DEMENTIA IN THE PUBLIC DOMAIN

A GUIDE TO VOICE, AGE AND CAMPAIGNING

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SUPPORTED BY

CONTENTS

ABOUT
THE GUIDE

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This Guide is aimed at 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 Guide 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 Guide 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.

In this Guide, we present our work in three ways that examine Dementia in the Public Domain:

1. First, we look at the voice-perspective held by participants. 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, 2018b).

2. Second, 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, those in midlife, later midlife and older age. Because the participants we have studied are either in working life or are carers or people with dementia, then numbers who fall into each age group will vary depending upon their voice perspective (Biggs, Haapala & Carr, 2018).

3. Third, 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 (Haapala, Carr & Biggs, 2019).

Each contain, to different degrees, a connection 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 guide 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.

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 et al., 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.

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						
				Professionals		
	People with dementia n=19	Carers n=28	Professionals n=64	Health care n=21	Social work n=23	Services n=20	All n=111
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, others with Alzheimer's disease or vascular dementia. Time since diagnosis varied between 4 and 15 years. Nine participated with their care partner. 2) Carers were either currently or in the 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 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 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 (See Haapala, Carr & Biggs, 2018b).

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 this Guide, we have focussed primarily on the Impact of Dementia and the Priorities for future campaigning. Other themes are used to provide additional context and background material on Voice perspectives. More detail on methodology can be found in our scientific publications (see References).

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. 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.

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 were invited from a wide spectrum including consumers, people working with provider organisations, policy-makers and others concerned with influencing public agendas on dementia. Their observations were added to the research outcomes in order to create recommendations for future policy, practice and research.

ABOUT
THE PROJECT

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Limitations of the study

There are certain limitations to the current study: First, while the percentage of participants from culturally and linguistically diverse backgrounds (CALD) in our study paralleled Australian population statistics, the number of participants was too small to allow a CALDbased 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 considered in two separate papers (Biggs, Haapala & Carr, 2018; Haapala I, Carr A, Biggs S. 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 been explored elsewhere (Haapala, Carr & Biggs, 2018b).

Fourth, our sample comprised predominantly women, except for people with dementia who were predominantly men. 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.

VOICE PERSPECTIVES ON DEMENTIA

In this section we present a snapshot of our findings on Voice.

Findings are presented as percentage of expressions, 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. Campaigning should focus on social acceptance, dignity and respect as a means to a meaningful life and to live well with 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.

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.

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 need the 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.

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.

For further information, see the Summary Foldout at the end of this Guide (Appendix).

THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

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In this section, we look at the impacts of dementia as reported by each Voice perspective. 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. Here we 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 1). 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. (For more detail, see Carr, Haapala & Biggs, 2019.)

SOCIAL DISADVANTAGE

Social disadvantage can be understood as a lack of resources (Heap, Lennartsson & Thorslund, 2013) and limitations preventing social participation (Vinson & Rawsthorne, 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 1 illustrates the importance given to each impact by Voice perspective, and these will be discussed on the following pages. Percentages in Figure 1 are calculated from the total expressions of impact within each Voice and presented by type of impact.
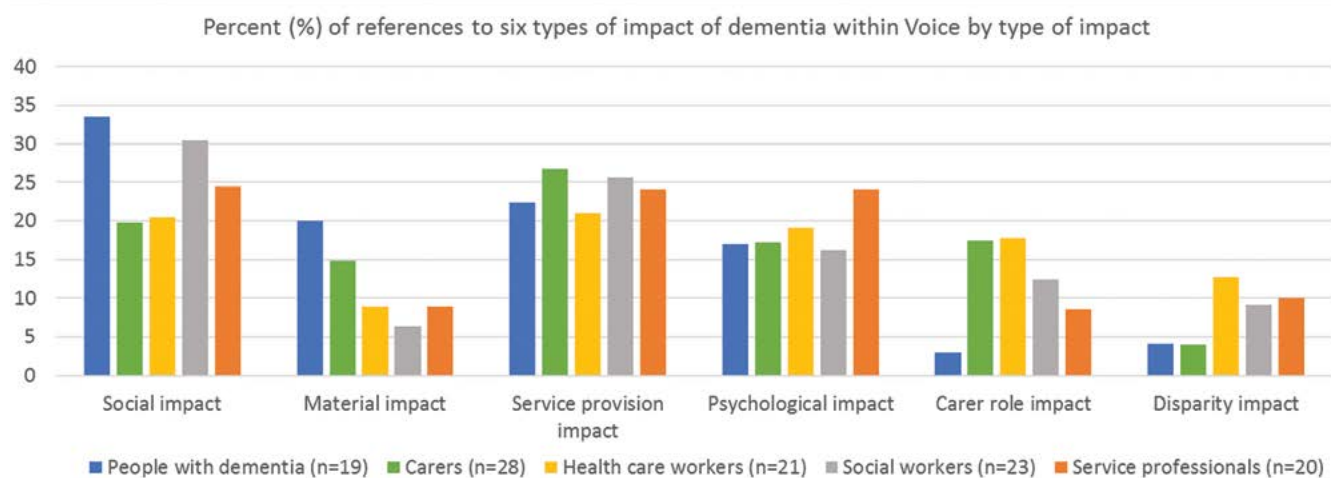
SOCIAL IMPACT

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 1.)

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.

Figure 1. Comparison of percent (%) of references within Voice by type of impact.

Percent (%) of references to six types of impact of dementia within Voice by type of impact

THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

MATERIAL IMPACT

People with dementia mentioned material impacts at 20% of all references to impact within their group (Figure 1), 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.

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 1). 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.

THE IMPACT OF DEMENTIA AS A FORM OF DISADVANTAGE

PSYCHOLOGICAL IMPACT

Most groups mentioned psychological impacts at about the same rate (16-19%), though service professionals mentioned it most, at 24.1% (Figure 1). 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.

CARER ROLE IMPACT

The caring impact was perceived to be an issue by most groups (Figure 1). 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.

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 1). 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.

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 and 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:

1. Dementia can create its own forms of social disadvantage and exclusion

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

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

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

PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE

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

Six priority areas were identified through a thematic analysis of their interviews. These can be seen on the 'radar' diagram below (Figure 2). 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 2) 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 heath 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 2. Campaign priorities by Voice; percent of expressions within Voice group.
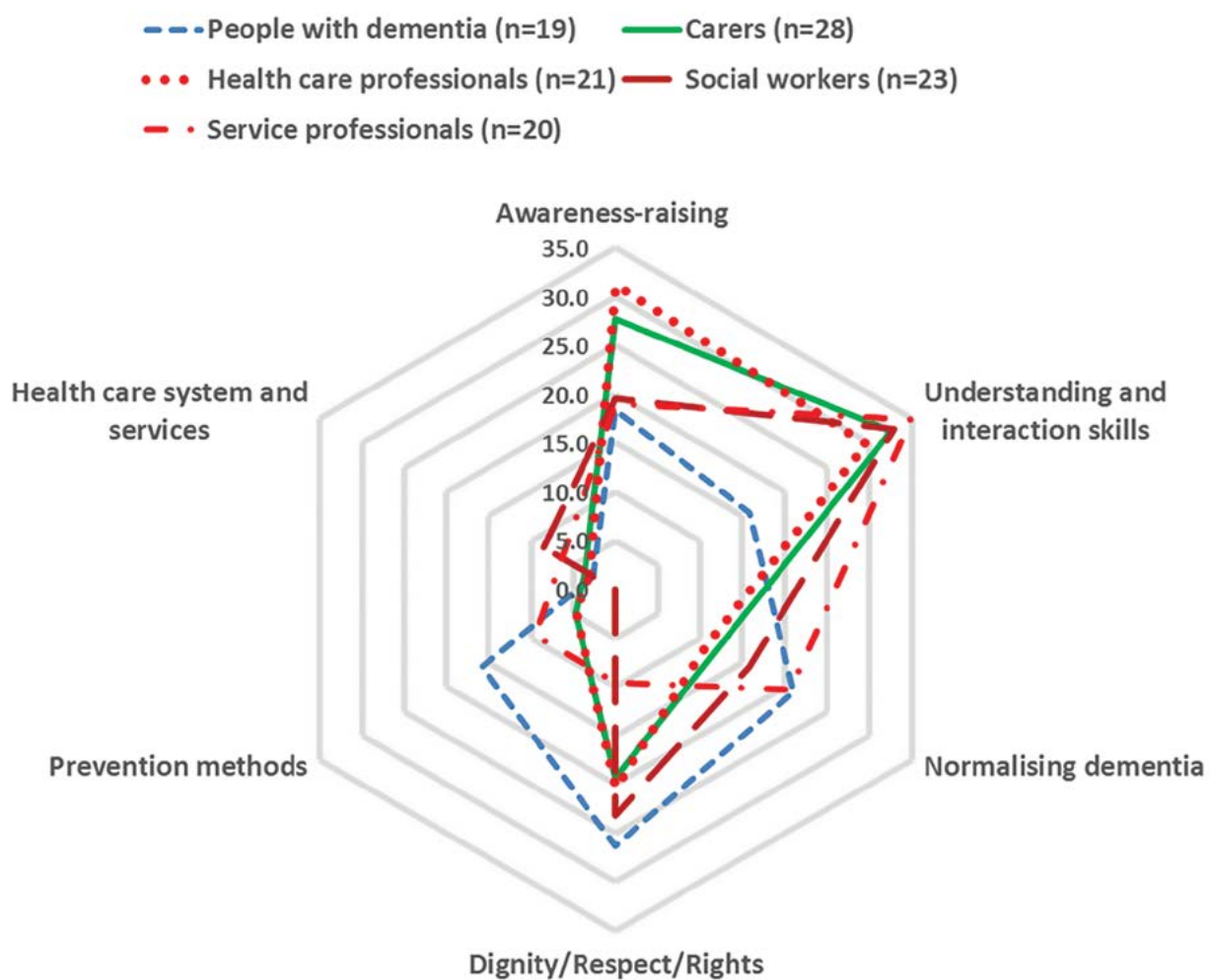
PRIORITIES FOR CAMPAIGNS ON DEMENTIA BY VOICE

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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 attempts to advocate for and on behalf of 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-related symptoms and promote help-seeking behaviour.

Heath Care System and Services

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

VOICE & AGE PERSPECTIVE ON CAMPAIGN PRIORITIES

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

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

The 'radar' diagrams (Figures 3a-3c) 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 3a. People with dementia: Campaign priorities; percent of expressions by Age group.
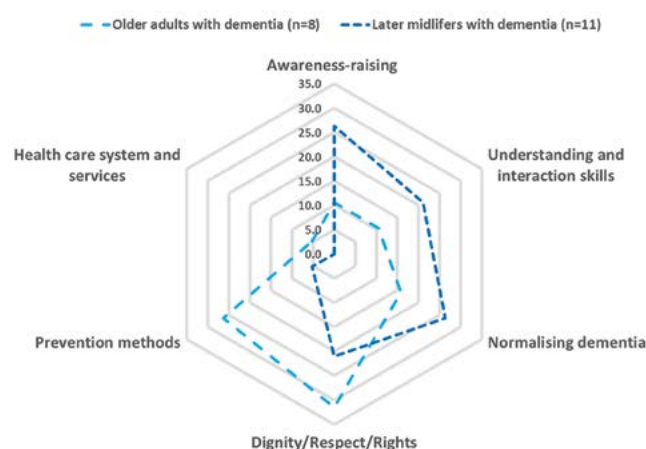
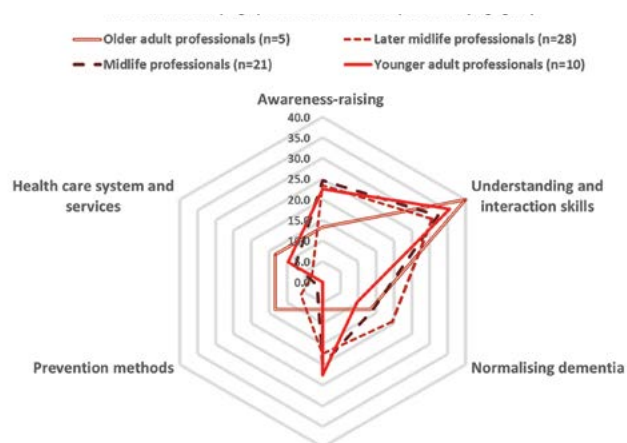**Figure 3b. Carers: Campaign priorities; percent of expressions by Age group.**
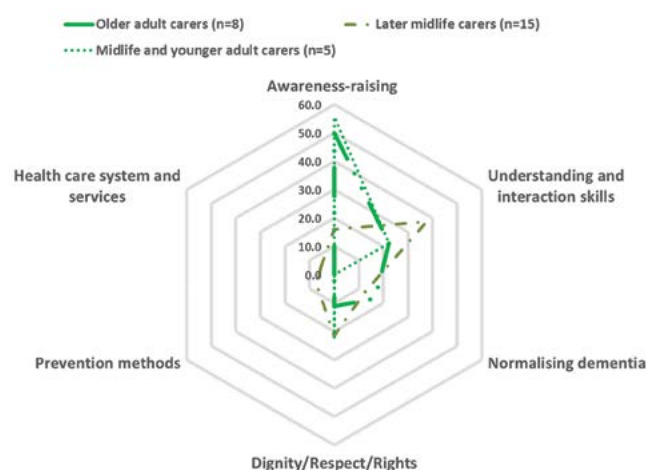
Third, when professionals' combined responses are looked at, **Younger adult (n=10), Mid-life (n=21)** and **Later midlife professionals (n=28)** showed a close alignment, prioritising increased understanding and interaction skills but also on awareness-raising and dignity, respect & rights issues, with 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.

Figure 3c. Professionals: Campaign priorities; percent of expressions by Age group.

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.

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.

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)

Drivers for National campaigning priorities:

- 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 their specific contexts.

National Top Priority Areas: Dignity, Respect and Rights (aligned with 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).

*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 4, 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.
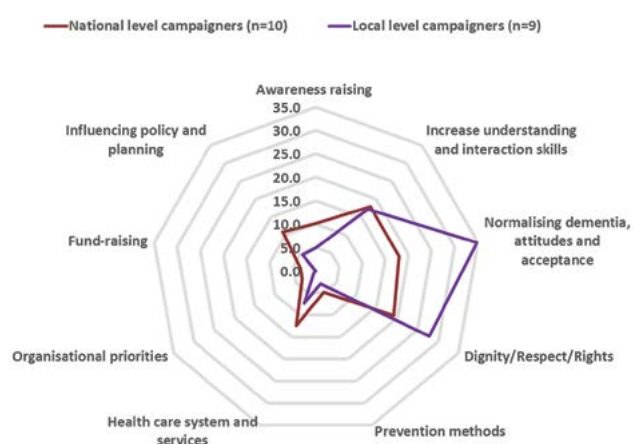
LOCAL LEVEL CAMPAIGNERS (N=9)

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

CAMPAIGNERS' PERSPECTIVE

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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 or 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:

When we looked at what campaigners expressed as facilitators for effective campaigning, the following patterns emerged (see Figure 5).

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.

In comparison (see Figure 5), 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.

Figure 5. Campaigners' views on facilitators for campaign effectiveness. Percent (%) of mentions within group.
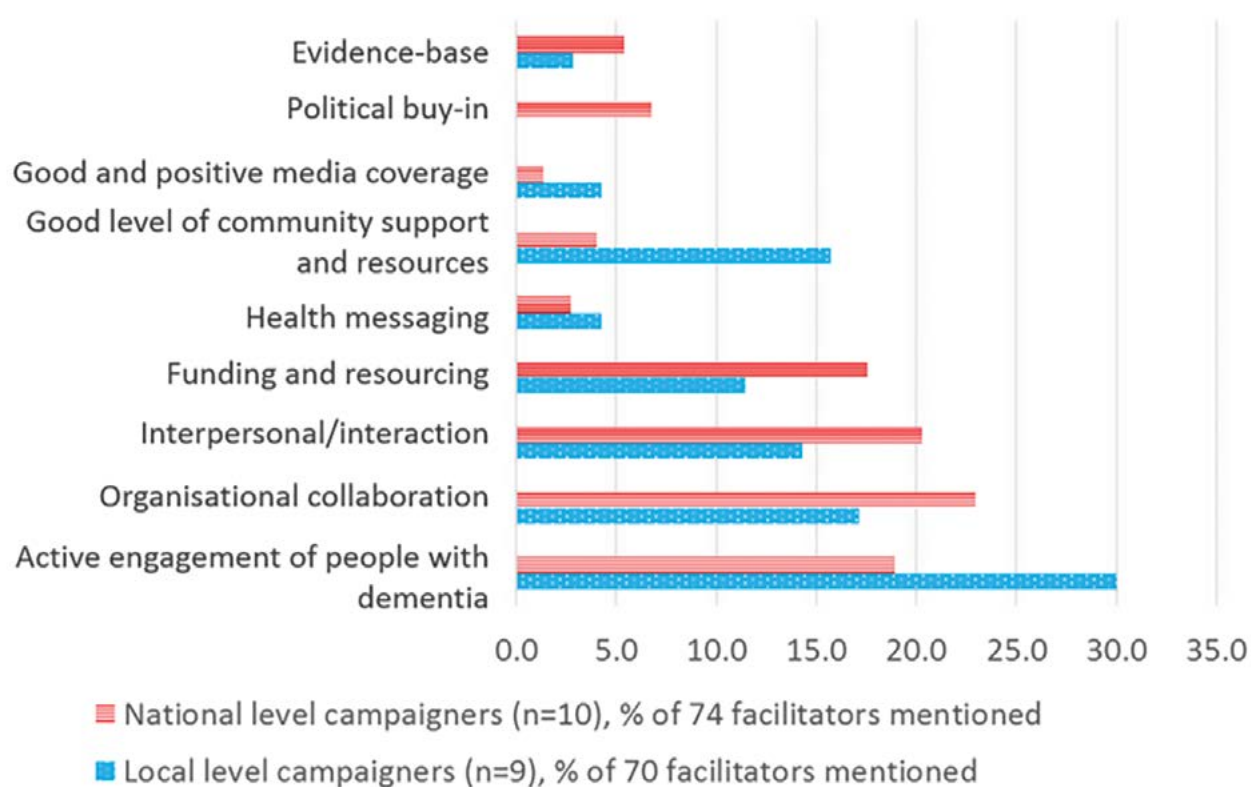
COMPARING PRIORITIES BETWEEN CAMPAIGNERS' AND VOICE PERSPECTIVES

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When National level campaigners', Local level campaigners' and priorities by Voice perspective were compared, patterns of overlap and distinctiveness emerged (see Figure 6).

CONNECTING CAMPAIGNERS AND VOICE PERSPECTIVES

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; and 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 heath perspective.

2. Increasing mutual understanding and how to interact with people with dementia was important for all Professional groups and Carers.

Both National and Local campaigners gave some emphasis to health care systems and services, together with Social work professionals (Figure 6). 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 (reported in Haapala, Carr & Biggs, 2018b).

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.

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 6. Perspectival views on campaigning priorities: Views among five Voices and National and Local level campaigners.
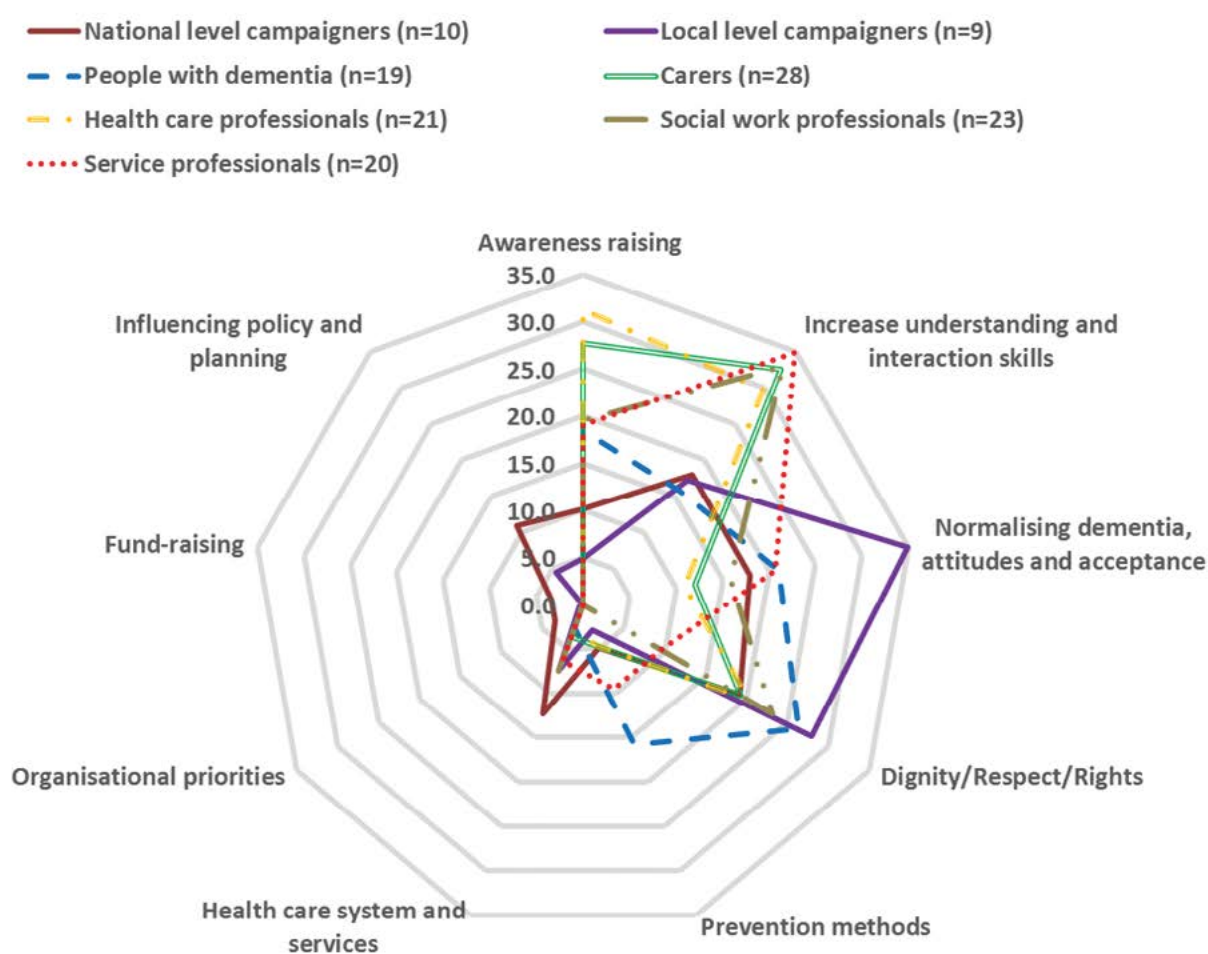
Footnote: In addition to the campaign priorities recognised by Voice perspectives there were three new priorities identified by campaigners (see "Campaign priorities explained" in Section: "Priorities for Campaigns on Dementia by Voice").

COMPARING PRIORITIES BETWEEN CAMPAIGNERS' AND VOICE PERSPECTIVES

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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 WHO guidelines.

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. However, these needs were not emphasised by campaigners.

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.

CONCLUSIONS AND RECOMMENDATIONS FOR A WAY FORWARD

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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: IMPACTS AND DISADVANTAGE

Our findings on dementia and disadvantage indicate 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 are 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 is 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

Participant's 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 focussed on improved public understanding, greater social interaction and awareness-raising.

- Professionals focused primarily on increasing interpersonal skills.

- Age also reveals 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.

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SPECIAL THANKS

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www.bsl.org.au/

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APPENDIX: SUMMARY FOLDOUT ON 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.