



DEMENTIA IN THE PUBLIC DOMAIN

VOICE AND AGE-BASED
PERSPECTIVES ON DEMENTIA,
SOCIAL DISADVANTAGE AND
PUBLIC HEALTH CAMPAIGNING

Simon Biggs, Irja Haapala and Ashley Carr

The project was part of the Cognitive Decline Partnership Centre (CDPC, <http://sydney.edu.au/medicine/cdpc>) receiving support from the Australian National Health and Medical Research Council in partnership with leading provider organisations and strong involvement from the National Consumer Network and Dementia Australia. University of Melbourne Project Ethics ID: HREC 1647136.1, 2016-2018.

Photo overleaf: “Billibellary’s Walk Totem Poles Signage” (Photo: Peter Casamento). Further information on this sculpture can be found at: <https://murrupbarak.unimelb.edu.au/engage/billibellarys-walk>

Published by University of Melbourne

ISBN: 978 0 7340 5475 3 (EBOOK)
978 0 7340 5474 6 (PRINT)

Copyright: the authors. You may copy, distribute, display, download or otherwise freely deal with this work for any purpose, provided that you attribute the authors as the owner. However, you must obtain permission if you wish to a) include the work in advertising or a product sale, or b) modify the work.

Suggested citation: Biggs, S., Haapala, I., & Carr, A. (2019). Dementia in the Public Domain Voice and Age-based Perspectives on Dementia, Social Disadvantage and Public Health Campaigning. Melbourne: University of Melbourne.

We acknowledge the traditional owners of the country that this sculpture celebrates, the Wurundjeri people of the Kulin nation. We honour their elders past and present. We also honour other elders who participated in this project.

SUPPORTED BY



CONTENTS

| | |
|--|----|
| About the Report | 3 |
| About the Project | 5 |
| Perspectives on Dementia - Mapping the Current Evidence-base | 14 |
| Voice Perspectives on Dementia | 17 |
| Comparison of Voice Perspectives | 20 |
| Voice and Family Connection Perspectives on Dementia | 24 |
| Voice & Age Perspectives on Dementia | 30 |
| Comparing Attitudes: Age, Voice and the General Public | 37 |
| The Impact of Dementia as a Form of Disadvantage | 41 |
| Priorities for Campaigns on Dementia by Voice and Age | 51 |
| Campaigners' Perspective | 58 |
| Discussion, Conclusions and a Way Forward | 65 |
| References | 75 |
| Contacts and more information | 79 |
| Acknowledgements | 80 |
| Appendix | 82 |
| Summary Table 2A: People with dementia and Carers Voice & Age Perspectives | 88 |
| Summary Table 2B: Professionals' Voice & Age Perspectives | 90 |



ABOUT THE REPORT

This Report is for people interested in the public perception of dementia and how campaigning can better reflect key perspectives on dementia as a social issue.

We identify the distinctive viewpoints of people with dementia, carers and professionals in health, social work and in everyday service industries. We examine overlaps and differences between these perspectives and their connection to local and national campaigning. A key finding is that rather than responding to stigma, people with dementia want to live normally in their neighbourhoods and communities, while others want to know how to communicate with them. It's suggested that dementia can be seen as a source of disadvantage rather than simply reflecting certain risk factors. The Report should help policy makers, campaigners and those engaged in public relations, helping professionals and people affected by dementia in their understanding of multiple perspectives and changes needed when dementia is seen as a specifically social phenomenon.



“Campaigning tells a story about dementia that both reflects and affects public attitudes. ‘Dementia in the Public Domain’ aims to provide support for positive forms of public dialogue, through engaging with specific voices and campaigner’s priorities for intervention, to improve the lives of people with dementia and their carers.”

Professor Simon Biggs



ABOUT THE PROJECT

This Report draws on findings from a three-year research project called Dementia in the Public Domain.

The project was funded by the National Health and Medical Research Council via the Cognitive Decline Partnership Centre, a national research initiative to improve the lives of people with dementia and their carers. It examined current perceptions of dementia from a range of perspectives to inform future public dialogue.

BACKGROUND: DEMENTIA AS A PUBLIC ISSUE

The place of dementia in the public domain is becoming increasingly important for a number of reasons.

First, there are more people with dementia. This is mostly a consequence of rising numbers of older people. This gives us a paradox: that even though the likelihood of getting dementia is actually falling amongst the older population itself, the total number of people with dementia is growing as a proportion of the population as a whole (Matthews *et al.*, 2016).

Second, finding a cure has emerged as a much more complex and difficult problem to solve than first expected. This has led to a renewed interest in helping people manage the diverse symptoms and consequences of the dementias in both clinical and care settings (Prince, 2017).

Third, a shift toward care in the community has made dementia more visible. This includes the delivery of care packages to people in their own homes plus a reliance on family carers, so that only people with the most severe disabilities need to go into residential care. It is also reflected in the development of specific dementia-friendly communities and the adoption of dementia-friendly practices by local councils (Phillipson *et al.*, 2018).

Fourth, attitudes to ageing and to dementia have increasingly been shown to affect older people's sense of confidence, social engagement and positive or negative identity. If a group, such as people with dementia, are faced with social exclusion and stigmatising reactions from others, this not only affects their ability to interact successfully in society, it also affects their inner sense of self-worth. When associated with ageing, dementia can amplify fears of growing old (Biggs, 2018).

Fifth, dementia has become associated with the rising costs of health and social care provision, both nationally and internationally (OECD 2015- <http://www.oecd.org/health/addressing-dementia-9789264231726-en.htm>). This has been used for political purposes to generate competition between age groups rather than addressing growing inequality within societies.

Sixth, following the wider disability movement, people with dementia are finding a political voice. This implies not only that professional voices would no longer be the dominant perspective determining service systems and wider public attitudes, it also indicates that carers and people with dementia should be distinguished from each other. Simple distinctions between providers and consumers become more difficult to sustain (Dementia Alliance International, 2018).

These points indicate that a person's position or 'voice' in connection to dementia, age and life-course priorities, plus degrees of family support, can all affect how people feel, think and act in the public domain, how they construct a perspective on dementia and those close to it. This in turn will influence their priorities when it comes to social responses to the phenomenon, the perceived relevance of campaign messages and the place of people with dementia in society.

ABOUT THE PROJECT

In order to understand the relationship between public attitudes toward dementia, how it is experienced from different perspectives and its relation to campaigning, we asked the following research questions:

- What are different people's voices saying, especially those who interact with dementia on an everyday basis? This connects to questions of public attitudes and the possibilities for public empathy and engagement. What, in other words might make people better able to understand dementia, its impacts and consequences for people living with it, carers and others.
- To what degree does contemporary campaigning take voice and age into account in their messaging priorities? Here the question goes beyond issues of target marketing and whether predefined messages have been understood, to considering the degree of connection between the messages being sent and the questions that the intended recipients are asking.

By posing the question of increased public understanding, we explore whether living with dementia actually generates forms of disadvantage, as well as being subject to wider forms of social risk.

DEMENTIA

We have used dementia as an umbrella term to refer to the different types of progressive neurological conditions affecting the brain (Winblad et al., 2016). While dementia consists of a number of diverse conditions, in the public mind, these frequently exist as a common and simplified social category (Cheston, Hancock & White., 2016). In this report, we refer to people who have various forms of the disease as 'people with dementia', while 'people affected by dementia', also includes those in family and unpaid caring roles whose day to day lives are influenced by dementia. In addition, we use the phrase 'condition' to refer to dementia's psychological and functional correlates.



IN THIS REPORT, WE PRESENT OUR WORK IN FOUR WAYS THAT EXAMINE DEMENTIA IN THE PUBLIC DOMAIN:

First, we look at the voice-perspective held by participants. The qualitative methods we used, allowed the authentic voice of each perspective to come out. The term 'voice' is used to identify distinctive standpoints, often in relation to a particular issue, where historically certain perspectives have been disempowered. In this research, these include the perspectives of people with dementia themselves, carers who were family members and professionals, including those working in health care, social work and care coordination, plus people working in the service sector such as hospitality staff, hairdressers, librarians and people working in small businesses. (Haapala, Carr & Biggs, 2018a).

Second, we have examined closeness in terms of whether people have a family connection to dementia. This overlaps with voice to some degree but allows members of the three professional groups to be identified by their personal experience as well as their public position (Haapala, Carr & Biggs, 2018b).

Third, we look at age difference. There is a volume of evidence that suggests that different age groups have distinctive priorities depending upon their own position in the life-course and the age group they are interacting with (Biggs, Haapala & Lowenstein, 2011). Each will influence a person's attitudes toward adult ageing, later life and dementia. Here, we have looked at people in early adulthood, mid-life, later mid-life and older age. Because the participants we have studied were either working or caring or living with dementia, the number of participants in each age group will vary depending upon their voice perspective (Biggs, Haapala & Carr, 2018).

Fourth, we examine the relationship between National and Local campaign priorities, based on nine countries and six initiatives within Australia. Representatives of these national and local organisations were interviewed. Their perceptions were then compared to the voice perspectives identified above (Biggs, Haapala & Carr, 2019b).

Each contain, to different degrees, a link to dementia as a social phenomenon and the possibilities for influencing attitudes to dementia in the public domain.

Voice and Age are used in this Report to analyse responses on the impact of dementia and on people's campaign priorities. Voice is also used to examine the priorities identified by National and Local Campaigning. These perspectives allow us to ask questions about the way different forms of social connection interact with the impacts and priorities arising from the condition.

ABOUT THE PROJECT

OUR APPROACH

Our research project consisted of six distinct phases. Throughout, we have worked closely with an advisory group representing care service providers, and carers and people with dementia under the auspices of Dementia Australia (See Acknowledgements).

In Phase 1, we explored current literature on public perceptions of dementia and used this evidence-base to design our qualitative research.

Phase 2 involved in-depth semi-structured interviews of 111 participants in five Australian states. Five different perspectives on dementia were included; the Voice of people with dementia (n=19); carers (n=28); health care professionals (n=21) including nurses, general practitioners, allied health professionals, care service directors; social work professionals (n=23), including care coordinators, community support workers and care managers; and service professionals (n=20), including hairdressers, e-learning- and media consultants, small business owners and employees, librarians, teachers and hospitality staff (Table 1).

SIX PHASES OF THE PROJECT:

- Phase 1** Mapping current research evidence
- Phase 2** Interviewing five Voices: People with dementia, carers, health care, social work and service professionals
- Phase 3** Interviewing campaigners at community and national level
- Phase 4** Analysis and Synthesis
- Phase 5** Future-Search Workshop & Consultation
- Phase 6** Publications and Dissemination

Table 1. Participant characteristics by perspective group

| | People with dementia n=19 | Carers n=28 | Professionals n=64 | Professionals | | | All n=111 |
|------------------|---------------------------|-------------|--------------------|------------------|------------------|---------------|-----------|
| | | | | Health care n=21 | Social work n=23 | Services n=20 | |
| Gender | | | | | | | |
| Men (n) | 13 | 4 | 11 | 1 | 5 | 5 | 28 |
| Women (n) | 6 | 24 | 53 | 20 | 18 | 15 | 83 |
| Age Group | | | | | | | |
| Younger Adults | 0 | 3 | 10 | 5 | 4 | 1 | 13 |
| Mid-Lifers | 0 | 2 | 21 | 6 | 8 | 7 | 23 |
| Later Mid-Lifers | 11 | 15 | 28 | 10 | 9 | 9 | 54 |
| Older Adults | 8 | 8 | 5 | 0 | 2 | 3 | 11 |
| Age (years) | 59 - 87 | 30 - 86 | 25 - 71 | 28 - 62 | 25 - 70 | 33 - 71 | 25 - 86 |

Footnotes to Table 1. 1) The majority (13/19) of interviewees with dementia had been diagnosed with young onset dementia, Lewy body, frontotemporal or unspecified at 53 – 63 years of age; others with Alzheimer’s disease or vascular dementia, at 69-81 years. Time since diagnosis varied between 1 and 8 years. Nine participated with their care partner. 2) Carers were either currently or in the recent past had been in a carer’s role for their partner, parent(s) and/or a close relative. They had been a carer for five years on average, from 4 months to over 15 years. 3) Participants were grouped into four age-groups: Younger Adults (25-35 years), Mid-lifers (36-50 years), Later Mid-lifers (51-65 years) and Older Adults (66-87 years).

Participants were recruited through public advertisements via professional and consumer organizations and with calling cards placed in community-centres, cafes and shops inviting participation from within the community and from as wide an age range as possible starting with 18 years. The final sample had an age range from 25 years to 87 years (Table 1).

The interviews, lasting for approximately one hour, were conducted via telephone for professionals and most of the carers. People with dementia were interviewed face-to-face, unless they preferred by phone.

During the interview we asked the interviewees to speak about five main themes:

1. **First thoughts on dementia.** Here we asked two questions: When I say 'dementia', what do you think about and To what degree is it a normal part of ageing? These were designed to provide us with the participant's immediate response to the condition and to elicit views on ageing and its association with dementia.
2. **Public perceptions and generational difference.** Here we asked two questions: How do you think dementia is perceived by people in the street and How do you think the perceptions might differ between generational groups? These posed the question of public attitudes to dementia and how it is affected by age differences. Overall responses were also analysed by age-group.
3. **Main impacts of dementia.** Here we drew on the narrative analysis of the entire interview and from responses to the question: In your mind, what are the most important impacts of dementia?
4. **Personal priorities.** Here we asked two questions: If you were diagnosed with dementia, what would you want, and alternatively, when interviewing people with dementia: Is there something you would want, going forward with living with dementia? These questions aimed at bringing the issue home to respondents themselves, as either a first step to an empathic understanding or by tapping into a personal connection to the issue.

5. **Priorities for action and campaigns related to the condition.** Here two questions were used to engage with action wanted in the public domain: In your mind, what are the three most important things that should be done about dementia and What would an effective campaign on dementia look like?

In Phase 3 of the project, we interviewed representatives from nine national/state level organisations and campaigning organisations and six local community initiatives in Australia. This included ten participants (two men and eight women, aged between 27 and 58 years) representing nine national/state level organisations and nine participants (three men and six women, aged between 47 and 74 years), from six local community initiatives in Australia. In their organisation, our participants were involved in design, implementation, evaluation and/or marketing of campaigns and interventions and policy-influencing. The interviews explored campaigner perceptions on dementia and priorities for campaigns and interventions on dementia. These views were compared to the voices of people with dementia, carers, and professionals interviewed in Phase 2.

Phases 4, 5 and 6 have involved the analysis and synthesis of our findings and recommendations, via consultation with our Advisory Group, and through a Future Search Workshop. The aim of the Future Search workshop was to engage participants in critical reflection on public campaigning and future possibilities for appropriate forms of public intervention as voiced by the participants in this qualitative study. Participants (n=25, six men and 19 women) were invited from a wide spectrum including people living with dementia, carers, people working with provider organisations, policy-makers and others concerned with influencing public agendas on dementia. Their observations and recommendations for future policy and practice contributed to recommendations for a way forward.

ABOUT THE PROJECT

METHOD

We collected research data through qualitative semi-structured interviewing to examine perceptions and attitudes for each voice perspective plus national and local campaigners in 2017. The project was funded through the Cognitive Decline Partnership Centre receiving support from the Australian National Health and Medical Research Council (NHMRC) and our other supporting partners. The study was approved by the University of Melbourne Humanities and Applied Sciences Human Ethics Sub Committee (HESC 1647136).

Participant Recruitment and Characteristics

A total of 111 interviews among community-living self-selected people were carried out between March and September 2017, (83 women, 28 men) in five states, QLD, SA, WA, NSW and VIC; majority (n=84) in urban areas and 27 in rural or regional areas. We aimed to recruit interviewees from as wide an age range as possible starting with 18 years, and the final sample has an age range from 25 years to 87 years (Table 1).

Participant characteristics presented in Table 1 indicate that the youngest interviewees were in the two professional groups and oldest among people with dementia. Carers were in the middle by age. The 28 carers interviewed were either currently or in the recent past had been in a carer's role; 14 for their partner, 14 for their parent(s) and sometimes also for other relative (uncle or sister). Median time as a carer was 5.5 years, varying from 4 months to over 15 years. The type of dementia in question also varied including Lewy Body, fronto-temporal and Alzheimer's; ten were caring for a person with young onset dementia. There were nine couples, in which one of whom was diagnosed with dementia and the other was their care partner.

Within the 19 people with dementia, at the time of the interviews, eleven were in later mid-life and eight were older adults. Thirteen had been diagnosed with young onset dementia (Lewy body, fronto-temporal or unspecified) at the age of 53-63 years, 1-8 years ago; six with Alzheimer's disease or vascular dementia at the age of 69-81 years, also between 1 and 8 years ago. Their first signs or symptoms of dementia had reportedly started between four and some 15 years ago. We did not specifically ask about medications our interviewees were taking for their symptoms.

Campaigners at national and local level were approached by email and a follow-up telephone call inviting them to participate in an interview to discuss their current and future campaign priorities. Ten campaigners representing national organisations accepted and three declined the invitation due to other commitments. All of the nine local level campaigners accepted. Interviews were conducted between November 2017 and April 2018 with representatives from seven English speaking and two Nordic national organisations, plus six local Australian community organisations, three of which were based in the state of Victoria and one each from the states of New South Wales, Queensland and Western Australia. Final sample included ten participants (two men and eight women, aged between 27 and 58 years) representing nine national/state level organisations and nine participants (three men and six women, aged between 47 and 74 years), from six local community initiatives in Australia.

Participants to the Dementia in Public Domain Future Search Workshop were invited from a wide spectrum of interests, including people living with dementia, carers, and people working with provider organisations, policy-makers and others concerned with influencing public agendas on dementia. A total of 25 people (six men and 19 women) from across five states, including VIC, WA, QLD, ACT and NSW, participated in this four-hour workshop arranged at the University of Melbourne in November 2018 with the aim of contributing to our recommendations for a way forward. The workshop consisted of a description and discussion of the findings, followed by a guided discussion within five small groups on ways to address the impacts of dementia through public health campaigning and other initiatives. Small group deliberations were documented on paper and audio-recorded to generate a more detailed contribution toward the recommendations of this research project.

Data Collection Procedures

Semi-structured, audio-recorded telephone interviews lasting about an hour were carried out by two members of the researcher team (Carr and Haapala), independently, with frequent debriefing of progress with each other and the project lead (Biggs). Both interviewers had previous experience and training in this field. The advisory group consisting of three representatives from care provider organisations and four from the

consumer dementia research network was also briefed and consulted at regular intervals. An interview protocol, including a set of questions, was developed and pilot-tested with two participants in each interviewing phase, resulting in minor changes to wording. People with dementia and their care partner, were interviewed face-to-face, unless they preferred by phone. Most were interviewed separately; however, a small number chose to have their partner present during the interview. All participants provided signed informed consent following the guidelines in National Statement on Ethical Conduct in Human Research, 2007 (Updated May 2015) (NHMRC, 2015) and the Alzheimer Europe (2011) Report on Ethics for Dementia Research. Each participant, excepting campaigners, received an AU\$40 gift voucher to major national retailers.

Data Organisation, Code Development and Analysis Procedures

Data from 111 transcripts in Word was imported into NVivo 11 and coded first by interview question. Next, 40% of the transcripts for the three questions were coded by emerging themes by one of the interviewers, and 20% of these by the second interviewer to ensure inter-coder reliability. Interview data was analysed to identify thematic content and suitable coding categories. Additional categories arising in the process of coding were discussed and added. Data coding was carried out by two of the researchers (Carr and Haapala) with frequent briefing on progress with each other, the project lead (Biggs) and advisory group. Any discrepancies in coding were discussed and resolved. Higher order thematic grouping of the first level of identified themes was carried out to present the data in a concise manner without losing essential content, resulting in categories of second and third level themes as described in the Appendix tables. Appendix Table A1 shows the number of coded items per theme. The validity of this process was supported by researcher triangulation between the two coder-interviewers and principal investigator and consultation with the advisory group of dementia research consumer network.

Categorised data was extracted and imported into Excel 2016 and IBM SPSS Statistics 24 to produce the descriptive tables. Data is presented as a proportion of mentions within each group and entire sample, calculated as the number of mentions divided by the total number of mentions within the group of interest (e.g., within Voice) under each question. Most interviewees had more than one comment to give on each question. Individual representative quotes were also used to illustrate thematic areas. Here, participants were given pseudonyms and identified by Voice perspective and age.

Limitations of the Study

There are certain limitations to the current study:

First, our participants were predominantly from English speaking backgrounds. While 34% of our sample were born overseas, only twelve (10.8%) reported speaking a language other than English at home, which is less than in the Australian population (16%) (Australian Bureau of Statistics, 2012; <http://www.abs.gov.au>). This meant that the number of participants from culturally and linguistically diverse backgrounds (CALD) in our study was too small to allow a CALD-based analysis. Aboriginal and Torres Straights Islander people were not part of the study. Future research should be undertaken to include these perspectives.

Second, because age groups were unevenly spread across the voice perspectives, it was not possible to fully compare these categories. For example, younger adults were over-represented amongst professionals relative to other groups and people with dementia only included later midlife and older adults. Age categories are also considered in two separate papers (Biggs, Haapala & Carr, 2018; Haapala, Carr & Biggs, 2018a).

Third, sampling included an element of self-selection which may have skewed participation in favour of people who already had some connection with dementia. Family connection has also been explored elsewhere (Haapala, Carr & Biggs, 2018b).

ABOUT THE PROJECT

Fourth, our sample comprised predominantly women, except for people with dementia who were predominantly men, in later midlife and with young onset. Again, this may reflect an element of self-selection, gender expectations plus ratios in the helping professions and that people with dementia were occasionally recruited through their partners.

A further limitation would be that because we wanted people with dementia to answer for themselves rather than through a third-party advocate, we restricted interviews to people who could undertake the interview themselves and provide signed informed consent. Future research should attempt to access the views of people with more advanced stages of the condition. Also, because gender and age covary to a certain extent for people with dementia, further research on the relationship between this voice perspective, age and gender should be undertaken. Finally, our findings reflect age of participants with dementia and this should not be confused with age of onset. There were two people in the older adult group (n=8) who also experienced younger onset before the age of 60.

As a strength to our study, the validity of our findings is supported by the large number of interviews and the volume of data, computer-assisted data coding and analysis, involvement of two collaborating researchers in data collection, triangulation between three researchers in data coding analysis and interpretation of results, plus an active consumer advisory group in consultation throughout the study.

Also, the voices of people with dementia and professionals from the service industries are underrepresented in contemporary research and are represented here with equal weight to other voice perspectives.





PERSPECTIVES ON DEMENTIA - MAPPING THE CURRENT EVIDENCE-BASE

VOICE AND PUBLIC ATTITUDES TOWARD DEMENTIA

The place of dementia in the public domain will be influenced by a number of factors, including public health perspectives, the rise of distinctive voices connected to dementia, attitudes to ageing and degrees of family connection.

Developing a Public Health Perspective

Public health activity on dementia has been on the increase. Finding a cure has proved more difficult than first imagined and maintaining or preventing dementia in community settings seems to be producing results. By the end of 2017, 195 countries had established a national action plan and strategy for dementia in line with the World Health Organisation's Global Action Plan on the Public Health Response to Dementia (2017-2025) (WHO, 2016), and at least 90 countries have a central association for the condition under the name of Alzheimer's or Dementia (Alzheimer's Disease International 2017 website: <https://www.alz.co.uk/associations>). And there are good reasons to assume that something can be done about it. The key messages of the Lancet Commission on 'dementia prevention, intervention and care' (Livingston *et al.*, 2017) include exhortations to be ambitious about prevention, to individualise dementia care and to reduce the risks to family carers. Research evidence from large scale observational cohort studies and preventive intervention trials has shown that relatively small changes to lifestyle-related risk factors can prevent or stall cognitive impairment and dementia (Kivipelto *et al.*, 2017). Comparing two prevalence surveys of adults age 65 and over almost two decades apart (1989 and 2008), researchers found that the 2008 cohort had significantly lower prevalence of dementia (Matthews *et al.*, 2016). This they attribute to public health campaigning, less about dementia itself than the mediating effects of cardiovascular disease, provoked by smoking, poor diet and low exercise. However, these findings stand beside enduring evidence that the view that Dementia is a natural part of ageing persists, in spite of widespread campaigning to point out that it is a separate disease, and that uptake of public health messaging is at most patchy (Léon *et al.*, 2015; Cheston, Hancock & White, 2016; Miron *et al.*, 2017).

Recognising Distinctive Voices

Traditionally research on Dementia has taken the perspective of health and social care professionals. Professional handbooks have focussed on presenting problems and assessment, diagnostic and treatment concerns plus quality of life and intervention strategies (Ravdin & Katzen, 2019; Smith & Farias, 2018). And while person-centred care has been instrumental in influencing the perception of people with dementia by others (Brooker & Latham, 2015) relatively few researchers have attempted to access the experience of dementia from a first-person perspective. The viewpoint taken has been almost exclusively from the outside, a position which becomes increasingly untenable as dementia activists insist that their perspective be heard and distinctions are made between the voices of carers (Yeandle, Kröger & Cass, 2012) and those living with dementia (Swaffer, 2015; Bartlett *et al.*, 2017). This not only questions the assumption that all users of services can be lumped together as 'consumers', it also challenges ideas of expertise and active engagement.

Examining Family Connection to Dementia

Survey data from several countries (Léon *et al.*, 2015; Cheston, Hancock & White, 2016; Miron *et al.*, 2017) has indicated that the degree of contact with dementia influences receptiveness to public health campaigning. In particular, a family connection to dementia (Cheston, Hancock & White, 2016) appears to affect understanding and priorities, but in complex ways that need further exploration. Miron *et al.* (2017) refer to the considerable ambivalence that encountering dementia can provoke and that close connection is not necessarily connected to increased empathic understanding. Family and community connection, as a variable in the relative success of peoples understanding of health-related priorities, have now been brought together in the WHO's Global Action Plan on Dementia (2017-2025) (WHO, 2016) that emphasises awareness raising, health care and prevention.

Connecting Age and Dementia

Public perceptions of dementia are closely connected to wider attitudes toward ageing and the life-course. Different age groups appear to hold distinctive perspectives on the life-course, based on their own age and on the prospect of growing older, which affect the ability to empathise with others (Biggs & Lowenstein, 2011). Research has shown negative social perceptions based on age (North & Fiske, 2012) and negative effects on people's sense of personal worth (Lamont, Swift & Abrams, 2015) to be widespread in the general population. In addition, public policy most commonly positions both ageing and dementia as an economic threat (See Intergenerational Report by the Commonwealth of Australia, 2015; OECD, 2015 website: <http://www.oecd.org/health/addressing-dementia-9789264231726-en.htm>). Attitudes to older age and to dementia have become closely connected (Cheston, Hancock & White, 2016; Miron et al., 2017). In the Public domain, dementia can provoke extreme forms of the fear, avoidance and denial already associated with adult ageing (Biggs, 2018). Dementia's place in the public imagination has been described as a 'black hole', with an absence of meaningful identity and social location (Higgs & Gilleard, 2015; 2017). In popular culture Behuniak (2011) has claimed that dementia has become associated with dehumanised 'zombies'. Whether one agrees with these descriptions or not, they point to a close association between age and dementia, not only in terms of demography but as a personal and social phenomenon.

Toward Degrees of Closeness

Voice, Age and Family Connection are three ways in which Closeness to Dementia can be studied and appropriate ways to influence wider public attitudes might emerge. Such an approach differs from existing survey research in so far as rather than focussing on receptivity to pre-determined public health information, attention is drawn to the expressed priorities of specific groups. If people avoid dementia as a topic, or the messaging is not tailored to their own circumstances and priorities, they will be less likely to adopt public health advice or to critically address the values and social attitudes that determine the inclusion of people affected by dementia in wider society. From the perspective of carers, people with dementia and members of the public working in the service professions, these messages may be seen as coming from the outside. To date few pieces of research have looked from these alternative perspectives how the intended recipients see dementia, what their priorities might be and what they consider an effective campaign might look like.

In this context, the ways that distinctive voices might connect with one another, that extreme views have been reported on dementia and that they might be connected to the age of the perceiver, and that family connection may give us an insight into the ways different groups engage with dementia, all require further investigation if we are to understand dementia as a social phenomenon. Each of the above allows a particular way of addressing the issue of closeness and may add to our grasp of dementia as a social phenomenon.



VOICE PERSPECTIVES ON DEMENTIA

In this and the two following sections, we present a snapshot of our findings on Voice; first, in regard to the five Voice Perspectives, second by Voice and Family connection to dementia and third by Voice and Age.

The snapshots presented below are drawn from the many different views expressed by participants from across the whole of the research findings, based on themes that emerged from the data. As the views of people with dementia and those working in the service industry are underrepresented in research, we hope also to add to understanding of their priorities and contributions.

KEY VOICES

People with dementia (n=19)

People with dementia emphasised different ways of coping with the limitations that dementia imposed on their daily and social lives. They were often more positive in their views about dementia and more present-focused than other groups, communicating a level of personal acceptance that spoke to ‘dementia with a silver lining’. People with dementia were very aware of the difficulties faced by the imminent process of cognitive loss, the realisation of a shrinking social network and the anticipation that they would be treated negatively because of their condition. No one in this group saw dementia as normal part of ageing, rather it was seen as a disease with a sometimes higher likelihood of getting it as one ages. People with dementia wanted most of all to be accepted and treated as ‘normal’ and to remain socially engaged with family, friends and the broader community. For this to happen they brought up the need for improved public attitudes towards dementia, more research and better systems of support. They felt that campaigning should focus on social acceptance, dignity and respect as a means to a meaningful life and to live well with dementia.

‘... if people can be seen being normal a bit, in inverted commas, then it helps I think to overcome that fear of the person with dementia or the fact that because somebody’s got dementia you wipe them off your list.’ (Jinny, Person with dementia, 70y)

‘Just be who I am and not, sort of, think I’ve got something peculiar wrong with me ... I’d like people just to accept me as I am.’ (Audrey, Person with dementia, 78y)

‘... when people are diagnosed with dementia, particularly if they’re young, they still can lead a meaningful, productive life within the community with adaptations and so on ... it doesn’t stop us from doing the things we enjoy doing, we should be allowed to do the things that we can do.’ (Kieran, Person with dementia, 66y).

VOICE PERSPECTIVES ON DEMENTIA

Carers (n=28)

Carers focused on the adverse effects of dementia for both individuals and families. They reported negative experiences of service provision and diagnosis, a general lack of understanding in various settings, and poor reactions from friends and neighbours that could lead to a cycle of social isolation. They often felt alone and overwhelmed by their caring responsibilities and, significantly, changes in the relationship with the person they cared for. As such, dementia was presented as holding significant negative repercussions for home, family, work, their finances and social life. They felt that public perceptions were overly negative, and that there was much that could be done in areas, such as education, support, care systems, awareness-raising and grassroots action to improve the lives of themselves and people with dementia. They wanted to see increased levels of understanding, particularly for the caring role and to help improve social interaction between themselves, those they cared for and other people in both the public and private spheres. They also wanted greater recognition of the dignity and rights of people with dementia.

‘It’s a devastating thing and not just for the person that’s suffering it, but the people around them ... [When] I think of dementia, I just think of this giant, big cloud of mess and evil stuff.’ (Fiona, Carer 49y).

‘It takes up your whole life. It absorbs everything. It’s a full-time job. You don’t find much time for yourself, but you can’t do anything else.’ (Barry, Carer 83y).

‘isolation, the dropping off of friends. They don’t get asked to things because, well, they’ve got dementia.’ (Amy, Carer 53y)

‘... for me it’s been shattered hope, shattered dreams if you like.’ (Dorothy, Carer 60y).

Health care professionals (n=21)

Health care professionals presented dementia in predominantly neutral terms, as a disease or behavioural condition but with major, mainly negative, personal and social implications. Cognitive and functional loss were highlighted as were the impacts on carers. They generally did not view dementia as a normal part of ageing and communicated a good understanding of the different types of dementia, its varying symptoms, and how dementia affects an individual’s personal, social and care needs. They saw public perceptions as mainly negative, and they expressed empathy for both people with dementia and those caring for them. The impact of dementia on health care services was considered, as was the negative impact of public attitudes, stereotyping and fear for those living with dementia. To address these concerns, they highlighted the need for the public to be more aware of dementia and for levels of understanding to be increased. They saw education, research, improved systems of support, increased funding and the dignity and respect of people with dementia as priorities.

‘When I think of dementia, I think that it is a marked decrease in the cognitive ability of people, mostly as they get older. And that these people need a different type of care and you need a special carer to be able to look after them because their needs are different to the rest of the general population ... they become different people, they’re not who they were and I think that’s really sad.’ (Nancy, Health care professional, 35y).

‘I think that someone who hasn’t had experience with a person with dementia and a family member with it would think that someone could be stupid or that they are being belligerent or intentionally forgetting things or that they’re just old and senile.’ (Sophie, Health care professional, 32y).

‘... the more people that are aware of it, whether you’re a health worker or a retailer, just means that you’ve got more resources to deal with behaviour. So, awareness would be everything.’ (Rena, Health care professional, 61y).

Social work professionals (n=23)

Social work professionals presented neutral and negative descriptions of physiological change though with high levels of empathy shown towards people with dementia, and particularly carers and families. While they generally did not consider dementia a normal part of ageing, they thought stigma and fear were important factors explaining negative public attitudes. They focused on the social impacts of dementia such as social isolation, the effects of cognitive loss, service impacts and the need for good professional care, carer disadvantage and relationship change. They thought that public perceptions towards dementia were mainly negative and felt a lot needed to be done to increase understandings of dementia, promote positive interactions between people with dementia and others and community integration. There was a strong desire to improve the dignity and rights afforded to both carers and people with dementia. To this end they saw education, attitude and behaviour change and research as the main campaign priorities.

‘... what I’ve seen in my work is that for people who have dementia they experience a very profound shift in their daily lives and their relationships. And that is partly because of their social networks declining.’ (Isaac, Social work professional, 35y).

‘I think there’s very few out there that really know how to assist people living with dementia.’ (Maja, Social work professional, 55y).

‘We have to have an education program. We have to make it a word that is not built around fear, that’s not built around a strangeness ... dementia is not something to be frightened of.’ (Angela, Social work professional, 70y).

Service professionals (n=20)

Service professionals, many of whom had a family connection to dementia, were more likely to see dementia as a normal or accepted part of ageing. They emphasised the poor prognosis that dementia presented for people with the condition and the negative effect on their families in terms of psychological well-being and social engagement, plus perceived gaps in service provision. While able to identify positive public perceptions of dementia, they generally felt that dementia did not have much of a presence in the public domain and that knowledge levels were low. They thought people found out about it on an ‘as needs’ basis, and generally didn’t know how to interact with people with dementia. For these reasons they thought more attempts needed to be made to increase public understandings of dementia, normalise the condition and raise general awareness, particularly amongst younger age groups and in community settings. They felt that good/professional care and support for maintaining personal connections and social engagement were important for people with dementia and their families.

‘First thing that comes to my mind is related to old people ... that it’s something to do with when you are getting old.’ (Amber, Service professional 43y).

‘... sometimes we can just be too busy and see it but don’t recognise it. And so, I’d say in general people aren’t aware of it ... The general public possibly don’t think how broad, how wide it is, because you can’t see it.’ (Lloyd, Service professional 69y).

‘... they don’t understand it, so they just don’t talk about it, or they are very uneasy talking about it. They don’t know a lot about it, they just see it as it’s portrayed in the media as a terrible disease that causes death.’ (Bonnie, Service professional 48y)

For further information on Voice Perspectives, see the Summary Foldout on the back cover.

COMPARISON OF VOICE PERSPECTIVES

In this section, we present comparative data and a summary comparing the Voice perspectives.

Findings in Tables 2-5 are presented as a percentage of total number of mentions within each Voice perspective in relation to: their first thoughts on dementia; their views on whether dementia is a normal part of ageing; their views on the attitudes among the general public; and on the three most important things that should be done about dementia.

First Thoughts on Dementia

Findings on participants' first thoughts showed the following main differences between Voice perspectives (Table 2):

- People with dementia were the most likely of all groups to cite positive thoughts
- Carers showed the highest number of negative thoughts and thoughts connected to ageing
- Professionals were more likely to think about physiological changes and symptoms they associated with dementia. These were considered to reflect a neutral or cognitive understanding.

Thoughts on Dementia as A Normal Part of Ageing

Findings on whether participants thought dementia was a normal part of ageing, which it is not according to scientific evidence (Winblad et al., 2016), showed some differences between the Voice perspectives (Table 3):

- People with dementia and carers were most likely to be uncertain about the answer
- Service professionals were the most likely to say that it was a normal part of ageing
- Majority of all Voice perspectives believed dementia was not a normal part of ageing, but a disease of the brain.

Saying that it is a normal part of ageing; however, may hide a number of interpretations: that dementia is a disease that one is more likely to get as one ages; that it emerges as part of the normal ageing process, or that compared with other age groups, larger numbers of older people get it. Taken together, responses associating ageing and dementia were not frequent amongst the participants.

Table 2. Percentage of “first thoughts” categorised according to valence (tone of the expressed thought) by perspective.

| First thoughts according to valence: tone of expression (%) | People with dementia n=19 | | Carers n=28 | | Professionals | | | All n=111 |
|---|---------------------------|--|-------------|--|------------------|------------------|---------------|-----------|
| | | | | | Health care n=21 | Social work n=23 | Services n=20 | |
| Negative thoughts | 35.3 | | 39.6 | | 23.8 | 35.0 | 33.3 | 33.5 |
| Positive thoughts | 29.4 | | 10.4 | | 19.0 | 17.5 | 9.1 | 16.8 |
| Neutral thoughts | 32.4 | | 33.3 | | 50.0 | 40.0 | 48.5 | 40.6 |
| Age-related thoughts | 2.9 | | 16.7 | | 7.1 | 7.5 | 9.1 | 9.1 |
| Total % (number of thoughts) | 100 (34) | | 100 (48) | | 100 (42) | 100 (40) | 100 (33) | 100 (197) |

Table 3. Can dementia be considered a normal part of ageing? Number and percentage of responses by Voice, coded into three categories, Yes, No, Not sure/Maybe.

| Response categories | People with dementia n=19 | | Carers n=28 | | Professionals | | | | | | All n=111 | |
|---------------------|---------------------------|-------|-------------|-------|------------------|-------|------------------|-------|---------------|-------|-----------|-------|
| | | | | | Health care n=21 | | Social work n=23 | | Services n=20 | | | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Yes | 0 | 0 | 2 | 7.1 | 1 | 4.8 | 3 | 13.0 | 7 | 35.0 | 13 | 11.7 |
| No | 12 | 63.2 | 19 | 67.9 | 18 | 85.7 | 18 | 78.3 | 9 | 45.0 | 73 | 68.5 |
| Not sure/Maybe | 7 | 36.8 | 7 | 25.0 | 2 | 9.5 | 2 | 8.7 | 4 | 20.0 | 22 | 19.8 |
| Total | 19 | 100.0 | 28 | 100.0 | 21 | 100.0 | 23 | 100.0 | 20 | 100.0 | 111 | 100.0 |

Views on Public Perception

Findings on participants' views on public perception and attitudes toward dementia showed mostly negative views amongst the participants (Table 4):

All Voice perspectives described current public perceptions as predominantly negative which indicated social exclusion, negative stereotyping and labelling, stigma and misattributions due to lack of understanding of the condition

- People with dementia were most likely to have something positive to say about public perception relating it to encounters with caring, considerate and more accepting people
- People with dementia were also most likely to talk about the lack of acknowledgement of the condition and inhibition in everyday communication about dementia in the public domain
- Carers had the most negative views, overall, and were more likely to identify ageist attitudes in the public domain
- Professionals were more likely to focus on the public fear and apprehension.

Table 4. Views on public perception of dementia by voice: percentage of views expressed within Voice.

| View | People with dementia n=19 | Carers n=28 | Professionals | | | All n=111 |
|--|---------------------------|-------------|------------------|------------------|---------------|-----------|
| | | | Health care n=21 | Social work n=23 | Services n=20 | |
| Negative social attitudes | 30.8 | 35.6 | 31.6 | 41.2 | 16.3 | 33.1 |
| Negative personal psycho-social response | 11.5 | 21.2 | 24.1 | 30.6 | 20.9 | 22.6 |
| Not well understood | 11.5 | 12.5 | 15.2 | 10.6 | 18.6 | 13.2 |
| Ageist | 5.8 | 10.6 | 5.1 | 1.2 | 7.0 | 6.1 |
| Negative, no open talk | 15.4 | 5.8 | 5.1 | 4.7 | 16.3 | 8.0 |
| Positive social attitude | 5.8 | 1.9 | 2.5 | 1.2 | 4.7 | 2.8 |
| Positive personal psycho-social response | 15.4 | 4.8 | 5.1 | 5.9 | 7.0 | 6.9 |
| Fairly well understood | 0.0 | 1.0 | 2.5 | 2.4 | 0.0 | 1.4 |
| Positive with increasing contact | 3.8 | 6.7 | 8.9 | 2.4 | 9.3 | 6.1 |
| Total % (total number) | 100 (52) | 100 (104) | 100 (79) | 100 (85) | 100 (43) | 100 (363) |

COMPARISON OF VOICE PERSPECTIVES

The Most Important Things to Be Done About Dementia

Findings on participants' suggestions for the three most important things to be done about dementia revealed considerable cohesion amongst the participants in terms of public education, research and improving the support and care systems. We have summarised the data and present in Table 5 the top three and bottom two things mentioned by Voice:

- People with dementia were most focused on improved public attitudes, perceptions and behaviour and more research
- Both the carers and professional groups focused on getting more education to be offered to specific target groups (including care work professionals), through strong professional networks and multi-disciplinary approaches

- Carers were the most likely to call for both the provision of support and better access and availability of quality support systems and information
- All Voice perspectives called for more research on understanding dementia, its cause and cure, medications and interventions to slow down the progression, including psycho-social and community-based interventions
- Medical care and design issues were not prioritised for action by any Voice perspective on this question.

Views on Impact of Dementia and Priorities for Campaigns

For the comparison of participants' views on the impact of dementia, see the Section "The Impact of Dementia as a form of Disadvantage" and for comparison of participants priorities for campaigns on dementia, please see the related section, "Priorities for Campaigns on Dementia by Voice".

Table 5. Top three and bottom two "things that should be done about dementia*" by Voice Perspective. Percentage of expression from all expressions within each Voice Perspective.

| People with dementia (n=19) | Carers (n=28) | Professionals | | |
|--|--|--|---|--|
| | | Health care (n=21) | Social work (n=23) | Services (n=20) |
| Top three | | | | |
| Attitudes, perceptions and behaviour 34% | Education to specific target groups on specific topics 18% | Education to specific target groups on specific topics 22% | Education to specific target groups on specific topics 37% | Education to specific target groups on specific topics 22% |
| Research 23% | Provide support 16% | Research 17% | Research 10% | Provide support 17% |
| Improve support and care systems, information and availability 15% | Improve support and care systems, information and availability 14% | Improve support and care systems, information and availability 15% | Improve support and care systems and information... 9% /Increase funding 9% | Research 14% |
| Bottom two | | | | |
| Medical care 0% | Medical care 3% | Design issues 3% | Medical care 1% | Medical care 2% |
| Design issues 0% | Design issues 1% | Medical care 1% | Design issues 1% | Design issues 2% |

*For detail on "three most important things to be done", please see the coding frame in Appendix.



VOICE AND FAMILY CONNECTION PERSPECTIVES ON DEMENTIA

This section examines how people’s thoughts about dementia differed by degrees of family connection, reflecting a form of closeness to dementia as a condition.

In this section, we focus on two themes: 1) First thoughts and 2) Personal priorities if diagnosed with dementia analysed by Voice, taking into account their Family Connection to dementia. Details of the methods and coding frames can be found in “Our Approach” and the Appendix.

Family Connection and Perspective by Degrees of Closeness to Dementia

We have defined “Family connection” as participants’ closeness to dementia through family or personal experience, thus identifying four groups in our sample: 1) people with dementia (n=19), 2) carers, all of whom in our study were carers for a family member (n=28), 3) professionals with a family connection to dementia (n=31) and 4) professionals without a family connection (n=33) (Table 6). Table A6 in the Appendix shows participants’ family connection by age group.

These four groups also represent four new “perspectives”: people with dementia in the “first-person perspective” and carers in the “second-person perspective”; helping professionals (health care, social work or service sector) without personal contact with dementia through family in a “third-person perspective” and professionals with a reported and enduring contact with a family member with dementia in an “intermediate group between the second- and third-person perspectives”. The questions asked during the interview included: “When I say dementia, what do you think about”; “If you were diagnosed with dementia, what would you want?” or “Is there something you would want going forward with living with dementia?” when interviewing people with dementia.

Table 6. Family connection to dementia by professional group.

| Family connection* | Professionals | | | All n=64 |
|--------------------|------------------|------------------|---------------|----------|
| | Health care n=21 | Social work n=23 | Services n=20 | |
| Yes (n) | 9 | 9 | 13 | 31 |
| No (n) | 12 | 14 | 7 | 33 |

*Family connection refers to reported and enduring contact with a family member with dementia.

Comparison of First Thoughts on Dementia by Family Connection

As discussed in the “Voice Perspectives on Dementia” section, people with dementia were the most likely to refer to positive thoughts (29%) and carers the least likely (10%) (Table 7). Professionals with a family connection to dementia held a higher positive perspective (17%) than professionals without the connection (14%) though the differences were small. Carers and professionals without family contact were the most likely to see dementia as age-related, though the percentage reports were low (at 17% and 11%) (See Table 7).

The percentage of negative thoughts about dementia appeared to decrease as people had less of a connection to it. Neutral thoughts correspondingly appeared to increase. (See Table 7).

Table 7. Percentage of “first thoughts” categorised according to valence (tone of the expressed thought) by Family connection.

| First thoughts by valence: tone of expression (%) | People with dementia n=19 | Professionals | | | All n=111 |
|---|---------------------------|---------------|---|--|----------------|
| | | Carers n=28 | With family connection to dementia n=31 | Without family connection to dementia n=33 | |
| Negative thoughts | 35.3 | 39.6 | 33.9 | 26.8 | 33.5 |
| Positive thoughts | 29.4 | 10.4 | 16.9 | 14.3 | 16.8 |
| Neutral thoughts | 32.4 | 33.3 | 44.1 | 48.2 | 40.6 |
| Age-related thoughts | 2.9 | 16.7 | 5.1 | 10.7 | 9.1 |
| Total % (number of thoughts) | 100.0 (34) | 100.0 (48) | 100.0 (59) | 100.0 (56) | 100.0 (197) |

VOICE AND FAMILY CONNECTION PERSPECTIVES ON DEMENTIA

Comparison of Personal Priorities in ‘What would I want’ by Family Connection

Several interesting patterns can be identified in the data as presented in Figure 1 which shows the percentage of mentions from the total number of mentions within each perspective for the four groups based upon closeness to dementia.

Key patterns in personal priorities in response to question “What would I want” (if diagnosed with dementia) (See Figure 1):

- The three most frequent responses from People with dementia referred to engagement and inclusion, interpersonal connection and support and a desire for continuity dignity and respect, while little emphasis was given to good/professional care or prevention
- Carers most frequently prioritised interpersonal connection and support, good/professional care, plus continuity, dignity and respect, and least mentioned priorities of love and affection and prevention
- Professionals with a family connection showed a top three priorities of good/professional care, social support and social engagement, with least emphasis on love and affection and end of/ending life
- Those without a connection emphasised good professional care, prevention and preparation and love and affection, with lowest mentions of engagement with society and end of life.

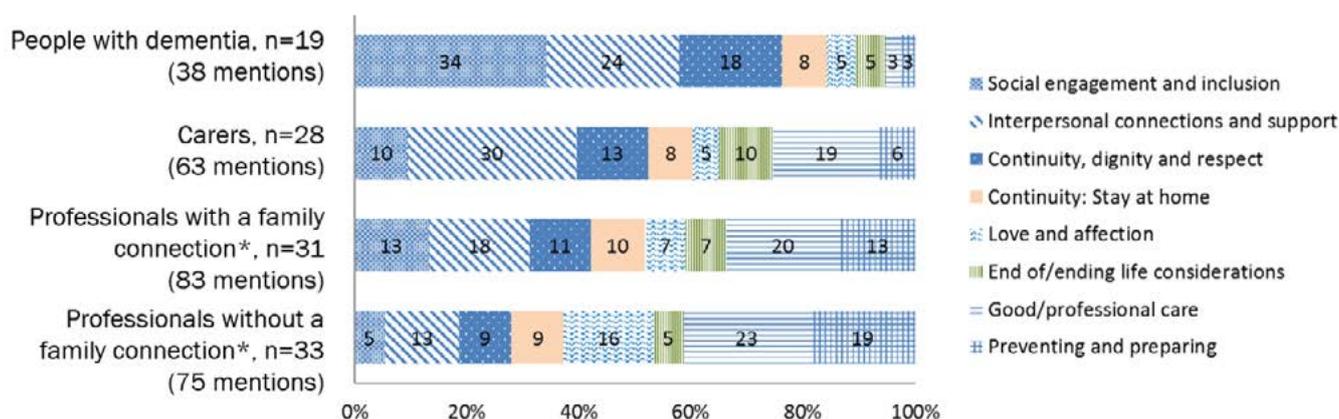
See also quotes on page 28.

It would appear, then, that people with dementia were most concerned with forms of social inclusion, connection and respect at different levels in society. Carers were most concerned with interpersonal connections and support, reflecting a priority for continued social engagement, while professionals with or without a family connection prioritised good/professional care.

When we compared these themes across the four perspective groups by family connection/closeness to dementia, five main points emerged:

- Emphasising love and affection decreased with closeness of personal experience, with those without a family connection showing the greatest concern, followed by professionals with a connection and then carers plus people with dementia
- This trend was also true for preventing and preparing, and good/professional care, both grew in importance the further away respondents were from dementia
- A concern with continuity dignity and respect moved in the opposite direction, with a first-person perspective giving them the most priority and no connection the least
- Concern with end of life and ending life issues was most frequently mentioned by carers and others with a family connection, but the frequency was small
- There were multiple trends within the data, with carers sometimes showing priorities closer to a person with dementia and sometimes to a third person, especially when this included some family experience of dementia itself.

Figure 1. Percentage of responses to themes emerging from responses to question on “What would I want, if I was diagnosed with dementia” by perspective based on closeness of connection to dementia.



Footnote to Figure 1. For details on the coding of responses and formation of categories, please see Table A7 in the Appendix.

*Family connection refers to reported and enduring contact with a family member with dementia.

Is There a Continuum in Responding based on Closeness?

When we compared trends on family connection to dementia as a form of closeness, certain trends could be seen. In Figure 1, looking at responses given by carers, then professionals with a family connection, and on to those without a family connection, we found that some themes increased with distance and some decreased.

Looking at the responses to the question 'What would I want':

- The priority given to Interpersonal connection and Support decreased the less connection there was. Same trend can be seen for the theme Continuity, dignity and respect. So, a reduced family connection seems to reduce the perceived importance of forms of social engagement.
- The priority given to Love and affection, plus the public health priorities of good/professional care and Preventing and preparing for living with dementia, appeared to decrease as connection increased. This would indicate that an increased distance may be associated with a greater value given to these more personal themes.

These findings would suggest that a continuum exists with themes related to social engagement, showing a trend in the opposite direction to themes connected to more individual pursuits such as care of the self and care for others.

Looking at participants' 'First thoughts about dementia':

- Negative thoughts increased with increasing family connection. This would suggest that the closer people are to dementia in others, the more negative they tend to feel about the condition
- Neutral thoughts travelled in the opposite direction, with increased distance associated with more neutral and descriptive thoughts
- Positive thoughts were most commonly reported by people with dementia and professionals with a family connection, but there was no clear trend in this evidence.

A continuum seems to exist also in people's first thoughts about dementia, in so far as the closer the people are to dementia in others, the more negative the thoughts.

In summary, these findings suggest that there are some marked differences in priority depending upon closeness and family connection. The most notable being that first-hand and carer experience increases awareness of social implications of dementia relative to other forms of connection. The direction of a number of themes identified in this study varied according to a person's degree of connection, suggesting a relationship between emotional responding, empathy and distance from the condition, living with dementia. Concerns for social inclusion appeared to increase with closeness to dementia, whereas traditional public health priorities tended to travel in the other direction. However, the relationship between connection and particular themes is complex and does not appear to reflect a direct correspondence between family connection and emotional closeness.

VOICE AND FAMILY CONNECTION PERSPECTIVES ON DEMENTIA

QUOTES ON "WHAT WOULD I WANT"

PEOPLE WITH DEMENTIA

I'd like to know that more people who have dementia are comfortably finding support to help them with their dementia, their understanding of dementia, which would help not just them but their family and their loved ones. (Ray, Person with dementia, 64 y)

"I would want a driver's license and otherwise, I just do what I want to do. The perceptions should change to consider people living with dementia as they are: fine." (George, Person with dementia, 59 y)

"If I have to leave home, then I don't want ... that's when I just want to stop it." (Phillip, Person with dementia, 79 y)

CARERS

'I'd like to be acknowledged to be encouraged to be the person I am. I'd like support right on diagnosis.' (Jacqueline, Carer, 64 y)

'I would want someone who knows what they're doing to look after me.' (Doc, Carer, 66 y)

'I would like to stay in my own home as long as I could, with support.' (Dorothy, Carer, 60 y)

'I'd want kindness and patience, people to understand that I'm still me.' (Vron, Carer, 57 y)

PROFESSIONALS WITH A FAMILY CONNECTION

'I would want to be treated with respect and kindness. I would want to be involved in the decision-making around my healthcare and ongoing treatment. I would want professionals around me who worked with me on an equal basis, not from a control – power control sort of angle. And I wouldn't want to be shoved away in an aged care facility and made to feel old and useless.' (Heather, Health Care Professional, 59 y)

'I would not want people not to give up on me. I wouldn't want to be left alone. I'd want interaction. I think I'd want some familiarity in terms of - it's not just about whether I was home or not. I think ideally, I'd like to be at home, but that's not always possible. I think I would like to feel supported and secure. I think that would be important to me. (Nathan, Social work Professional, 49 y)

PROFESSIONALS WITHOUT A FAMILY CONNECTION

'I think I would just want my family to care for me and support me through what I was going, and not be scared to visit me or see me in a state that I was once in. Yeah, so I think just love and support from my family. And I guess, on a medical side as well, just like medical support and - yeah, just to be well cared for.' (Zoe, Social work Professional, 25 y)

'I'd like to be cared for at home. I'd like to stay home as long as I could. If I became too difficult to manage and had to be put into care, as in a nursing home, I'd want to be a good-quality one with good safety facilities and good staff-to-resident ratios'. (Danielle, Health Care Professional, 49 y)



VOICE & AGE PERSPECTIVES ON DEMENTIA

In this section, we continue to explore the Voice perspectives, this time taking age of the participant into consideration.

Participants were grouped into four age-groups: Younger Adults (25-35 years), Mid-lifers (36-50 years), Later Mid-lifers (51-65 years) and Older Adults (66-87 years). The number of participants in each age group varies depending on the Voice being examined (See Table 1 under 'Our Approach'). There are, for example, no younger adults among people with dementia. For this reason, we have looked at the data making the reader aware of the relationship between age within the voice groups and voice within the age groups. Professional groups have also been combined in this analysis.

First, we looked primarily at Voice and asked how the responses of participants in our study differed depending on their age, within each Voice perspective. Next, we considered the findings the other way around. So, in the second section we prioritised age and looked at Voice group within each Age group. This also included asking our participants a separate question on how they thought different age groups in the general population might think about dementia.

VOICE AND AGE PERSPECTIVES ON DEMENTIA: AGE GROUP WITHIN EACH VOICE PERSPECTIVE

In this section, we present comparative data in tables and summarise the findings on participants' views by Voice and Age perspective groups. Findings in Tables 8a-8d and 9a-9c are presented as a percentage of total number of mentions within each Voice & Age perspective in relation to: their first thoughts on dementia; their views on whether dementia is a normal part of ageing; what they would want for themselves; and on the most important things that should be done about dementia. Due to the addition of Age group as a variable in this analysis, we have combined the three professional groups into one larger group to achieve a sufficient number of participants in each age group.

Views among People with Dementia by Age group

The Voice perspective of People with dementia included two age groups: Later mid-lifers and Older Adults. While the views of People with dementia stood out most from the other Voice perspectives, there were also clear distinctions based on age within the group. These existed beside views held in common within this Voice perspective. (Tables 8a-8d).

Similarity in views:

Two thirds of participants in both age groups viewed public perceptions of dementia as predominantly negative

For what should be done about dementia, both age groups prioritised improving public attitudes, perceptions and behaviour, and both wanted more research and improved support and care systems, information and availability. Older adults with dementia also emphasised provision of more education on the topic.

Difference in views:

- Later mid-lifers spoke about negative social attitudes plus a lack of visibility and open talk on the condition, in other words they were more concerned with social effects of dementia
- Older adults spoke more frequently about lack of public understanding of the condition which led to negative, fearful, stigmatising and stereotyping responses, with a greater focus on people's personal reactions
- Later mid-lifers were more likely to have something positive to say in their first thoughts about dementia, relating to acceptance, coping skills and engaging in advocacy work. They wanted greater social engagement (including work) inclusion plus social support, whereas older adults placed more emphasis on personal continuity, dignity and respect
- End of life/ending life considerations were more frequent among older adults, though from a low base
- Later mid-lifers were more strongly of the opinion that dementia was not a normal part of ageing when compared to older adults.

Table 8a. People with dementia and Carers: “First thoughts” by Voice & Age group perspective. Percentage of thoughts and valence (tone of the expressed thought).

| First thoughts by valence: tone of expression (%) | People with dementia (n=19) | | Carers (n=28) | | |
|---|-----------------------------|--------------------|-----------------------------------|-------------------------|--------------------|
| | Later mid-lifers (n=11) | Older adults (n=8) | Younger adults & Mid-lifers (n=5) | Later mid-lifers (n=11) | Older adults (n=8) |
| Negative thoughts | 31.6 | 40.0 | 44.4 | 36.0 | 42.9 |
| Positive thoughts | 42.1 | 13.3 | 11.1 | 8.0 | 14.3 |
| Neutral thoughts | 26.3 | 40.0 | 33.3 | 36.0 | 28.6 |
| Age-related thoughts | 0.0 | 6.7 | 11.1 | 20.0 | 14.3 |
| Total % | 100 | 100 | 100 | 100 | 100 |
| (number of thoughts) | (19) | (15) | (9) | (25) | (14) |

Table 8b. People with dementia and Carers: “What would I want” by Age group perspective.

| Theme | People with dementia (n=19) | | Carers (n=28) | | |
|---------------------------------------|-----------------------------|--------------------|-----------------------------------|-------------------------|--------------------|
| | Later mid-lifers (n=11) | Older adults (n=8) | Younger adults & Mid-lifers (n=5) | Later mid-lifers (n=11) | Older adults (n=8) |
| Social engagement and inclusion | 38.5 | 25.0 | 0.0 | 15.8 | 0.0 |
| Interpersonal connections and support | 23.1 | 25.0 | 30.0 | 31.6 | 26.7 |
| Continuity, dignity and respect | 7.7 | 41.7 | 10.0 | 13.2 | 13.3 |
| Continuity: Stay at home | 11.5 | 0.0 | 0.0 | 5.3 | 20.0 |
| Love and affection | 7.7 | 0.0 | 20.0 | 2.6 | 0.0 |
| End of life consideration | 3.8 | 8.3 | 10.0 | 10.5 | 6.7 |
| Good/professional care | 3.8 | 0.0 | 30.0 | 13.2 | 26.7 |
| Preventing and preparing | 3.8 | 0.0 | 0.0 | 7.9 | 6.7 |
| Total % | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |
| (number of thoughts) | (26) | (12) | (10) | (38) | (15) |

VOICE & AGE PERSPECTIVES ON DEMENTIA

Table 8c. People with dementia and Carers: Three most important things to be done about dementia; Views by Voice & Age group perspective.

| Theme | People with dementia (n=19) | | Carers (n=28) | | |
|--|-----------------------------|--------------------|-----------------------------------|-------------------------|--------------------|
| | Later mid-lifers (n=11) | Older adults (n=8) | Younger adults & Mid-lifers (n=5) | Later mid-lifers (n=15) | Older adults (n=8) |
| Education to specific target groups on specific topics | 2.9 | 10.5 | 31.3 | 17.0 | 11.5 |
| Attitudes, perceptions and behaviour | 32.4 | 36.8 | 6.3 | 10.6 | 11.5 |
| Research | 26.5 | 15.8 | 0.0 | 6.4 | 7.7 |
| Awareness-raising | 11.8 | 5.3 | 18.8 | 10.6 | 7.7 |
| Provide support | 8.8 | 5.3 | 12.5 | 14.9 | 19.2 |
| Improve support and care systems, information and availability | 14.7 | 15.8 | 12.5 | 19.1 | 3.8 |
| Funding | 0.0 | 5.3 | 0.0 | 8.5 | 19.2 |
| Grassroots action on dementia | 2.9 | 5.3 | 6.3 | 8.5 | 19.2 |
| Medical care | 0.0 | 0.0 | 12.5 | 2.1 | 0.0 |
| Design issues | 0.0 | 0.0 | 0.0 | 2.1 | 0.0 |
| Total % (number of expressions) | 100.0 (34) | 100.0 (19) | 100.0 (16) | 100.0 (47) | 100.0 (26) |

Table 8d. Can dementia be considered a normal part of ageing? Percentage of responses coded by Age within Voice into three categories, Yes, No, Not sure/Maybe.

| Response categories | PWD (n=19) | | Carers (n=28) | | | Professionals (n=64) | | | |
|---------------------|------------------|--------------|-----------------------------|------------------|--------------|----------------------|------------|------------------|--------------|
| | Later mid-lifers | Older adults | Younger adults + Mid-lifers | Later mid-lifers | Older adults | Younger adults | Mid-lifers | Later mid-lifers | Older adults |
| Yes | 0.0 | 0.0 | 0.0 | 6.7 | 12.5 | 20.0 | 14.3 | 17.9 | 20.0 |
| No | 72.7 | 50.0 | 40.0 | 73.3 | 75.0 | 60.0 | 76.2 | 71.4 | 60.0 |
| Not sure/Maybe | 27.3 | 50.0 | 60.0 | 20.0 | 12.5 | 20.0 | 9.5 | 10.7 | 20.0 |
| Total % (n) | 100.0 (11) | 100.0 (8) | 100.0 (5) | 100.0 (15) | 100.0 (8) | 100.0 (10) | 100.0 (21) | 100.0 (28) | 100.0 (5) |

Voice and Age Perspectives: Carers' Views by Age Group

Carers' Voice perspective includes all four age groups. However, due to lower numbers, Younger adults and Mid-lifers have been combined into a single Age group. The two other groups included Later mid-lifers and Older adults.

When examined by age group, carers' views appeared to have some similarities as well as extensive differences. (Tables 8a-8d).

Similarity in views:

- All age groups held predominantly negative thoughts about dementia, followed by neutral thoughts. Positive thoughts were rare
- All age groups thought that interpersonal connection and support were of primary importance.

Difference in views:

- Younger adults and mid-lifers, held the most negative views and often spoke of age in this context
- Later mid-lifers were the most likely to think of dementia in relation to age
- Older adults were most likely to have something positive to say about the condition/living with dementia, though from a low base

- On public perception, older adult carers were more likely to hold positive views, with younger ones being the least likely
- Younger carers emphasised the need for continued love and affection more than any other age group. Otherwise it was rarely mentioned. They, with older adults also emphasised good/professional care if they were to be diagnosed with dementia
- Older adults were most likely to emphasise continuity, emphasising the need to stay at home if diagnosed with dementia. This was rarely mentioned by other age groups
- The younger age groups were more likely than the older adults' age group to call for action on education, improving support and care systems, and making information available to the public and those affected by dementia
- Older adults were more likely than the other age groups to emphasise the need for more support, funding and grassroots action
- Younger adults and mid-lifers were more uncertain about whether dementia was a normal part of ageing than older groups who believed that it was not.

See also Summary Tables 2a & 2b on Voice & Age Perspectives at the end of this Report.

VOICE & AGE PERSPECTIVES ON DEMENTIA

Professionals' Views by Age Group

Professionals were the only Voice perspective to include every age group. There were both similarities and differences between the professionals' views when compared by age. (Tables 8d and 9a-9c). The three professional groups (Health care, social work and service professionals) are combined into one group in this analysis.

Similarities in views:

- Neutral thoughts, rather than evaluative thoughts, that described the physiological changes taking place with dementia, were the most numerous across all age groups. Older adults were the most likely to report neutral thoughts
- If they were to be diagnosed with dementia, the three younger age groups thought they would hope for good/professional care, preventive approaches plus maintaining interpersonal connections and support. They also thought that they would party while they could
- End of life/ending life considerations came up more frequently among the midlife and older groups, but from a low base
- Education to specific target groups was first on the list of all four age groups for the most important things to be done about dementia
- The four age groups' views also converged on the top three action points: Education, research, improved support and care systems, information and availability
- Generally, all age groups believed that dementia was not a normal part of ageing; with mid-lifers evidencing the strongest trend.

Difference in views:

- Younger adults held the most positive first thoughts, with an emphasis on empathic understanding
- Mid-lifers had the least amount of positive thoughts about dementia
- Older adults expressed no age-related thoughts, whereas among the other age groups this was also a topic, albeit not a common one

- Younger adults most markedly of all age groups brought up a need for continued love and affection if diagnosed with dementia
- Mid-lifers were the most likely to consider end of/ending life issues, albeit from a low base
- Older adults were most likely to emphasise the need for continuity if diagnosed with dementia; this meant continuity as in being able to stay at home and continuity in terms of dignity and respect, love and affection plus social engagement and inclusion
- The two Mid-life age groups were most likely to call for more research
- The two older age groups were most likely to call for more improvement in support and care systems, information and availability
- Younger adults were most likely to call for more awareness-raising and funding
- In contrast to other ages, older adults gave almost no priority to preventing and preparing for dementia or interpersonal connections and support
- Age seems to affect the focus placed on research which was more important for all mid-lifers, and care support systems which were more important for later mid-lifers and older adults. Awareness raising was emphasised by younger adults.

In summary, the effects of age varied depending upon the Voice perspective being examined.

People with dementia showed a marked difference based on age, with younger members of the group being more positive about their experience and wishing to engage with the public sphere as a normal part of social life. Older people with dementia reported more negative experiences. Carers shared certain attitudes across all ages, but also some marked differences. The differences were complex and were related to the negative consequences of caring, emotional ambivalence and perceptions of public attitudes. Professionals were generally neutral in their responses, possibly relying on role identities to reduce other influences. However, there were differences marked by age in the emotional and practical responses that professionals reported concerning the condition.

Table 9a. Professionals: “First thoughts” by Age group perspective. Percentage of thoughts categorised by valence (tone of expression).

| First thoughts by valence: tone of expression (%) | Professionals (n=64) | | | |
|---|-----------------------|-------------------|-------------------------|--------------------|
| | Younger adults (n=10) | Mid-lifers (n=21) | Later mid-lifers (n=28) | Older adults (n=5) |
| Negative thoughts | 26.3 | 32.4 | 30.2 | 33.3 |
| Positive thoughts | 21.1 | 8.1 | 18.9 | 16.7 |
| Neutral thoughts | 42.1 | 48.6 | 45.3 | 50.0 |
| Age-related thoughts | 10.5 | 10.8 | 5.7 | 0.0 |
| Total % (number of thoughts) | 100.0 (19) | 100.0 (37) | 100.0 (53) | 100.0 (6) |

Table 9b. Professionals: “What would I want” by Age group perspective.

| Theme | Professionals (n=64) | | | |
|---------------------------------------|-----------------------|-------------------|-------------------------|--------------------|
| | Younger adults (n=10) | Mid-lifers (n=21) | Later mid-lifers (n=28) | Older adults (n=5) |
| Social engagement and inclusion | 4.5 | 7.8 | 11.0 | 16.7 |
| Interpersonal connections and support | 18.2 | 17.6 | 15.1 | 8.3 |
| Continuity, dignity and respect | 4.5 | 5.9 | 13.7 | 16.7 |
| Continuity: Stay at home | 4.5 | 11.8 | 6.8 | 25.0 |
| Love and affection | 27.3 | 7.8 | 8.2 | 16.7 |
| End of life consideration | 0.0 | 9.8 | 5.5 | 8.3 |
| Good/professional care | 22.7 | 19.6 | 24.7 | 8.3 |
| Preventing and preparing | 18.2 | 19.6 | 15.1 | 0.0 |
| Total % (number of thoughts) | 100.0 (22) | 100.0 (51) | 100.0 (73) | 100.0 (12) |

Table 9c. Professionals’ views on the “Three most important things to be done about dementia” by Voice and Age group Perspective. Percentage of expressions.

| Theme | Professionals (n=64) | | | |
|--|-----------------------|-------------------|-------------------------|--------------------|
| | Younger adults (n=10) | Mid-lifers (n=21) | Later mid-lifers (n=28) | Older adults (n=5) |
| Education to specific target groups on specific topics | 29.4 | 33.3 | 19.8 | 50.0 |
| Attitudes, perceptions and behaviour | 8.8 | 10.1 | 12.1 | 8.3 |
| Research | 5.9 | 14.5 | 16.5 | 8.3 |
| Awareness-raising | 11.8 | 2.9 | 7.7 | 8.3 |
| Provide support | 17.6 | 2.9 | 14.3 | 8.3 |
| Improve support and care systems, information and availability | 8.8 | 8.7 | 14.3 | 16.7 |
| Funding | 11.8 | 11.6 | 9.9 | 0.0 |
| Grassroots action on dementia | 5.9 | 7.2 | 4.4 | 0.0 |
| Medical care | 0.0 | 4.3 | 0.0 | 0.0 |
| Design issues | 0.0 | 4.3 | 1.1 | 0.0 |
| Total % (number of expressions) | 100.0 (34) | 100.0 (69) | 100.0 (91) | 100.0 (12) |



COMPARING ATTITUDES: AGE, VOICE AND THE GENERAL PUBLIC

In this section, we examine data on Voice perspectives by organising it by Age group first, and then within each Age group, by Voice.

First, we looked at how the responses of participants in our study differed depending on their age and family connection to dementia. Then, we asked our participants to consider how different age groups in the general population were thought to perceive dementia. Finally, we compared the two: what people said about themselves with how they perceived the views of their own age group in the general population.

AGE GROUP DIFFERENCES IN ATTITUDES TO DEMENTIA ACROSS THE VOICES

We start with a snapshot of each age-group, taking into account distinctions based on Voice. In each snapshot, the proportion of people from each voice varies in line with the participant's characteristics shown in Table 1 (in Section 'Our Approach').

The way that dementia is perceived depended on age in sometimes unexpected ways:

- **Younger Adult participants'** responses were marked by emotional identification, but most strongly from a distance, where there was little direct family contact. Otherwise, personal contact, when it was there, was primarily through grandparents or at work, and more information would be accessed on an 'as needs' basis. For younger participants in a carer's role, the contact was primarily through their parent with dementia. The professionals in this age group, expressed emotional empathy toward people with dementia, who were identified as being considerably older, and to some extent toward carers. While showing greater emotional empathy than other age groups, this was rarely based on significant contact. It could be called a 'poor them' reaction, possibly reflecting easier emotional relations with a generation once removed from parental associations. Dementia here was the far-off other that one can safely feel sorry for while aiming to provide support from a professional perspective. Younger adults who were in a carer's role found themselves struggling to find support and had a different experience and emotional reaction to others in this age-group.
- **Mid-life participants'** responses were largely cognitive. Participants in this age group sought knowledge about the condition and raised questions about the availability and appropriateness of services. There was some interest in preventative approaches and changes to lifestyle that could reduce the likelihood of contracting the condition. Where family contact occurred, the focus was on what could be done to find an appropriate response for the "other", closely followed by a response for oneself should one become diagnosed. Participants in a carer's role found themselves in a stressful situation searching, on the run, for information, resources and support. For the professionals in this age group, dementia was essentially something that happened to others and evoked a practical 'What to know and what to do' approach. In life-course terms, dementia was a "possible, but distant future me", eliciting some sympathy, and an intellectual response. Information was still often sought only on an 'as needs' basis.
- **Later Mid-life participants'** responses were more likely than younger age groups to include interpersonal contact, in the sense of how to communicate with the other who has been affected by dementia. Personal contact was primarily through family and involvement around one's partner's or one's parents' care and support arrangements or one's own personal experience of living with dementia. This age group's concerns focussed on how to help people engage and talk with people with dementia and how to provide more support. Professionals' responses were still predominantly aimed at another person, an 'other' rather than the self, who had a different experience to one's own. While their response also overlapped with elements of mid-life and older adult perspectives, it could be characterised as a 'how do I communicate' approach. For professionals in this age group, dementia elicited a practical response aimed at interaction with others. With direct personal experience, for both the person with dementia and the carer, the response reflected more of a "how do I mix in" approach, relating to a person's need for continued social engagement in work and community settings, social inclusion plus support to do so. People with dementia in later midlife were the most likely of all age groups to report positive elements of their experience.

COMPARING ATTITUDES: AGE, VOICE AND THE GENERAL PUBLIC

- **Older Adult participants** were most likely to see dementia as an issue arising in interaction with peers; many of whom were perceived as “rather keeping mum about it”, i.e., still rather not bringing up or talking about the topic in the public sphere. Older adult professionals were also most concerned with what the symptoms might be and often found themselves and their peers monitoring their own thinking, memory and behaviour in that light. Awareness of dementia for them and their peers occurred in an ‘is it me’ context. They were most likely to know about the day-to-day challenges of dementia, and perceived people in mid-life as very resourceful in their support for people with dementia. In this age group, dementia was seen as a matter of practical likelihood, both in oneself and in relation to others. Older adults with dementia or in a carer’s role had very little positive to say about living with dementia and its negative impacts on their personal circumstance via social isolation, lack of health and social services, lack of social engagement and continuity in finances and home living.

In summary, while younger adult professionals showed a form of distanced empathy, mid-lifers saw the other from a predominantly cognitive viewpoint and later mid-lifers as another encountered in practical communication. Younger carers struggled to find anything positive in current social attitudes and care and service systems, while older carers focused on managing the situation as best they could. People with dementia divided by age with the younger group showing a more outgoing and the older group showing more personal concerns. Older adult professionals exhibited a set of attitudes slanted toward proximity and interaction. In the current sample, responses evidenced benign forms of othering rather than evoking avoidance or stigma. Age differences influenced both the form of connection participants had with dementia and the form of empathic understanding that took place. Their interest paralleled age-based priorities depending on their position in the life-course and age-related closeness to the phenomenon.

PERCEPTIONS OF ATTITUDES HELD BY AGE GROUPS WITHIN THE GENERAL PUBLIC

All Age and Voice perspective groups considered the general public to hold negative attitudes toward dementia, with carers most likely to see other’s perceptions as negative. People with dementia and professionals were more likely to see a mix of responses, which also included sympathy and tolerance. All age group responses within the general public were perceived to be contact dependent, with closer family contact provoking greater knowledge and understanding.

There was a relatively high degree of agreement about the views held by different age groups within the general public:

- **Younger people** and mid-lifers were most likely to be perceived as too busy with other priorities to give dementia much attention. Unless they had had some personal contact with the condition they were thought to be uninterested in it. Younger people were perceived to be more distanced from the condition, but also more optimistic and sometimes better educated on the topic.
- **People in mid-life and later mid-life** were perceived to see dementia in terms of a risk-related discourse. They would be principally concerned with genetic disposition and things that could be done to reduce the likelihood of contracting the disease. Otherwise dementia was seen to be something to be avoided or ignored. Mid-lifers were also perceived to have a mixed or ambivalent emotional response to dementia and people affected by it, often manifested as fear or avoidance.
- **Older people** were perceived to be expecting the condition as a deterministic event in old age and to be more tolerant of its effects. They were thought to be either alarmed by or resigned to personal risk and to be more exposed to dementia on a day-to-day basis. They were perceived to be generally more pessimistic than other groups. Dementia was thought to be more real for older adults and therefore more accepted as part of their current or future lives.

In summary, younger adults were perceived to be disinterested, mid- and later mid-lifers to be concerned with risk and prevention while older adults were perceived to be more accepting and more exposed to the condition. A guiding principal in how general attitudes are perceived might be that the closer one is in age to later life, the more accepting and nuanced is the response thought to be.

GENERAL PUBLIC COMPARED TO PARTICIPANT'S OWN RESPONSES

When our participant's own responses were compared to those thought to be held by the corresponding age group in general public, age-based similarities and differences emerged.

First, there was some overlap between the personal responses of our mid- and later mid-life participants and those perceived to be prevalent in the general public for this age group. These mostly occurred in the context of risk and prevention. However, rather than recognising later mid-lifer participant's own expressed concerns with interpersonal communication, the general public was perceived to hold at best ambivalent feelings and at worst tendency to avoid dementia entirely.

Second, rather than agreeing with perceptions that among the general public closeness in age made dementia easier

to cope with, older age groups saw their own and other's responses differently. Older participants saw their age peers as in denial or increasingly alarmed by dementia. They themselves, however, reported an interest in interacting with peers and engaging in prevention, and older adults with dementia were, likewise, concerned about preventing the progress of the condition. While there was some evidence of acceptance as a coping strategy by people with dementia, the view that older people in some way accept dementia appears to be a myth.

Third, Younger adults across carers and professional groups gave the greatest emphasis on wanting 'love and affection'. However, the younger general public were perceived to be dismissive, excepting when they had a family connection.

Finally, that people living with dementia in later mid-life could see a positive element was not recognised as a theme in what was perceived to be the general public's thinking.

In summary, there are certain mismatches between what people think the different age groups in the general public think and what they think themselves. The assumption that the closer the age to later life, the more accepting the response, is not borne out. Neither is the view that the younger one is, the more dismissive one might be. Rather, the character of the connection and the shape their understanding takes, varies by age.



THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

In this section, we look at the impacts of dementia as reported by each Voice perspective, first by Voice and then briefly by Voice and Age. We suggest that dementia may create its own forms of disadvantage.

To date the relationship between social disadvantage and dementia has been based on its connection to other sources of inequality, such as social class, gender and ethnicity. If one falls into one group or another, one's risk of developing dementia is expected to increase or decrease, as is the likelihood of experiencing barriers to accessing treatment, care and support. We now explore an additional possibility, that dementia itself might produce particular forms of disadvantage.

We describe the six types of impact and how these have been experienced and understood as particular forms of social disadvantage by different Voice perspectives. These impacts include social, material and service provision, psychological, carer role and sources of disparity (see Figure 2). The first three impacts, plus disparity, follow recent research on social exclusion in later life. However, dementia has not featured prominently in social exclusion research. Psychological and carer role impacts appear to be specifically connected to the experience of dementia.

The coding frame explaining how each impact arises from our data is in the Appendix, Table A4. (For more detail, see Carr, Haapala & Biggs, 2019.)

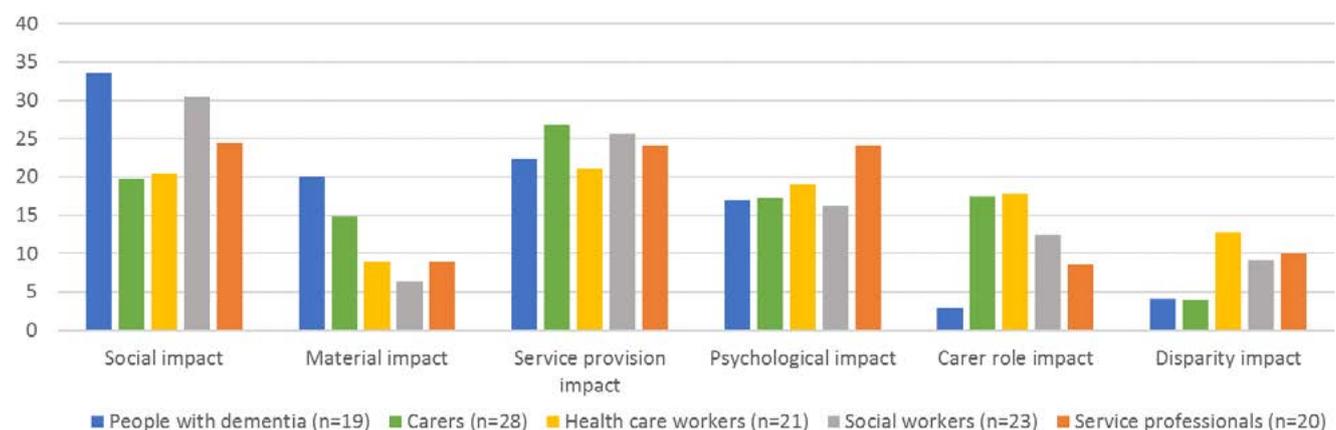
Figure 2 illustrates the importance given to each impact by each Voice perspective, and these will be discussed on the following pages. Percentages in Figure 2 are calculated from the total mentions of impact within each Voice and presented by type of impact. These percentages are also presented in Appendix Table A5.

SOCIAL DISADVANTAGE

Social disadvantage can be understood as a lack of resources (Heap, Lennartsson & Thorslund, 2013) and limitations preventing social participation (Vinson et al., 2015). It is associated with particular demographic and socio-economic features (Heap, Fors & Lennartsson, 2017).

It is closely connected to processes of social exclusion, which can lead to an unwanted situation in which people are prevented from engaging in mainstream society, with detrimental consequences for the individual and society (Walsh, Scharf & Keating, 2017).

Figure 2. Comparison of percent (%) of references within Voice by type of impact.



THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

SOCIAL IMPACT

Social impacts of dementia received the most mentions of all impact areas. It was the most referenced area for people with dementia (33.5%), social work (30.4%) and service professionals (24.4%), and the second most referenced area for health care professionals (20.4%) and carers (19.8%) (See Figure 2.)

People with dementia and carers communicated a shrinking social world following the onset of dementia. This was due to the loss of friends, feeling peculiar, embarrassed or spoken to rudely in public, and being treated differently because of the condition. Whereas carers provided more concrete examples of the above, people with dementia commonly referred to the anticipation of stigma and differential treatment, which made some wary about disclosing their condition to others. A small number of people with dementia referred to new opportunities for social participation arising because of dementia and more positive interactions in public settings.

Professional groups mentioned similar impacts, such as friends dropping off, a shrinking social circle, the negative effects of stigma and the exclusion of people with dementia from decisions-making.

Participants from all voice perspective groups tended to account for social isolation due to family, friends and communities not having the skills to interact with and include people with dementia and carers, and/or because the social and physical environment did not accommodate their needs. Only a minority suggested cognitive decline alone as the main cause of social isolation.

‘... not only do you lose your thinking process, you lose your friends because they’re not – don’t have dementia and they’re still all the same age as me.’ (William, Person with dementia, 62y).

‘I haven’t mentioned to any of them [activity group members] that I’ve been diagnosed with vascular dementia. To be quite honest with you, I don’t want to. I’m not quite sure ... how they would react to me ... I don’t know what to expect.’ (Karl, Person with dementia, 76y).

‘It’s like you’re labelled, and I think that’s the biggest thing because one minute you’re a normal person, the next minute you’ve got this label and people treat you differently.’ (Margaret, Carer, 58y).

‘[People with dementia] become very isolated because the network of people in their life often don’t have the skills or the knowledge or the understanding to actually respond appropriately in a way that actually values people with dementia.’ (Fay, Carer, 60y).

‘They become quite significantly socially isolated, and they lose friends because people don’t know how to, I guess, engage with that person anymore. They don’t know – they obviously feel bad about or don’t understand what dementia is well enough to provide that ongoing emotional support for people.’ (Odette, Social work professional, 36y).

MATERIAL IMPACT

People with dementia mentioned material impacts at 20% of all references to impact within their group (Figure 2), at a much higher rate than other voice perspectives. They principally referred to work/employment and transport. Carers mentioned material impacts at 14.9% and were more likely to mention financial and monetary difficulties.

Work and employment was a major issue for people with dementia. Some were forced from their jobs due to dementia, while others made the decision to retire, although often reluctantly. Not being able to work affected self-esteem and financial well-being.

Restrictions on travel, especially through loss of a driver's license, impacted significantly on people with dementia. Relying on others for transport, which could require formal services and planning, affected their independence. Restrictions were also experienced in relation to getting about on public transport, travelling overseas and travelling on their own.

Carers were impacted in relation to employment and financial problems. The caring role precipitated changes in type of employment and availability to work. Finances and money were negatively affected, and often because of restricted employment options. Many carers had to assume full responsibility for household finances, and often worried about the costs of care.

Material impact was only occasionally mentioned by professional groups and reflected the costs of caring and of services.

'Because the job I was doing I was speaking to hundreds of people and all that sort of stuff, and I just can't put two words together anymore.' (Simon, Person with Dementia, 62y).

'We still travel as much as we can [but] I'll tell you this, I absolutely loath the insurance industry for not giving me a chance to get travel insurance to go overseas.' (Bruce, Person with dementia, 65y).

'Some of the issues are financial, that's a big one in our family because I'm now the breadwinner ... and so it's changed all of our plans. We don't have the income to say go on a cruise or do what friends are doing. It has actually limited what we can do financially.' (Dorothy, Carer, 60y).

'... because of the way life is structured now, everybody has to work. So, if you have to work, you can't care.' (Barbara, Social work professional, 46y).

'My life has changed completely ... I've had to move to a rural area, before I was working in a city. I've had to retrain and change the jobs that I do now and look for jobs here which was difficult too.' (Lisa, Carer, 54y).

THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

SERVICE PROVISION IMPACT

Service provision impact was referred to second only to social impact and was referenced at similar rates across all voice perspective groups (Figure 2). Carers made it their highest impact area (26.7%) as did health care professionals (21.1%). Access to services was the main concern, followed by negative experiences/values of services, positive experiences/values of services, and diagnosis.

People with dementia and carers rated the impact of diagnosis higher than did other groups. Delays in diagnosis, misdiagnosis, being ignored by professionals and poorly communicated diagnoses were common experiences. Diagnosis could also be accompanied by exclusionary social expectations, such as advice to stop working. A small number of people with dementia and carers expressed diagnosis as a relief, though for most, diagnosis provoked a mix of emotions.

Following diagnosis, carers and people with dementia often struggled to interact with a complex service system. In the worst cases, they felt left to navigate the system alone. Access to services related to the difficulties getting information on services, finding specialists, service costs, with some linking lack of services with social isolation and negative effects on relationships. Some overlap between access to services and finances/money was observed by professionals: many felt those with less ability to pay were at a disadvantage; access to services was seen as a challenge, especially in regional areas.

Drawing further on qualitative data it emerged that, for most groups, equal weight was given to the positive and negative value of service provision, though carers and service professional were more likely to emphasise the negative.

Negative values and experiences of services included: poor staffing/training, meaningless activities, issues of restraint, rigid services and poor physical environments. Many felt negative services contributed to cognitive decline, entry into residential care and carer stress.

Positive values and experiences of services related to: committed caring staff, flexible services, consistency of staff, provision of meaningful activities, and dignified care. Positive views of services were felt to reduce the stress that people with dementia experienced, enable carers to get on with their lives, and help maintain positive relations between all involved.

‘It took two years, from 2008 to 2010 to get a diagnosis. It was a very, very confusing and tumultuous period of time ... I did neuropsych tests, did a whole range of things ... at one stage, I was put on anti-psychotics, because they thought that might solve the problem, but it didn’t.’ (Kieran, Person with dementia, 66y).

‘When he was diagnosed, then they were completely unhelpful. They were like “here’s your diagnosis, see you later”.’ (Josephine, Carer, 30y).

‘... the complexity of what people are required to deal with at a time they’re most vulnerable in terms of accessing government aged care services and a whole range of health services is very, very difficult.’ (Fay, Carer, 60 y).

‘Like a lack of appropriate supports for people with dementia I think is probably the biggest challenge and that we actually don’t have - our society actually isn’t properly equipped to support people with dementia.’ (Kylie, Health care professional, 36y).

‘There’s a huge emphasis on community aged care and people staying in their own homes, living independently and all that sort of stuff [and] there is going to be more people with dementia living in their own homes. To what extent they will be socially isolated, disconnected from community, disconnected from services, is a real concern.’ (Hugh, Social work professional, 59y).

PSYCHOLOGICAL IMPACT

Most groups mentioned psychological impacts at about the same rate (16-19%), though service professionals mentioned it most, at 24.1% (Figure 2). Most references to psychological impact related to individual and emotional responses to cognitive loss and relationship change. A smaller but significant number of references were made about difficulties planning for the future.

The main psychological impact for people with dementia was responding to cognitive loss. They felt sadness at such loss and disadvantaged by cognitive changes. Most had come to accept the condition, though not without expressing shock at developing it in the first place. They coped with loss and cognitive change by: adopting a positive attitude, embracing healthy living, focusing on remaining abilities, and personalised strategies to compensate for sensory challenges.

Carers referenced relationship change as a major psychological impact. They mentioned losing the person they loved, not being recognised by their loved one, role changes and communication breakdown. A few mentioned forming a new relationship with their loved one in order to cope.

Dementia made planning for the future difficult. Some carers were forced to change retirement and holidaying arrangements because of dementia and the caring role. The progressive nature of the condition meant they often found it hard to imagine a positive future.

Among the professional groups, psychological impacts were the third most often mentioned type.

Health care professionals were more likely than the other groups to mention the difficulties of planning for the future as part of the psychological impact. They stressed the uncertainties faced by people with dementia and carers, but also the need to make future plans while one was still able.

Social work professionals tended to focus on both the consequences of cognitive decline and its effects on relationship.

Service professionals were the most likely to refer to psychological impacts. They focussed on the psychological consequences of cognitive loss for individuals living with dementia, loss of identity, memory and other mental functions. They were also concerned about the impact on family relationships and of losing the person one loved.

‘Unfortunately [I’m retired] ... Because the job I was doing I was speaking to hundreds of people and all that sort of stuff, and I just can’t put two words together anymore and that’s just very strange to me.’ (Simon, Person with dementia, 62y).

‘When we first got the diagnosis, we came home and basically stayed in bed for a week and cried. Because at that stage the information that I had was how horrific this journey would be ... we instantly went to like the end of the disease basically, felt like we were already there without realising it was going to be such a slow [process]’. (Ann, Carer, 55y).

‘Personally, it is doing the juggle of working and planning for the future when you don’t know what the future is. ... In our life we plan for next year’s holidays or retirement in ten years or whatever it is you’re sort of planning for this long-term future, whereas for me now, everything has got a rider on it.’ (Vron, Carer, 57y).

‘Losing the connections with your loved one, I think that’s extremely difficult’ (Anita, Service professional, 33y).

‘For the person who has dementia, when they start realising they lose their memory, they get very distressed. Then once the memory is gone, it’s very hard on the families, it’s very hard on the children to have their parent not know who they are.’ (Dawn, Service professional, 59y).

THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

CARER ROLE IMPACT

The caring impact was perceived to be an issue by most groups (Figure 2). Carers (17.4%) and health care professionals (17.8%) were most likely to refer to this impact, whilst people with dementia mentioned it least.

Carers recounted the all-consuming nature of the role, of lives changed completely, the shattering of hopes and dreams and the emotional impact of caring. They also emphasised societal expectations that pressured them to care. Carers' views highlighted the ripple effects of dementia, from individual experience through to family and social connection and the wider community.

Many of the professional participants were of the view that carers were more affected by dementia than were those living with the condition. Whereas people with dementia were able to identify positive aspects of their situation, carers were generally not.

The carer role impact overlaps with other impact areas, including psychological impacts, service provision and materially in relation to work/employment. Carers appear particularly vulnerable to experiencing inter-linking forms of social disadvantage across different parts of their lives.

'I loved my work. It was very good, but I found [my husband] needed more support so I had to retire ... I wasn't ready to retire ... it was very hard, very hard.' (Olivia, Carer, 61y).

'It's very confusing, it's not nice for anybody really. It's very draining, very emotional. It's mentally exhausting.' (Dina, Carer, 32 y).

'The whole thing of carers, the whole notion of what that means and how stressful it is to be a carer and how it's not recognised, it's not paid, it's not anything, and it's usually women that end up doing it.' (Hilary, Carer, 64 y).

'I get cross with the Government, the Federal Government expecting people, or wanting people to stay in their own home but expecting the family to do the caring, which isn't always possible.' (Noel, Carer, 69y).

'I think for the carers of those younger people, it's an incredible challenge to sustain their relationship. Because they're at the stage of still being together as a family and a couple, and the intimacy within that relationship is really challenging. They have to keep the family safe as well.' (Sylvia, Social work professional, 67y).

DISPARITY IMPACT

Disparity refers to the unequal impact of social factors on people from less privileged backgrounds. The disparity impacts, including age of onset, socio-economic status, rural/urban setting and level of education, was the least mentioned category by carers and people with dementia (Figure 2).

Health care professionals (at 12.8%) and social work professionals (at 9.1%) rated these mediating factors above material impacts; service professionals (at 10%) rated this impact area above material impacts and carer role impact. Carers and people with dementia referenced disparity factors at particularly low rates (about 4% each).

All voice perspective groups, excepting service professionals emphasised age of onset as important, specifically the idea that younger onset was most likely to be more disruptive to individuals and their families and lead to greater levels of social disadvantage.

There was little agreement amongst participants on the role of socio-economic status, rural/urban setting and level of education in mediating social exclusion or disadvantage. People with dementia and carers tended to view having dementia as a form of 'bad luck'. Most participants felt that dementia caused declining social status and standing rather than being affected by other forms of inequality.

'Socio-economic groups, I don't know that that makes a difference really ... it's not dependent upon socio-economic status ... I think it's more dependent on the people themselves and their values and their relationships.' (Caroline, Health care professional, 62y).

'...for people who are diagnosed young, it has significant ramifications for their life ... if a person is diagnosed with what they call younger onset dementia ... they could ... still be working. They could still have a young family. They could still have a mortgage ... so it has economic implications for the family. Not to mention the impact it has on the children of the marriage.' (Kieran, Person with dementia, 66y).

'Maybe people with disadvantage would find it very difficult because of all the stresses and issues that come up with dementia ... and the care which costs money. So, dementia becomes ... very difficult to deal with when you're already disadvantaged. It becomes more burdensome in a way.' (Sally, Service professional, 47y).

'I suppose on an academic level ... if people have more education they're likely to understand on an intellectual basis and have different attitudes, but when it comes down to person to person I'm not really sure that areas of living or social disadvantage impact that much.' (Heather, Health care professional, 59y).

'... in a rural environment the sense of community can be a bit stronger. And even though their knowledge and actual knowledge of dementia and the symptoms and what the medicine would say you need to do to support someone with dementia [might be less than other areas], actually their sense of community there may help to support people at home a bit longer to prevent social isolation.' (Darren, Health care professional, 36y).

THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

COMPARING DIFFERENT VOICES, AGE AND IMPACT

In this section, we compare the reports of impact across Voice & Age perspectives.

People with dementia

Comparing the two, Older adults with dementia were more concerned than their younger counterparts with the social and service impacts of dementia, but equally concerned with the material impacts. Significantly, each placed a different emphasis on the psychological impacts. For Later mid-lifers with dementia the psychological impact was a principal concern, second only to social impact, whereas for Older adults with dementia it was rarely mentioned at all.

Taking age group differences into account:

- **Later mid-lifers** with dementia (n=11) were particularly impacted by social isolation and lack of community engagement plus disadvantages experienced through loss of employment and challenges accessing supportive services.
- **Older adults** with dementia (n=8) were impacted mostly by social isolation, anticipation and experience of stigma, challenges accessing services and diagnosis, and difficulties with transport and loss of employment.

Carers

There were high degrees of agreement about the impacts across age groups. Carers of all ages mentioned the challenges accessing services and diagnosis more than any other voice perspective. Regardless of age, carers tended to refer to social and carer role impacts at approximately the same high rates.

The order of priorities according to age changed in subtle ways, including an increasing emphasis on material impacts from the younger to older age groups.

- **Younger adult** and mid-life carers (n=5) were mostly impacted by challenges accessing services and support, the psychological effects of dementia and relationship change and then social and carer impacts. When compared to older age groups, they placed less emphasis on the material impacts of dementia, but more on disparity factors, especially age of onset.
- **Later mid-lifer** carers (n=15) emphasised challenges accessing services and diagnosis, followed by social isolation and stigmatising attitudes, then the impact of the caring role on personal relations, employment and family finances. While they rated the social impacts the highest of all groups, they did not give the same priority to the psychological impacts.
- **Older adult carers** (n=8) were impacted equally by challenges accessing services and diagnosis, and social isolation and lack of community engagement. Psychological and financial effects of dementia on their life and relationships were often connected to the caring role.

Professionals

Similar to carers, there was a high level of agreement on the impacts of dementia, with the top three categories of impact – social, services and psychological – the same across all age groups.

Some important differences between the age groups did emerge, however.

- **Younger adult professionals** (n=10) gave greater emphasis to the psychological impacts and were slightly more likely to refer to disparity factors, such as socio-economic status and rural/urban setting as influencing the effects of dementia.
- **Mid-life professionals** (n=21) gave less emphasis to psychological impact, but more weight to the material impacts, such as employment and financial difficulties.
- **Later midlife professionals** (n=28) gave some consideration to disparity factors, but rarely mentioned the material impacts.
- **Older adult professionals** (n=5) were more likely than other age groups to mention the social and service impacts, and the least likely to mention material or carer impacts.

Conclusions on Dementia as A Form of Disadvantage

Dementia presents a range of factors contributing to social disadvantage for those affected by it. While there is some overlap with social exclusion research on age in the areas of social, material and service impacts (Walsh, Scharf & Keating, 2017), the consequences of adopting a caring role, plus psychosocial and emotional impacts may be specific to dementia. These appear to be closer to impacts associated with mental health issues (Morgan et al., 2007), than with age, although the dynamics are different. This is a different way of looking at the relationship between dementia and disadvantage than is most commonly the case, as it suggests that in addition to seeing forms of pre-existing disadvantage as risk factors, dementia generates forms of exclusion and disadvantage because of the way it is perceived and responded to in the public domain.

DEMENTIA AND DISADVANTAGE

Our findings on dementia and disadvantage illustrate four important points:

Dementia can create its own forms of social disadvantage and exclusion

Some impacts are held in common with ageism and social exclusion, though they may take distinctive forms

Impacts associated with psychological consequences and adopting a carer role may be specific to dementia

Differences in the emphasis given to particular impacts varied depending on age and voice

There is a high level of agreement across perspectives that dementia creates social exclusion.



PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE AND AGE

CAMPAIGN PRIORITIES EXPLAINED

Description of these campaign priorities arises from the contents of participant interviews. Six priorities (themes) are shared between voice perspectives and campaigners:

Awareness-Raising

Raising awareness in the public domain about dementia as a condition, such as definitions of dementia, incidence and prevalence rates, information on dementia-related symptoms and its impact on individuals and society. Includes raising awareness about the organisations and services that can help.

Understanding and Interaction skills

Emphasis on communicating a deeper understanding of how to help and interact with people with dementia, a sense of inhibition toward people with dementia amongst the general public, professionals and in public places, the need for information to counter stereotypes, and the use of life stories and case studies to highlight real lived experiences. Aims to change current attitudes and behaviours, specifically a better understanding of the needs of people with dementia.

Normalising Dementia

Focus to make dementia an accepted part of everyday life and conversation by increasing visibility of people with dementia, emphasising the positive aspects of dementia and care, and promoting social inclusion and dementia-friendly communities. Aims to reduce negative perceptions and language and can appeal to citizenship values, such as the responsibility of individuals to increase support for and acceptance of people with the dementia.

Dignity, Respect & Rights

Focus on respecting people with dementia as still the same person and their right to live a valued and meaningful life. Includes advocacy for people with dementia and ensuring that carers are adequately supported. Can involve providing a platform for people with dementia to speak for themselves, the co-design of services and local initiatives, and ways to maintain and increase community engagement.

Prevention Methods

Promotion of proven ways to reduce the incidence and risk of dementia, such as good dietary habits and exercise. Focus also on the benefits of early intervention to help reduce the severity of dementia and promote help-seeking behaviour.

Health Care System and Services

Focus on improving the care and support provided to people with dementia via the health and care systems and services; providing information on services available, the need for additional funding and supports, and the provision of effective approaches to care.

Three additional themes brought up by the campaigners (See the section “Campaigners’ Perspective”):

Organisational Priorities

Emphasises the needs of organisations engaged in public campaigning to sustain their activities, including care and support services. Includes demonstrating the need for services, making the services of the organisation more visible and promoting branding.

Fund-raising

Focus on attempts to raise funding for organisations providing help and support, for research, for community groups and local services, and for increased government support for people with dementia, their carers and services.

Influencing Policy and Planning

Engaging in the political and policy-making process through lobbying, appeals to political representatives, and promoting civic discussion to change and/or improve dementia-related care and other relevant policies. Also includes involving people with dementia directly in policy development and the use of research and evidence to influence the policy-making process.

In this section, we look at how these campaign themes were prioritised based on Voice and Age.

PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE AND AGE

We asked people from different Voice perspectives about their priorities for campaigning, using the question: “What would an effective campaign on dementia look like?”

PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE

Six priority areas were identified through a thematic analysis of their interviews. These can be seen on the ‘radar’ diagram below (Figure 3). The radar shows us how the Voices constellate around the priority areas, helping us to identify areas of overlap and distinctiveness. More detailed descriptions of the priority areas can be found in the box: ‘Campaign Priorities Explained’.

The radar diagram (Figure 3) shows us several interesting patterns in the data:

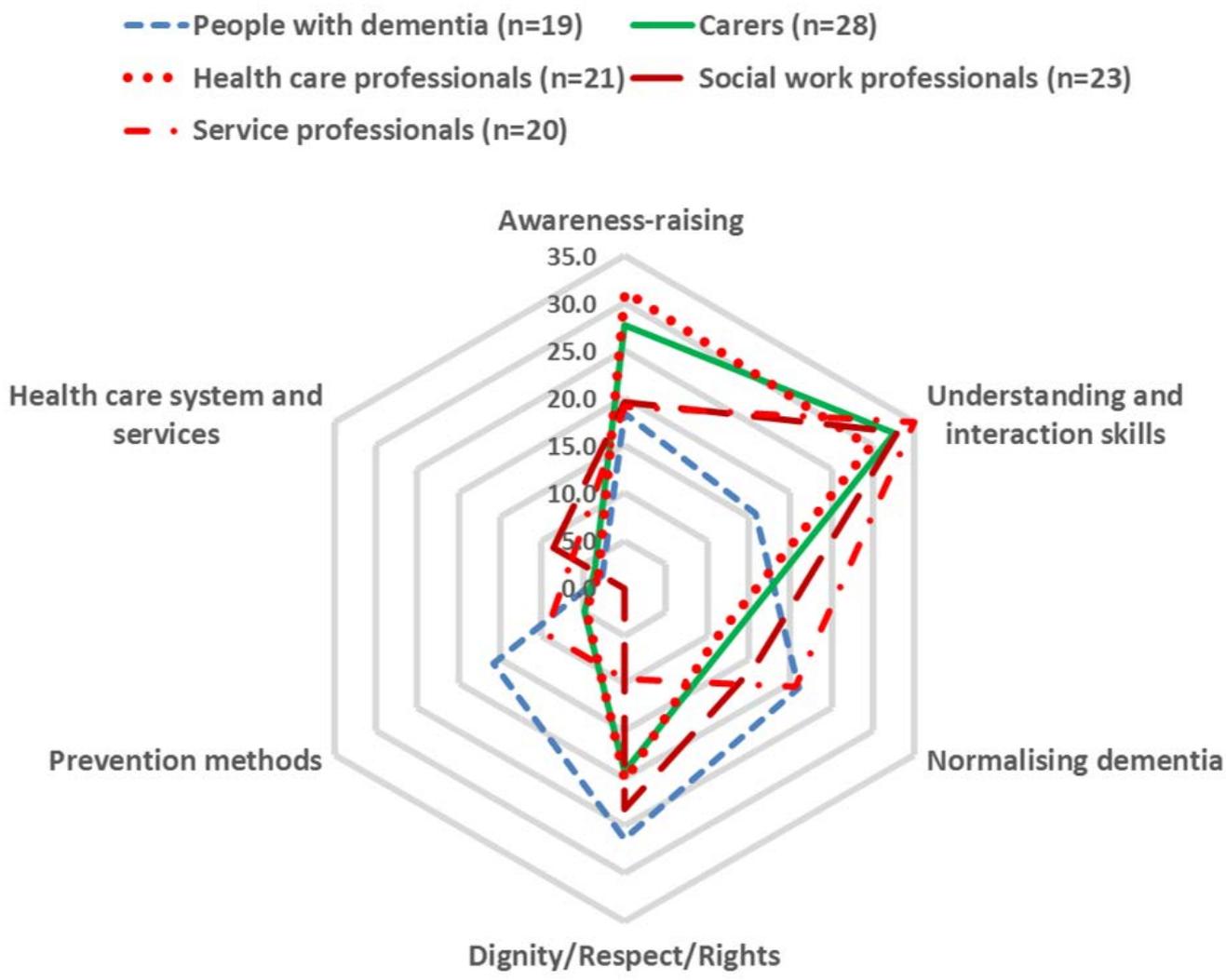
- First, priority has been placed on increasing understanding and interaction skills by all groups, with the exception of people with dementia. This would imply that when examined by perspective, the views of people with dementia differ from the other groups while the latter are somewhat similar.
- Second, people with dementia distinctively placed some emphasis on campaigns related to prevention methods and stalling the progression of the condition. Most of all they emphasised campaigns to normalise dementia in the public sphere and to secure the dignity, respect and rights of people with dementia.
- Third, there is considerable overlap between the voice of carers and health care professionals in focusing on raising awareness, increasing understanding and interaction, and campaigns to secure the dignity, respect and rights of people with dementia.
- Fourth, service professionals and social work professionals were closer to the emphasis placed by people with dementia on normalising dementia. While the two professional groups also suggested campaigns on awareness-raising and increasing understanding and interaction skills, they diverged on prevention methods and dignity, respect and rights issues, with the former mentioned more often by service professionals and the latter by social work professionals.
- Fifth, and most surprisingly, given the emphasis of contemporary public health campaigning, health care systems and services were not prioritised by any group, including health care professionals.

Finally, when taken together, increasing understanding and interaction skills and normalising dementia may represent complementary categories based on perspective. People with dementia may be wishing for social inclusion, while other groups want to know how to interact with them.

SUMMARY

Attitudes and views on effective future campaigning reflected a desire for greater social inclusion but did not focus on health care services and systems. Professionals focused primarily on increasing interpersonal skills. People with dementia emphasised accepting dementia both personally, by others and as a right to continued engagement in communities. Dementia, in other words, should be seen as a normal part of everyday life. They also highlighted prevention aimed at slowing the progress of the condition. Carers focussed on improved public understanding, greater social interaction and awareness-raising.

Figure 3. Campaign priorities by Voice; percent of mentions within Voice group.



PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE AND AGE

PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE & AGE PERSPECTIVE

In this section, we have looked at people’s priorities for campaigning, adding Age to the Voice perspectives discussed earlier.

The ‘radar’ diagrams (Figures 4a-4c) illustrate the degree of emphasis placed on specific campaigning priorities (topics) by each Voice and Age perspective. Participants were asked “What would an effective campaign on dementia look like?”

Details of campaign priorities are explained in the above section: Priorities for Campaigns on Dementia by Voice.

As age groups varied between voice perspectives, people with dementia, carers and professionals have been analysed separately. Here we can distinguish differences in emphasis between age groups within each perspective thus providing more detail on the concerns of particular groups.

First, later midlife and older people with dementia showed differing patterns of campaign priority. **Later mid-lifers with dementia (n=11)** focused on campaigns to normalise dementia and awareness-raising, but also on increasing understanding and interaction skills plus dignity, respect & rights issues. **Older adults with dementia (n=8)** focused on campaigns on dignity, respect & rights and prevention to slow down the progression of the condition.

Second, when Carer’s responses were analysed, **Younger adult and mid-life carers (n=5)** focused principally on awareness-raising, but also on increasing understanding and interaction skills and on dignity, respect & rights issues.

Later mid-life carers (n=15) focused on campaigns that would increase understanding and interaction skills as their first priority, followed by dignity, respect & rights issues and awareness-raising. **Older adult carers (n=8)** focused most strongly on awareness-raising campaigns, and to a lesser extent on campaigns to increase understanding and interaction skills and to normalise dementia.

Figure 4a. People with dementia: Campaign priorities; percent of expressions by Age group.

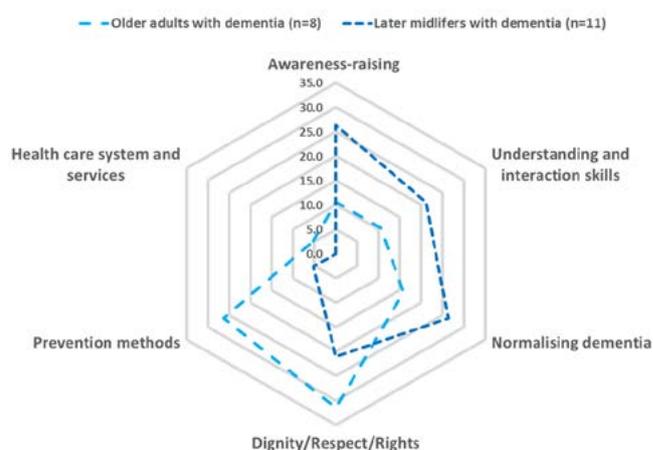
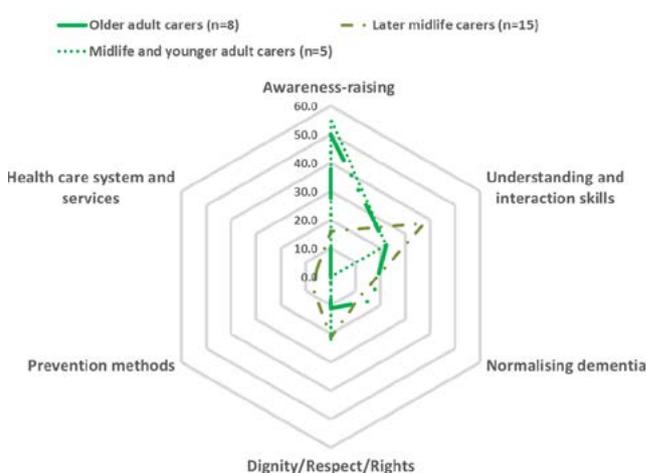


Figure 4b. Carers: Campaign priorities; percent of expressions by Age group.

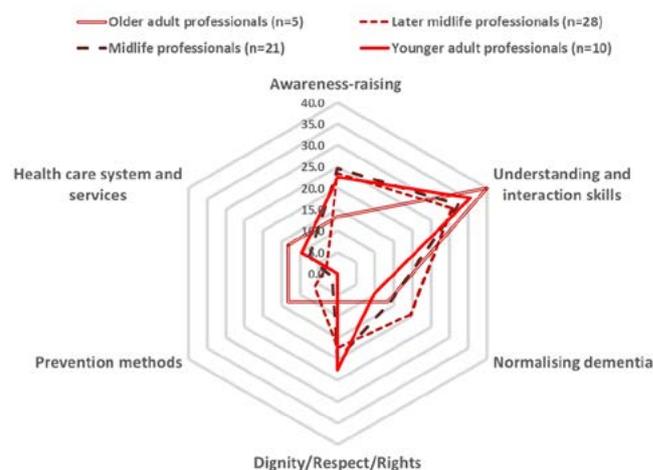


Third, when professionals' combined responses are looked at, **Younger adult (n=10)**, **Mid-life (n=21)** and **Later midlife professionals (n=28)** showed a close alignment, prioritising increased understanding and interaction skills but also on awareness-raising and dignity, respect & rights issues, with later mid-lifers giving some priority to normalising dementia. **Older professionals (n=5)** showed a modified pattern, with the strongest emphasis on understanding and interaction skills, some emphasis on prevention and health care, but little on awareness-raising and rights.

CAMPAIGN PRIORITIES IDENTIFIED

- **Awareness-raising campaigns** were most strongly identified by with carers in younger adulthood and mid-life, plus older adult carers, but rarely by later midlife carers.
- **Understanding and interaction skills** were emphasised by all professional age groups regardless of age, as well as by later midlife carers. It was less important for other carer age groups and people with dementia.
- **Normalising dementia** appeared as most important to later mid-lifers with dementia, followed by later midlife professionals. It was not emphasised by younger and midlife carers.
- **Dignity, respect and rights** were most emphasised by older adults with dementia, but not by older adult professionals.
- **Prevention**-related priorities were most emphasised by older adults with dementia.
- **Health care systems and services** –related campaigns were not prioritised by any age group or perspective.

Figure 4a. People with dementia: Campaign priorities; percent of expressions by Age group.



IN SUMMARY

interactions are complex between age, voice and campaigning, but certain trends stand out:

- Age reveals distinctive patterns between later midlife and older people with dementia. While both groups emphasised dignity, respect and rights, the younger one focused more on normalising and interactive agendas and the older on preventing the progress of the disease.
- While younger and older carers showed a close alignment in prioritising awareness-raising, carers in later midlife showed a different pattern with a greater emphasis on understanding and interaction skills than other age-groups.
- Professional groups showed a strong combined alignment toward understanding and interaction skills, regardless of age. Age did distinguish older professionals in some areas.

PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE AND AGE

QUOTES ON PRIORITIES FOR CAMPAIGNS

‘Campaign against too much pigeonholing. People want to take you out of the equation. Let people enjoy life. Let people live. Let people have a go.’
(Bruce, Person with dementia, 65 y)

‘For an early diagnosis, so screening for dementia ... you know the bowel test that you get, you’re aware of that now. And breast screening, you’re more aware of it. And you do something about it.’
(Grace, Person with dementia, 67 y)

‘I think loneliness, of the campaign, is that when people become aware of it and helping them where to go, where to look, you’re not alone in one sense and don’t be ashamed of having dementia.’
(Jinny, Person with dementia, 70 y)

‘I think ... one is the person, two is the family, three is good friends, and four would be ... understanding ... get people thinking about it, and get people understanding what it is.’
(Simon, Person with dementia, 62 y)

‘It’s just so unpredictable. Maybe more advertising on what would happen. Maybe a sequence of steps of what to do if it happened to you. So, kind of like a preparation if it did happen, maybe like ... Like you know what to do if someone has an asthma attack.’
(Jenny, Carer, 30 y)

‘Tell people what dementia is and what people are going through and how you can actually pick up on it when it first happens.’ (Lucky, Carer, 74 y)

‘Perhaps showing people in their day to day life, what - how they’re good still good at some things. It was just a real awakening thing for me ... There were still parts of it that gave them such joy ... I think that positive sort of spin on it would - takes away a bit of fear.’
(Marion, Carer, 62 y)

‘I think you would have to really educate people, actually letting them know upfront what is dementia, how people will present, how can communities be more understanding towards them, all the things that can be done to help.’
(Chloe, Social Work professional, 33 y)

‘Awareness-raising: probably fairly gentle and fairly friendly and show a positive side. Not doom and gloom. People with dementia are normal people that this is happening and a lot still live very full lives with dementia.’
(Erin, Service professional, 48 y)

‘Behavioural change to encourage exercise, social connection and brain activity; staving off dementia.’
(Ivan, Service professional, 52 y)

‘It’s going back to the quality of life and getting assistance from funding because everybody you’re interviewing with dementia are saying they want to stay where they are they don’t want to go in a home.’
(Heidi, Service professional, 71 y)

‘Just a few key words that signifies that the personality is there, they just can’t get it out in some ways and things like that.’
(Sophie, Health care professional, 32 y)

‘Perhaps just raise awareness around what is it and how common is it and a few quick practical things that you can do. Maybe show in those campaigns show how people with dementia are still contributing in society. Because I just don’t think the society knows, I don’t think people know what to do with it.’
(Kylie, Health care professional, 36 y)



I'm making
the change
for dementia.

#BeTheChange2017

Change starts
with me.

TheChange2017

Nothing
about me,
without me.

#BeTheChange2017

I'm leading
change for
dementia.

#BeTheChange2017

I'm tr
dem
pr

CAMPAIGNERS’ PERSPECTIVE

In this section, we present findings from our interviews with representatives from National and Local campaigning organisations on their current and future priorities and what facilitates a good campaign*.

NATIONAL LEVEL CAMPAIGNERS

Ten interviews took place with representatives from nine participating National organisations, including seven English speaking and two Nordic countries. National campaigning reflected areas of domestic priority, often connected to National Strategic Planning or grasping public attention in their specific contexts. Their priorities echoed historical foci on specific service areas, cultural understandings of dementia and carer roles, a relative emphasis on market positioning, branding and fundraising depending on type of welfare economy, and alliances with other campaigning groups.

Taken as a group, their coverage of campaign priorities was relatively even-handed between the issues that had concerned specific voice perspectives. Their priorities reflected: Dignity, Respect and Rights; Increased Understanding and Interaction Skills and Normalising Dementia. They paid greater attention to Fundraising and Organisational priorities than voice or local campaigner’s perspectives, reflecting the generic concerns of large national not-for-profit organisations. Greater attention was also paid to Influencing policy and planning, including alliances with like-minded organisations, than did other perspective groups.

In the next major section, we compare campaigners’ priorities to the views of People with dementia, Carers, plus Health, Social work and Service professionals on what an effective campaign would look like.

NATIONAL LEVEL CAMPAIGNERS (N=10)

Current National campaign efforts included:

- Raising general awareness to improve understanding and support.
- Aligning the aims of national, other dementia strategies and public health priorities with the activities of dementia-focused organisations.
- Gaining the support and commitment of national and state or local political representatives for particular policy goals.
- Empowering people with dementia through advocacy and public information.

National level campaigners reflected national areas of priority, often connected to National Strategic Planning or gaining public attention in specific contexts.

National Top Priority Areas: Increasing understanding and interaction skills, plus coping with dementia (aligned with views among Professionals and Carers); normalising dementia (aligned with People with dementia and Service professionals); and dignity, respect and rights (aligned with Local campaigners, People with dementia and Social work professionals).

*For explanation of Campaign Priorities categories, please see the earlier Section: “Voice Priorities for Campaigns on Dementia”.

LOCAL LEVEL CAMPAIGNERS

Nine interviews took place with representatives of six local Australian campaigns. Between Local campaigner groups there was a relatively high level of consensus on key foci. Their focus was skewed toward Normalising dementia (not to be mistaken with dementia as a normal part of ageing, nor with dementia as demographically connected to ageing), as wanting people living with it to be accepted as a normal part of daily neighbourhood life. Other priorities included Increased understanding and know-how when it comes to interaction between People with dementia and others, plus Dignity, Respect & Rights issues.

Local campaigners' response, in other words, was more uniform as a group than National campaigners, possibly reflecting a common experience of local priorities. They strongly prioritised Normalising agendas and then Dignity, Respect & Rights and to some degree Understanding and Interaction Skills. Local campaigners, unsurprisingly, emphasised community level actions, interpersonal skills, making dementia a normal part of neighbourhood life, increasing its visibility and the experience of dementia plus co-creation and governance driven by people with dementia themselves.

COMPARING NATIONAL AND LOCAL CAMPAIGNING PRIORITIES

When Local and National campaigner priorities are compared, as in Figure 5, National campaigns appear to give a balanced weight to multiple priorities. Local campaigns appear closer to each other in their view of priority issues, but more skewed in the priority emphasis given to specific concerns. Local campaigns were particularly concerned to normalise dementia within communities with an emphasis on dignity, respect and rights.

LOCAL LEVEL CAMPAIGNERS (N=9)

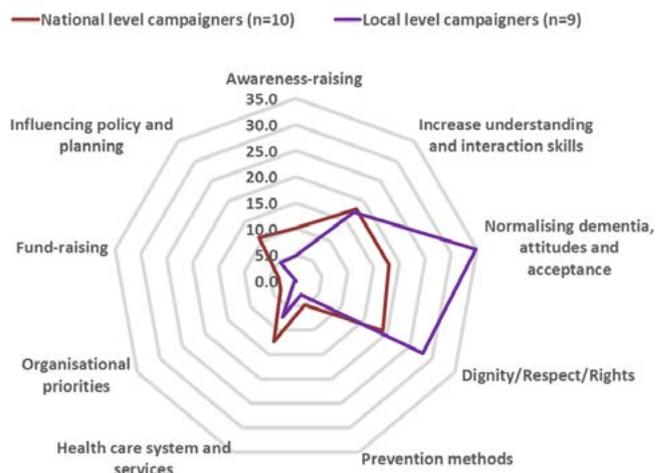
Drivers for Local campaigning priorities:

- Creating dementia-friendly communities through initiatives with local councils, care and support services, parks and amenities, businesses and shopping centres and the public.
- Training and education activities to improve care services and interactions in public.
- Promoting local events on the human rights and dignity of people with dementia.
- Providing a platform for people with dementia and their supporters to advocate for themselves.

Local level campaigners reflected relatively high level of consensus on key foci reflecting a common experience of local priorities.

Local Top Priority Areas: Normalising Dementia (aligned with People with Dementia and Service Professionals) plus enhancing Dignity, Respect & Rights of People with Dementia (aligned with People with Dementia and Social work professionals).

Figure 5. Campaigners' priorities for campaign: Percent of mention within group, National level (n=10) and Local campaigners (n=9).



CAMPAIGNERS' PERSPECTIVE

CAMPAIGNERS' VIEWS ON PUBLIC PERCEPTION AND FACILITATORS OF AN EFFECTIVE CAMPAIGN

Public Perceptions

National level campaigners felt that public perceptions toward dementia were predominantly negative and related to stigma, fear, ageist views, notions of dementia as a debilitating disease and of confining people with dementia to nursing homes. They thought that poor levels of understanding, such as seeing dementia as a normal part of ageing or simply as an older person's disease were common. National level campaigners did not refer to positive social attitudes at all, though some made reference to levels of understanding beginning to increase, albeit from a low base.

Local level campaigners identified public perception as mostly negative, and related to stigma, ageism, seeing people with dementia as crazy and focusing on the end stages of the condition. They thought that fear, avoidance and seeing dementia as the worst possible condition to have, were common responses to dementia in the public domain. While no positive attitudes were referred to, some local level campaigners felt that levels of knowledge and understanding amongst the public were on the rise.

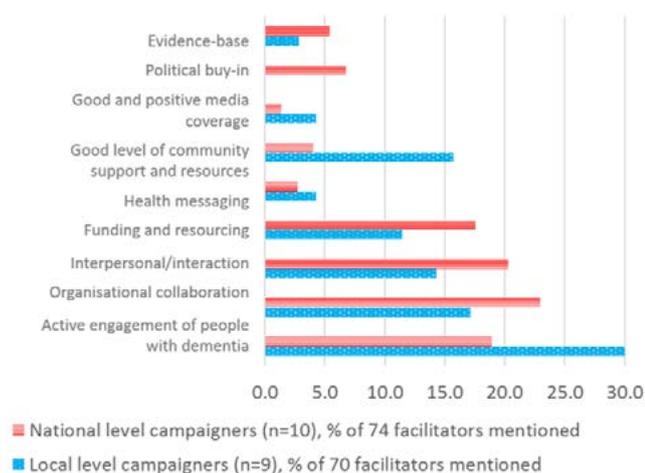
Facilitators for Effective Campaigning

When we looked at what campaigners expressed as facilitators for effective campaigning, the following patterns emerged (see Figure 6).

National campaigners identified organisational and inter-sectoral collaboration as one of the most important facilitators of an effective public campaign on dementia. Effective campaigning was seen as including understanding and action at the interpersonal level, plus a focus on people with dementia being actively involved. Adequate funding and resourcing were given importance, particularly for sustaining campaign efforts, targeting specific groups and appealing to the broader public. Campaigners at this level also referred to gaining political support and developing an evidence base.

Local level campaigners believed that effective campaigns needed most of all the active involvement of people with dementia. This was particularly the case with local dementia-friendly initiatives, which need people with dementia in key governance, organisational and spokesperson roles. A collaborative approach involving local government, organisations and businesses, educational institutions and the broader community should be aimed at, in order to harness community support and resources. Some emphasis was also given to campaign activity that focussed on understanding at the interpersonal level, plus adequate resourcing and funding.

Figure 6. Campaigners' views on facilitators for campaign effectiveness. Percent (%) of mentions within group.



In comparison (see Figure 6), National campaigners gave greater priority than Local ones when it came to inter-organisational collaboration, interpersonal skills and funding. They also gave more emphasis to what were perceived as lesser issues among Local ones, such as political buy-in and having an evidence-base. Local campaigners placed greater emphasis on active involvement by people with dementia, good levels of community support, and less on issues such as media support and health messaging. Perhaps surprisingly, neither National nor Local campaigners placed particular weight on health messaging, positive media coverage, political buy-in or having an evidence-base.

WHAT DOES ALL THIS SAY ABOUT CAMPAIGNING?

While there has been general acceptance that dementia is a disease and not a normal part of ageing, this is no longer perceived to be a campaign priority. In other words, assumptions in the critical literature, that campaigning would reflect a particular focus on medicalisation, does not appear to be borne out. Neither do findings correspond with priorities as reflected in public health research and the World Health Organisation (WHO, 2016) guidelines concerning service and prevention.

Both National and Local campaigners gave some emphasis to health care systems and services, together with Social work professionals (Figure 7). Otherwise there was an unexpected lack of emphasis on this topic. Perhaps reflecting a tacit view that this priority was already in the public domain. It corresponds with an under-emphasis of health care and prevention in answer to the question 'What would I want?' (in a hypothetical or real situation that one was diagnosed with dementia) by almost every voice perspective.

Health service issues have taken second place to social priorities in the minds of each perspective we asked. This includes making dementia a normal part of civic and community life, plus the reciprocal importance of fostering interpersonal skills. There is evidence, however, of some mismatch between the priorities identified in the public health literature and those of the recipients of their messaging.

The new finding that Carers and Professionals want more understanding on how to interact with people with dementia in the public domain, indicates inhibition and a lack of appropriate social skills. An absence of these, rather than the effects of stigma, are perceived to be important barriers to normalising dementia.

While both National and Local campaigning recognised the priority for a normalising agenda, which was also the concern of People with dementia, there was relatively little emphasis being given to Carer and Professional priorities around interpersonal communication and understanding plus awareness (Figure 7).

Voice and Age are two ways in which connection to dementia can be studied and appropriate ways to influence wider public attitudes might emerge. Such an approach differs from existing survey research in so far as rather than focussing on receptivity to pre-determined public health information, attention is drawn to the expressed priorities of specific groups.

If people avoid dementia as a topic, or the messaging is not tailored to their own circumstances and priorities, they will be less likely to adopt public health advice or to critically address the values and social attitudes that determine the inclusion of people affected by dementia in wider society.

CAMPAIGNERS' PERSPECTIVE

COMPARING PRIORITIES BETWEEN CAMPAIGNERS' AND VOICE PERSPECTIVES

When National level campaigners', Local level campaigners' and priorities by Voice perspective were compared, patterns of overlap and distinctiveness emerged (see Figure 7).

Connecting Campaigners and Voice Perspectives

When we looked at alignment between National campaigners and Voice perspectives, we found that National campaigners focused on

- Dignity, Respect and Rights which aligned with priorities of Local campaigners, People with dementia and Social work professionals;
- Increasing Understanding and Interaction Skills, aligned with all Professional groups and Carers
- Normalising dementia, aligned with People with dementia and Service professionals.

Local campaigners prioritised Normalising agendas which most closely aligned with People with Dementia and Service Professional perspectives; and then Dignity, Respect & Rights, aligned with People with Dementia and Social work professionals. These connections are perhaps what would be expected if neighbourhood-based organisations are more likely to be embedded in everyday community activities. To a lesser degree they focused on Understanding and Interaction Skills, aligned with all Professional groups and Carers.

While there are areas congruence, two areas stand out as being valued by Voice perspective groups that were not given the same degrees of emphasis by either National or Local campaigners. These included:

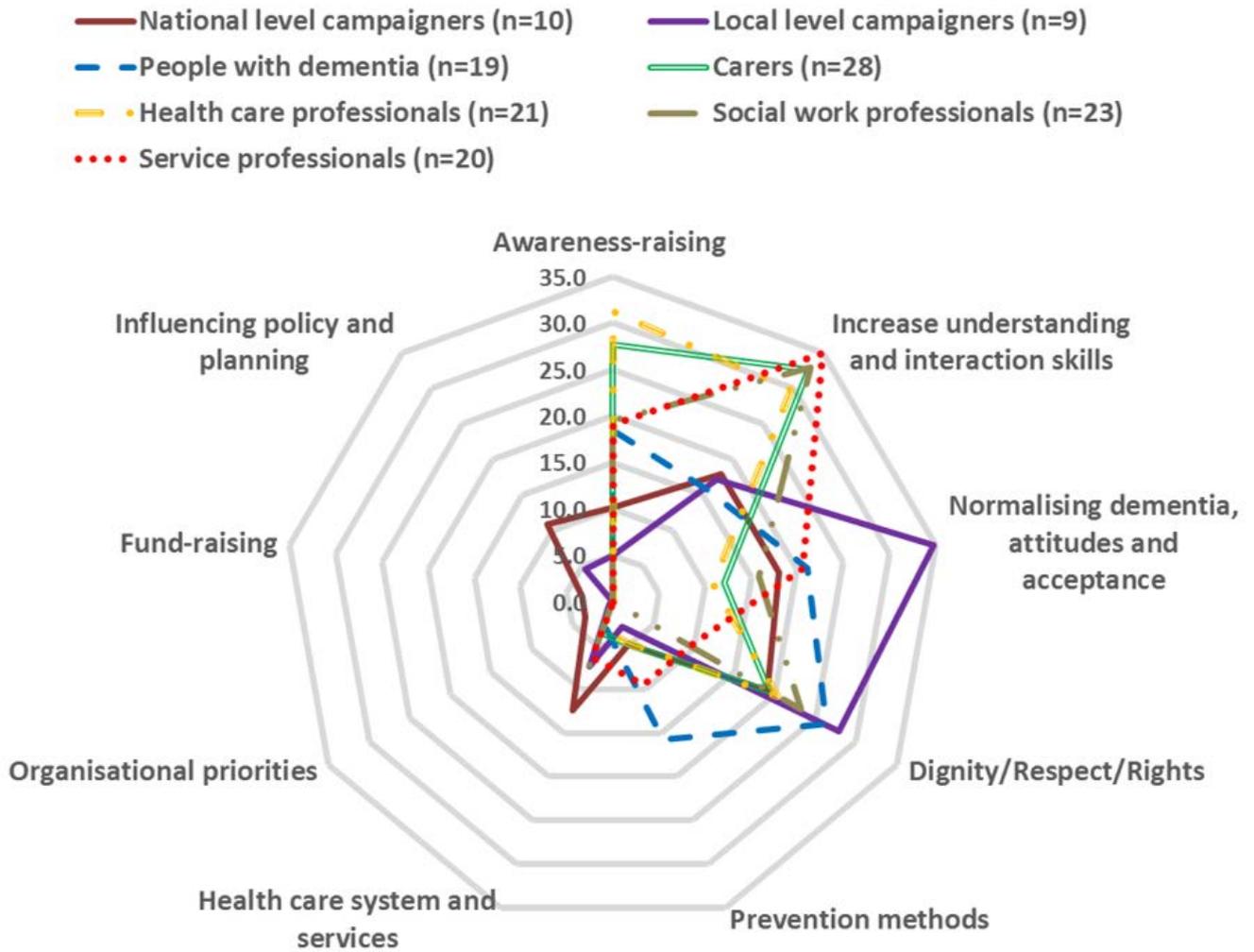
1. Awareness-raising, most emphasised by health professionals and carers. Carers being concerned with increasing general awareness of what living with dementia was like and its consequences, and health professionals focussing on awareness from a public health perspective.
2. Increasing mutual understanding and how to interact with people with dementia was important for all Professional groups and Carers.

This would suggest, surprisingly, given the numbers of carers and professionals engaged in campaigning organisations, that carer and professional concerns may be under-represented in campaign priorities, at least when it comes to interpersonal issues, something that is particularly true in local initiatives. This may reflect a certain altruism and contemporary respect for the views of the first-person end-user voice. However, if there are issues surrounding public awareness of caring as a form of disadvantage plus difficulty in communication, and therefore genuine negotiation between people with dementia and others, then normalising alone is unlikely to generate lasting solutions. If normalising agendas and a desire to communicate are seen as two sides of the same coin, then an exclusive emphasis upon one perspective, in this case the perceived needs of people with dementia, misses the essentially interactive nature of social exchange and the possibilities for mutually negotiated solutions.

COMPARING CAMPAIGNERS' AND VOICE PERSPECTIVES:

- There was a general consensus that dignity, respect and rights were an important priority for campaigning now and in the future.
- National and particularly Local campaigning organisations gave greatest priority to seeing people with dementia as a normal part of society. As did People with dementia themselves and service professionals.
- Professional groups' and Carers' emphasis on skills for increasing mutual understanding and how to interact with people with dementia was only partially reflected in the priorities of Campaigning organisations.
- While national priorities included health care systems and services to some extent, this was not a priority for other groups.
- People with dementia were the only group to give some emphasis to prevention.
- In general, social factors such as normalising relations in communities and skills for interaction between groups, were given greater emphasis than those related to physical health.

Figure 7. Perspectival views on campaigning priorities: Views among five Voices and National and Local level campaigners.



Footnote to Figure 7: In addition to the campaign priorities recognised by Voice perspectives there were three new priorities identified by campaigners (see “Campaign priorities explained” in Section: “Priorities for Campaigns on Dementia by Voice”).



DISCUSSION, CONCLUSIONS AND A WAY FORWARD

The findings in this report have important implications for understanding dementia from the perspectives of people with dementia, carers and the helping professions, and for policy and the practice of public health campaigning.

The findings are particularly valuable because people with dementia and professionals from the service industries have been under-represented in contemporary research in this area.

In answer to our two questions at the beginning of this paper of whether different groups have different perspectives and priorities toward dementia, and how current and future campaigns should take this into account, we found that:

- First, it appears that voice, family connection and age, each of which offers a perspective on people's closeness to dementia, do affect the perspectives people take, their priorities and the perceived impact of the condition.
- Second, the priorities of these 'recipients' of public health messaging differ in important ways from three priorities set by the WHO (2016) and the Lancet reports (Winblad et al., 2016; Livingston et al., 2017) of understanding the disease, health service priorities and preventative measures, while there are important degrees of overlap with National and Local campaigning organisations and Voice perspectives from our study.

THE DYNAMICS OF DEMENTIA

Researching 'Dementia in the Public Domain' has drawn out a number of issues that both connect our findings to the wider scientific literature and help us make sense of the ways in which social attitudes might change. Here we look at distinctive perspectives, the possibilities for empathic understanding and the impact of dementia on social exclusion. These factors form a complex dynamic which can inform our understanding of how people affected by dementia can be recognised and engage with society in individual, interpersonal and social ways.

People with dementia evidenced a distinctive perspective which showed some surprising differences in emphasis from the perspective of contemporary public health literature. Social engagement, rights and inclusion, enabling public acceptance and normal social relations were a priority. Further, dementia was seen

to have some positive as well as negative implications by this group. Emphasis was given to a normalising approach which can see the positive as well as the negative aspects of living with dementia. Also distinctive was the concern by other groups to understand and acquire the skills to engage with those affected by the condition. This was refreshing given a number of reports by carers that previous acquaintances shun and even family members may avoid people with dementia and their carers (Robinson et al., 2011; Nay et al., 2015; Hutchinson et al., 2016); and that there is a danger of cumulative social isolation (Biggs, Haapala & Carr, 2019a). It also indicates that stigma may be perpetuated by inhibition in the context of ageist attitudes toward dementia as a social category. The complementary relationship between people with dementia and carers' priorities and those of professionals, plus what has been perceived in members of the public, may have less to do with increasing stigmatisation and more to do with a frustrated desire to connect and communicate. This would have implications for both training and public campaigning and offer sharper focus on what awareness-raising might mean at an interpersonal level.

Reference to empathic understanding, however, was not uniform, with reference to love and affection, understanding and helping, and in what people would want for themselves plus their first thoughts on dementia, varying by age and family connection. Empathy appeared to be highest amongst those who were distanced from the condition either by an absence of family connection or by relative youth. Persons with no connection to dementia and younger professionals showed greater emotional connection than other groups. Empathic understanding then began to increase again amongst older participants in relation to social interaction. Generational empathy may be reflected in emotional concern for families with dementia among younger adults, displaced onto knowledge and prevention amongst mid-lifers and reflected in concern for communication and interaction amongst older groups. Our findings parallel those of Cheston, Hancock and White (2016) in so far as closeness to dementia affects understanding and priorities, but in complex

DISCUSSION, CONCLUSIONS AND A WAY FORWARD

ways that need further exploration. The question of empathic understanding touches on findings reported by Miron et al. (2017) indicating a greater sense of 'humanness characteristics' under 'low perspective-taking conditions'. In other words, these researchers were puzzled by lower degrees of contact predicting a greater sense of empathic understanding, which may also be present in our participants' perspectives. Similar findings have been reported in studies of personal care worker behaviour by Bailey et al. (2015) and Carr and Biggs (2017; 2018) where a balance was needed between the emotional demands of care and the ability to stand back and problem solve. Biggs (2018) has argued that such tensions may indicate that a balance needs to be struck between the emotional labour demanded by caring and the understanding required for an effective person-centred perspective. It is possible that a similar relationship is being picked up here, in so far as contact arises in a 'U' shaped relationship with certain forms of emotional closeness. It may, in effect, be possible to be 'too close' to dementia for an emphasis on putting oneself in the place of the other to work. Miron et al. (2017) refer to the ambivalence that encountering dementia can provoke. There may not be a linear relationship between closeness in age and family connection, even though this was expected in our participants' views on the general public. And it is perhaps here that future interventions can draw on the considerable body of work on different forms of conflict, ambivalence and solidarity that can emerge in family relations (Bengtson & Lowenstein, 2003; Silverstein & Giarrusso, 2013). The findings also support the positive effect support can have, where formal care and respite can create space for carers and others to focus on their relationship with the person with dementia that might otherwise be eclipsed by functional care tasks (Daatland et al., 2010; Feast et al., 2016). The implications for intervention might include a more nuanced approach toward targeted campaigning and interventions aimed at improving social and familial engagement.

The consistent message from public health and epidemiological research has been that social disadvantage and dementia are interconnected: with those suffering disadvantage being more at risk of developing dementia in later life (Hulko, 2004; Jones, 2017). They do not, therefore, address the possibility that social identity and social location may be impacted by

dementia itself and that unique forms of disadvantage and exclusion arise because of the condition. People with dementia experience the double jeopardy of ageing with a cognitive impairment. For women, who often find themselves in a family carer's role, this would be a triple jeopardy; and when other socio-economic variables are taken into account, a multiple jeopardy (Winblad et al., 2016). Social exclusion based on age can lead to an unwanted situation in which people are prevented from engaging in mainstream society, with detrimental consequences for the individual and society (Walsh, Scharf and Keating, 2017), yet only a handful of authors have pointed to a connection to dementia (Innes, Archibald and Murphy 2004; Österholm and Samuelson 2015). Dementia has not, in other words, featured prominently in research on exclusion in later life (Walsh, Scharf & Keating 2017). A more complete understanding has emerged from our data on impacts, one that demonstrates how individuals experience multiple forms of exclusion arising from chronic illness and the additional possibility: that the experience of dementia itself might produce particular forms of disadvantage and exclusion. We found that dementia presents a range of factors contributing to social disadvantage and exclusion for those affected by it. While there is some overlap with age-based social exclusion for social, material and service impact, the consequences of adopting a caring role plus psychosocial and emotional impacts may be specific to dementia. This is a different way of looking at the relationship between dementia and disadvantage than is most commonly the case, as it suggests that in addition to seeing forms of pre-existing disadvantage as risk factors, dementia itself generates forms of exclusion and disadvantage because of the way it is perceived and responded to in the public domain. If this is the case, policy and practice interventions need to move beyond assessing demographic risk factors to address forms of psycho-social exclusion that actively affect people's individual, interpersonal and service-related circumstances. This will also require a shift in research activity from starting 'from the outside' through examining external risk to 'starting from the inside' of lived experience and examining the relationship between the two.

Taken together, these observations point to interventions that emphasise a recognition of distinctive perspectives in the context of processes of understanding and exclusion. As suggested by generational intelligence theory (Biggs and Lowenstein, 2011), the form that attitudes took varied by age group and by degrees of family connection. ‘Positive othering’ has been suggested as a way of recognising distinctive positions occupied by other people, even if these overtly challenge dominant social attitudes (Biggs, 2018). This might form a first step to bridging the divide between people with dementia, carers and other people with little experience of the condition. As suggested by generational intelligence, positive personal contact might then succeed in enhancing emotional and cognitive connections to dementia while also recognising difference. Recognising the distinctive experience and circumstances of people with dementia as compared to others, will become increasingly important if alliances are to be made in the shift from a medical to a rights-based understanding of dementia as a social phenomenon (Swaffer, 2015; Bartlett, 2017). Awareness-raising can be notoriously short on the ‘how’ of here and now responding. Considering the findings reported here, dementia in the public sphere may be significantly influenced by increasing our level of understanding of how people with and without dementia can communicate and interact to secure continued engagement in society, reduce the effects of social exclusion, and increase opportunities to live well with dementia at home, work and in our communities.

DEMENTIA, VOICE, FAMILY CONNECTION, AGE AND THEIR IMPLICATIONS FOR CAMPAIGNING

Overall, the research raises a number of points.

- It appears that there are age-differences in the perception and responsiveness to dementia which could be used to understand the design of public health campaigning. Age-based priorities and life-course position should be considered an important element in the perception of dementia and how messages are responded to.
- While the condition was perceived to be negative, there was little evidence of negative attitudes toward people with dementia or carers. Understanding was often sympathetic, especially where there had been some form of personal or family connection with

dementia in the past.

- The focus of understanding varied between the four age groups we studied, with younger adults showing greater emotional empathy, yet a lack of significant contact; mid-lifers focussing on cognitive understanding and service issues; later mid-lifers on communication, and older adults on forms of interpersonal connection.
- Concern about dementia seems to increase where there is a personal connection through family or friends. Interest in dementia may not otherwise appear on one’s personal radar.
- Differences also emerged between people’s own views and the views they thought were held by their age group in general. This raises some interesting questions of a mismatch between the actual perceptions of age groups and the attribution of views supposedly held in the public sphere.
- Interaction with people living with dementia or their families was the most frequently cited reason for people to be receptive to campaigning on the issue, even though it was also cited as something that the general public avoided.
- A possible game changer is reflected in the importance attributed to personal contact with dementia and a focus on communication and practical understanding. This would shift attention away from stigma to contexts that create positive contact between those affected by dementia and others and the skills people have for interaction across the dementia divide.
- While both National and Local campaigning organisations have included the voices of people with dementia, there was a tendency for both to underplay the psychological and carer role impact of the condition.

DISCUSSION, CONCLUSIONS AND A WAY FORWARD

CONCLUSIONS AND A WAY FORWARD

We have outlined our principal findings below, drawing out elements that might inform a deeper understanding of the distinctive voices engaged in debate about dementia as a social phenomenon and the implications for future campaigning and initiatives around changing public attitudes.

Voice Perspectives: Family Connection and Age

- Interactions were complex between age, voice and campaigning, but certain trends stand out:
- There were differences in priority given to dementia depending upon closeness and family connection
- The themes identified in this study varied according to a person's degree of connection, suggesting a 'U' shaped relationship between emotional responding, empathy and distance from the condition
- Concerns for social inclusion appeared to increase with closeness to dementia, whereas traditional public health priorities tended to travel in the other direction
- Age revealed distinctive patterns between later midlife and older people with dementia. While both groups emphasised dignity, respect and rights, the younger one focused more on normalising and interactive agendas and the older on preventing the progress of the disease
- While younger and older carers showed a close alignment in prioritising awareness-raising, carers in later midlife showed a different pattern with a greater emphasis on understanding and interaction skills than other age-groups
- Younger carers struggled to find anything positive in current social attitudes and care and service systems, while older carers focused on managing the situation as best they could
- Professional groups showed a strong combined alignment toward understanding and interaction skills, regardless of age. Age did distinguish older professionals in some areas
- There were mismatches between what our participants assume the different age groups in the general public think and what they think themselves.

Voice Perspectives: Impacts and Disadvantage

Our findings on dementia and disadvantage indicated that:

- Dementia can create its own forms of social disadvantage and exclusion
- These include Social, Material, Service provision, Psychological, Carer-role, and Disparity impacts that could form a basis for future analysis of social engagement and intervention
- The most commonly mentioned impact was social in origin, including shrinking networks and social circle, being treated differently by family, friends and neighbours following the onset of dementia, plus fear of stigma in the public domain
- Some impacts were held in common with ageism and social exclusion, though in the case of dementia they may take distinctive forms
- Impacts associated with psychological consequences and adopting a carer role may be specific to dementia
- There was a high level of agreement across voice perspectives on the ways dementia impacts the lives of those affected by it.

Voice Perspectives: Priorities for Campaigns

Participants' priorities reflected a focus on social aspects of the condition and a desire for greater social inclusion:

- People with dementia emphasised accepting dementia personally, by others and as a right to continued engagement in communities
- Carers focused on improved public understanding, greater social interaction and awareness-raising
- Professionals focused primarily on increasing interpersonal skills
- Age also revealed distinctive patterns within each voice perspective, including younger and older people with dementia and carers, but less so for professionals
- People with dementia in later midlife appeared to have differing priorities to older people with dementia
- People with dementia identified positive elements connected to the condition
- Stalling the progression of the condition after diagnosis was mentioned by people with dementia.

When taken together, increasing understanding and interaction skills and normalising dementia may represent complementary categories based on perspective. People with dementia may be wishing for social inclusion, while other groups want to know how to interact with them.

Campaigners' priorities for campaigns

- National and Local level campaigners showed both overlapping and distinctive priorities:
- National level campaigners wished to coordinate areas of priority, often connected to National Strategic Planning, gaining support and commitment from policy makers, plus grasping public attention in specific societal contexts. They tended to reflect multiple voice perspectives
- Local level Campaigners reflected a relatively high level of consensus on key foci reflecting a common experience of local priorities. These included creating dementia-friendly communities through initiatives with local councils, care and support services, parks and amenities, businesses and shopping centres and the general public. A strong emphasis was placed on people with dementia leading initiatives and in governance
- Surprisingly, given the emphasis of contemporary public health campaigning, health care systems and services were not prioritised by any group
- Social factors such as normalising relations in communities and skills for interaction between groups were given greater emphasis than those related to physical health.

Recommendations for a Way Forward

Our findings have raised a number of questions about the relationship between the impacts and priorities of different voice perspectives and how these connect to campaigning. Here we summarise some key recommendations for a way forward:

- Campaigning should reflect a common feeling that dementia should become a normal part of social life
- Specific forms of disadvantage and exclusion arising from the experience of dementia should be reflected in future campaigns and interventions
- Greater emphasis should be placed on people with dementia and their carer's social inclusion and engagement in neighbourhoods and wider society
- Professional groups and others should be offered training and education in how to understand and interact with people with dementia
- Policy making should explicitly recognise that people with dementia and carers hold distinctive positions and should not be lumped together as 'consumers'
- National and local initiatives hold different, but complementary priorities indicating the need to promote multiple forms of intervention
- The low priority given to health services and prevention messaging may reflect a mismatch between public health messaging and the priorities of other groups
- Distinctive perspective and age-based priorities might provoke a rethink of how campaigns are targeted. This should include taking the priorities of the recipient more explicitly into account compared to the reception of pre-defined messages.

DISCUSSION, CONCLUSIONS AND A WAY FORWARD

ELABORATING THE WAYS FORWARD VIA A FUTURE SEARCH WORKSHOP

The following more detailed ways forward arose from a workshop arranged by the research team with people with dementia, carers, care providers, campaigners and policy advisers (invited participants, n=25) to discuss the findings of the research. Discussion was prompted by a presentation of the findings focusing on five impacts identified in the study as leading to social exclusion and disadvantage. These included social, material, service provision, psychological and carer role impacts. Disparity impacts were included as a cross-cutting theme.

Many of the suggestions connect to the Australian National Framework for Action on Dementia 2015-2019 (Australian Government, 2015). The national framework, unlike those of other countries, such as Scotland and France, does not include specific target which should be set to ensure implementation (see a resource bank of National guidelines via the Alzheimer's Disease international website at <http://www.alz.co.uk>).

Here, we have organised the suggestions around specific implementation areas, including: Education and Training, Diagnosis and Follow-up, Employment, Support to Carers, plus Communities and Neighbourhoods. The specific impacts from which the suggestions for a way forward arose are identified in brackets. An introductory paragraph connects them to our findings.

Education & Training (Service Provision and Social Impacts)

Workers inside and outside the helping professions, plus members of the wider community, were often thought to be ill-informed about dementia. This deficit should be addressed by specific inclusion in professional training and updating, plus targeted interventions aimed at schools, workplaces and in the public sphere.

Specific suggestions from the workshop under this topic included:

- Education for all professionals who interact with the general public, for example those in the service industries
- Mandatory inclusion of learning modules on dementia, including social impacts and communication skills, within existing professional training in health, social work and social care
- Training on interaction and communication skills with people with dementia to be made available to workers in practice, for example, via short bite-sized videos and cue cards that model and aid memory of appropriate helping and communication strategies
- Inclusion of dementia and communication skills in school curricula as a part of modules on active citizenship looking at living with dementia
- Inclusion in workplace Human Relations in-house training modules
- Promotion of Care Work as a positive career choice and dementia care as an area requiring a specialist skill set
- Training offered to care workforce should specifically include building dementia-friendly communities, meaningful communication and interaction skills and the use of capability and resilience frameworks
- Social marketing and engagement with communities via multimedia presentations in public spaces, including short videos modelling behaviours and communication skills in interaction between people with dementia and others.

Diagnosis and Follow-Up (Service Provision, Psychological and Carer Role Impacts)

Diagnosis arose as a key turning point that was difficult for professionals and consumers to handle. Often people with dementia and their carers reported that when they were given a diagnosis, they were then simply left to deal with the social and psychological consequences on their own. In the absence of a cure, strategies should be put in place that support living well with the disease, as is the case with other chronic conditions such as cancer and diabetes.

Specific suggestions from the workshop under this topic included:

- Timely diagnosis and follow up should be made mandatory to reduce psychological distress, social isolation and depression
- Post-diagnostic pathways should be identified as part of an explicit care plan
- Any care packages that are put together should explicitly pay attention to issues of continued social engagement and social inclusion and not limit themselves to functional tasks
- Following diagnosis, information on care pathway options and support services should be made available to carers and people with dementia as is the case for other chronic conditions such as diabetes or cancer
- Immediate support should include referrals for speech therapy, occupational therapy, mobility, rehabilitation specialists depending on the form of dementia and its associated symptoms
- Carers' own health and wellbeing issues should be independently identified and addressed. This should include separate funding support to carers for packages of support
- An easily understood script for referrals should be distributed to GPs, health care and social work related professionals at triage and other points of systems entry
- Navigators should be appointed upon diagnosis, that support those affected by dementia negotiate the complex care and financial systems that arise
- Unified Federal regulation should be established concerning medical review and eligibility for driver's licences and related issues to achieve national consistency and clear guidelines for medical review.

Employment (Material, Psychological, Social, Carer Role and Service Provision Impacts)

Access to continued work was seen as an area that was almost completely absent from the current debate on dementia, even though other countries, such as Finland and the UK have initiated workplace schemes. Workplaces should be required to put strategies in place that support carers and people with dementia to continue working. Access to continued work is a primary means of addressing material, social and psychological impacts of dementia in the public domain. This could be called a Work, Care & Life Balance approach.

Specific suggestions from the workshop under this topic included:

- People with dementia should be offered appropriate forms of workplace support, as are given to people with other forms of disability. This should be made a mandatory workplace requirement
- Practices of forced early retirement, bullying and harassment at work arising from effects of dementia should be prohibited by law
- Flexibility should be offered to carers and people with dementia in terms of hours worked and specialised leave arrangements
- Affordable alternative care and support should be offered that allows carers to continue working where they require it
- In-house workplace support, including re-enablement and cognitive rehabilitation approaches should be given post diagnosis to allow people with dementia to continue working for as long as they require it
- Dementia-friendly workplace design practices should be made mandatory as is the case for other forms of disability
- A code for dementia-friendly workplace practice should be created along the same lines as family-friendly policies for working life
- Compensation for lost earnings, personal super and savings should be available to carers and people with dementia where the condition results in early retirement.

DISCUSSION, CONCLUSIONS AND A WAY FORWARD

Support to carers (Carer Role, Psychological and Service Provision Impacts)

Care and living with dementia happen as mutually interdependent relationships. Support one and you help the other. Carers and people with dementia also have separate and distinctive needs, both of which require support. Unpaid care provides the backbone of fiscal policies that have attempted to reduce the costs of an adequate health and aged care system. Meeting the distinctive requirements of carers should form an explicit part of governmental approaches to dementia.

Specific suggestions from the workshop under this topic included:

- The employment needs of carers should be addressed both during the caring role and in terms of future planning
- Carers employment issues should be addressed in the same way as for nominated persons with a disability including offering support early; offering family support; providing a clear pathway to support
- Make people aware of the triple jeopardy constituted by the link between ageism, dementia and gender issues
- Critical consideration should be given to cultural issues related to gender, concerning expectations for unpaid care, plus willingness to accept changes in status or family and workplace roles
- Psychological support should be offered to carers. This might include counselling on future planning and cognitive-behavioural-therapeutic approaches
- There should be an independent element added to the funding for care packages that incorporate a response to the distinctive personal and social impacts on the carer
- Carers' own health needs should be assessed as part of the process of taking on a carer role.

Communities and Neighbourhoods (Social, Psychological and Carer Role Impacts)

The consistent objective of all voices was that people with dementia, carers and others affected by the condition was that they should remain a normal part of the public domain, in civic, community and neighbourhood life. Continued social engagement, a positive sense of identity and self-worth were considered to be mutually reinforcing factors. This objective would require changes to the way those affected by dementia are currently perceived in the public domain.

Specific suggestions from the workshop under this topic included:

- Dementia-friendly community support should be created to increase the capabilities and resilience of families and friendships living with dementia
- Culturally sensitive language and recognition skills should be created to address the social engagement and other distinctive needs of those affected by dementia from indigenous communities. Similar strategies should be used to raise awareness and support that is sensitive to the needs of members of culturally and linguistically diverse (CALD) communities
- Questions of language do not simply refer to distinctive linguistic groups, but also to the ways in which dementia is recognised and described, plus the needs of first language support as one grows older with the condition
- Community-based initiatives and community engagement have been negatively affected by individualised care packages and should be given identified funding streams in their own right
- Accessible, affordable, point-to-point dementia-friendly transportation services should be made available. This is especially the case in order to avoid social exclusion in the event of a driver's licence being revoked
- Mediating factors such as gender roles and masculinity and health behaviours in Australian men (the bush culture) may affect caring, self-esteem, social isolation and delay diagnosis and support-seeking and should be subject to targeted campaigning

- Continuing engagement should be included as an objective for aged care regulatory requirements. These should, in addition, allow for participation in activities that feel real, respectful and linked to a person's continuity of identity
- Services should prioritise continued engagement with communities and a normal social life in order to creatively connect social engagement with building a positive identity in public sphere.

A persistent finding arising from our research is the complementary relationship between continued social engagement and the development of understanding and interaction skills amongst professionals and the general public. Policies with consequences, unintended or otherwise, that may reduce funding available for dementia-friendly community projects and ongoing activities to support living well with dementia in the community or that may reduce the time professionals and other workers have to interact with people with dementia and carers, would have a negative effect on social inclusion of this disadvantaged group. These consequences would potentially increase social isolation, depression and reduced feeling of self-worth. Personalised budgeting in the context of marketised service systems should be critically re-assessed in this light. Dementia should be treated as a disability which provides protection against discrimination and rights abuse. However, policy should go beyond an individual model of rights to recognise the interdependence of personal, family, social and community impacts in order to improve the lives of all people affected by dementia.



REFERENCES

- Alzheimer-Europe. 2011. The ethics of dementia research, Alzheimer Europe. Available online: <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2011-Ethics-of-dementia-research> [Accessed November 12]
- Australian Government 2015. National framework for action on dementia 2015–2019. Department of Social Services, Canberra.
- Bailey, S., Scales, K., Lloyd, J., Schneider, J., & Jones, R. 2015. The emotional labour of health-care assistants in inpatient dementia care. *Ageing and Society*, 35(2): 246-69.
- Bartlett, R., Windemuth-Wolfson, L., Oliver, K. & Dening, T. 2017. Suffering with dementia: the other side of “living well”. *International Psychogeriatrics*, 29, 177-179.
- Behuniak, S. 2011. “The living dead? The construction of people with Alzheimer’s disease as zombies.” *Ageing and Society*, 31, 70-92.
- Bengtson, V. L. & Lowenstein, A. (Eds). 2003. *Global aging and its challenge to families*, New Jersey: Transaction Publishers.
- Biggs, S. 2018. *Negotiating Ageing: Cultural Adaptation to the Prospect of a Long Life*. London: Routledge.
- Biggs, S. & Lowenstein, A. 2011. *Generational intelligence: A critical approach to age relations*. New York, NY: Routledge.
- Biggs, S., Haapala, I. & Carr, A. 2018. Generational perceptions of dementia: age, othering and generational intelligence. In G. Macdonald & J. Mears (Eds), *Dementia as social experience. Valuing life and care*. Pp 77-104. London: Routledge. <https://www.routledge.com>
- Biggs, S., Haapala, I. & Carr, A. 2019a. *Dementia in the Public Domain. A Guide to Voice, Age and Campaigning*. Melbourne: University of Melbourne.
- Biggs, S., Haapala, I. & Carr, A. 2019b. What you say and what I want: Priorities for public health initiatives in relation to dementia Submitted for publication in *Australasian Journal on Ageing*.
- Biggs, S., Haapala, I. & Lowenstein, A. 2011. Exploring generational intelligence as a model for examining the process of intergenerational relationships. *Ageing & Society* 31: 1107-1124. DOI: <http://dx.doi.org/10.1017/S0144686X10000978>.
- Brooker, D., & Latham, I. 2015. *Person-centred dementia care: Making services better with the VIPS framework*. Jessica Kingsley Publishers.
- Carr, A. & Biggs, S. 2017. *Exploring regulatory clusters in dementia care. Research Insight 3*. Melbourne: Brotherhood of St Laurence.
- Carr, A. & Biggs, S. 2018. *The Organisation of Risk*. Melbourne: Brotherhood of St Laurence.

REFERENCES

Carr, A., Haapala, I. & Biggs, S. 2019. Dementia as a form of disadvantage, Submitted for publication in *Australasian Journal on Ageing*.

Cheston, R., Hancock, J., & White, P. 2016. A cross-sectional investigation of public attitudes toward dementia in Bristol and South Gloucestershire using the approaches to dementia questionnaire. *International Psychogeriatrics*, 28(10), 1717-1724.

Commonwealth of Australia 2015. The Intergenerational Report. Available online: <http://www.treasury.gov.au/PublicationsAndMedia/Publications/2015/2015-Intergenerational-Report> (Accessed May 8, 2017).

Daatland, S-O., Herlofson, K., & Lima, I. A. 2010. Balancing generations: On the strength and character of family norms in the West and East of Europe. *Ageing in Society*, 31(7),1159-1179.

Dementia Alliance International. 2017. Available at: <http://www.dementiaallianceinternational.org/> [Accessed 4 October, 2018]

Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. 2016. Behavioural and psychological symptoms in dementia and the challenges for family carers: systematic review. *The British Journal of Psychiatry*, 208(5), 429-434.

Haapala, I., Carr, A. & Biggs, S. 2018a. Differences in priority by age group and perspective: implications for public health education and campaigning in relation to dementia. *International Psychogeriatrics*. <https://doi.org/10.1017/S1041610218000935>

Haapala, I., Carr, A. & Biggs, S. 2018b. What would I want? Dementia perspectives and priorities amongst people with dementia, family carers and service professionals? *International Journal of Care and Caring*. <https://doi.org/10.1332/239788218X15321005902545>

Heap, J., Lennartsson, C., & Thorslund, M. 2013. Coexisting disadvantages across the adult age span: A comparison of older and younger age groups in the Swedish welfare state. *International Journal of Social Welfare*, 22(2), 130-140. <https://doi.org/10.1111/j.1468-2397.2012.00886.x>

Heap, J., Fors, S., & Lennartsson, C. 2017. Coexisting Disadvantages in later Life: Demographic and Socio-Economic Inequalities. *Journal of Population Ageing*, 10(3), 247-267.

Higgs, P., & Gilleard, C. 2015. *Rethinking old age: Theorising the fourth age*. Palgrave Macmillan.

Higgs, P., & Gilleard, C. 2017. Ageing, dementia and the social mind: past, present and future perspectives, *Sociology of Health & Illness*, 39 (2): 175–81.

Hulko, W. 2004. Social science perspectives on dementia research: intersectionality. In: A. Innes, C. Archibald & C. Murphy (Eds.) *Dementia and Social Inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*. London, UK: Jessica Kingsley: 237–254.

Hutchinson, K., Roberts, C., Daly, M., Bulsara, C. & Kurrle, S. 2016. Empowerment of young people who have a parent living with dementia: a social model perspective, *International Psychogeriatrics*, 28(4): 657-68.

Innes, A., Archibald, C., & Murphy, C. (Eds.) *Dementia and Social Inclusion: Marginalised groups and marginalised areas of dementia research, care and practice*. London, UK: Jessica Kingsley.

Jones, I. R. 2017. Social class, dementia and the fourth age. *Sociology of Health & Illness*, 39(2): 303–317.

Kivipelto, M., Mangialasche, F. & Ngandu, T. 2017. Can lifestyle changes prevent cognitive impairment?. *The Lancet Neurology*, 16, 338-339.

Lamont, R. A., Swift, H. J. & Abrams, D. 2015. A review and meta-analysis of age-based stereotype threat: Negative stereotypes, not facts, do the damage. *Psychology and aging*, 30, 180.

Léon, C., Pin, S., Kreft-Jais, C. & Arwidson, P. 2015. Perceptions of Alzheimer's disease in the French population. *Journal of Alzheimer's Disease*, 47, 467–478.

Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., . . . Cohen-Mansfield, J. 2017. Dementia prevention, intervention, and care. *The Lancet* 390(10113): 2673-734.

Matthews, F. E., Stephan, B. C. M., Robinson, L., Jagger, C., Barnes, L. E., Arthur, A., Forster, G. 2016. A two decade dementia incidence comparison from the Cognitive Function and Ageing Studies I and II. *Nature Communications*, 7. <https://doi.org/10.1038/ncomms11398>

Morgan, C., Burns, T., Fitzpatrick, R., Pinfold, V., & Priebe, S. 2007. Social exclusion and mental health: conceptual and methodological review. *The British Journal of Psychiatry*, 191(6), 477-483.

Miron, A. M., McFadden, S. H., Hermus, N. J., Buelow, J., Nazario, A. S. & Seelman, K. 2017. Contact and perspective taking improve humanness standards and perceptions of humanness of older adults and people with dementia: a cross-sectional survey study. *International Psychogeriatrics*, 29, 1701-1711.

Nay, R., Bauer, M., Fetherstonhaugh, D., Moyle, W., Tarzia, L. & McAuliffe, L. 2015. Social participation and family carers of people living with dementia in Australia. *Health & Social Care in the Community*, 23(5): 550-8.

NHMRC. 2015. *National Statement on Ethical Conduct in Human Research (2007) (Updated May 2015) Section 4: Ethical considerations specific to participants. Chapter 4.5: People with cognitive impairment, an intellectual disability, or a mental illness*. Australian Government. Canberra: National Health and Medical Research Council.

North, M. S. & Fiske, S. T. 2012. An inconvenienced youth? Ageism and its potential intergenerational roots. *Psychological bulletin*, 138, 982

REFERENCES

- Phillipson, L., Hall, D., Cridland, E., Fleming, R., Brennan-Horley, C., Guggisberg, N., . . . Hasan, H. 2018. Involvement of people with dementia in raising awareness and changing attitudes in a dementia friendly community pilot project. *Dementia*, 1471301218754455.
- Prince, M. 2017. Progress on dementia—leaving no one behind. *The Lancet*, 390(10113), e51-e53.
- Ravdin, L. D., & Katzen, H.L. (Eds.) 2019. *Handbook on the Neuropsychology of Aging and Dementia*. New York, NY, USA: Springer.
- Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K. & Manthorpe, J. 2011. The transition to dementia—individual and family experiences of receiving a diagnosis: a review. *International Psychogeriatrics*, 23(7): 1026-43.
- Silverstein, M. & Giarrusso, R. 2013. *Kinship and cohort in an aging society: From generation to generation*, Baltimore: JHU Press.
- Smith, G. E., & Farias, S. T. (Eds.) 2018. *APA handbook of dementia*. Washington, DC, US: American Psychological Association.
- Swaffer, K. 2015. Dementia and prescribed disengagement™. *Dementia* 14, 3-6. <https://doi.org/10.1177/1471301214548136>
- Vinson, T., Rawsthorne, M., Beavis, A., & Ericson, M. 2015. *Dropping off the edge 2015*. Jesuit Social Services and Catholic Social Services Australia, Melbourne, www.dote.org.au.
- Walsh, K., Scharf, T., & Keating, N. 2017. Social exclusion of older persons: a scoping review and conceptual framework. *European Journal of Ageing*, 14(1), 81-98.
- WHO. 2016. *WHO Global Action Plan on the Public Health Response to Dementia 2017–2025*. Geneva, Switzerland, World Health Organisation.
- Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., . . . Feldman, H. 2016. Defeating Alzheimer’s disease and other dementias: a priority for European science and society. *The Lancet Neurology*, 15(5), 455-532.
- Yeandle, S., Kröger, T. & Cass, B. 2012. Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland. *Journal of European Social Policy*, 22, 432-445.
- Österholm, J. H. & Samuelsson, C. 2015. Orally positioning persons with dementia in assessment meetings. *Ageing and Society*, 35: 367–388.

CONTACTS AND MORE INFORMATION

PARTNERS



UNIVERSITY OF MELBOURNE

School of Social and Political Sciences
Parkville, Vic 3010

www.unimelb.edu.au/



CDPC

Sydney Medical School
The University of Sydney, NSW 2006

sydney.edu.au/medicine/cdpc/



DEMENTIA AUSTRALIA

www.dementia.org.au/



BRIGHTWATER CARE GROUP

Osbourne Park, WA 6017

www.brightwatergroup.com/



HAMMONDCARE

Sydney, NSW 2000

www.hammond.com.au/



HELPING HAND AGED CARE

North Adelaide, SA 5006

www.helpinghand.org.au/



BROTHERHOOD OF ST LAURENCE

Fitzroy, Vic 3065

www.bsl.org.au/

ACKNOWLEDGEMENTS

Research consisted of a three-year project (2016-2018) funded through the Cognitive Decline Partnership Centre (CDPC; <http://sydney.edu.au/medicine/cdpc/>) receiving support over three years) from the Australian National Health and Medical Research Council (NHMRC) and partners including Hammond Care, Dementia Australia, Brightwater Care Group and Helping Hand Aged Care. The study was approved by the University of Melbourne Humanities and Applied Sciences Human Ethics Sub Committee (HESC 1647136).

The project was undertaken by Professor Simon Biggs, Dr Irja Haapala and Mr Ashley Carr from the University of Melbourne between 2016 and 2018. It was supported by the NHMRC Cognitive Decline Partnership Centre (GNT9100000). The Centre receives support from the Australian National Health and Medical Research Council and funding partners including Dementia Australia, Brightwater Care Group, HammondCare and Helping Hand Aged Care. The contents of the published materials are solely the responsibility of the individual authors and do not reflect the views of the NHMRC, the Centre or the funding partners.

The researchers would like to thank the funding bodies, partner organisations and Advisory Group members for their support during the project.

We would also like to thank the Brotherhood of St Laurence for in-kind support plus interviews with staff and care users.

Finally, we would like to thank the many research participants, whose involvement was critical in understanding different perspectives on dementia in the public domain, and the campaigning organisations who participated and are listed here with permission (location by state/country): Dementia-Friendly Kiama (NSW), Peninsula Dementia Action Group (Vic), Bigger Hearts Campaign and Dementia-Friendly Ballarat (Vic), Celebrate Ageing and Museum of Love (Vic-based), Dementia-Friendly Initiatives in City of Melville (WA) and Dementia-Friendly Training, Education and Initiatives (QLD), Alzheimer's New Zealand, Alzheimer's Association (USA), Alzheimer's Scotland, The Alzheimer's Society of Ireland, Alzheimer's Society (UK), The Alzheimer Society of Finland and The Swedish Dementia Centre, Alzheimer's WA, and Dementia Australia.

ABOUT THE AUTHORS

Simon Biggs is Professor of Gerontology and Social Policy, University of Melbourne, Australia, School of Social and Political Sciences and Adjunct Professor at the University of Helsinki, Finland. He runs a research team at the Brotherhood of Saint Laurence in Melbourne. From 2008 to 2016 he was founding member of the World Economic Forum's agenda council on ageing and is a Fellow of the British Academy of Social Science. His research interests include intergenerational relations, the ageing life course and public policy.

Irja Haapala is a Senior Research Fellow at the University of Melbourne, Australia, School of Social and Political Sciences and Senior Lecturer at the University of Eastern Finland, Department of Educational Science and Teacher Education. Her research interests include public health promotion, intergenerational education and nutrition studies.

Ashley Carr is a Research Fellow at the University of Melbourne, Australia, School of Social and Political Sciences, currently researching public perceptions of dementia and the role of regulation in dementia care, under the Cognitive Decline Research Partnership Centre. Research interests include social care, research translation, evidence-based practice and public policy.

SPECIAL THANKS

We would especially like to thank members of the Advisory Group:

- Danijela Hlis (Consumer, Dementia Australia)
- Joan Jackman (Consumer, Dementia Australia)
- Tara Quirke (Consumer, Dementia Australia)
- Tony Ramshaw (Consumer, Dementia Australia)
- Sam Giorgatzis (Helping Hand)
- Meredith Gresham (HammondCare)
- Wendy Hudson (Brightwater Care)

Their efforts and knowledge shaped key aspects of the research and helped make the project relevant to the lived experience of dementia and public campaigning activities.



APPENDIX

Table A1. Contribution to coded data. Number of coded expressions (first level codes) by voice.

| Coding topic | People with dementia n=19 | Carers n=28 | Professionals | | | All n=111 |
|-------------------------------|------------------------------|----------------|---------------------|---------------------|------------------|--------------|
| | | | Health care n=21 | Social work n=23 | Services n=20 | |
| First thoughts | 34 | 48 | 42 | 40 | 33 | 197 |
| Views on public perception | 52 | 104 | 79 | 85 | 43 | 363 |
| Generational perceptions | 55 | 122 | 105 | 109 | 92 | 483 |
| Major impact of the condition | 173 | 430 | 309 | 507 | 271 | 1690 |
| What would I want | 38 | 63 | 57 | 56 | 45 | 259 |
| Three most important things | 53 | 89 | 69 | 78 | 59 | 348 |
| Future campaigns | 38 | 83 | 64 | 82 | 63 | 330 |
| Campaign targets | 23 | 42 | 39 | 44 | 39 | 187 |
| Total | 466 | 981 | 764 | 1001 | 645 | 3857 |

Table A2. Coding of question: When I say dementia, what do you think about? (First thoughts on dementia.)

| Tone of mention (Second level) | Emerging Theme (First level) |
|--------------------------------|--|
| Negative thoughts | Loss and sadness, personal fear, people's lack of understanding, negative consequences, stigma felt or experienced |
| Positive thoughts | Empathy, acceptance, acknowledgement, coping with dementia |
| Neutral thoughts | Physiology/pathology, cognitive changes & symptoms, relation to age (older and younger age at onset), organisation of care |

Table A3. Coding of question: How do you think dementia is perceived by people in the street?

| Theme (Second level) | Tone of perception: Emerging theme (First level code) |
|----------------------------------|---|
| Social (public) attitudes | <p>Negative: Stereotypical negative labelling, irrational negativity, stigma, misattribution to mental illness, madness, stupidity, intoxication, laziness, lacking cognitive faculty. Perceiving it as just one illness, exhausting, contagious, debilitating, immediate end stage, funny, nuisance, not fully human, burden, baby-like state, inappropriate behaviour/ rudeness, behavioural problems, easily aggravated/ belligerent, repeating themselves, cannot remember family, curious/strange or as getting lost. Associating it with loss of self, lost capacity, communication and decision-making skills, disengagement, end stage of life or euthanasia. Treating it as a disability which leads to exclusion, discrimination, hopelessness, discarding people with it, dismissing people with it to a nursing home, thinking they have no need for access to community facilities, or focusing on it like any disability/ condition instead of a person with other qualities. Positive: Lessened stigma, improved perception as an illness that requires us to give more time and accommodate, people are intrigued and open to seeing it in a more positive light.</p> |
| Psycho-social responses | <p>Negative: Frightened, saddened, worried, horrified, resorting to avoidance, feeling embarrassment, pity, confusion, hopelessness, guilt, personal failure, ready to die if diagnosed, fear of losing control, respect and dignity, but also not taking it realistically, or adopting a sense of prescribed helplessness-hopelessness. Positive: Compassionate, considerate, caring, helping, understanding, not blaming, interested, empathic and supportive.</p> |
| Relating to ageing | <p>Negative: Associated with old age or as a normal part of ageing. No positive comments.</p> |
| Knowledge and skill level | <p>Negative: Low level of understanding, misattribution to forgetfulness, low awareness level, misunderstanding the risk factors and opportunities for preventive action. Positive: Good level of knowledge and understanding, increasing level of awareness.</p> |
| Visibility and openness | <p>Negative: Lacking visibility due to nature of the condition which cannot be seen like a broken leg, lack of open discussion. Positive visibility and more discussion with increasing contact.</p> |

APPENDIX

—

| Table A4. Coding frame for the question: What are the main impacts of dementia? | | |
|--|---|--|
| Type of impact (Third level theme) | Specific impact (Second level theme) | Description of impact (Emerging first level theme) |
| Social impact | Social Isolation Stigma Rights Abuse | Refers to the impact of dementia on social activities and social engagement for PWD and carers, specifically with regard to family relations, friends and networks, and communities. Social impact captures the potential for people living with dementia/carers to experience social isolation, the effects of social stereotyping and labelling, and changes to individual/social rights. |
| Psychological impact | Individual, emotional response to cognitive loss Relationship change Planning for the future Situation in comparison to others | Encompasses the psychological effects of and emotional responses to cognitive loss for individuals and families and the various coping mechanisms individuals adopt to manage the condition. The impacts of relationship change and difficulties planning for the future are also covered. Psychological impact presents forms of social disadvantage relevant to well-being, coping and psychological stress. |
| Material impact | Work/employment Finance and money Transport Home/housing Accessibility of environment (physical) | Encompasses the negative effects of dementia in relation to work/employment, finances, home and housing and transport. These material impacts impinge on the ability of individuals to remain socially engaged and may affect access to goods and resources. |
| Service provision impact | Access to services Diagnosis Negative experience and value of services Positive experience and value of services | Refers to challenges accessing appropriate care and support services as a result of dementia, including diagnosis. Also included are the positive and negative experiences and values of service provision, which can enhance or hinder social participation. |
| Carer role impact | Carer disadvantage | Often understood as carer burden, the impact of dementia on informal carers, such as partners, families and children, is well-documented and recognised as a key factor leading to social exclusion. The term carer disadvantage is preferred and may be applied to the demands of providing care, the effects of the caring role and the barriers to social participation that arise as a result. |
| Disparity impact | Age of onset Socio-economic status Rural/urban setting Education | Encompasses factors traditionally understood to contribute towards social disadvantage, such as socio-economic status, education and location, but also factors specific to dementia, such as age of onset. |

Table A5. Impact of dementia. Number and percentage of expressions of impact by Voice.

| Type of Impact | People with dementia n=19 | | Carers n=28 | | Professionals | | | | | | All n=111 | |
|--------------------------|------------------------------|-------|-------------|-------|---------------------|-------|---------------------|-------|------------------|-------|-----------|-------|
| | | | | | Health care n=21 | | Social work n=23 | | Services n=20 | | | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Social impact | 57 | 33.5 | 85 | 19.8 | 62 | 20.4 | 154 | 30.4 | 66 | 24.4 | 424 | 25.2 |
| Material impact | 34 | 20.0 | 64 | 14.9 | 27 | 8.9 | 32 | 6.3 | 24 | 8.9 | 181 | 10.8 |
| Service provision impact | 38 | 22.4 | 115 | 26.7 | 64 | 21.1 | 130 | 25.6 | 65 | 24.1 | 412 | 24.5 |
| Psychological impact | 29 | 17.1 | 74 | 17.2 | 58 | 19.1 | 82 | 16.2 | 65 | 24.1 | 308 | 18.3 |
| Carer role impact | 5 | 2.9 | 75 | 17.4 | 54 | 17.8 | 63 | 12.4 | 23 | 8.5 | 220 | 13.1 |
| Disparity impact | 7 | 4.1 | 17 | 4.0 | 39 | 12.8 | 46 | 9.1 | 27 | 10.0 | 136 | 8.1 |
| Total | 170 | 100.0 | 430 | 100.0 | 304 | 100.0 | 507 | 100.0 | 270 | 100.0 | 1681 | 100.0 |

Table A6. Family Connection by Professional group by Age group

| Professional group | Age group | | | | All |
|--|----------------|------------|------------------|--------------|-----|
| | Younger Adults | Mid-lifers | Later Mid-lifers | Older Adults | |
| Professionals with a family connection to dementia (n=31) | | | | | |
| Health care | 1 | 2 | 6 | 0 | 9 |
| Social work | 1 | 4 | 3 | 1 | 9 |
| Services | 0 | 5 | 6 | 2 | 13 |
| All (n) | 2 | 11 | 15 | 3 | 31 |
| Professionals without a family connection to dementia | | | | | |
| Health care | 4 | 4 | 4 | 0 | 12 |
| Social work | 3 | 4 | 6 | 1 | 14 |
| Services | 1 | 2 | 3 | 1 | 7 |
| All (n) | 8 | 10 | 13 | 2 | 33 |

APPENDIX

Table A7. Coding of question two: "What would I want if diagnosed with dementia" or "Is there something you would want going forward with living with dementia?" when interviewing people with dementia.

| Category (Second level theme) | Emerging Theme (first level) |
|--|--|
| Social engagement and inclusion | Social engagement, not being excluded by society, continuing to contribute, lead a full life, positive bucket list, encouraged to be the person I am, do things for myself, accept it, fight it, self-understanding, understanding by others, friendly communities, a driving licence. |
| Love and affection | Wish to be loved by family and partner, receive and give affection |
| Continuity, dignity & respect | Be acknowledged for who I am, continue to be happy, see my children grow, no progression of dementia, self-acceptance, being allowed to talk about dementia, being treated normally, respecting individual choices, care with respect. |
| Good/professional care | Not wanting to become a burden to family members, choose professional care, hoping to receive an early diagnosis, seek professional support and care |
| End of life considerations/plans | Considering palliative care options, euthanasia, suicide |
| Interpersonal connections and support | Importance of a support group, friends to come round, interpersonal support from family, external support to family, not become socially isolated |
| Preventing and preparing | Doing whatever one can for oneself, gathering information on how to stave off dementia or stall it, finding out the prognosis, looking into advance care planning, do what one can to secure and maintain a good quality of life. |

Table A8. Coding of responses on “What in your mind are three most important things that should be done about dementia?”

| Category (second level theme) | Emerging Theme (first level theme) |
|---|---|
| Education to specific target groups on specific topics | Refers to a broad range of educational activities targeting various audiences, including: the public, communities and service sector on dementia in general, its impacts, ways to help and everyday interactions, and preventive measures; to professional groups, such as GPs, clinicians, and health, home and residential care staff on how to provide appropriate care and support, as well as timely diagnosis and post-diagnostic support; to schools on dementia in general, diagnosis and ways to help. |
| Attitudes, perceptions and behaviour | Focus on changing public and community attitudes towards dementia from negative to positive, promoting respect and openness and reducing stigma by accepting people with dementia as part of their communities, involving them and their carers in social activities and increasing empathy, self-understanding, self-care and help-seeking behaviours including early diagnosis. |
| Research | Promotion of research on different dementia-related topics, such as causal factors, medications and interventions, effective treatments and cure, preventative approaches including non-pharmacological interventions, psychological support and social engagement in communities plus knowledge translation. |
| Awareness-raising | General awareness-raising on dementia, such its causes, symptoms and effects. |
| Provide Support | Provision of psychological counselling, advocacy and other support to help people with dementia, carers and families manage their every-day life, at home and in different care settings; to enable people with dementia to remain in the community, provide clarity around decision-making, and support forward planning, including power of attorney and advance care plans. |
| Improvements in support and care systems, information and availability | Improving systems of care and support for people with dementia and their families by: enhancing diagnosis and post-diagnostic support; increasing respite services; improving the quality, equity, availability and affordability of formal support services; providing information on services available; and making a career in aged care and geriatrics more attractive. |
| Funding | Providing more funding to improve and increase care and support services, including residential aged care places with reduced waiting times, for research on cause and treatment to slow down the progression, community-based programs to support staying at home, and also for not-for-profit and advocacy organisations for supportive services and education. |
| Grassroots action on dementia | Promoting grassroots and community-driven actions to enhance care/support and social acceptance, including dementia-friendly initiatives, community-based interventions and education plus different social activities to support people to stay living in their own homes and neighbourhoods. |
| Medical care | Focus on improving medical care related to diagnosis, medication and appropriate care and support. |
| Design issues | Using design to enhance care/support and social engagement, such as the promotion of technology to support safety at home and the adoption of dementia-friendly design principles in different public environments. |

SUMMARY TABLE 2A: PEOPLE WITH DEMENTIA AND CARERS VOICE & AGE PERSPECTIVES

LATER MID-LIFERS WITH DEMENTIA (N=11)

- More likely to hold positive first thoughts, such as acceptance and coping and advocacy for the otherwise negative circumstance
- Sometimes connect with age/ageing
- Consider the negative impacts of social isolation, lack of community engagement, loss of employment, and difficulties accessing support services
- Identify public perceptions as negative mainly due to the negative social attitudes and low visibility of dementia in the public sphere
- Would want to be socially engaged, included and have more social support; only a few would engage in end of/ending life considerations.

Action points: Improve public attitudes, perceptions and behaviour; do more research; and improve the support and care systems, information and availability.

Campaigns prioritised normalising dementia, raising awareness, increasing understanding and interaction skills and focusing on issues related to dignity, respect and rights.

OLDER ADULTS WITH DEMENTIA (N=8)

- Mixed view of neutral and negative thoughts with very few positive ones
- Sometimes connect with age/ageing
- Consider the negative impacts of social isolation, stigma, lack of services and difficulty receiving a diagnosis, plus difficulties with transport and loss of employment
- Identify mainly negative public attitudes reflecting people's personal fear and stigmatising attitudes due to lack of understanding in the public sphere
- Would want continuity, dignity and respect in every-day living, interpersonal connections, support, social engagement and inclusion; only a few would engage in end of/ending life considerations.

Action points: Improve public attitudes, perceptions and behaviour; do more research; improve the support and care systems, information and availability; and increase education to specific target groups on specific topics.

Campaigns prioritised dignity, respect & rights and focusing on prevention methods, particularly ways to slow down the progress of the condition.

YOUNGER ADULT AND MID-LIFE CARERS (N=5)

- Most likely to hold negative thoughts; focused on the progression of the condition and people's lack of understanding
- Younger adults with some positive thoughts reflecting empathy; mid-lifers connect with age/ageing
- Consider numerous negative impacts including access to services, diagnosis and ongoing support, the challenges of cognitive loss, loss of work, and difficulties with transport and finance; psychological impacts, the carer role impact and the impacts of stigma, social isolation and lack of community engagement
- Identify very negative social attitudes and people's lack of understanding
- Would want continued love and affection and good/professional care, interpersonal connections and support; would rarely engage in end of/ending life considerations.

Action points: Increase education to specific target groups on specific topics; raise awareness; improve the support and care systems, information and availability; provide more support and medical care.

Campaigns prioritised raising awareness, increasing understanding and interaction skills and dignity, respect & rights issues.

LATER MID-LIFE CARERS (N=15)

- Mixed view of neutral descriptions and negative thoughts of the progression of the condition with very few positive ones
- Often connect with age/ageing
- Consider the negative impacts of the difficulties in accessing services and diagnosis, social isolation and stigmatising attitudes, the impacts on the carer, personal relations and finances
- Identify very negative public attitudes of social disregard and stereotyping or misattribution to mental illness and old age/ageing; people's fear and avoidance in public spaces and lack of understanding of the condition
- Would want interpersonal connection and support, social engagement and inclusion, continuity, dignity and respect and good/professional care; many would engage in end of/ending life considerations.

Action points: Improve the support and care systems, information and availability; increase education to specific target groups on specific topics; and provide more support.

Campaigns prioritised increasing understanding and interaction skills, dignity, respect & rights issues and raising awareness.

OLDER ADULT CARERS (N=8)

- Focus on negative thoughts of the condition as a big and difficult issue that is little understood in the public domain; likely to express empathy
- Frequently connect with age/ageing
- Consider the negative impacts of the difficulties in accessing services and diagnosis, social isolation and lack of community engagement, the carer role and the financial and psychological impacts on their relationship and their life
- Identify a mix of negative public attitudes of misattribution to old age and memory loss, as a result of people's lack of understanding, and positive individual expressions of empathy, compassion and openness to talk about the condition as a result of increased personal contact and public exposure to dementia
- Would want interpersonal connections and support, good/professional care, continuity in housing, i.e., to stay at home; rarely would engage in end of/ending life considerations.

Action points: Increase action at the grassroots level; increase funding; and provide more support.

Campaigns prioritised raising awareness, increasing understanding and interaction skills, and normalising dementia.

SUMMARY TABLE 2B: PROFESSIONALS' VOICE & AGE PERSPECTIVES (HEALTH CARE, SOCIAL WORK AND SERVICE PROFESSIONALS)

YOUNGER ADULT PROFESSIONALS (N=10)

- Most likely to focus on positive thoughts, including empathy
- Focus on neutral thoughts describing the physiological changes, and negative ones, including the loss of the person and personal fears
- Sometimes connect with age/ageing
- Consider impacts of social isolation and stigma, the psychological impact on individuals and families, difficulties accessing services and the carer role impact; the role of mediating factors, such as the type of dementia, age of onset and differences in urban and rural settings
- Identify negative social attitudes, lack of understanding, dismissive treatment and misattribution to mental illness
- Identify also some increase in public awareness
- Would want continued love and affection, good/professional care, interpersonal connections and engaging in preventing and preparing; no end of/ending life considerations.

Action points: Increase education to specific target groups on specific topics; provide support; more funding; and raising awareness.

Campaigns prioritised increasing understanding and interaction skills, raising awareness and dignity, respect & rights issues.

MID-LIFE PROFESSIONALS (N=21)

- Less likely to hold positive thoughts
- Focus on neutral descriptions of the physiological changes, people's lack of understanding and the sadness of the prognosis
- Sometimes connect with age/ageing
- Consider the impacts of lack of access to services, the negative effects of poor services, stigma and social isolation, lack of community engagement; the carer role, the challenges of cognitive loss and the overall negative material impact
- Identify negative public attitudes leading to exclusion; negative stereotyping and misattribution to stupidity or madness and emphasising dementia as a debilitating disability with no communication or decision-making skills or functional capacity; feelings of fear, apprehension and pity, lack of understanding of the condition, and a likely desire to die if diagnosed
- Identify also some increase in levels of openness about dementia in the public sphere
- Would want good/professional care, engaging in preventing and preparing, interpersonal connections, support, and continuity, such as to stay at home; many would engage in end of/ending life considerations.

Action points: Increase education to specific target groups on specific topics; do more research; and provide more funding.

Campaigns prioritised increasing understanding and interaction skills, raising awareness and dignity, respect & rights issues.

LATER MIDLIFE PROFESSIONALS (N=28)

- Some positive thoughts reflecting empathy and acceptance
- Focus on neutral descriptions of the physiological changes but also on issues related to care arrangements, or negative thoughts related to loss of the person, the sad prognosis of dementia, and personal fears
- Rarely connect with age/ageing
- Consider the social, service and psychological impacts, including social isolation and lack of community engagement, lack of access to services, especially support needed with family relationships, and the effects of cognitive loss and the impacts on carers; considered also the mediating effects of urban/rural settings and socio-economic circumstance
- Identify negative public attitudes of negative stereotyping, stigma and misattribution to mental illness or loss of self and humanity; dismissive treatment, fear and apprehension about one's ability and skills to interact with people with dementia
- Identify also some increase in levels of openness about the topic and more contact with people with dementia in the public sphere
- Would want good/professional care, interpersonal connections, support, engaging in preventing and preparing; and continuity, dignity and respect; some would engage in end of/ending life considerations.

Action points: Increase education to specific target groups on specific topics; do more research; provide more support; and improve the support and care systems, information and availability.

Campaigns prioritised increasing understanding and interaction skills, raising awareness, normalising dementia and dignity, respect & rights issues.

OLDER ADULT PROFESSIONALS (N=5)

- Many positive thoughts reflecting empathy
- Most likely to focus on neutral descriptions of the condition
- No mention of age/ageing in this context
- Negative thoughts related to sadness, loss and personal fears
- Consider the impacts of social isolation, the lack of community engagement and access to services that could provide support around family relationships; the psychological impacts of cognitive loss, the carer role, and some of the disparity impacts
- Identify mainly negative public attitudes arising from mistaking dementia as a mental illness, social apprehension, embarrassment and saddened reactions to dementia in the public sphere; lack of understanding of the condition
- Would want continuity in living arrangements (i.e., to stay at home) and in dignity and respect, love and affection, social engagement and inclusion; few would engage in end of/ending life considerations.

Action points: Increase education to specific target groups on specific topics; and improve the support and care systems, information and availability.

Campaigns prioritised raising awareness.



SUMMARY FOLDOUT TABLE 1: VOICE PERSPECTIVES

PEOPLE WITH DEMENTIA (N=19)

- Positive coping within negative circumstances
- Personal acceptance of dementia with its limitations
- Focus on meaningful life with dementia - recognising the opportunities
- Limited horizons - immediate concerns and the present
- Anticipating stigma and negative stereotyping
- Sadness over social isolation and exclusion
- Consider the social and material impact and the services available
- Would want to be treated as a 'normal' member of society, be socially engaged and included, have interpersonal connections and secure continuity, dignity and respect.

Action points: Improve public attitudes, perceptions and behaviour; do more research; and improve the support and care systems, information and availability.

Campaigns prioritised dignity, respect and rights; normalising dementia and increasing public understanding and interaction skills, targeting mainly the public but also local communities, families, professionals in care services, adolescents and young adults and people with dementia.

CARERS (N=28)

- Most likely to see dementia as age-related and partly/perhaps an expected part of ageing
- Focus on the negative, often devastating, effects on the person, carer and family; powerlessness and guilt for it
- Consider the service impact, lack of access to and the availability of services and the poor experience during the time of seeking a diagnosis; social impact in terms of social isolation; carer burden and psychological impact on their relationship
- Identify mostly negative public attitudes and mistaking dementia for insanity; discarding people with it, seeing them as crazy and rather confined to a care home; the condition is the great unknown which leads to avoidance and lack of interaction skills in the public sphere
- Would want interpersonal connection and support, good professional care and continuity, dignity and respect; likely to consider end of life in "as if situation".
- Would want to be treated as a 'normal' member of society, be socially engaged and included, have interpersonal connections and secure continuity, dignity and respect.

Action points: Provide more education to specific target groups; provide support and improve the support and care systems, information and availability.

Campaigns prioritised increasing understanding and interaction skills, awareness-raising and on dignity, respect and rights, targeting mainly the public but also families, adolescents and older adults.

HEALTH CARE PROFESSIONALS (N=21)

- Focus on the physiological changes that come with the disease/condition
- Empathy and sadness over the loss of the person but holding hope for a cure
- Consider the impact of available services, the social and psychological impacts and the caring burden on carers, families and the services
- Identify background mediating factors on the impact of dementia
- Identify negative public attitudes of stereotyping and exclusion of people with a disability plus personal fear and lack of understanding
- Would want to engage in prevention and preparing, receive good professional care plus love and affection.

Action points: Provide education to specific target groups (including care work professionals, through strong professional networks and multi-disciplinary approaches), more research and improved support and care systems, information and availability.

Campaigns prioritised awareness raising, increasing understanding and interaction skills and on dignity, respect and rights, most often to families, health care sector, and adolescents, after the public.

SOCIAL WORK PROFESSIONALS (N=23)

- Focus on neutral descriptions of the physiological condition and some to its relation to age.
- Empathy for the carers and families
- Consider the strong social impact of stigma, social isolation and community response, caring burden and the psychological impact of cognitive loss as a form of disadvantage
- Identify very negative public attitudes of stereotyping and misattribution for mental illness, and psycho-social responses of fear
- Would want good professional care, continuity, dignity and respect and interpersonal connections and support plus love and affection.

Action points: Provide more education to specific target groups; improve attitudes, perceptions and behaviour; and research.

Campaigns prioritised increasing understanding and interaction skills, dignity, respect and rights and awareness-raising, most often at selective settings, families, homes, communities, after the public.

SERVICE PROFESSIONALS (N=20)

- Often with family connection to dementia
- Focus on the sad prognosis and reality for the person and family
- Often connect it with normal part of ageing
- Consider the social and psychological impacts of social isolation, stigma and cognitive loss as a form of disadvantage and the impact of gaps in service provision
- Identify also positive public perceptions but regard the knowledge level low, attitudes as negative and fearful and visibility as negligent
- Would want interpersonal connection and support, good professional care, end of life considerations and social engagement; likely to consider end of life in "as if situation".

Action points: Increase education to younger age groups, provide more support and research.

Campaigns prioritised increasing understanding and interaction skills; normalising dementia and awareness raising targeting (most often) children and adolescents through schools, and all age groups via communities, after the public.

SUPPORTED BY



Australian Government
National Health and Medical Research Council

