan is training an entire country to help with dementia’, *thestar.com,* Toronto Star Newspapers Ltd., Toronto [online] (Accessed 10/08/2017) <https://www.thestar.com/news/world/2015/11/22/how-japan-is-training-an-entire-country-to-help-with-dementia.html> |
| 81. | Grey  Journalism | Google | Feature on Bruges’s approach to DFCs | Davies, R., (2015) ‘Is Bruges the most dementia-friendly city?’, *The Guardian*, Guardian News and Media Limited, London [online] <https://www.theguardian.com/society/2015/apr/21/bruges-most-dementia-friendly-city> (Accessed 10/08/2017) |
| 82. | Grey  Journalism | Google | Speech given at Alzheimer's Disease International of Singapore | Rees, G., (2015) ‘Dementia Friendly Communities: Global Initiatives and Future Directions, *Dementia Alliance International,* Iowa [online] <https://www.dementiaallianceinternational.org/dementia-friendly-communities-global-initiatives-and-future-directions-by-glenn-rees-am/> (Accessed 10/08/2017) |

The team also gathered details of a range of Toolkits to inform the next phase of the European Union Joint Action on Dementia Project from established DFC initiatives around the world. These are listed in Table 2 below:

Table 2: Toolkits

|  |  |  |  |
| --- | --- | --- | --- |
| **Title** | **Country** | **URL (Shortened)** | **Comments** |
| ACT: Dementia Friendly Toolkit | Minnesota, USA | http://bit.ly/2cEa9lf | Good resource in relation to evaluation |
| Dementia Friendly America: Toolkit inventory | USA | http://bit.ly/2x3pWjc | Includes action for sectors |
| A Toolkit for Building Dementia-Friendly Communities. Wisconsin’s Healthy Brain Initiative Project | Wisconsin, USA | http://bit.ly/2wPBlEa | Good example of process and sustainability (p.24) |
| Alzheimer Scotland: Action on Dementia: Dementia Friendly Toolkit | Scotland, UK | http://bit.ly/2w9I1Ql | Several resources are accessible:   * a leaflet for shops and businesses * Environmental poster and audit tool * Charter of rights for people with dementia |
| Deep (Dementia Engagement and Empowerment Project) | UK | http://bit.ly/1PI1SKx | Includes a range of engagement guides and a booklet of ‘Our Rights’ |
| Local Government Association: Dementia friendly communities: Guidance for councils | UK | http://bit.ly/2uOuARv | Local Government Association (LGA) Guidelines |
| Innovations in Dementia (IiD): How to do an access audit | UK | http://bit.ly/2vCWNO0 | How-to guide on conducting an audit to make buildings easier for people with dementia |
| Age UK: How to make your Age UK dementia friendly | UK | http://bit.ly/2v10MQV | How to make a local organisation working with older people dementia friendly |
| Alzheimer’s Disease International: Dementia Friendly Communities: Key Principles | International | http://bit.ly/2wdRl4L | Key principles paper |
| Alzheimer’s Disease International: Dementia Friendly Communities: Global Developments | International | http://bit.ly/2fJDfSq | Good for descriptions of how tools are being used |
| Alzheimer’s Australia: Creating Dementia Friendly Communities: Community Toolkit | Australia | http://bit.ly/2weD9bA | * Includes good and simple ideas along with a template for action * Good checklists for environment, both indoor and outdoor, and for social interaction |
| Alzheimer’s Australia New South Wales: A Guide to Becoming a Dementia friendly Community | NSW, Australia | http://bit.ly/2e4RjVe | Good resource on Strategy – Kotter 8 step change model |
| Alzheimer’s Australia: Creating Dementia Friendly Communities Business Toolkit | Australia | http://bit.ly/2uIjYaC | Business Toolkit |
| Alzheimer’s Australia: Creating Dementia Friendly Communities: A Toolkit for Local Government | Australia | http://bit.ly/2vD16sK | Good resource for sample surveys and templates |
| Is it Dementia: A resource for recognising the signs of dementia | Australia | http://bit.ly/2i4lY7j | Sector specific awareness resources |
| Alzheimer’s Australia: CALD Dementia Resources for Families and Professionals | Australia | http://bit.ly/2uOMinG | Good resource for Black, Asian and Minority Ethnic Groups |
| Alzheimer’s Australia: Your Shed and Dementia A Manual | Australia | http://bit.ly/2v1jcki | A manual on making the ‘Men’s Sheds’ programme more accessible to people with dementia |
| Alzheimer’s Australia WA: Dementia Friendly Communities Project: Creating a Dementia friendly WA | Western Australia | http://bit.ly/2wPUhSX | Good resource for how to set up an evaluation to include people with dementia |
| Alzheimer’s Australia: A Practical Model for Local Governments, Civic Services and Community Organisations | Australia | http://bit.ly/2uIn922 | Guidelines for communities (aimed at local government and a good rationale for DFCs and on alignment with age friendly work. |
| Dementia Enabling Environments | Australia | http://bit.ly/2fKs63Q | Good assessment tool for mapping journey to accomplish specific tasks – useful for events and public buildings |
| Dementia Action Alliance: Creating a local dementia action alliance | England, UK | http://bit.ly/2wPnZYq | Guidance for setting up a Dementia Action Alliance |
| Alzheimer’s UK: A guide for MPs and councillors to create dementia-friendly communities in England | UK | http://bit.ly/2weuBl7 | Guidance for local politicians |
| Alzheimer’s UK: Becoming a dementia-friendly arts venue: A practical guide | UK | http://bit.ly/2wPBtn4 | Aimed at arts venues |
| Alzheimer’s UK: Creating a dementia friendly workplace | UK | http://bit.ly/2kPh76v | Creating a dementia friendly workplace |
| Alzheimer’s UK: Dementia Friendly Technology | UK | http://bit.ly/2prBHwm | Technology charter |
| Alzheimer’s UK: Making financial services more dementia friendly | UK | http://bit.ly/2weeiF6 | Financial Services Charter |
| Alzheimer’s UK: Guidance and tips for staff to help people with dementia | UK | http://bit.ly/2w9OmuX | Tips for customer facing staff |
| Alzheimer’s UK: Creating a dementia-friendly generation | UK | http://bit.ly/2wPh9Cf | Creating a dementia friendly generation |
| Alzheimer’s UK: Becoming a dementia-friendly retailer: A practical guide | UK | http://bit.ly/2fKtkfj | Retailers guide |
| Alzheimer’s UK: How to become dementia friendly: Quick tips for organisations and businesses | UK | http://bit.ly/2ngBOgN | Tips for businesses and organisations |
| Dementia Enabling Environments | Australia | http://bit.ly/2fKs63Q | Comprehensive and clear guidance on accessibility |
| Public Health Agency of Canada: Age-friendly communities  valuation guide  Using indicators to measure progress | Canada | http://bit.ly/2w9BN2N | Age friendly indicator development: useful in planning evaluations |
| WHO: Measuring The Age-Friendliness of Cities  A Guide to Using Core Indicators | International | http://bit.ly/2ncUm0d | Comprehensive guide to setting up evaluation processes |
| WHO: Check list of Essential Features of Age-friendly Cities | International | http://bit.ly/1FOWnPN | Checklist of age-friendly features |
| Belfast City Council: Age-Friendly Belfast | Northern Ireland | http://bit.ly/1swJWWl | Intergenerational Toolkit/leaflet |
| AARP: Evaluating Your  Age-Friendly Community Program  A Step-by-Step Guide | USA | http://bit.ly/2w0QTaw | A straightforward and accessible guide to evaluation of age-friendly initiatives |
| Swimming.org: Dementia Friendly Swimming | England | http://bit.ly/2uIlsln | * Resources that include training materials * Thorough access and audit guide for leisure centres * Marketing materials * Feedback forms * Planning Materials * Role-specific set of training outlines |
| Joseph Rowntree Foundation, Alzheimer’s Society Northern Ireland and British Deaf Association: Dementia friendly  communities:  supported learning and outreach  with the deaf community | UK | http://bit.ly/1Ykt6FL | Deafness and Dementia in relations to DFCs |
| Dementia Without Walls | UK | http://bit.ly/2uIwqr8 | Resources on evaluation |
| West Yorkshire Playhouse: Guide to Dementia Friendly Performances | Yorkshire, UK | http://bit.ly/1sm2vyM | Dementia Friendly Performances |
| NHS England: Dementia Friendly Dentistry: Advice and guidance for the primary dental care team: Dementia Toolkit | UK | http://bit.ly/2vDxECK | Guidelines for dentists |
| Tunbridge Wells Museum & Art gallery: Dementia Toolkit | UK | http://bit.ly/1Rv3V4F | Guide for creating dementia friendly museums |
| The Alzheimer’s Society of Ireland: Supporting people with dementia: A guide for retailers | Republic of Ireland | http://bit.ly/2wauQ1A | Retailers guide |
| Genio: Inclusion of People with Dementia in the Design of Services | Republic of Ireland | http://bit.ly/2uIZeQ5 | Guide to involving people with dementia in service design |
| Dementia Elevator | Republic of Ireland | http://bit.ly/2uJkHbT | Sector specific awareness courses |
| Dementia Action Alliance: Guidance for businesses | England, UK | http://bit.ly/2wfoJYP | Factsheet for businesses |
| Dementia Action Alliance: Examples of Actions | England, UK | http://bit.ly/2vDG8Ki | List of actions by sector |
| Social Care Institute for Excellence (SCIE): Dementia – What it is and what it isn’t | UK | http://bit.ly/2uPpS64 | Open learning course |
| Social Care Institute for Excellence (SCIE): | UK | http://bit.ly/2vINB9j | Good resource concerning environments |
| How to become a dementia friendly practice | England, UK | http://bit.ly/2wfiSD5 | Guidance for primary care staff |

# PRIMARY QUALITATIVE DATA COLLECTION FROM STAKEHOLDERS

Central to our methodology was to engage with people who are personally affected by dementia and the organisations that represent them. We did this in four ways (discussion groups, online survey, professional phone interviews and a meeting in Brussels of the European Working Group of People with Dementia).

Discussion groups with people with dementia in England

First, via Innovations in Dementia’s connections to the DEEP network, we conducted two discussion groups, one in Bradford with the members of the ‘Face It Together (FIT) group (here 6 people joined the discussion for approximately one hour), and the second in Redditch with the Redditch Friends Together group (7 members attended for a one-hour discussion).

To maintain consistency, we devised a topic guide that included the following questions/topic areas:

* What are your experiences in your local community: what is your biggest complaint?
* What does a truly DFC look like?
* How would it make you feel?
* What would help this happen?
* What would hinder this?

To thank our participants for their time, we made small ‘thank you’ payments.

All participants were able to offer informed consent and this was audio recorded in writing at the time of interview. The team discussed the feasibility of asking individuals to complete a monitoring questionnaire asking for demographic information, however it was decided that this would could be stressful and off-putting for individuals (who attend without the support of a care-giver). Furthermore, it was felt that, perhaps the most pertinent aspect of demographic profile, i.e. the degree of severity of a person’s condition, would be almost impossible to assess in a meaningful and reliable way and risked medicalising the ethos of the group.

The discussions were audio recorded, written up as transcripts and analysed thematically under the ‘cornerstone’ themes of ‘People’, ‘Place’, ‘Networks’, ‘Resources’ and ‘the involvement of people with dementia’.

# CALL FOR EVIDENCE

Secondly, using a long list of contacts provided by the England Department of Health, we sent a mass mail-out to 71 European counterparts in 29 countries with a ‘call for evidence and information request’. As well as using this avenue to collect primary information and data, this also provided the opportunity to directly engage those involved with initiatives. We initiated telephone interviews with a selection of those who responded to call.

A list of EU countries we attempted to contact and detail of progress / response is given below in Table 3:

Table 3: Countries Included

|  |  |
| --- | --- |
| **Country** | **Data Collection** |
| Austria | Exchanged email contact but did not return for interview, included practice e.g. based on published evidence |
| Belgium | Did not respond to invite |
| Bosnia and Herzegovina | No contact available |
| Bulgaria | In-depth phone interview |
| Croatia | Did not respond to invite |
| Cyprus | Did not respond to invite |
| Czech Republic | Responded by email to say there were no initiatives in the Czech Republic at present, however they were represented at the EWGPWD and interviewed |
| Denmark | Did not respond to invite |
| Estonia | Did not respond to invite |
| Finland | Interviewed at the EWGPWD |
| France | Email response saying too early to collect data as initiatives at launch stages during the review |
| Germany | Conducted two in-depth telephone interviews and also interviewed at EWGPWD |
| Greece | Conducted an online focus group with three Greek participants |
| Hungary | Did not respond to invite |
| Ireland | Received 2% of our responses from the Republic of Ireland and conducted an in-depth interview, also interviewed at EWGPWD |
| Italy | Received a very late survey response (for which we extended our deadline to include), and conducted an in-depth interview |
| Latvia | Did not respond to invite |
| Liechtenstein | Did not respond to invite |
| Lithuania | No contact available |
| Luxembourg | Did not respond to invite |
| Malta | Did not respond to invite |
| Netherlands | Received 2% of survey responses from the Netherlands. The team tried to arrange an interview with a spokesman from the Netherland but no response was forthcoming, however the team received helpful and informative feedback on the report. |
| Norway | Received 22% of our survey responses from Norway, and conducted two in-depth telephone interviews, also interviewed at EWGPWD |
| Poland | Received 2% of survey responses from Poland |
| Portugal | Interviewed at the EWGPWD |
| Romania | No contact available |
| Scotland | Received many survey responses and conducted an in-depth phone interview; also interviewed at EWGPWD |
| Slovak Republic | Did not respond to invite |
| Slovenia | Did not respond to invite |
| Spain | Received 2% of our responses to the online survey and conducted an in-depth phone interview with two specialists using an interpreter |
| Sweden | Exchange email contact and information sharing, interviewed at EWGPWD and included practice example based on published evidence. |
| UK (England, Wales and Northern Ireland) | Received the majority of survey responses and around half of our interviews from the UK |

# PROFESSIONAL INTERVIEWS

We conducted 20 interviews with 25 participants consisting of 14 1-1 in-depth phone interviews lasting for up to one hour with the exception of an interview conducted in Spanish with an interpreter, which took over an hour. 3 group interviews via phone / Skype and 3 1-1 interviews in person. We conducted interviews during face-to-face visits with individuals who were based in the North of England and where this allowed us to meet face-to-face with people with dementia and their supporters. We visited:

* One individual living in a care home;
* A theatre which has been working to become dementia friendly, since this allowed us to meet a group of people with dementia and observe part of the regular creative session they attend, as well as interview the Community Development worker;
* A regular pub meeting of a ‘grassroots’ Dementia Friendly initiative, where we were able to speak informally to people with dementia and their caregivers as well as interview the voluntary coordinator before the session began.

These opportunities enable us to see some dementia friendly initiatives in action.

We developed a menu of questions to be used flexibly in the interviews, the purpose of which were:

* To identify and gather information on case studies;
* To understand some of the national differences (dementia infrastructure, culture, etc.) which might influence the opportunities and barriers for the development of DFCs;
* To identify what is needed from this evidence review, the forthcoming toolkit and pilots to support development of DFCs in this context?
* To explore how the concept of a DFC is understood and defined.

The menu of questions asked in the phone interviews included:

* What is a ‘Dementia Friendly Community’? Do you feel there are differences of opinion/ ambiguities here?
* How would you describe the evidence base in relation to DFCs at present? Where are the gaps? Are you able to tell us about studies or reports in your country / organisation which we should include in our review? How do you know DFCs work?
* What are the key features of a good DFC from your perspective?
* What helps to build and maintain a DFC or accessible communities?
* What gets in the way?
* What difference should a good DFC make to those living within it: those affected by dementia, businesses, public services and community organisations?
* What is the gap that this report can fill in your view? What evidence is needed to help policy makers and people in communities and service providers launch, nurture sustain and promote DFCs (in your country)?
* Tell us about your good practice in relation to DFCs.

Researchers wrote up their interview notes and these were thematically analysed, using the headings of the ‘cornerstones model’ as nodes.

Table 4 below provides detail of interviewees:

Table 4: Professional Interviewees

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Name** | **Role** | **Organisation** | **Country** | **Method** |
| Shima Mehrabian | Member of Executive Board  Neurologist, Bulgaria | Bulgarian Society of Dementia  University Hospital Alexandrovska, Sofia | Bulgaria | 1-1 phone interview |
| Gabriele Kreutzner | Information and Publicity Lead | Demenz Support Stuttgart gGmbH | Germany | 1-1 phone interview |
| John Starr | Chair | Saffron Walden Dementia Action Alliance | England | 1-1 phone interview |
| Petra Weritz-Hanf | Civil servant responsible for health in old age, help with dementia | Federal Ministry for Family Affairs, Senior Citizens, Women and Youth  Federal Government | Germany | 1-1 phone interview |
| Anna Buchanan | Director, People affected by dementia programme | Life Changes Trust | Scotland | 1-1 phone interview |
| Avril Easton | Project Leader - Dementia Friendly Communities | Alzheimer’s Society Ireland | Ireland | 1-1 phone interview |
| Ioanna Petroulia | Centre for Health Services Research | Department of Hygiene and Epidemiology Medical School University of Athens | Greece | Group discussion via Skype |
| Antonios Politis | Associate Professor, Geriatric Psychiatry | National and Kapodistrian University of Athens | Greece |
| Antonis Mougias | Psychiatrist  President | Nestor Psychogeriatric Association (specialist dementia clinic), Athens  Association of Caregivers for Patients with Alzheimer’s Disease and Related Disorders | Greece |
| Kari Midtbø Kristiansen | Executive manager | Norwegian National Advisory Unit on Ageing and Health | Norway | 1-1 phone interview |
| Randi Kiil | Head of Comms | Norwegian Health Association (Nasjonalforeningen for folkehelsen) | Norway | Group interview via phone |
| Ingrid Rise Fry | Dementia Friendly Communities Programme Manager | Norwegian Health Association  (Nasjonalforeningen for folkehelsen) | Norway |
| Assumpció González Mestre | Lead for Patient Expert Group of Catalonia | Strategic Programme for Prevention and Care in Chronicity Department of Health of Catalonia | Spain | Group interview via phone |
| Paloma Amil | Member of Patient Expert Group of Catalonia | Strategic Programme for Prevention and Care in Chronicity Department of Health of Catalonia | Catalonia (Spain) |
| Esther Sánchez | Member of Patient Expert Group of Catalonia | Strategic Programme for Prevention and Care in Chronicity Department of Health of Catalonia | Catalonia (Spain) |
| Mario Possenti | Association Coordinator | Federazione Alzheimer Italia | Italy | 1-1 phone interview |
| Ana Diaz | Project Officer | Alzheimer Europe | Luxembourg | 1-1 phone interview |
| Ann Johnson | Person living with dementia and retired nurse educator | UK Prime Minister’s Champions Group for Dementia | England | 1-1 interview in person |
| Becca Reed | Community Engagement Administrator, Dementia Friends Team | Alzheimer’s Society | England | 1-1 phone interview |
| Emma Fraser | Senior Development Officer  Community Safety Policy and Projects | London Fire Service | England | 1-1 phone interview |
| Jo Hughes | Project Coordinator, Side-by-side | Alzheimer’s Society, Worcestershire | England | 1-1 phone interview |
| Tracy Sneider | Dementia Friendly Communities Project Officer | Kent County Council | England | 1-1 phone interview |
| Nicky Taylor | Community Development Manager | West Yorkshire Playhouse | England | 1-1 interview in person |
| Peter Smith | Voluntary coordinator (and former family care-giver) | Dementia Friendly Rothwell, Leeds | England | 1-1 interview in person and informal conversations with people with dementia and care-givers attending session |
| Shibley Rahman | Author and Retired Medic | Independent | England | 1-1 phone interview |

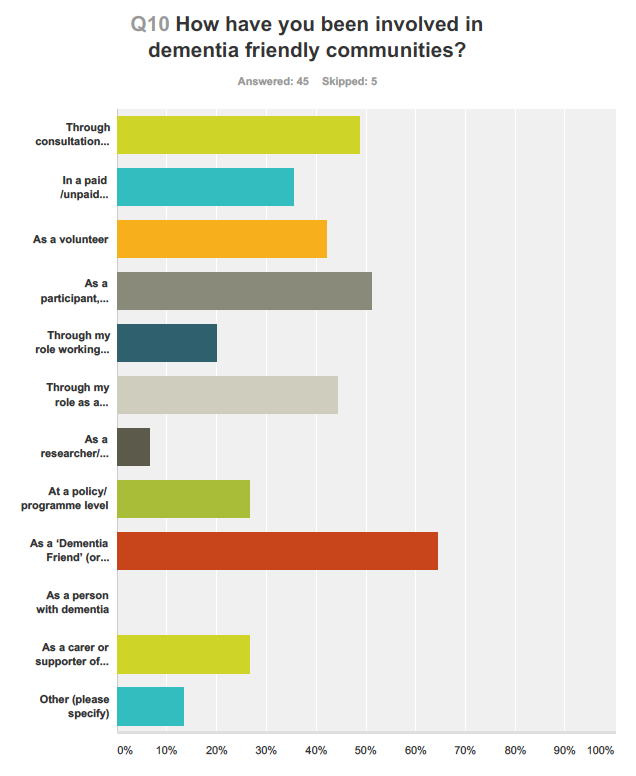
# ONLINE SURVEY

Thirdly, we devised an online survey using Survey Monkey, which was aimed at capturing the views of a broad range of DFC stakeholders including people with dementia and those with other lived experience. Participants were offered the opportunity to fill in the survey in their own language. Using our contact list from the ‘call for evidence’ and any new contacts made from the responses, we sent out a second mass mail to invite European counterparts to take part in the survey and to distribute it amongst their networks. Our research assistant in charge of the survey analysed the findings thematically to inform the final report.

Our online survey provided 57 responses in total and respondents were asked the following:

* What helps people with dementia to take part in everyday life in your local area?
* Which people or organisations (can) help this to happen?
* What stops people with dementia from taking part in everyday life in your local area?
* Which people or organisations can remove these barriers?
* What does the term ‘Dementia Friendly Community’ mean to you?
* What they thought about the strengths and weaknesses of four alternative definitions supplied (definitions listed below):
  + 1: ‘A dementia friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them’;
  + 2: ‘A dementia friendly community is one that enables people with dementia to: i) Find their way round and be safe; ii) Access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices); and iii) Maintain their social networks so they feel they continue to belong’;
  + 3: ‘A dementia friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value’; and
  + 4: ‘Dementia friendly communities are geographic areas where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people are aware of and understand dementia, and people with dementia feel included and involved, and have choice and control over their day-today lives. A dementia friendly community is made up of individuals, businesses, organisations, services, and faith communities that support the needs of people with dementia’.
* How have you been involved in DFCs?
* Please tell us which country you are based in.
* How, in your view, can we tell if DFC initiatives are working?
* We are currently looking for examples which highlight what works in getting DFCs started, publicising them, and keeping them going. We want to include examples from different countries and contexts. If you would like to suggest an example, please give us contact details or a link so we can find out more.

The survey asked people to say whether or not they had lived experience of dementia for monitoring purposes and asked how respondents were involved with DFCs. Details of the involvement are produced in the chart below:



The survey link was sent out to 26 countries via a list of email addresses provided by the England Department of Health, however 8 of those email addresses did not contain information on their country of origin. Organisations and roles of contacts were not provided. A representative table of countries receiving the survey is given in Table 5 below:

Table 5: Countries receiving online survey

|  |  |
| --- | --- |
| **Country** | **# Contacts distributed to** |
| Austria | 1 |
| Belgium | 1 |
| Croatia | 1 |
| Cyprus | 2 |
| Czech Republic | 1 |
| Denmark | 1 |
| Estonia | 1 |
| Finland | 1 |
| France | 3 |
| Germany | 2 |
| Greece | 3 |
| Hungary | 2 |
| Ireland | 4 |
| Italy | 6 |
| Latvia | 2 |
| Liechtenstein | 2 |
| Luxembourg | 3 |
| Malta | 1 |
| Netherlands | 1 |
| Norway | 6 |
| Poland | 2 |
| Portugal | 1 |
| Scotland | 2 |
| Slovak Republic | 2 |
| Slovenia | 1 |
| Spain | 3 |
| UK (England, Wales and Northern Ireland) | 1 |

Although the survey received 57 responses, it is not possible to describe this as a response rate as contacts were asked to distribute the survey throughout their networks. The survey was also anonymous.

# FOCUS GROUP WITH EUROPEAN WORKING GROUP OF PEOPLE WITH DEMENTIA

The following members participated in the group interview:

* Helen Rochford Brennan (Ireland) Chairperson
* Alv Orheim (Norway) Vice-Chairperson
* Chris Roberts (UK – England, Wales and Northern Ireland) Vice-Chairperson
* Helga Rohra (Germany)
* Nina Balackova (Czech Republic)
* Carol Hargreaves (UK – Scotland)
* Karin Gustafsson (Sweden)
* Idalina Aguiar (Portugal)
* Markku Parkkisenniemi (Finland)

Four care-givers supporting these members (Jane, Lars, Nelida and Berit) also contributed actively to the discussion. Ana Diaz, Project Officer, Alzheimer’s Europe took detailed notes of the discussion. An audio recording of the session was also made but, due to the tight timescales and the degree of details of the notes made by Ana, it was decided not to transcribe the full discussion, which lasted a total of three hours, including breaks and presentations. The write up was analysed, again using the thematic headings of the four cornerstones model.

We include overleaf:

* The information we sent out to participating members of the group one week before the meeting;
* The slide deck we used to structure this discussion.

Information sent out to participating members

**Information to go out to members of the European Working Group of People with Dementia about the session on the morning of Tuesday 13th December**

**Who are we?**

Imogen Blood and Steve Milton

**Imogen** runs the independent research consultancy, **Imogen Blood and Associates**.

We work with governments and services to make services and policies fairer and better.

We are passionate about using research to make sure that diverse (and often unheard) voices are at the heart of this.

You can find out more about us at: [www.imogenblood.co.uk](http://www.imogenblood.co.uk)

**Steve** is a director of **Innovations in Dementia** - a social enterprise focused on the voices of people with dementia. Innovations are probably best known for the DEEP project - a network of groups of people with dementia in the UK.

You can find out more at [www.innovationsindementia.org.uk](http://www.innovationsindementia.org.uk)

**What are we doing?**

We are doing a piece of work for the English Government (Department of Health) as part of the European Union’s Joint Action on Dementia.

This involves drawing together what is already known about how to create ‘Dementia Friendly Communities’ across Europe and beyond.

Our findings will inform a toolkit and some pilot projects across Europe on Dementia Friendly Communities in 2017.

We hope that people involved in developing Dementia Friendly Communities across Europe will read our report and use it to help them:

* Understand what makes communities ‘dementia friendly’ (and what doesn’t);
* Come up with ideas of actions they might take in their communities;
* Involve people with dementia in this work in a meaningful way; and
* Understand whether what they are doing is actually making a difference to the quality of life of people with dementia and those who support them.

Our report needs to be written by Christmas.

**How have we gone about this?**

So far, we have:

* Met with two small groups of people with dementia (in Redditch and Bradford in the UK) to hear what they think makes a community ‘dementia friendly’;
* Found and read over 70 reports and articles relevant to ‘Dementia Friendly Communities’. We have been particularly interested in what has been learned so far from these projects, what works well and what difference it makes to the lives of people with dementia;
* Sent out an online survey to national representatives in each of the European countries and asked them to send these out to anyone with an interest in Dementia Friendly Communities. These have asked people what makes their communities accessible/ inaccessible and what has been done to improve this. We have had over 60 responses; and
* Interviewed around 20 people involved in Dementia Friendly Communities across Europe. We have done most of these by phone, but we have been out to visit some local projects in England and this has included meeting people with dementia who are involved.

**Why are we coming to your meeting?**

We are looking now at what we have learned from all this and starting to write it up into a report.

We are really keen to share some of the headlines with you and see whether these fit with your experiences and views and whether you have things to add.

We are particularly keen to feed in your practical advice as to how people with dementia can be engaged at the start and heart of Dementia Friendly Community initiatives.

We are really delighted that you are setting aside the morning session of Tuesday 13th December to help us in this.

We will be arriving at the hotel the evening before and hope to meet as many of you as we can over dinner on Monday evening and/or breakfast and lunch on the Tuesday. This should give us a chance to get to know each other better and to hear your views in a more informal setting.

**What will we do during the session?**

**Part 1: What are your experiences in your local community?**

We would like to spend the first part of the session hearing about your individual experiences and (where you feel in a position to do this) those of others with dementia about the accessibility of YOUR community.

Questions will include:

1. **What helps you (and/or other people with dementia) to take part in day-to-day life in your local area?**
2. **Which people or organisations help this to happen?**
3. **What stops you (and/or other people with dementia) from taking part in day-to-day life in your local area?**
4. **Which people or organisations can remove these barriers?**

**Part 2: Sharing key messages from our project**

We would then like to share with you some of the key messages from our project.

We will present a slide with one or two bullet points on it; explain what we mean by this then pause to find out whether you think this resonates with your experiences.

We expect to share between 4 and 6 of these headlines depending on the time.

We haven’t yet decided on these headlines (as we will be working on them between now and then!) but an example might be:

“A ‘dementia friendly community’ is more about the people than about the physical environment”

**Part 3: Practical examples of how best to involve people with dementia in ‘Dementia Friendly Communities’**

**Have you been involved in creating ‘Dementia Friendly Communities’? If not - you will have been asked to be involved in dementia-related discussions.**

We wondered if you might think of two examples:

* When your engagement went well - and why…
* When it did not go so well, and why…

Given these experiences, what advice might we give to those planning to set up Dementia Friendly Communities about what they need to do to make sure people with dementia are involved at the heart and from the start?

We will take a 30 minute break in the middle of this session.

If everyone is happy with this, we will record the session so we can capture your views accurately.

We hope to use some quotes from the discussion in our report to make sure that the voices of people with dementia speak out through it. However, we will not say which individual said each quote. Do let us know if there is anything you would rather we did not include.

We really look forward to meeting you in Brussels.

If there are any questions before the meeting, you can get in touch with us at:

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Presentation to European Working Group 





























# HOW WE DEVELOPED THE DEFINITIONS, MODEL AND PROPOSED INDICATORS

The online survey feedback in relation to the four existing definitions was analysed, drawing out key themes in the response to each definition. These were synthesised, along with data from the interviews and group discussions in which definitions had been specifically discussed and along with the key messages about the core values and objectives of a DFC drawn from across the data sources. From this, a list of key principles and considerations for a definition was identified. The team them drafted the definition with the intention of responding as far as possible to key definitions, within a succinct form of words.

In the first draft of the report, the team proposed a list of the core features of and essential participants in a ‘good’ DFC, based on the evidence reviewed. The senior researchers subsequently met and checked alignment with the key components of other existing models (such as the Alzheimer’s Society England’s recognition process (Alzheimer’s Society and DAA 2015), the British Institute of Standards (BSI 2015) and the EFID (Williamson 2016) review). From this, we distilled and developed the visual model.

In the first draft of the report, the team proposed a set of indicators for each of the four ‘cornerstones’ of People, Place, Networks and Resources, based on the evidence reviewed and on our appraisal of the methods used in existing DFC evaluations.

We have subsequently tightened up the structure of these in order to align them to the World Health Organisation’s work to develop Age Friendly indicators.

1. http://www.efid.info/eng/resources/dementia-friendly-community-case-studies/ [↑](#footnote-ref-1)