The impact of a national public awareness campaign on dementia knowledge and help-seeking intention in Ireland

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Abbreviations

AD	Alzheimer Disease
API	Asian Pacific Islander
CI	Confidence Interval
CT	Computed Tomography
DED	District Electoral Division
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
HSE	Health Service Executive
MeSH	Medical Subject Headings
MMSE	Mini-Mental State Examination
MRI	Magnetic Resonance Imaging
NDS	National Dementia Strategy
OR	Odds Ratio
PLWD	People Living with Dementia
RCT	Randomised Controlled Trial
RTÉ	Raidió Teilifís Éireann
SPSS	Statistical Package for the Social Sciences
TV	Television
UK	United Kingdom
US	United States
WHO	World Health Organisation

Summary

Dementia represents a growing public health concern in Ireland due primarily to ageing of the population. Increasing public knowledge of dementia has been identified as a key research and policy priority to reduce the global burden of this disease, e.g. through prevention and early diagnosis.

In 2016, a nationally-representative survey of over 1,200 adults living in Ireland was conducted in order to inform the development of a national dementia awareness campaign entitled Understand Together. This survey examined multiple domains including socio-demographic characteristics, knowledge of dementia and help-seeking intention. Following the launch of Understand Together in late 2016 a further nationally-representative tracking survey of over 1,000 respondents based on the original survey was conducted in early 2018. By comparing data from the 2016 and 2018 surveys this quantitative study evaluated public awareness of the Understand Together campaign and its association with dementia knowledge and help-seeking intention.

Since the launch of the Understand Together campaign in 2016, awareness of recent dementia advertising, self-reported knowledge of dementia and knowledge of the modifiable nature of dementia risk have increased. Certain population subgroups were more likely to be aware of the communication campaign including women (Adjusted OR1.51, 95% CI 1.14-2.00, p-value=0.004), those living in rural areas (Adjusted OR 1.48, 95%CI 1.10-2.00, p-value=0.01), those aged 40-59 years old (Adjusted OR 1.96, 95%CI 1.40-2.74, p-value<0.001), those aged 60+ years old (Adjusted OR2.18, 95%CI 1.47-3.22, p-value< 0.001) and those with personal experience of someone with dementia (Adjusted OR 2.06, 95%CI 1.55-2.75, p-value<0.001). Multivariable analysis of the 2018 survey data demonstrated a statistically significant positive association between awareness of recent advertising on dementia and positive views of the potential benefits of early diagnosis (Adjusted OR 1.97, 95%CI 1.35-2.88, p-value<0.001). In addition, there was a statistically significant positive association between awareness of advertising and being unlikely to delay help-seeking (Adjusted OR 1.81, 95%CI 1.36-2.40, p-value<0.001).

Future public communication campaigns on dementia should continue to focus on increasing awareness of the modifiable nature of dementia risk to support disease prevention. There should be an increased emphasis on public communication targeted at population subgroups that are more difficult to reach. In order to inform future public communication strategies, it is

recommended that evaluation of the Understand Together campaign take place following its completion. This evaluation should employ both quantitative and qualitative methodologies.

Chapter 1. Introduction

1.1 Background

Dementia is an umbrella term employed to describe a group of neurodegenerative diseases which typically result in chronic and progressive impairment of multiple cognitive and functional abilities. Communication skills, executive capacity and reasoning abilities frequently deteriorate to such a degree that social and independent functioning are significantly affected. Additional sequelae may include personality change and mood disorder.

Alzheimer disease (AD) is the most common of these diseases, accounting for 60% to 70% of all cases (1), followed by Vascular Dementia. These may coexist resulting in a Mixed Dementia clinical picture (AD and Vascular Dementia). Dementia with Lewy Bodies is another relatively common type of dementia which presents with progressive deterioration in cognition, fluctuations in attention and alertness, and parkinsonian motor symptoms, e.g. muscle rigidity, impaired mobility and slowness of movement. It may also be associated with mood disturbance such as depression (2). Other rarer forms of dementia include Wernicke-Korsakoff Syndrome, Frontotemporal Dementia, Creutzfeldt-Jakob disease, Huntington's Disease and Dementia associated with Parkinson's Disease. A small proportion of dementia cases can be due to treatable conditions such as normal pressure hydrocephalus, thyroid disorders and Human Immunodeficiency Virus (HIV).

1.2 Pathogenesis, diagnosis and progression of dementia

The neuropathological markers of AD include the presence of neurofibrillary tangles and amyloid plaques. Plaques contain the protein beta-amyloid which is produced from amyloid precursor protein. Tangles are formed as a result of excessive phosphorylation of tau, a protein which acts to maintain nerve cell structure. Oxidative stress, in which oxygen molecules (free radicals) induce a toxic effect on the brain, is also believed to contribute to the pathological process (3). These mechanisms eventually cause the irreversible destruction of neurons and cerebral atrophy, resulting in the development of AD.

Dementia is diagnosed through a combination of clinical history and examination, laboratory tests, cognitive assessments, and brain imaging if available (Computed Tomography (CT) or Magnetic Resonance Imaging (MRI)). These may be conducted by primary care physicians and/or hospital specialists, including those working in medicine for the elderly, neurology and

psychiatry.

Dementia progresses differently depending on the specific type of disorder, and may be influenced by other individual factors (for example in AD, these may include older age at diagnosis, lower baseline cognition, and higher baseline neuropsychiatric symptoms (4). The progression of AD is described in terms of early, middle, and late/advanced stages; the International Work Group proposed a diagnostic spectrum consisting of three phases: at-risk state asymptomatic, symptomatic prodromal AD and AD dementia (5). Vascular Dementia typically occurs as a result of atherosclerosis of the small vasculature of the brain and/or a series of strokes. It has been classically described as step-wise in progression with deterioration occurring with successive cerebrovascular events. Dementia with Lewy Bodies is caused by deposits of alpha-synuclein protein, known as Lewy Bodies, within the nuclei of neurons in areas of the brain that govern specific aspects of motor control and memory (2). There is frequently disease overlap in patients with various neurodegenerative disease processes coinciding with dementia.

1.3 Epidemiology of dementia globally and in Ireland

Internationally, approximately 50 million people have dementia and there are almost 10 million new cases each year. The global prevalence of dementia is estimated to increase to 82 million by 2030, and to triple to 150 million by 2050 (1).

Dementia is closely associated with ageing which represents the single greatest risk factor for developing the condition. In Ireland, significant demographic ageing of the population is forecast in the coming decades. In 2011 it was estimated that there were approximately 47,000 people in Ireland living with dementia, with this figure expected to double to 94,000 by 2031 (6). This coincides with an estimated doubling of the older population (aged 65 years and older) from 531,600 in 2011 to 991,000 by 2031 (6) . A significantly higher prevalence of dementia exists amongst women in Ireland (two-thirds of all cases), as has been similarly demonstrated in other countries (6). It is estimated that over 60% of people with dementia in Ireland live in the community (i.e. private households), which corresponds with a pattern that has also been observed in other developed countries. Marked regional variation in estimated prevalence of dementia has been observed with the west of Ireland (Connaught) having a significantly higher proportion of people living with dementia (PLWD) (1.24%) compared to the east of the country (Leinster) which has the lowest (0.95%) (6).

1.4 Wider consequences of dementia

There are considerable costs from dementia to the affected individual, their family/carers, the health system and society more generally. The estimated global economic cost to society of dementia was US$ 1 trillion in 2018, with this figure expected to rise to US$ 2 trillion by 2030 (7). It is anticipated that this financial burden will continue to increase into the future. The wider non-financial costs to individuals, families, and communities across the globe are difficult to quantify but are likely to be substantial.

At an individual level there is a multitude of potential secondary deleterious consequences that PLWD may experience including loss of independence, social disconnectedness, deterioration in physical health, and cessation or reduction in workforce engagement. There is often a negative impact on the lives of family and caregivers due to the burden of care that is required. These effects aggregate to produce an overall adverse impact on the wellbeing and functioning of society as a whole, and it can be anticipated that these negative effects will continue to increase over the coming decades.

1.5 Prioritisation of dementia

The report published by the World Health Organisation (WHO) in 2012, "Dementia: a public health priority", highlighted dementia as a crucial global health issue (8). It recommended a multifaceted approach to this issue which included establishing a dementia-friendly global society, ensuring dementia is recognised as an urgent public health and social care need, ameliorating attitudes and understanding of the disease, investing in dementia care services, and highlighting dementia as a research priority.

In Ireland, dementia is increasingly being recognised as a critical public health issue. In 2014, the National Dementia Strategy (NDS) was published as part of the Programme for Government 2011-2016 (9). It was developed with input from an expert working group comprising relevant clinicians, researchers, allied health professionals, and representatives from the Health Service Executive (HSE) and the Department of Health. The strategy is based on six priority areas for action:

- improving awareness and understanding of dementia
- timely diagnosis and intervention
- integrated healthcare services for individuals with dementia and their carers/families
- training and education
- research and information systems
- leadership

1.6 Dementia prevention

The absence of any effective disease-modifying treatments for dementia has lent further importance to focusing on prevention through risk reduction. Previous evidence has shown that there are only moderate benefits to be garnered from single risk factor intervention aimed at preventing dementia and AD (10). Given that dementia is believed to be multifactorial in origin, and has an extended asymptomatic phase, interventions that occur early and are multifaceted in their approach are thought to be the most effective. Currently there are three large multi-domain prevention studies underway in Europe with the overarching aim of reducing cognitive impairment, AD and dementia in older people with various risk profiles (10).

Studies have shown that there are multiple inherited, vascular, and lifestyle risk factors which commonly co-occur throughout the life cycle contributing to overall risk of developing dementia and AD (11). Lifestyle and vascular risk factors related to the development of dementia and AD include smoking, hypertension, obesity, physical inactivity, and diabetes mellitus. There is already substantial expert opinion and epidemiological evidence to support the prevention and management of these modifiable/treatable risk factors (12).

1.7 Timeliness of diagnosis

Poor levels of knowledge and understanding of dementia exist in many countries and have resulted in stigmatisation, obstacles to diagnosis and appropriate care, along with multiple negative physical, psychological, social and economic consequences for PLWD, their families, and their communities (8). A recently published review defined "timely diagnosis" as occurring at a stage when individuals first become sufficiently concerned to seek help from physicians resulting from concern about changes in cognitive ability, behaviour, or functional capacity not necessarily due to dementia (13). Early diagnosis allows access to a pathway of evidence-based care and support and also provides a key opportunity for advanced care planning at a time when the affected individual and informal caregivers have the capacity to make important decisions about their future care (14, 15). Early therapeutic interventions can aid cognition and treat associated conditions such as depression. Other potential benefits include improved patient safety, cost reduction, and delayed institutionalisation (13).

1.8 Public communication on health

Maibach and colleagues defined health communication as "the production and exchange of information to inform, influence or motivate individual, institutional and public audiences about health issues" (16). The overarching objective of any mass media campaign is to

influence the information environment by increasing the amount of available information on the topic of interest, e.g. television advertisements, print material etc., and also by framing the issue as a considerable public health problem to increase its relevance and attract the attention of the target audience (17). There are numerous modalities through which mass media public health campaigns may be delivered. The traditional approach has primarily involved modalities such as television, radio, print media and printed information materials. Over recent years there has been an emergence of innovative forms of communication including internet websites and social media applications accessible through computers and smart devices.

Online health promotion is a rapidly expanding health communication medium. A recent large randomised controlled trial (RCT) examined the impact of advertisement to promote healthy food choices and daily exercise in users of the Bing search engine and associated advertisement system (18). In this seminal RCT on internet health advertisement, 794,000 internet users underwent randomisation to receive either one of several professionally produced campaign advertisements or advertisements that would otherwise have been delivered (the "status quo"). Both groups' engine searches for health-promoting items or services were examined from one-month pre-intervention to one-month post-intervention. The results of the trial demonstrated that one in two people who were exposed to the professionally developed health promotion advertisements made future searches for information related to weight loss, compared to just one in three in the control group. Although this RCT was limited to users of a single internet platform and thus cannot be considered externally valid, the results indicated the potential benefits of employing health advertisements to encourage internet users to obtain health information, possibly leading to behavioural change and improved health outcomes. The researchers concluded that online health campaigns may be more effective by targeting internet users based on individual preferences and sociodemographic factors.

In addition to general internet use including traditional websites and search engines, social media has developed into a rapidly expanding modality that is used for formal and informal health communication. Examples of social media applications/tools include Facebook, Twitter and blogs. The main uses of social media include the facilitation of information sharing and obtaining health messages. In addition, social media platforms are widely accessible across all subgroups of the population compared with traditional media which may be more limited; though certain factors including age, personality, and sex may differentially impact on individual engagement (19). Social media also facilitates peer-to-peer interaction

on health topics in a way that is not possible with traditional internet websites or other media. This may strengthen peer, emotional, and social support for patients, their families and carers, and the wider general public.

A number of potential weaknesses in utilising social media for health communication have been identified (19). Social media communication is frequently informal and relatively unregulated. Information quality and consistency may vary, with wide scope for individual users to upload information regardless of accuracy. In addition, postings may become permanent record and have high exposure, often with posters unaware of the potential size of their online audience. Despite the potential benefits and limitations discussed above it is difficult to fully determine the current and future role and impact of social media in health communication as there is a paucity of higher quality evidence from studies with large sample sizes and robust methodologies (such as well-designed RCTs and longitudinal studies). Although currently there may be considerable research gaps, the potential role for social media in promoting health communication is likely to be substantial.

1.9 Understand Together – a national awareness campaign on dementia in Ireland

As part of the NDS the Dementia Friendly Ireland Steering Group was established in 2015. It aimed to develop a nationwide health, social education and awareness campaign to support PLWD and their carers.

In order to inform this campaign an extensive research strategy was developed in mid-2015. This strategy aimed to review international evidence on previous education/communication campaigns on dementia, measure and describe existing awareness, attitudes and behavior regarding dementia in Ireland, and utilise the knowledge gained to inform the proposed campaign. The research strategy comprised a systematic literature review and both qualitative and quantitative research. The quantitative research component encompassed the HSE Dementia Omnibus Survey Questionnaire which was first conducted in 2016 and was completed by 1,217 adults aged 16 years and older living in the community in Ireland. This questionnaire examined multiple domains including socio-demographic characteristics, experience of dementia, knowledge of dementia, attitudes toward PLWD (and their carers) and help-seeking behaviour. The findings from this survey were used to evaluate knowledge and attitudes to dementia in the general public in order to inform the development of the Understand Together campaign. In addition to the quantitative component, qualitative

research using focus groups with PLWD, carers and health professionals were also conducted to inform the campaign. The aim of the focus groups was to gain a deeper understanding of the principal issues and needs in relation to dementia amongst these key groups.

In October 2016, the HSE launched the national awareness campaign entitled Dementia Understand Together, representing one of the six key elements of the NDS (20). The campaign is led by the HSE working with The Alzheimer Society of Ireland and Genio, as well as more than 30 other partners from a diverse range of areas such as business, academia, healthcare, and the voluntary sector.

The campaign aims to develop a society in Ireland that is inclusive and supportive of PLWD and their families (21). It uses its website, advertising, the media and community activation to increase awareness of dementia.

The objectives of the Understand Together campaign are as follows:

- To improve awareness of dementia and its effect on individuals, families and communities
- To communicate the lived experience of PLWD and their caregivers.
- To provide accurate information on dementia and appropriately signpost to services and supports available to those living with dementia, their caregivers, health professionals and the general public.
- To support better co-ordination of dementia programmes and initiatives throughout Ireland.
- To encourage the uptake of dementia awareness training and the dissemination of information on brain health and dementia prevention.
- To provide inspiration and encouragement to individuals, organisations, businesses and local communities to take measures to develop inclusive and supportive environments for PLWD and their families.
- To promote and highlight the positive actions of individuals, businesses and communities to help PLWD and their families.

The information in the remainder of this section has been provided to the author by the Understand Together campaign.

Campaign funding

The total funding allocated for research, development, implementation and evaluation of the campaign between 2015 to 2019 was €3.3 million. This funding was provided by Atlantic Philanthropies and the HSE.

Key campaign messages

Presented below are the key messages that the campaign aims to effectively deliver to all individuals, families and communities across Ireland.

Key message 1:

Any one of us can get dementia

Key message 2:

What dementia is

Key message 3:

A lot of people in Ireland are affected by dementia and this is set to increase substantially

Key message 4:

Every one of us can play a part in making life better for people living with dementia

Key message 5:

Dementia changes your life but you can live well with dementia

Key message 6:

Keep your brain healthy at every age

Campaign structure

The campaign was broadly divided into three phases of implementation (Table 1.1).

Table 1.1 Campaign phase structure

Phase	Time Period	Activities
1	Oct 2016- Sep 2017	• Brand/campaign launch via a high-profile mass media campaign/support from partner coalition (from public, private and voluntary sectors). • Social media presence developed since 2016 (e.g. Facebook). • Campaign telephone helpline launched 2016. • Website launch, July 2017 (understandtogether.ie). HSE microsite was in place prior to official website launch. • Campaign partners participated in Stakeholder Event to network and share learning to support the roll-out of initiatives throughout their local networks countrywide. Partners engaged with the campaign by training staff, creating awareness among staff/public, social media promotion, public relations, and promotional activities.
2	Oct 2017- Dec 2018	• Launch of personal stories through television (TV) and radio advertisement (real life experiences of Paddy, Maureen and the Mullans family) rolled out every three to four weeks. • Engagement with partners and development of framework for community activation. This grassroots framework has been tested with members of the public, PLWD and key stakeholders. It involves a movement of Community Champions, national partners and individuals effecting local change. It aims to promote understanding and inclusivity in communities where people with dementia and their families are respected and supported. In October 2018, a Community Champions Event took place which was attended by 75 Champions from 20 counties. • Campaign information resources (posters, leaflets, infographics and

		badges) were disseminated between October 2016 to October 2018. • Dementia Friendly Garden at Bloom 2018 (Phoenix Park, Dublin). This event resulted in over 80 pieces of media coverage and 12,000 information leaflets distributed. High-level of positive engagement from visitors to the event. The garden has been re-located to Arklow town (Wicklow). • Press campaign developed for Brain Health Awareness Week in 2018.
3	Jan 2019 onwards	• Implementing the framework and embedding a sustainable approach to communication activation. • Additional funding received to continue the national media campaign (including TV and radio advertisement) until May 2019.

Campaign exposure

In total, the campaign has generated over 500 items of local and national news and broadcasting coverage focused on key messages from the campaign. Further detail is presented in Table 1.2. The campaign has attracted over 270,000 visits to the website as well as substantial engagement via social media and the telephone helpline (Table 1.3). Almost 80,000 written information resources and promotional items were disseminated by late 2018.

Table 1.2 Media campaign exposure metrics (as of January 2019)

Media	Broadcaster/publication	No. of items	Nature of items/comments
National TV	TV3, RTÉ (Raidió Teilifís Éireann)	10	• High-profile interviews with campaign leads/champions/dementia experts, mention of campaign/website etc.
National Radio	RTÉ Radio 1, Newstalk, Today FM	24	• High-profile interviews with campaign champions/dementia experts.
Local Radio Stations	Multiple local/regional radio stations nationwide	76	• Interviews with campaign champions/dementia experts.
National Publications	Irish Mirror, RTÉ Guide, Irish Examiner, Daily Mail, The Star, Irish Independent, Irish Times, Irish Sun, The Herald, Irish Country, and others.	77	• Items related to campaign. • Estimated total circulation of these items - 2,939,098 (based on available data).
Local Newspapers	Multiple local/regional newspapers nationwide	224	• Interviews, items related to campaign. • Estimated total circulation related to these items - 2,547,027 (based on available data).
Online	National and local newspaper websites, radio websites, Journal.ie, Breakingnews.ie, Facebook.com, and others	100	• Interviews, items related to campaign.

Table 1.3 Online, social media, helpline and written information resource/promotional items campaign exposure metrics (as of January 2019)

<table>
<tr><th>Media</th><th>Nature of items/comments</th></tr>
<tr><td>Campaign website</td><td>

Over 270,000 sessions (visits) to the website between July 2017 and October 2018 with the quarterly number increasing successively since its launch.

<table>
<tr><td></td><td>Q2 2017</td><td>Q3 2017</td><td>Q1 2018</td><td>Q2 2018</td><td>Q3 2018</td></tr>
<tr><td>Website sessions</td><td>12,300</td><td>39,919</td><td>44,439</td><td>46,271</td><td>51,184</td></tr>
</table>

Over 15,500 campaign information documents downloaded from website.
Over 8,500 individuals used the service finder to locate a relevant dementia service or support in their local area.
Social media is a substantial driver to the campaign website with 45% of all visitors reaching the website from social media platforms.

</td></tr>
<tr><td>Social media</td><td>

The Understand Together Facebook page has been followed by over 19,000 people (as of January 2019).
The engagement rate on the Facebook page is above average (9% compared to industry average of 1%).

</td></tr>
<tr><td>Helpline</td><td>

Received calls and engaged with 4,979 service users in 2016, 5,290 in 2017 (+6% on 2016), and 4,368 from January 2018 to September 2018 (+10% on same period in 2017). In 2018, one in two service users with concerns about their own or a loved one’s cognitive health who contacted the helpline indicated that they had seen or heard the campaign advertisements.

</td></tr>
<tr><td>Written information resources and promotional items</td><td>

Over 77,000 written information and promotional resources (posters, leaflets, infographics and badges) were distributed between October 2016 and October 2018.

</td></tr>
</table>

1.10 Study rationale

Dementia represents a growing public health concern in Ireland due predominantly to significant ageing of the population. Increasing public awareness and understanding of dementia has been identified as a top research (22) and policy priority (23, 24) to decrease the global burden of this disease e.g. through prevention and early diagnosis.

There has been very limited analysis of previous national or international efforts to raise awareness of, and combat the stigma associated with, dementia amongst the general public. In this context, this quantitative study was conducted to evaluate the impact of the Dementia Understand Together campaign on dementia knowledge and help-seeking intention amongst the general public in Ireland by comparing data from the 2016 and 2018 HSE Dementia Omnibus Baseline Survey Questionnaires. It is envisaged that the findings from this study can be used to better inform the ongoing campaign and the development of future education campaigns on dementia and other health conditions.

Chapter 2. Literature review

2.1 Literature search strategy

In order to inform the research process, a comprehensive literature search was performed on PubMed. Both Medical Subject Headings (MeSH) terms and key words (in title/abstract) relevant to the topic of interest were employed in the PubMed search (Appendix A). Multiple terms that describe the same or similar conditions were used in order to maximise the search output (e.g. Alzheimer Disease, cognitive impairment). A manual search of article references from the initial search was also conducted. A supplementary search was performed on Google Scholar. Relevant publications from the grey literature were also included. Search criteria were limited to those involving human subjects and publication in the English language from 2008 to 2018. Abstracts, conference proceedings, books, reports, and letters to editors were excluded from the literature review. Following this process 89 articles were included in the literature review.

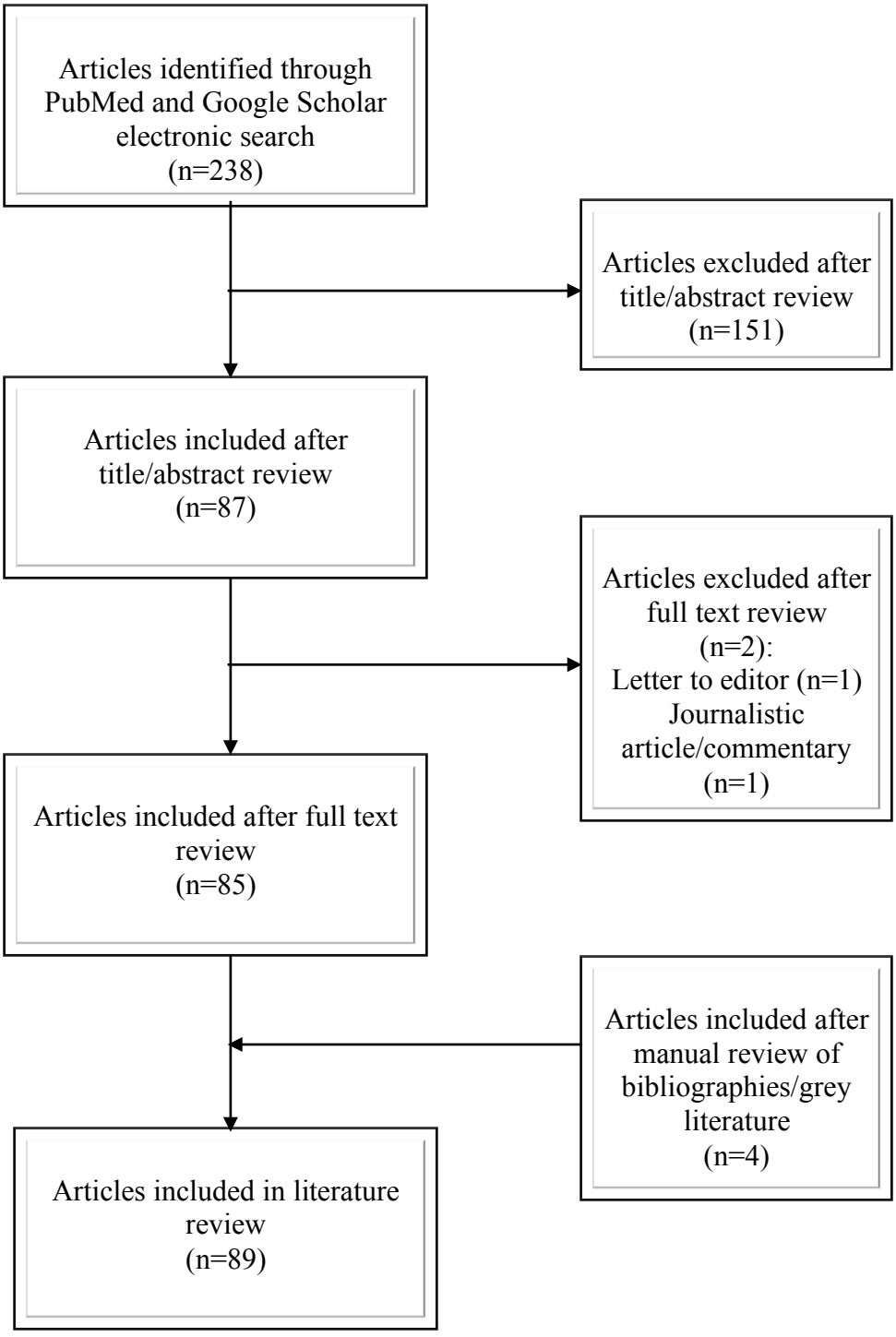

Figure 2.1: Flow chart of literature search

2.2 Knowledge of dementia

Knowledge of dementia broadly comprises awareness and understanding of the condition, its treatments and associated risk/aetiological factors.

A key systematic literature review of 40 international studies published over a 20-year period (25) reported an overall fair to moderate level of knowledge and understanding of dementia/Alzheimer's disease among the general public. However, almost half (n=19) of the studies reported poor to very limited knowledge levels. While knowledge of genetic risk factors was fair to good, awareness and understanding of modifiable risk factors was consistently poor. Conclusions drawn from the systematic review clearly illustrated two commonly identified misperceptions: that dementia is a part of the normal ageing process and that the risk of developing dementia is not modifiable.

A recently published United Kingdom (UK)-wide survey of over 2,300 adults conducted in 2018 on public perceptions of dementia found that only one-third (34%) believed it is possible to reduce the risk of dementia compared with 77% for cardiovascular disease and 81% for diabetes (26). In addition, one in two UK adults were not able to identify any known risk (e.g. hypertension) or protective factors (e.g. physical exercise) for dementia. More than half of the population (52%) reported that they knew someone with dementia.

Similar findings were seen in a recent Irish study which indicated that knowledge of dementia was low in the general public. The study by Glynn et al. (27) which utilised nationally-representative data from the 2016 HSE Dementia Omnibus survey questionnaire found that over half of the sample of 1,217 respondents knew someone living with dementia (52%). However, in keeping with international findings (25), knowledge of risk and protective factors was poor with only 39% reporting that they would be confident in distinguishing between the early signs of dementia and normal ageing. In addition, only 46% believed that there were measures they could take to decrease their risk of developing dementia. Although differences were noted in knowledge of risk and protective factors across different socio-demographic groups (for example, rural versus urban) and whether respondents knew or had known a person with dementia, even categories of participants with higher awareness showed substantial overall deficiency in knowledge of the condition.

2.3 Stigma and dementia

Evidence of stigma associated with dementia was reported in the 2015 British Social Attitudes survey which involved computer-assisted interviews of a nationally-representative sample of over 2000 adults aged 18 or older (28). More than a quarter of respondents (27%) agreed that they "would find it hard to talk to someone with dementia" while just over half of respondents (52%) believed that people with dementia can "enjoy life to the full". Over 6 in 10 respondents (62%) agreed that "people with dementia can often be violent and aggressive".

Research has indicated that there is a tendency for media to reinforce stigmatising attitudes associated with dementia. A qualitative study by Van Gorp and Vercruysse (2012) aimed to understand the dominant media imagery in relation to dementia (29). From this analysis a number of frames (the way in which the media and the public represent a topic) were developed to define dementia. These frames encompassed mainly negative themes such as the tendency to believe that people with dementia lose their identity and humanity. The study findings supported the view that dementia as a public health issue is worsened by the negative regard in which the disease is held by society. It also identified counter-frames which could potentially be used in health communication to oppose negative societal perspectives and stigmatisation by disseminating positive messages. These include the view that PLWD should be considered persons in their own right, regardless of their condition, and that there is time still left to live and moments to enjoy even after being diagnosed.

2.4 Help-seeking and dementia

Although it is recognised that timely diagnosis of dementia could offer considerable benefits for patients and their families, studies have repeatedly demonstrated delay in help-seeking, with a range of mean duration from symptom onset to seeking professional assessment of 12 months to 4 years (30-35). A number of key barriers to accessing specialist assessment have been identified in the literature including poor knowledge and stigma. Poor knowledge may manifest in the form of misattribution of dementia symptoms (particularly non-cognitive symptoms such as mood disturbance) to causes other than dementia such as depression or stress (36, 37). Normalisation of the early symptoms of dementia also plays a key role in delaying help-seeking, resulting in incorrect attribution of symptoms to a normal ageing process or personality type (31, 38, 39).

A number of markers for perceived stigma have been shown to act as barriers to help-seeking including shame and fear (40, 41). Similar perceived barriers to help-seeking have also been found to emerge in relation to other conditions such as eating disorders (42). The literature also revealed multiple barriers to accessing healthcare experienced by people with dementia from ethnic minority groups including poor knowledge and stigma (43-45). Such factors may be more prevalent in these communities and help explain why individuals from minority ethnic groups commonly present to healthcare services at an advanced stage of disease (46).

2.5 Public communication on dementia

There is evidence indicating that effective awareness campaigns are associated with higher knowledge of dementia. Recent research conducted in Singapore, a multiracial population, demonstrated a relatively high level of recognition of dementia in a survey of approximately 3,000 respondents (47). The survey employed a vignette approach to examine awareness of multiple mental health conditions including dementia, depression and schizophrenia. Of these conditions, dementia was the most highly recognised at 66% of participants. Singapore is currently experiencing a rapid growth in its older population and has recently conducted public education programmes on dementia. The researchers linked the high level of awareness in this study with the impact of measures that have been introduced nationally by the government including public education initiatives.

In addition, a longitudinal review of 1,075 patient referrals to a memory clinic in Singapore between 2009 and 2015 found that an increasing number of patients with less advanced dementia sought medical care as the study period progressed (48). Furthermore, the proportion of patients attending the clinic who were subsequently diagnosed with dementia decreased, while the proportion of those who did not have dementia increased. These findings further support the hypothesis that help-seeking for suspected dementia has risen in Singapore in recent years in conjunction with the implementation of multiple policies and programmes aimed at improving public awareness of the condition.

A longitudinal study conducted in Germany examined trends in referral to a memory clinic between 1985 and 2009 (49). Amongst the 3,951 study subjects it found a positive association between Mini Mental State Examination (MMSE) score (cognitive assessment tool) and year of first examination, indicating that patients were referred at an earlier stage of cognitive deterioration as the study period progressed. Of those patients who were subsequently diagnosed with dementia, a positive correlation was also found between their MMSE scores

and year of initial clinic examination. These findings suggest that increased public awareness over the three decades of the study period resulted in progressively earlier diagnostic assessment of patients as a result of improved help-seeking behaviour.

In order to build an effective awareness strategy, it is important to determine the type of information that is interesting and capable of addressing the needs of the public. A recent study examining YouTube as a platform for the communication of health information on Alzheimer's disease identified 271 relevant uploaded videos from 2013 to 2015 (50). It found that videos commonly focused on AD symptoms (83/271, 31%), AD causes (80/271, 30%), and treatment of the condition (76/271, 28%). Quality of life of PLWD was less frequently addressed (34/271, 13%) but generated more views than the more commonly addressed topics. Only 37% of videos (100/271) contained mobilising information (such as links to additional resources). These findings suggest that a gap potentially exists between the type of information disseminated and viewers' needs and interests.

Public communication on dementia may be delivered within broader community-based, collaborative models of dementia care. In California, poor awareness and stigmatisation of dementia has been reported in the ethnically-diverse Asian Pacific Islander (API) community. Due to cultural factors within API communities it is also frequently believed that caring for older persons is a familial responsibility and there has been a predisposition to avoid seeking help outside the immediate family. To address these issues health authorities, along with community and non-governmental partners, developed a collaborative dementia model over 20 years called the Dementia Care Network (51). In addition to key goals focused on needs assessment, capacity building and service development, the model also involved the implementation of a number of interventions to increase understanding of dementia and the importance of promoting earlier diagnosis. There was an emphasis on education about the caregiver role and the importance of help-seeking outside the family nucleus. Dementia care advocates were trained on providing presentations in various community settings. As a result of the community-building activities described, it was estimated that care advocates reached over 850,000 individuals and disseminated educational material to over 9,000 individuals (51).

2.6 Public communication on dementia and caregivers

There is considerable potential for the use of public communication to alleviate the burden experienced by caregivers of PLWD. Recently a qualitative study by Shanley et al. (2017) focused on improving understanding of how surrogate decision-makers for PLWD (primarily family carers) can be most appropriately supported in their role (52). The Australian study which employed semi-structured interviews of 34 surrogate decision-makers identified community knowledge of dementia and its impact as a primary theme. Specifically, the research found a number of key issues that were cited as important in regard to community awareness: knowledge about the incremental loss of capacity with dementia, the need for individuals in society to become surrogate decision-makers if a family member develops the condition, and that the disease is terminal with a generally predictable trajectory. With greater understanding in the community of such issues, it was felt that surrogate decision-makers would be better prepared to take on the role and engage in advanced care planning if needed.

In addition, lack of knowledge of dementia may impact on the burden of care experienced by family members of PLWD by contributing to increased levels of stigma. A mixed methods study in the United States (US) involving 82 participants by Kahn et al. (2016) highlighted the association between stigma and the burden of caring for a family relation with dementia or a memory disorder, particularly amongst female caregivers (53). The study found that stigma and care burden were positively correlated. Caregivers in the study identified public communication on dementia as a potential approach to reduce stigma.

2.7 Summary of literature review

There is substantial evidence of poor knowledge of dementia symptoms, treatments, and risk factors among the general public in Ireland and internationally. Common public misperceptions on dementia include the belief that it is part of the normal ageing process and that the risk of developing dementia is non-modifiable.

There is considerable evidence of stigmatisation of dementia in society with research also indicating that this is reinforced by the media. Although it has been acknowledged that early diagnosis of dementia may offer substantial benefits for patients and their families, studies have repeatedly shown that help-seeking can be delayed by up to four years. Key barriers to seeking professional assessment include poor knowledge and stigma. In relation to the former, normalisation and misattribution of the symptoms of dementia represent principal barriers to

help-seeking. Markers of perceived stigma, meanwhile, include shame and fear, and these also contribute to delay in help-seeking. These issues may be more prevalent in ethnic minority groups and may help explain why these groups are at particular risk of delay in help-seeking.

Higher knowledge of dementia at the population level has been associated with public awareness campaigns on this topic. Improved public knowledge may encourage help-seeking from healthcare services at an earlier stage. The literature also suggests that there may be a mismatch between the type of information on dementia that is disseminated and the needs of the public. Public education on dementia should be considered within the context of wider inter-organisational and collaborative dementia strategies which may also aim to address population needs assessment, capacity and healthcare service building. Public communication may also support dementia caregivers directly and indirectly by increasing community knowledge of dementia and reducing stigma.

Chapter 3. Aim and objectives

3.1 Aim

To evaluate the impact of a national communication campaign on dementia knowledge and help-seeking intention amongst the general public in Ireland.

3.2 Objectives

1. To assess the level of awareness of public communications on dementia, by examining data from nationally representative surveys of the general public in Ireland conducted in 2016 and 2018.

2. To investigate changes in levels of dementia knowledge and help-seeking intention, according to sociodemographic factors.

3. To evaluate the association of awareness of public communication on dementia with knowledge and help-seeking intention.

4. To use the results of this evaluation to inform the ongoing national communication campaign including the development of key messages for the community activation component of the campaign.

Chapter 4. Methodology

Two nationally representative surveys of the general public in Ireland on dementia have been conducted. The first survey was performed in 2016 to assess levels of awareness, knowledge and attitudes in relation to dementia and to utilise these findings to inform the initial phase of the Dementia Understand Together campaign. The second tracking survey was conducted in 2018 with a different study sample to assess for change in levels of awareness, knowledge, and attitudes in relation to dementia following the campaign outlined in Tables 1.1 and 1.2. The same methodological approach, as described below, was employed in both surveys. The questionnaires are included in Appendix B (2016) and Appendix C (2018).

4.1 Study population

The study population for the surveys was adults aged 16 years and older living in the community in Ireland.

4.2 Study samples

The study samples consisted of adults as defined in the study population who completed the HSE Dementia Omnibus Baseline Survey Questionnaire in 2016 and 2018. The dataset output from these surveys has been made fully accessible and available for the purposes of this study with permission granted for its use by the Campaign Steering Group. Participants were selected by quota sampling (weighted for sex, age, social class and marital status) with reference to the most recent Census (2011 and 2016 for the 2016 and 2018 surveys, respectively). In the 2016 survey, the subgroup of participants aged 60 years and older was supplemented by 217 resulting in a total of 1,217 adults completing the survey. This facilitated ascertainment of attitudinal and behavioural prediction accuracy in the Irish population with a precision of +/- 3%. Participants were interviewed face-to-face in January 2016 (first survey) and in January and February 2018 (tracking survey). Prior personal diagnosis of dementia was the only exclusion criterion applied.

4.3 Study design

This was an analytical study which used quantitative statistical analysis of the collated data (descriptive, univariable and multivariable logistic regression analysis). Comparative analyses employing 2016 and 2018 questionnaire data were utilised.

4.4 Study instrument

The study instrument was a survey questionnaire based on a number of other national and international surveys/questionnaires as listed below:

- Alzheimer Society of Ireland Surveys, 2008-2015
- Dementia Omnibus Baseline Survey Questionnaire, Northern Ireland, 2015
- Attitudes to and knowledge of dementia in Northern Ireland, 2010
- Alzheimer Australia Survey, 2012
- DK-20 questionnaire

The design of this survey was also influenced by input from members of the Campaign Steering Group and Campaign Reference Group.

The questionnaires collected data on:

- **Socio-demographic characteristics**: age, sex, social class, area (urban/rural) and region of residence, marital status, employment status and education (2018 survey only)
- **Experience of dementia:** personal experience of knowing someone with a diagnosis of dementia
- **Knowledge of dementia:** general knowledge of dementia, self-rated knowledge, knowledge of symptoms and signs of early dementia (2016 survey only), knowledge of dementia risk factors (2016 survey only) and the potential for their modification, confidence in their ability to distinguish between signs of dementia and normal ageing (2016 survey only).
- **Attitudes toward people living with dementia (and their carers) and help-seeking behaviour(s) when a potential diagnosis of dementia is suspected**

4.5 Research ethics approval

Research ethics approval to carry out this survey (and the analysis of the data acquired as described hereafter) was granted by the Chairman of the St. James' and Tallaght Hospital Ethics Committee (Appendix D).

4.6 Data collection

Interviews were conducted by trained interviewers, coordinated by Behaviour and Attitudes (B&A) Ltd. and KICK Communications, on behalf of the HSE. Sixty-three DEDs (district electoral division) in Ireland were randomly selected for the survey. A house number on a street address within the DEDs was identified at random. The interviewers then selected every fifth household to participate in the survey (utilising a zig-zagging approach in urban areas). Only one individual in each selected household was eligible to participate in the survey. If no individual in a particular residence matched the prescribed census-related quota, the interviewer progressed to the fifth next household. Persons from each subgroup of the general population (for example, men/women aged 60 years and older) were surveyed until the study quota was reached. Eligible participants were initially informed of the purpose of the survey. Those who had already been diagnosed with dementia were to be excluded (no person was excluded for this reason). Consistency and validity of data collection was ensured by the appropriate training of interviewers and the subsequent systematic approach to participant identification as described above.

4.7 Data analysis

The survey data were collected, collated, and cleaned by B&A Ltd. and provided to the HSE in Statistical Package for the Social Sciences (SPSS). Weightings were then applied to the datasets to match with the relevant census (2011 or 2016) by sex, age, region, urban/rural area, social class, and nationality. This weighting ensured that the subgroup distribution in the study sample conformed with that which exists in the population of Ireland. The HSE, with permission from the Campaign Steering Group, provided the datasets to the author.

The author then constructed electronic databases through transformation and coding of variables of interest. The demographic variables examined were sex, age, area of residence (rural/urban), social class and education (in the 2018 dataset only). Age was categorised into three groups (16-39 year, 40-59 years, and 60 years or older). Social class was also transformed into three categories: ABC1 (higher social classes), C2DE (lower social classes), and F (Farmers). Education status was transformed into: no formal education, primary school, secondary school (junior/leaving certificate), post-secondary school (Post-Leaving Certificate/diploma/professional qualification, and 3rd level degree. Sex (male and female) and area of residence (rural and urban) were transformed into appropriate categories. Finally, all variables were re-coded as appropriate to facilitate analysis.

The data were analysed utilising SPSS Version 20. Descriptive analysis was first conducted to describe frequency distribution across each variable. Chi-square analysis was then employed to examine for differences in responses between groups of individuals.

Finally, multivariable logistic regression was performed to examine the association between various sociodemographic factors (sex, age, area of residence, education and social class), prior experience of dementia* and the following outcome variables of interest:

- awareness of recent dementia advertising ("Yes", "No", "Don't know"),
- self-reported knowledge of dementia (scale: "nothing at all", "not very much", "some", "quite a lot", "a great deal"),
- recognition of potential benefit of early diagnosis (that it allows the person more of an opportunity to make decisions about their care) ("True", "False", "Don't know"),
- awareness that dementia risk is modifiable ("True", "False", "Don't know") and,
- help-seeking intention (if respondents were concerned they might have the signs of early dementia how likely would they be to delay seeking help for as long as possible: "extremely unlikely", "unlikely", "not sure", "likely", "extremely likely").

Multivariable analysis used 2018 survey data only. Level of significance for all group differences in this study was set at 5% ($p<0.05$).

* Respondent reported that they personally knew someone who has/had dementia

Chapter 5. Results

5.1 Descriptive analysis

The study samples consisted of 1,217 and 1,003 randomly selected adults resident in Ireland in 2016 and 2018, respectively. Gender split was balanced in both samples with 51% female. The weighted mean age was 43.9 years (range 16-95) in 2016, and 46.4 years (16-95) in 2018. More than half lived in an urban area in both samples. Further baseline descriptive statistics including actual numbers, percentages and distributions are detailed in Table 5.1 below.

Table 5.1 Baseline characteristics of participants in 2016 and 2018 dementia surveys

	2016 Survey			2018 Survey		
		Unweighted	Weighted		Unweighted	Weighted
Variables	**n**	**%**	**%**	**n**	**%**	**%**
Total participants	1217	100	100	1003	100	100
Gender						
Male	584	48.0	49.1	486	48.5	49.0
Female	633	52.0	50.9	517	51.5	51.0
Age (years)						
16-39	430	35.3	46.1	360	35.9	40.9
40-59	389	32.0	30.9	371	37.0	34.2
60+	398	32.7	23.0	272	27.1	24.9
Social class						
ABC1	550	45.2	41.0	482	48.1	41.8
C2DE	605	49.7	52.7	474	47.3	52.0
F	62	5.1	6.2	47	4.7	6.2
Area						
Urban	771	63.4	61.2	654	65.2	63.0
Rural	446	36.6	38.8	349	34.8	37.0
Dementia experience						
Yes, they know/knew someone who has/had dementia	693	56.9	52.1	462	46.1	43.6
No, they don't know/haven't known someone who has/had dementia	524	43.1	47.9	541	53.9	56.4
Employment status*	NA					
Employed				543	54.1	51.3
Unemployed				67	6.7	8.4
Other (e.g. retired, student)				393	39.2	40.4
Education level	NA					
No formal education				5	0.5	0.6
Primary school				66	6.6	6.9
Secondary school (junior/leaving cert)				546	54.4	55.9
Post-secondary school				246	24.5	22.7
3rd level degree (undergrad/postgrad)				140	14.0	14.0

NA=Not available; *Employed: full-time, part-time, self-employed; Other=home duties, retired, student

All further analysis in the remainder of this report was conducted using weighted data.

5.2 Awareness of recent advertising about dementia

A higher proportion of respondents reported that they were aware of recent advertising on dementia in 2018 (one in three) compared with 2016 (less than one in five). Substantially fewer reported that they were not aware of recent advertising on dementia in 2018 (52%) than in 2016 (76%). In addition, the percentage of respondents who did not know if they had seen/heard advertising about dementia increased from 7% (2016) to 16% (2018). This overall increase in awareness of recent dementia advertising between 2016 and 2018 was statistically significant (p-value <0.001) (Figure 5.1).

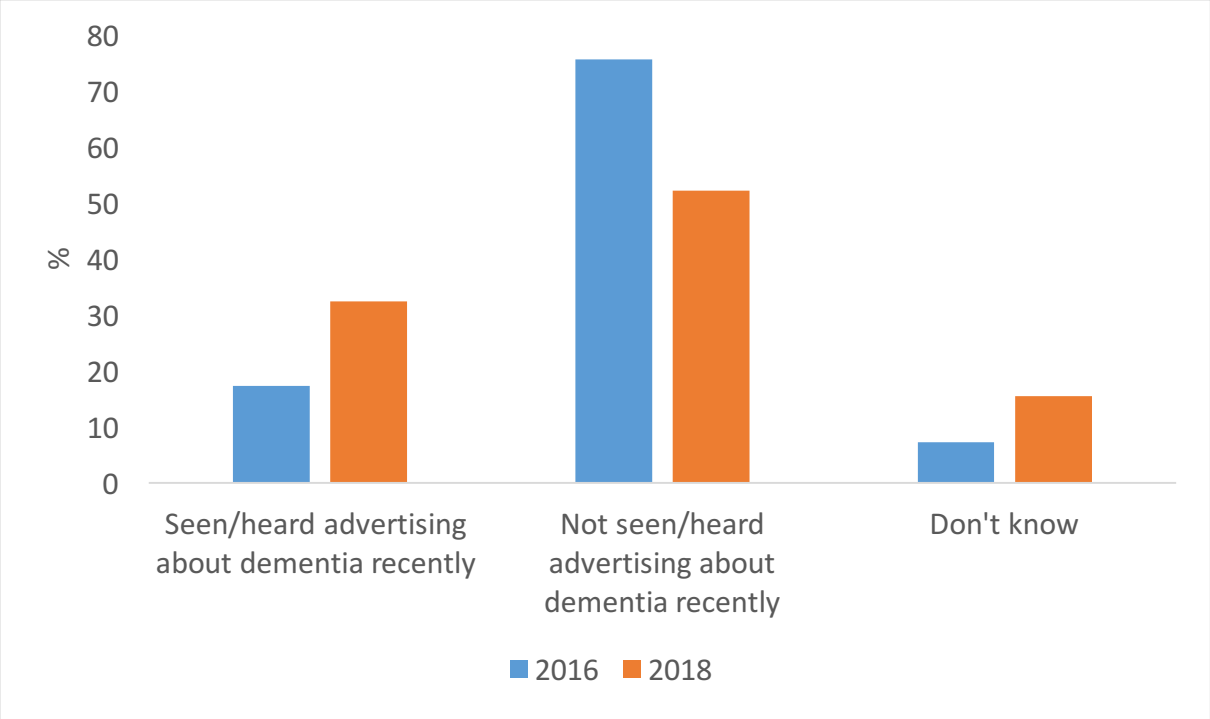

Figure 5.1 Awareness of recent advertising about dementia (%)

A large majority of respondents (87%) who were aware of recent advertising on dementia in 2018 had seen it on television (Table 5.2). This represents a substantial increase from just over one in two in 2016. In 2018, other modalities such as radio (6%), newspapers (2%), and online platforms (2%) were substantially less frequently reported.

Table 5.2 Media through which respondents saw/heard recent advertising about dementia (%)*

Media type	2016 (N= 1217)	2018 (N = 1003)
Television	53.0	87.0
Radio	17.1	5.6
Newspaper	10.7	1.5
Poster	2.8	1.2
Leaflet	5.6	0.5
Online	6.0	1.8
Other	2.5	0.7
Can't recall	2.3	1.6

*Some respondents reported exposure to the campaign through multiple modalities, included in the table but adjusted to total 100%

5.2.1 Awareness of recent advertising on dementia by sociodemographic factors

Awareness of recent advertising on dementia significantly increased in both men (13% change, p-value<0.001) and women (18% change, p-value<0.001) from 2016 to 2018 (Table 5.3). A higher proportion of females than males said they had seen/heard recent advertising on dementia, with the gap widening between 2016 and 2018 (6% and 8% difference between men and women in 2016 and 2018, respectively). There was also a doubling of awareness of recent advertising on dementia in those aged 60 years and older in 2018 (42%) compared with 2016 (19%) (p-value<0.001). There was a larger increase in awareness of recent advertising on dementia in those living in rural areas (21% change, p-value<0.001) than urban dwellers (12% change, p-value<0.001) between 2016 and 2018. There was also a doubling of awareness of recent advertising on dementia amongst the lower social classes (C2DE) between 2016 (15%) and 2018 (33%) (p-value<0.001), with a smaller increase seen in the higher social classes (ABC1) (p-value<0.001). In addition, awareness of dementia almost doubled between 2016 (24%) and 2018 (44%) amongst those with experience of someone with dementia (p-value<0.001). The percentage who did not know if they were aware of recent advertising on dementia increased across all subgroups between 2016 and 2018.

Table 5.3 Awareness of recent advertising on dementia by sociodemographic factors (%)

		Seen/heard recent advertising on dementia		Not seen/heard recent advertising on dementia		Don't know		p-value[a]
		2016	2018	2016	2018	2016	2018	
Gender	**Male**	14.4	26.9	78.2	57.8	7.4	15.3	**<0.001**
	Female	20.0	37.5	73.1	46.7	6.9	15.8	**<0.001**
Age Group	**16-39**	14.8	22.2	78.8	61.5	6.4	16.3	**<0.001**
	40-59	19.9	37.6	72.6	47.8	7.4	14.6	**<0.001**
	60+	18.9	42.0	72.6	42.4	8.5	15.6	**<0.001**
Area	**Urban**	17.2	28.9	77.4	56.1	5.4	15.0	**<0.001**
	Rural	17.5	38.3	72.3	45.3	10.1	16.4	**<0.001**
Social Class	**ABC1**	19.8	31.5	74.5	50.6	5.6	17.9	**<0.001**
	C2DE	14.8	33.0	78.3	54.1	6.9	12.9	**<0.001**
	F	22.1	32.8	57.1	45.3	20.8	21.9	0.292
Experience[b]	**Yes**	23.8	44.3	68.7	41.8	7.6	13.9	**<0.001**
	No	10.3	23.1	83.0	60.1	6.7	16.8	**<0.001**

[a]Pearson's Chi-square test; [b]Experience=Know/knew someone who has/had dementia

5.2.2 Sociodemographic factors associated with having recently seen/heard advertising on dementia (2018 data)

In 2018, on multivariable analysis, females were more likely than males to be aware of dementia advertising (adjusted OR 1.51, 95%CI 1.14-2.00, p-value=0.004) (Table 5.4). Those aged 40 to 59 years (adjusted OR 1.96, 95%CI 1.40-2.74, p-value<0.001) and older than 60 years (adjusted OR 2.18, 95%CI 1.47-3.22, p-value<0.001) were also more likely to be aware of dementia advertising when compared with respondents aged 16 to 39 years. Those living in rural areas had almost 1.5 higher odds (Adj OR 1.48, 95%CI 1.10-2.00, p-value=0.010) than those in urban areas of being aware of dementia advertising. Respondents who had previous experience of someone with dementia were twice as likely as those without previous experience of being aware of dementia advertising (Adj OR 2.06, 95%CI 1.55-2.75, p-value<0.001). There was no statistically significant difference in likelihood of being aware of advertising based on social class or level of education. The percentage of respondents who reported that they did not know if they had seen/heard recent dementia advertising increased across all sociodemographic subgroups except farmers.

Table 5.4 Association in 2018 between awareness of recent advertising on dementia and sociodemographic factors

		Seen/heard dementia advertising recently (%)	Unadjusted OR (95%CI)	p-value[a]	Adjusted OR (95%CI)[b]	p-value[c]
Total	**1003**					
Gender	**Male (ref)**	26.9				
	Female	37.5	1.63 (1.25-2.13)	**<0.001**	1.51 (1.14-2.00)	**0.004**
Age Group	**16-39 (ref)**	22.2				
	40-59	37.6	2.13 (1.55-2.93)	**<0.001**	1.96 (1.40-2.74)	**<0.001**
	60+	42.0	2.54 (1.81-3.59)	**<0.001**	2.18 (1.47-3.22)	**<0.001**
Area	**Urban (ref)**	28.9				
	Rural	38.4	1.53 (1.17-2.01)	**0.002**	1.48 (1.10-2.00)	**0.010**
Social Class	**ABC1 (ref)**	31.5				
	C2DE	33.0	1.07 (0.82-1.41)	0.617	1.04 (0.76-1.43)	0.787
	F	33.3	1.06 (0.60-1.87)	0.844	0.77 (0.41-1.47)	0.431
Education	**No formal (ref)**	40.0				
	Primary school	36.2	0.85 (0.14-4.97)	0.854	1.01 (0.16-6.26)	0.990
	Secondary school	31.2	0.68 (0.12-3.77)	0.659	1.15 (0.20-6.66)	0.879
	Third-level	33.4	0.75 (0.14-4.19)	0.747	1.47 (0.25-8.67)	0.668
Experience[d]	**No (ref)**	23.1				
	Yes	44.4	2.64 (2.01-3.46)	**<0.001**	2.06 (1.55-2.75)	**<0.001**

[a]Pearson's Chi-square test; [b]Multivariable model adjusted for sex, age, area, social class, education and experience of dementia; [c]Multivariable logistic regression p-value; [d]Experience=Know/knew someone who has/had dementia

5.3 Knowledge of dementia

5.3.1 Self-rated knowledge on conditions

Self-reported knowledge of dementia increased between 2016 and 2018. A higher proportion of respondents said that they knew a great deal or quite a lot about dementia and AD in 2018 (almost one in three) compared with 2016 (almost one in four) (p-value<0.001) (Table 5.5). Fewer respondents reported knowing very little about dementia in 2018 compared with 2016 for both dementia (5% change) (p-value<0.001) and AD (6% change) (p-value<0.001). Similar trends over the same time period were seen in relation to cancer and depression but tended to be of a smaller magnitude of change.

Table 5.5 Self-rated knowledge of conditions (%)

	Know a great deal or quite a lot		Some knowledge		Know not very much or nothing at all		p-value[a]
	2016	**2018**	**2016**	**2018**	**2016**	**2018**	
Cancer	42.1	46.7	38.6	38.6	19.3	14.8	**0.012**
Depression	34.7	40.8	42.4	38.9	22.9	20.4	**0.012**
AD	23.6	32.0	38.8	36.5	37.6	31.6	**<0.001**
Dementia	23.5	32.8	37.9	33.9	38.6	33.3	**<0.001**

[a]Pearson's Chi-Square test

5.3.2 Self-rated knowledge of dementia by sociodemographic factors

There were increases in the proportions reporting that they knew a great deal or quite a lot about dementia in almost all of the sociodemographic subgroups in 2018 compared with 2016 (Table 5.6). There were marked increases amongst those aged 60 years and older (20% change) (p-value<0.001), those living in urban areas (13% change) (p-value<0.001), those in the lower social classes (C2DE) (13% change) (p-value <0.001) and those with previous experience of someone with dementia (13% change) (p-value<0.001). Moreover, across all subgroups there were lower proportions reporting that they had little knowledge of dementia.

Table 5.6 Self-rated knowledge of dementia by sociodemographic factors (%)

		Know a great deal or quite a lot		Some knowledge		Know not very much or nothing at all		p-value[a]
		2016	**2018**	**2016**	**2018**	**2016**	**2018**	
Gender	**Male**	18.4	27.5	34.7	34.0	46.9	38.5	**<0.001**
	Female	28.5	37.9	41.0	33.8	30.5	28.3	**0.003**
Age Group	**16-39**	20.1	23.9	34.2	30.0	45.6	46.1	0.240
	40-59	28.7	35.8	38.0	39.0	33.2	25.3	**0.036**
	60+	23.2	43.0	45.0	33.3	31.8	23.7	**<0.001**
Area	**Urban**	21.4	34.7	41.1	32.6	37.5	32.8	**<0.001**
	Rural	26.9	29.7	32.8	35.9	40.3	34.3	0.211
Social Class	**ABC1**	28.0	34.1	38.8	35.8	33.2	30.1	0.133
	C2DE	20.4	33.1	37.3	31.8	42.3	35.1	**<0.001**
	F	21.3	20.6	36.0	38.1	42.7	41.3	0.968
Experience[b]	**Yes**	36.8	50.1	42.1	34.1	21.1	15.8	**<0.001**
	No	9.1	19.4	33.2	33.7	57.7	46.8	**<0.001**

[a]Pearson's Chi-square test; [b]Experience=Know/knew someone who has/had dementia

5.3.3 Self-rated knowledge of dementia by awareness of recent advertising about dementia

There was no change between 2016 and 2018 in levels of self-reported knowledge in those who said that they had recently seen/heard advertising about dementia (p-value=0.998) (Table 5.7). However, amongst those who had not recently seen/heard advertising about dementia a significantly higher proportion reported that they knew a great deal or quite a lot in 2018 (30%) than in 2016 (20%) (p-value<0.001). There was also a lower proportion who reported that they knew not very much or nothing at all in 2018 (36%) than in 2016 (41%) (p-value<0.001).

Table 5.7 Self-rated knowledge of dementia by awareness of recent advertising about dementia (%)

	Know a great deal or quite a lot		Some knowledge		Know not very much or nothing at all		p-value[a]
	2016	**2018**	**2016**	**2018**	**2016**	**2018**	
Seen/heard advertising about dementia recently	40.8	40.9	33.2	33.2	26.1	25.8	0.998
Not seen/heard advertising about dementia recently	20.0	29.9	39.3	33.7	40.7	36.4	**<0.001**
Don't know	19.3	25.6	34.1	35.9	46.6	38.5	0.384

[a]Pearson's Chi-Square test

5.3.3 Association in 2018 between awareness of recent advertising and knowledge of dementia, adjusted for sociodemographic factors

On univariable analysis there was a statistically significant association between awareness of recent advertising on dementia and reporting higher knowledge of dementia (know a great deal/quite a lot/have some knowledge) (OR 1.68, 95%CI 1.26-2.26, p-value<0.001) (Table 5.8). However, on multivariable analysis adjusted for sociodemographic factors (sex, age, area, social class, education) and previous experience of someone with dementia, there was no statistically significant association (p-value=0.785).

Table 5.8 Association in 2018 between awareness of recent advertising and knowledge of dementia

	Know a great deal/quite a lot/some about dementia	Unadjusted OR (95%CI)	p-value[a]	Adjusted OR (95%CI)[b]	p-value[c]
Not aware of advertising (ref)	63.0				
Aware of advertising	74.2	1.68 (1.26-2.26)	**0.001**	1.05 (0.75-1.46)	0.785

[a]univariable analysis p-value; [b]Multivariable model adjusted for sex, age, area, social class, education and experience of dementia; [c]Multivariable logistic regression p-value

5.4 Knowledge of dementia risk as modifiable

5.4.1 Knowledge of dementia risk as modifiable

A higher percentage of respondents in 2018 agreed that the risk of dementia is modifiable (52%) than in 2016 (46%) (p-value<0.001). This trend was reflected across the breakdown of sociodemographic factors (Table 5.9).

Table 5.9 Knowledge of dementia risk as modifiable, by sociodemographic factors

There are things you can do to reduce your risk of getting dementia (%)								
		True		False		Don't know		p-value[a]
		2016	2018	2016	2018	2016	2018	
Total		45.7	51.5	20.9	11.9	33.4	36.5	**<0.001**
Gender	**Male**	46.2	51.8	18.6	10.6	35.2	37.6	**0.001**
	Female	45.2	51.2	23.2	13.3	31.6	35.5	**<0.001**
Age Group	**16-39**	43.7	48.3	21.2	11.7	35.1	40.0	**<0.001**
	40-59	48.5	51.0	20.0	11.1	31.5	37.9	**0.003**
	60+	46.1	57.6	21.4	13.2	32.5	29.2	**0.011**
Area	**Urban**	44.6	50.4	21.7	12.5	33.7	37.1	**<0.001**
	Rural	47.6	53.4	19.7	11.1	32.8	35.6	**0.003**
Social Class	**ABC1**	48.1	53.3	20.6	12.4	31.3	34.2	**0.004**
	C2DE	43.3	48.8	21.2	12.7	35.5	38.6	**<0.001**
	F	50.0	62.9	21.1	1.6	28.9	35.5	**0.003**
Experience[b]	**Yes**	53.8	55.1	22.6	14.9	23.7	30.0	**0.003**
	No	37.0	48.8	19.0	9.5	43.9	41.7	**<0.001**

[a]Pearson's Chi-Square test; [b]Experience=Know/knew someone who has/had dementia

5.4.2 Knowledge of dementia risk as modifiable by awareness of recent advertising about dementia

Between 2016 and 2018 the proportion of respondents who agreed that dementia risk is modifiable increased in both those who were aware of recent advertising on dementia (from 54% to 55%) (p-value<0.001) and in those who were not aware (from 44% to 49%) (p-value<0.001) (Table 5.10).

Table 5.10 Knowledge of dementia risk as modifiable by awareness of recent advertising about dementia (%)

	True		False		Don't know		p-value[a]
	2016	**2018**	**2016**	**2018**	**2016**	**2018**	
Seen/heard advertising about dementia recently	53.6	54.9	27.0	13.3	19.4	31.8	**<0.001**
Not seen/heard advertising about dementia recently	44.0	48.9	19.4	11.9	36.7	39.3	**0.001**
Don't know if saw/heard advertising about dementia recently	44.8	53.5	23.0	9.0	32.2	37.4	**0.011**

[a]Pearson's Chi-Square test

However, on multivariable analysis, awareness of recent advertising about dementia was not statistically significantly associated with knowing that dementia risk is modifiable (p-value=0.460) (Table 5.11).

Table 5.11 Association in 2018 between awareness of recent advertising about dementia and knowledge of dementia risk as modifiable

	Knowledge of dementia risk as modifiable - True %	Unadjusted OR (95%CI)	p-value[a]	Adjusted OR (95%CI)[b]	p-value[c]
Not aware of advertising (ref)	49.9				
Aware of advertising	54.9	1.22 (0.94-1.60)	0.137	1.11 (0.84-1.47)	0.460

[a]Univariable analysis p-value; [b]Multivariable model adjusted for sex, age, area, social class, education and experience of dementia; [c]Multivariable logistic regression p-value

5.4 Knowledge of potential benefit of early diagnosis

5.4.1 Knowledge of potential benefit of early diagnosis by socioeconomic factors

Despite an overall increase in knowledge of dementia as previously detailed, a lower percentage of respondents agreed in 2018 (78%) than in 2016 (85%) that diagnosis at an early stage is good because it allows the person more of an opportunity to make decisions about their care (p-value<0.001) (Table 5.12). The proportion that did not know if diagnosis at an early stage is beneficial increased across all sociodemographic subgroups, but was particularly evident in men, those aged under 40, those who resided in an urban area, and those who had previous personal experience of someone with dementia.

There were lower levels of agreement with the statement that early diagnosis is beneficial in 2018 (87%) compared with 2016 (94%) in respondents who were aware of recent advertising on dementia. Agreement with this statement was also lower in those who were unaware of recent advertising on dementia (decreasing from 83% in 2016 to 75% in 2018).

Table 5.12 Diagnosis at an early stage is good because it allows the person more of an opportunity to make decisions about their care, by sociodemographic factors (%)

		True		False		Don't know		p-value[a]
		2016	**2018**	**2016**	**2018**	**2016**	**2018**	
Total		85.2	78.2	4.0	6.5	10.8	15.3	**<0.001**
Gender	**Male**	83.8	74.9	5.2	6.5	11.1	18.5	**<0.001**
	Female	86.6	81.6	2.7	6.3	10.6	12.1	**0.009**
Age Group	**16-39**	81.1	74.4	4.6	5.1	14.3	20.5	**0.031**
	40-59	88.8	81.6	3.7	7.6	7.4	10.8	**0.017**
	60+	88.6	80.0	2.9	7.2	8.6	12.8	**0.015**
Area	**Urban**	85.5	77.3	4.0	5.5	10.5	17.2	**<0.001**
	Rural	84.7	79.8	3.8	8.1	11.4	12.1	**0.025**
Social Class	**ABC1**	87.0	80.7	3.2	4.5	9.8	14.8	**0.032**
	C2DE	83.6	76.2	4.7	7.9	11.7	15.9	**0.005**
	F	86.8	79.4	3.9	6.3	9.2	14.3	0.498
Experience[b]	**Yes**	91.8	82.4	3.6	6.4	4.6	11.2	**<0.001**
	No	78.0	75.1	4.3	6.5	17.7	18.4	0.216

[a]Pearson's Chi-square test; [b]Experience=Know/knew someone who has/had dementia

5.4.2 Association in 2018 between awareness of recent advertising on dementia and holding a positive view of the potential benefit of early diagnosis (adjusted for sociodemographic factors)

Respondents who were aware of recent advertising about dementia were almost twice as likely (Adjusted OR 1.97, 95%CI 1.35-2.88, p-value<0.001) to have a positive view of the potential benefit of early diagnosis compared to those who were not aware (Table 5.13).

Table 5.13 Association in 2018 between awareness of recent advertising about dementia and positive view on potential benefit of early diagnosis

	Early diagnosis is good – True %	Unadjusted OR (95%CI)	p-value[a]	Adjusted OR (95%CI)[b]	p-value[c]
Not aware of advertising (ref)	74.2				
Aware of advertising	86.8	2.28 (1.59-3.28)	**<0.001**	1.97 (1.35-2.88)	**<0.001**

[a]Univariable analysis p-value; [b]Multivariable model adjusted for sex, age, area, social class, education and experience of dementia; [c]Multivariable logistic regression p-value

5.5 Help-seeking intention

The proportion of respondents that said they would be likely or extremely likely to delay seeking help if they suspected that they had dementia decreased slightly from 26% in 2016 to 24% in 2018 (p-value<0.001) (Table 5.14). This trend was reflected across most sociodemographic subgroups, except amongst those aged 16 to 39 years old (p-value<0.05) and those in the higher social classes (ABC1) (p-value=0.002) which significantly increased from 22% to 24% and from 21% to 24%, respectively.

Overall, the percentage that would be unlikely or extremely unlikely to delay help-seeking reduced over the same period from 56% to 51%. The percentage who were not sure if they would delay help-seeking if early dementia was suspected also increased from 18% (2016) to 26% (2018).

Table 5.14 Likelihood to delay seeking help if early dementia suspected (%)

		Likely/ extremely likely		Unlikely/ extremely unlikely		Not sure/not applicable		
		2016	**2018**	**2016**	**2018**	**2016**	**2018**	**p-value[a]**
Total		26.0	23.9	56.0	50.5	18.0	25.7	**<0.001**
Gender	**Male**	26.1	23.2	53.6	48.1	20.3	28.7	**0.005**
	Female	25.8	24.4	58.4	52.9	15.8	22.7	0.131
Age group	**16-39**	21.6	23.7	57.7	50.1	20.7	26.2	**<0.05**
	40-59	28.7	21.9	56.1	51.3	15.2	26.8	**<0.001**
	60+	31.1	26.5	52.9	50.2	16.1	23.3	0.097
Area	**Urban**	23.5	22.3	58.5	51.8	18.0	25.9	**0.002**
	Rural	29.8	26.7	52.2	48.2	18.0	25.1	**0.042**
Social class	**ABC1**	20.8	24.4	61.4	50.2	17.8	25.4	**0.002**
	C2DE	29.8	23.9	52.8	49.2	17.4	26.8	**<0.001**
	F	27.6	19.0	48.7	63.5	23.7	17.5	0.215
Experience[b]	**Yes**	24.6	25.9	60.4	53.3	15.0	20.8	**0.023**
	No	27.4	22.2	51.3	48.3	21.3	29.5	**0.004**

[a]Pearson's Chi-square test; [b]Experience=Know/knew someone who has/had dementia

5.5.1 Help-seeking intention, by awareness of recent advertising about dementia

The percentage of respondents who would be likely/extremely likely to delay help-seeking decreased in both those who were aware of recent dementia advertising (27% in 2016 to 25% in 2018) (p-value=0.685) and in those who were not aware (26% in 2016 to 24% in 2018) (p-value<0.001) (Table 5.15). Amongst those who were aware of recent advertising the percentage that would be unlikely/extremely unlikely to delay help-seeking did not change between 2016 and 2018. However, there was an 8% decrease in the proportion of those who would be unlikely/extremely unlikely to delay help-seeking amongst those who were not aware of recent dementia advertising between 2016 (56%) and 2018 (48%) (p-value< 0.001).

Table 5.15 Likelihood of delaying help-seeking for dementia, by awareness of recent advertising about dementia (%)

	Likely/extremely likely to delay help-seeking		Unlikely/extremely unlikely to delay help-seeking		Not sure/not applicable		
	2016	**2018**	**2016**	**2018**	**2016**	**2018**	**p-value[a]**
Seen/heard any advertising about dementia recently	27.0	24.7	60.2	60.2	12.8	15.1	0.685
Not seen/heard any advertising about dementia recently	26.0	23.9	56.0	47.7	18.0	28.4	**<0.001**
Don't know	22.7	21.8	46.6	39.7	30.7	38.5	0.449

[a]Pearson's Chi-Square test

5.5.2 Awareness of dementia advertising and likelihood of delaying help-seeking (2018 data)

On univariable analysis, there was a statistically significant association between being aware of recent advertising and being unlikely/extremely unlikely to delay help-seeking (OR 1.78. 95%CI 1.36-2.33, p-value<0.001) (Table 5.16). A statistically significant positive association was also present on multivariable analysis (OR 1.81, 95%CI 1.36-2.40, p-value<0,001).

Table 5.16 Association in 2018 between awareness of recent advertising about dementia and being unlikely to delay help-seeking

	Unlikely/extremely unlikely to delay help-seeking %	Unadjusted OR (95%CI)	p-value[a]	Adjusted OR (95%CI)[b]	p-value[c]
Not aware of advertising (ref)	45.9				
Aware of advertising	60.2	1.78 (1.36-2.33)	**<0.001**	1.81 (1.36-2.40)	**<0.001**

[a]Univariable analysis p-value; [b]Multivariable model adjusted for sex, age, area, social class, education and experience of dementia; [c]Multivariable logistic regression p-value

Chapter 6. Discussion

The aim of this study was to evaluate awareness of a national communication campaign on dementia and its association with knowledge and help-seeking intention amongst the general public in Ireland. The key findings were that awareness of recent dementia advertising, self-reported knowledge of dementia and knowledge of the modifiable nature of dementia risk increased since the launch of the Understand Together national communication campaign in 2016. On multivariable analysis of 2018 survey data there was also a statistically significant positive association between awareness of recent advertising on dementia and holding a positive view of the potential benefit of early diagnosis. In addition, there was a statistically significant positive correlation between awareness of advertising and being unlikely to delay help-seeking. The burden of dementia in Ireland is expected to increase exponentially over the coming decades in line with rapid ageing of the population (6). Elevating public awareness of dementia through mass media campaigns and other communication modalities has been recognised as a key priority to advance progress in dementia care, treatment and prevention (54). In Ireland, this priority action has been enshrined in the NDS (9) which seeks to increase public awareness of dementia in order to improve understanding of the condition across society, reduce stigma, and support the implementation of Healthy Ireland (55) by emphasising the associated modifiable lifestyle and cardiovascular risk factors. As part of the implementation of the NDS, Dementia Friendly Ireland developed and rolled out Dementia Understand Together, an ongoing national campaign to increase public awareness and understanding of dementia in Ireland.

This study has demonstrated that since the launch of the Understand Together campaign in October 2016 awareness of dementia advertising has increased from one in five respondents in 2016 to one in three in 2018. Fewer respondents reported that they were not aware of dementia advertising in 2018 (one in two) compared to 2016 (three in four). In addition, the percentage of respondents who did not know if they had recently seen/heard dementia advertising increased from 7% to 16%. It is likely that the overall increase in awareness of dementia advertising was due to the impact of the Understand Together as no other national communication campaign was conducted during this time period. The large majority of respondents reported becoming aware of the campaign through TV advertisement. Despite the overall increase in awareness of public communication on dementia, analysis of the 2018 survey data indicated that certain subgroups were more difficult to reach including men, those aged less than 40, those living in urban areas and those who have no previous experience of

someone with dementia. Although dementia predominantly occurs in older individuals it is important that communication engages younger people as well. Younger family members and friends of people with early dementia are well placed to notice the symptoms and signs and may encourage help-seeking. They may also act as caregivers to family members living with dementia.

Thus, the impact of the campaign may be strengthened by focusing resources towards better engaging these "harder to reach" groups. This might include increased employment of different types of messaging strategies or communication modalities. For example, targeted social media communication may be better able to reach younger individuals or those living in rural areas than more traditional communication modalities such as printed media, television and radio. Social media has been increasingly used in public health and there is evidence that it can effectively target certain sociodemographic subgroups (e.g. age group or area of residence) (56). Using more personal stories involving younger people living with dementia or as caregivers may be another strategy to engage the interest of this group as such content may appear more relevant to them. Running a larger proportion of television advertisements during periods when younger or male viewers might be watching may also increase exposure in these subgroups. The community activation component of the campaign is also well placed to reach subgroups such as men or those living in rural areas. This arm of the campaign could increase engagement with men in Ireland by encouraging male members of the community to take on Champion roles (e.g. members of male organisations such as Men's Shed). A similar strategy could be used to focus on developing Champions amongst young people.

Mirroring the upward trend in awareness of dementia advertising, self-reported knowledge of dementia has also increased with almost one in three respondents reporting they knew a great deal or quite a lot about dementia in 2018 compared with just one in four in 2016. Moreover, fewer respondents reported having poor knowledge (not very much/nothing at all) in 2018 (one in three) compared to 2016 (two in five). Although there were broad increases in self-reported knowledge of dementia across the sociodemographic subgroups, there were marked improvements in those aged 60 years and older, those living in urban areas and those in the lower social classes. The campaign focused on promoting awareness amongst middle-aged and older age groups. It is therefore positive to see substantial increases in self-reported knowledge in those aged 40 and older. Improved knowledge amongst those aged 60 years and older is particularly notable as this is the age group that is most susceptible to developing dementia. Higher knowledge in this age group may have a positive impact on help-seeking by

increasing awareness of symptoms and promoting the benefits of early diagnosis. Positive messaging from the campaign, for example, that individuals may continue to live fulfilled lives following a diagnosis of dementia, may help to mitigate specific barriers to help-seeking such as fear and stigma. There was no significant change in knowledge amongst those aged less than 40. Although this age group is substantially less likely to be directly affected by dementia they can still play an important role as caregivers and in making communities more dementia-friendly by contributing to reduced stigma and the promotion of social inclusivity. As such, the campaign may have a greater impact by adjusting the emphasis to also target this age group.

Globally, there is substantial international evidence of poor awareness and knowledge of dementia in populations (25). This gap must be addressed through interventions such as mass communication strategies in order to increase understanding of the condition and to mitigate negative consequences such as stigma, social isolation and delayed diagnosis. Recently published research in Singapore has indicated that higher knowledge of dementia and increased likelihood to seek help earlier may be due to the impact of public education efforts (47, 48). In this study however, despite finding an increase in both knowledge and advertising awareness between 2016 and 2018, there was no statistically significant association between respondents being aware of advertising and having higher knowledge of dementia (knowing a great deal or quite a lot) when controlling for sociodemographic factors and previous experience of someone with dementia.

There are a number of possible explanations for this apparent lack of association. Firstly, there may an unrecognised impact of advertising in which awareness increased without respondents recalling actual exposure to the campaign. There is evidence from marketing research which indicates exposure to web advertising causes individuals to experience priming due to implicit memory, and to develop a more favourable attitude toward the advertising brand (or, health topic in this instance) regardless of the level of attention that was given to the advertisements (57). Secondly, knowledge of dementia may have improved as a consequence of other means such as education initiatives from dementia support organisations (which may be directly or indirectly linked to Understand Together partner organisation alliance) or the impact of high-profile individuals (such as professional sportspeople or entertainers) promoting awareness. Finally, it is not possible to exclude secondary impact from Understand Together raising societal consciousness on the importance of dementia, resulting in increased media coverage of the condition and those living with it.

The current absence of any effective disease-modifying therapies for dementia has lent further importance to disease prevention through population-level risk reduction. Lifestyle and vascular risk factors related to dementia and AD include hypertension, smoking, obesity, inadequate physical activity and diabetes mellitus (11). Substantial expert opinion and epidemiological evidence supporting the prevention and management of these risk factors is well-established (12). Recognition within the population that dementia risk can be reduced is therefore critical to engaging individuals in targeted risk reduction strategies including behavioural interventions. Despite the substantial evidence available supporting the potential for preventing dementia, international research has clearly demonstrated that there is a commonly held misperception in populations that the risk of developing dementia is not modifiable (25).

The importance of dementia prevention has been recognised in the Understand Together campaign and delivered through the key message: "keep your brain healthy at every age". This study found that overall awareness in the population in Ireland that dementia risk is modifiable has increased since the launch of the campaign in 2016. This increase was reflected both in those who were aware of recent advertising and in those who were unaware. However, multivariable analysis did not demonstrate any significant association between awareness of advertising and knowing that dementia risk is modifiable. This appears to indicate that the campaign has not significantly impacted on this area of knowledge. This may be due to differential emphasis in the campaign on other areas of knowledge and attitudes such as the promotion of overall awareness of dementia in society, help-seeking, and community acceptance and engagement with PLWD. Although there has been an increase in knowledge of the modifiable nature of dementia risk in Ireland, of concern, almost half of respondents in 2018 either thought that dementia risk was not modifiable or did not know the answer. This gap in knowledge highlights an area that needs to be addressed if effective prevention of modifiable risk factors is to be improved. Increased focus on promoting awareness of the modifiable nature of dementia risk in the ongoing Understand Together campaign, in particular within the community activation component, may be warranted in order to institute improved awareness in the population and subsequent behavioural change.

Timely diagnosis may confer a number of benefits for patients with dementia and their families including early commencement of treatment to control symptoms, avoidance of medication that might worsen the condition, and potentially, in the future, commencement of

treatment that might effectively slow or reverse disease progression (13). One of the key barriers to early diagnosis is lack of knowledge amongst the public on the potential benefits. This study found that fewer respondents agreed that early diagnosis was beneficial in 2018 (78%) than in 2016 (85%). The reasons for this unexpected finding are unclear. Despite an overall decrease in the proportion of respondents that believed early diagnosis is beneficial, a large majority still recognised its importance. In addition, multivariable analysis revealed a statistically significant association between being aware of recent advertising on dementia and holding a positive view on the potential benefit of early diagnosis. This suggests that Understand Together has had a positive impact on the view of early diagnosis of dementia among some groups in the population.

Promoting help-seeking for dementia presents a substantial public health challenge, especially as timely diagnosis may result in better outcomes for patients, their caregivers, and wider society (58). No clear trend emerged on likelihood to delay help-seeking over the study period, with the proportions of those who were likely/extremely likely and those who were unlikely/extremely unlikely to delay seeking help both decreasing between 2016 and 2018. However, the multivariable analysis indicated that there was a significant positive association between being aware of recent advertising and being unlikely to delay help-seeking when controlling for sociodemographic factors and previous experience of dementia. This significant linear correlation indicates that the Understand Together campaign has effectively promoted the importance of help-seeking when dementia is suspected.

Despite increased knowledge about dementia, there was also evidence of ambivalence about early diagnosis and help-seeking in some population subgroups, with increases in those who were unsure of benefits or of help-seeking intentions. This ambivalence may be promoted by perceived barriers to help-seeking. Evidence from a recent qualitative study by Devoy et al. (2017) on help-seeking intentions for early dementia in Irish adults indicated that barriers to help-seeking included poor knowledge, fear, loss, stigma and inadequate access to services (41). Such barriers may be mitigated through the encouragement of facilitators of help-seeking which included family, friends, and well-informed health professionals.

Study strengths

The strengths of this study include its use of large nationally-representative samples. The weighting of data by census breakdown allowed for increased accuracy in descriptive analysis and estimates of association between variables of interest. The study design also facilitated the collection of data at single points in time with relative ease and the analysis of multiple factors (exposures and outcomes) potentially influencing areas of interest in the study topic. Descriptive analysis and hypothesis testing around the subject of interest were also performed generating increased knowledge on the research topic.

Study weaknesses

Weaknesses included that, while the sample aimed to mirror the age and sex structure of the population, it was not possible to estimate a response rate and there was potential for self-selection bias through non-response at the sample selection stage. It is also acknowledged that it was not possible to establish temporality, causality or disease (or other health exposure or event) incidence using this study design. It may also be difficult to fully rely on the accuracy of self-reported knowledge of dementia. However, the questions on modifiable risk and the benefits of early diagnosis partially mitigate this issue by assessing objective knowledge of dementia on a broad level. It was not possible to further investigate trends in awareness of specific risk factors or other areas of knowledge as no additional questions on this subject were included in the 2018 survey.

Despite these limitations, this study has helped evaluate the impact the Understand Together campaign and its association with knowledge and help-seeking intentions amongst the general public in Ireland. That notwithstanding, key deficits in the public's knowledge of dementia remain and present considerable implications for public health.

Chapter 7. Implications for public health

The already substantial burden of dementia in Ireland is set to increase exponentially in the coming decades. In order to address this epidemic a comprehensive public health approach must be employed. This approach is enshrined in the NDS which aims to improve dementia care in Ireland so that individuals with dementia can live well for as long as possible, can die in comfort and dignity, and can have the best services and supports (9). The NDS sets out to achieve this through key priority actions including the promotion of better public awareness and understanding of dementia, as well as timely diagnosis and intervention.

The national communication campaign, Understand Together, was developed with the action areas of the NDS in mind. The findings from this study indicated that the campaign has positively contributed to the NDS objectives by increasing public awareness and knowledge of the modifiable nature of dementia risk in Ireland since its launch in 2016. However, a substantial proportion of the population still reported having no or little knowledge of dementia. In the current absence of any effective curative therapies, prevention efforts must be considered a public health priority. Findings from this study showed that awareness in the population that dementia risk is preventable has increased since 2016 but that there was no significant association with awareness of the campaign. Although it was not possible to demonstrate a link with the campaign, the upward trend in awareness of the modifiable risk of dementia is particularly welcome. It is important that this improved knowledge at a population level is harnessed in order to support individuals in communities across the country to engage in activities that promote brain health, including adequate physical activity, healthy eating and smoking cessation.

There is good evidence that management of hypertension decreases the incidence of dementia (59). A number of other interventions are also likely to have a beneficial impact on cognition including early life education, physical activity, social engagement, smoking cessation or reduction, diabetes management and hearing impairment treatment. Public Health must continue to play a substantial role in developing and implementing interventions to support the modification of these risk factors. Public Health must continue to support key national public health initiatives such as Healthy Ireland (55) and the National Physical Activity plan (60) which have set out actionable measures that can successfully promote brain health if they are effectively implemented.

Early diagnosis may provide a number of benefits including the opportunity for secondary prevention of vascular dementia and advanced care planning. Recognition of these potential benefits remains a particular challenge, with this study indicating that the proportion of the public who agree that early diagnosis is beneficial has decreased since 2016 despite the ongoing national communication campaign. It is therefore clear that further work is needed to address this gap. Although no clear trend emerged in this study with regard to likelihood to delay help-seeking in the population in Ireland this research showed that there was a positive correlation between awareness of the campaign and being unlikely to delay help-seeking. This indicates that there is substantial scope for encouraging positive change in the population by highlighting the potential benefits of early diagnosis and the importance of seeking help if early dementia is suspected. The campaign is well placed to achieve this during the remaining period of funding for media advertisement, and in particular, through the community activation phase. Its legacy work with a large network of over 30 public, private and voluntary partners must also be leveraged to promote positive changes in society in relation to help-seeking and other key messages even after the campaign concludes.

Chapter 8. Conclusions and recommendations

8.1 Conclusions

This report evaluated the impact of a large national public awareness campaign on dementia knowledge and help-seeking intention amongst the general public in Ireland. Findings from this study indicated that awareness of dementia advertising, self-reported knowledge of dementia and awareness of the preventable nature of dementia risk have increased since the launch of the campaign in 2016. In addition, there was a positive association between awareness of the campaign and both help-seeking and holding a positive view of the potential benefit of timely diagnosis.

The ever increasing and complex burden of dementia in Ireland highlights the importance of taking a whole of society, collaborative and multi-faceted approach to effectively promote and develop dementia friendly communities nationwide. Increasing knowledge and improving attitudes through effective public communication and education are key to reducing stigma, ameliorating inclusivity, promoting brain health and encouraging early diagnosis. Close collaboration with key stakeholders including public, voluntary, and private organisations that are invested in addressing the burden of dementia is essential to creating and nourishing a dementia friendly society that appropriately supports people with dementia and their families.

8.2 Recommendations

1. The theme of the Understand Together campaign was chosen to reduce stigma and encourage support for PLWD and their carers. Given the evidence of increased knowledge, the campaign should employ messaging (e.g. content specifically relevant to young people and men), forums (e.g. social media platforms, community youth groups, male community and health organisations), and community Champions that may better reach and impact on men and young people.

2. The Understand Together campaign should focus on increasing awareness of the modifiable nature of dementia risk. Appropriate information on specific modifiable risk and protective factors should be effectively communicated to the public.

3. Public Health Medicine, in partnership with relevant clinical specialties and stakeholders, should advocate for further funding to be made available for ongoing national monitoring of, and communication on, awareness, attitudes, and behaviours in relation to dementia.

4. There should be increased emphasis through media advertisement and community activation on key messages that promote the benefits of early diagnosis and help-seeking.

5. A comprehensive evaluation should be conducted on completion of the campaign. Such an evaluation should include appropriate quantitative and qualitative methodologies. Specifically, qualitative research may be able to examine more deeply the apparent disconnect between overall increased knowledge of dementia and ambivalence about help-seeking and the potential benefits of early diagnosis. The evaluation should also include an economic assessment of the impact of the campaign. Learning from the evaluation, along with the findings from this study, should be used to inform the development of future health communication campaigns.

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Appendices

Appendix A: PubMed search

((dementia[MeSH Terms] OR "cognitive health"[tiab] OR "alzheimer disease"[MeSH Terms] OR "mild cognitive impairment"[MeSH Terms] OR "dementia"[tiab] OR "Alzheimer Disease"[tiab] OR "Alzheimers Disease"[tiab] OR "Cognitive Impairment"[tiab] OR "Alzheimers"[tiab] OR "Alzheimer's"[tiab])) AND ((((("Health communication"[MeSH Terms] OR "Information dissemination"[MeSH Terms] OR "Community awareness"[tiab] OR "Community knowledge"[tiab] OR "Community education"[tiab] OR "Public awareness"[tiab] OR "Public knowledge"[tiab] OR "Public's knowledge"[tiab] OR "Public communication"[tiab] OR "Public education"[tiab] OR "Mass media"[tiab] OR "media awareness"[tiab] OR "social media"[tiab] OR "communication campaign"[tiab] OR "information campaign"[tiab] OR "education campaign"[tiab]))) OR ((("help seeking"[tiab]) OR "care seeking"[tiab]))))

Appendix B: HSE Dementia Omnibus Baseline Survey Questionnaire 2016

HSE Dementia Omnibus Baseline Survey Questionnaire

Hello. My name is ….from Behaviour & Attitudes. We are carrying out a survey across Ireland about people's understanding of dementia. This is an important national benchmark survey and I am wondering if you have about 10-15 minutes to answer some questions please. Everything you say to me is in total confidence. We will only be interrogating the data in aggregate form and no single individuals are ever identified.

SCREENER: Before I begin, I should say that we are only interviewing people who have not been diagnosed with either dementia or Alzheimer's disease. I am sure you can understand that anyone with such a diagnosis is likely to be better informed than the general public and our task today is to understand how well informed or not, the general public is on this subject matter. You may of course know someone or be caring for someone with dementia, and in those circumstances, we can still continue with the interview.

Can I therefore confirm that you have not been diagnosed with dementia or Alzheimer's disease?

Yes I have	THANK AND CLOSE
No, I have not	CONTINUE IF WILLING TO PARTICIPATE

SECTION 1 – KNOWLEDGE OF DEMENTIA

Q1. On a scale of 1-5, how much do you feel you know about each of the following conditions? 5 means you feel you know a great deal and 1 means you know little or nothing.

READ OUT AND ROTATE	A great deal	Quite a lot	Some	Not very much	Nothing at all
	5	4	3	2	1
Asthma					
Cancer					
Dementia					
Depression					
Diabetes					
Parkinson's disease					
Alzheimer's disease					

INTERVIEWER READ OUT: I am now going to ask you some questions mainly about dementia but which may include some questions about Alzheimer's disease. Alzheimer's disease is a type of dementia.

Q.2 What thoughts or ideas immediately spring to mind when you hear the word dementia? List as many as possible.

FIRST MENTION

ALL OTHER MENTIONS

Q. 3 There are many ways in which people might learn about dementia. I am going to read out a number of possible sources of information. For each one, can you nominate how much you have learned, if anything, about dementia from each of these sources?					
INTERVIEWER: READ OUT AND PROBE TO PRECODES **SCRIPTER: ROTATE ORDER OF PRESENTATION OF THESE STATEMENTS**	**Learned a lot**	**Learnt some**	**Not sure**	**Didn't learn much**	**Learnt nothing**
Personal experience (knowing or caring for someone who has been diagnosed with dementia)					
Media (e.g. newspapers, television, radio, film advertising campaigns, books or magazines)					
Word of mouth (e.g. through a friend, colleague or acquaintance)					
Professional(s) (e.g. doctor, GP, nurse, social worker)					
My job, which involves / involved working with people who have dementia					
Dementia Friends/ Dementia Champions training					
Phone helpline					
Internet (including social media and sites like twitter, facebook and youtube)					
Voluntary organisation or charity					
None of these					
Other (specify)					

Q.4 On a scale of 1-5, how confident are you that you could tell the difference between the symptoms of early dementia and the normal signs of ageing? Interviewer: PROBE TO PRECODES

Very confident	Fairly confident	Neither confident nor unconfident	Not very confident	Not confident at all	Don't know/ not sure	Refused

SECTION 2 – SIGNS AND SYMPTOMS

Q.5 What sort of symptoms or behaviour would make you suspect someone you knew was in the early stages of dementia? Please mention as many as you can think of.

Interviewer - Prompt with 'anything else' until the respondent cannot think of any more signs.
If the person says they do not know any, prompt with 'are you sure?' and if necessary 'take a minute to think about it'.
Type in all of the warning signs and symptoms that the person mentions exactly as they say it.
COLLECT FIRST MENTION AND ALL OTHER MENTIONS SEPARATELY.
FIRST MENTION

ALL OTHER MENTIONS

Q6. The following signs and symptoms may or may not be an indicator of early stage dementia. As I read out each to you, can you tell me whether you believe this symptom to be true, not true or whether you simply don't know whether it is a sign of early stage dementia or not.

READ OUT EACH AND PROBE TO PRECODES	True	False	Don't know
ROTATE ORDER OF PRESENTATION			
Memory loss, particularly for recent events			
Difficulty in performing everyday tasks			
Misplacing things regularly			
Changes in personality			
Feelings of disorientation in what should be familiar surroundings			
Changes in mood and behaviour			
Poor or decreased judgement			
Fear of contamination or dirt			
Problems with language			
Loss of interest in starting projects or doing things			

Q 7 Could you tell me whether you believe the following statements to be true or false?

READ OUT AND PROBE TO PRECODES. SCRIPTER ROTATE ORDER OF PRESENTATION.	True	False	Don't Know
The number of people living with dementia in Ireland is expected to more than double by 2040			
Dementia is a disease of the brain			
Getting diagnosed at an early stage is good because it allows the person more of an opportunity to make decisions about their care			
There are many different kinds of dementia			
Dementia is a normal part of getting old			
For someone with dementia, their condition gets worse over time			
Dementia is a mental illness			
Only old people get dementia			
Dementia can be cured			
There are things you can do to reduce your risk of getting dementia			
Dementia is a form of disability			
People younger than 65 years of age do not get dementia			

SECTION 3 - HELP-SEEKING BEHAVIOUR

Q.8. If you felt that you were becoming more forgetful and were concerned it might be the signs of early dementia, how likely or unlikely is it that you would seek help or advice from any of the following people

READ OUT AND PROBE TO PRE-CODES	Extremely Unlikely	Unlikely	Not sure	Likely	Extremely Likely	Not applicable
SCRIPTER: ROTATE ORDER OF						

PRESENTATION						
Partner(e.g. husband, wife, significant other)	1	2	3	4	5	6
Friend (not related)						
Parent						
Other relative/family member						
Counsellor, Psychologist or Psychiatrist						
Phone help line						
Doctor /GP						
Voluntary organisation or charity						
Online chat room or online forum						
I would not seek help from anyone						
I would delay seeking help for as long as possible						

If there are others from whom you would seek help, could you tell me who they would be and I will note them here.

Q.9 If you felt that YOUR PARTNER or close FAMILY MEMBER was showing signs of early dementia, how likely or unlikely is it that you would seek help or advice ON THEIR BEHALF from any of the following people:

SCRIPTER: ROTATE ORDER OF PRESENTATION	Extremely Unlikely	Unlikely	Not sure	Likely	Extremely Likely	Not applicable
Partner(e.g. husband, wife, significant other)	1	2	3	4	5	6
Friend (not related)						
Parent						

Other relative/family member

Counsellor, Psychologist or Psychiatrist

Phone help line

Doctor /GP

Voluntary organisation or charity

Online chat room or online forum

I would not seek help from anyone

I would delay seeking help for as long as possible

SCRIPTER: ALWAYS LAST. If there are others from whom you would seek help for your partner or close family member, could you tell me who they would be and I will note them here.

Q10 INTERVIEWER NOTE: THIS IS A SENSITIVE QUESTION. PLEASE TREAT CAREFULLY. The next question is about seeking help. If you had a symptom that you thought might be a sign of dementia how soon would you contact your doctor to make an appointment to discuss it? SINGLE CODE

Straight away (Within a month)	Within 3 months	Within 6 months	Longer than 6 months	I would not contact my GP

SECTION 4 – BARRIERS SEEKING BEHAVIOUR

Q.11 The next set of questions is about what barriers may stop people from seeking help. Sometimes people put off going to see the doctor, even when they have a symptom that they think may be serious. I am going to read out to you a number of barriers. For each one, could you tell me if this might put you off going to your doctor if you thought you might have early dementia?

INTERVIEWER: READ OUT EACH AND PROBE TO PRECODES	Yes	Maybe	No	Don't know

SCRIPTER: ROTATE ORDER OF PRESENTATION.

I would be too embarrassed

I would be too scared

I would be worried about wasting the doctor's

time

I wouldn't want to know

My doctor would be difficult to talk to

It would be difficult to make an appointment

with my doctor

I would be too busy to make time to go to the doctor

I have too many other things to worry about

It would be difficult for me to arrange

transport to the doctor's surgery

I wouldn't feel confident talking about my

symptom(s) with the doctor

I wouldn't bother going because there would be nothing the doctor could do for me even if I did have dementia

SCRIPTER: ALWAYS LAST Are there any other barriers that we have not thought of that you think would hold people back? **Interviewer – TYPE IN any other barriers the respondent mentions exactly as they say it**

SECTION 5 - KNOWLEDGE OF RISK FACTORS

Q.12 The next set of questions is about the possible risk factors for developing dementia. Can you think of anything which could affect a person's risk of developing dementia?

Interviewer - prompt with 'anything else' until the respondent cannot think of any more signs. If the person says they do not know any, prompt with 'are you sure?' and if necessary 'take a minute to think about it'. TYPE IN all of the risk factors that the person mentions exactly as they say it.

COLLECT FIRST MENTION AND ALL OTHER MENTIONS SEPARATELY.

FIRST MENTION

ALL OTHER MENTIONS

Q.13 I am now going to read out some statements about risk factors. Can you tell me to what extent you agree or disagree with each?

SCRIPTER: ROTATE ORDER **INTERVIEWER: READ OUT PROBE TO PRECODES**	Strongly disagree	Disagree	Not sure	Agree	Strongly agree	Don't know
High blood pressure increases your chance of getting dementia						
If one of your parents gets dementia, you are more likely to get it too						
Smoking has no effect on your chances of getting dementia						
If you live in a city you are more likely to get dementia						
If you eat a healthy diet you are less likely to get dementia						
People who drink heavily are more likely to get dementia						
You are more likely to get dementia as you get older						
If you take no physical exercise you are more likely to get dementia						
There's nothing you can do to reduce your chance of getting dementia						

SECTION 6 - PERCEPTIONS ABOUT DEMENTIA

Q.14 I am now going to read out some things that people have said about people who have dementia. To what extent do you agree or disagree with each. Please be honest. There are no right or wrong answers here. We are simply interested in what people think and feel.

SCRIPTER: ROTATE ORDER **INTERVIEWER: READ OUT PROBE TO**	**Agree Strongly**	**Agree**	**Neither Agree nor**	**Disagree**	**Strongly Disagree**

PRECODES	Disagree
Complex and interesting conversations cannot be expected from most people with dementia	
People with dementia are respected for their wisdom	
Most people with dementia would be considered to have poor personal hygiene	
Most people with dementia can be irritating because they tell the same stories over and over again	
People with dementia mostly live independently	
People with dementia don't really need to use our community facilities	
It is best that people with dementia live where they won't bother anyone	
The company of most people with dementia is quite enjoyable	
I would try and avoid eye contact with someone if I thought they had dementia	
People with dementia pass on valued traditions	
I don't like when people with dementia try to make conversation with me	
I personally would not like to spend much time with a person with dementia	
People with dementia participate in a wide variety of activities and interests	
People with dementia are a good source of knowledge	
I would prefer not to go to a social group if people with dementia are invited	
People with dementia receive priority in care	
I wouldn't bother visiting someone with dementia because they wouldn't remember that I came	
People with dementia have care and concern for other people	
There is no point in talking to people with dementia because they can't take in what I say	

Q15 I am now going to read out some things people say about caring for a family member with dementia. Once again, there are no right or wrong answers. Can you tell me the extent to which you agree or disagree with each.						
Caring for someone with dementia is… READ OUT AND PROBE TO PRECODES. SCRIPTER. ROTATE ORDER OF PRESENTATION.	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly	Don't Know
..often very lonely						
..often very rewarding						

..often means your own health suffers						
... worse than being diagnosed with dementia						
...often both difficult and rewarding						
…often very stressful						
…often physically demanding						
…can have a negative financial impact						
…part of what you do for those you love when they need your help						

Q.16 To what extent do you agree or disagree with each of the following statements.

READ OUT EACH AND PROBE TO PRECODES. SCRIPTER. ROTATE ORDER OF PRESENTATION.	**Agree Strongly**	**Agree**	**Neither Agree nor Disagree**	**Disagree**	**Strongly Disagree**
Most people would accept a person with dementia as a close friend.					
Most people believe that a person with dementia is as intelligent as the average person.					
Most people believe that a person with dementia is just as trustworthy as the average person.					
Most people feel that suffering from dementia is a sign of personal failure.					
Most people think less of a person who has had dementia					
Most people in my community would treat a person with dementia just as they would treat anyone.					
Once they know a person had dementia, most people will take his or her opinions less seriously.					

Q.17 Imagine you have just been told by your doctor that you have the first signs of dementia. To what extent do you agree or disagree with each of following statements.

If I had just been told I had the first signs of dementia… READ OUT EACH AND PROBE TO PRECODES. SCRIPTER. ROTATE ORDER OF PRESENTATION.	**Agree strongly**	**Agree**	**Neither agree nor disagree**	**Disagree**	**Disagree strongly**
...I would feel humiliated					
...I would no longer be taken seriously					
...I would be considered stupid and unable to do things					
...I would be ashamed or embarrassed					
...I would be depressed					

...I would be anxious about the future					
...I would give up on life					
...My doctor would not provide the best care for my other medical problems					
...My doctor and other health professionals would not listen to me					
...I would not want my health insurance company to find out					
...I would not want my employer to find out					
...I would not want my friends and family to know					
...I would still be able to have a good social life					
...I would prefer not to be told my diagnosis					
...I would be able to get help and support to manage my condition and plan my future					
...I would want as much information as possible					
...I would be scared					

SECTION 7 - AWARENESS OF EXISTING DEMENTIA CAMPAIGNS

Q.18a Have you seen/heard any advertising about dementia recently? Yes No Don't know

IF YES

Q.18b Where did you see/hear it? PROBE: Anywhere else? **INTERVIWER CODE ALL THAT APPLY**

TV

Radio

Newspaper

Poster where? _____

Leaflet

Online (including social media and sites like twitter, facebook and Youtube)

Other

FOR EACH ONE RECALLED ASK

Q.18c What was it about?

Record whatever the person says

SECTION 8 – EXPERIENCE OF DEMENTIA

Q.19 Do you currently know or have you known someone who has dementia? Interviewer PROBE TO PRECODES.		
	Yes	No
*Yes - My partner or a member of my family		
*Yes a friend(s) I know very/fairly well		
*Yes the family member of a friend/ an acquaintance(s)/someone you don't know well		
*Yes a colleague / someone at my work		
Yes my job involves / involved working with people who have dementia (including customers or clients)		
Other (please specify)		
Don't know anyone who has, or had, dementia		

IF JOB INVOLVES WORKING WITH PEOPLE WITH DEMENTIA (INCLUDING CUSTOMERS OR CLIENTS ASK Q.20a

Q.20a What type of work do you do with people who have dementia? TYPE IN

FOR EACH *EXPERIENCE OR CONTACT WITH DEMENTIA AT Q.19 ASK Q.20b. ALL OTHERS GO TO CLASSIFICATION

Q.20b Please nominate which, if any, of the following describes your level of involvement with the person you know or knew with dementia? INTERVIEWER: PROBE FOR ALL ASTERISKED CODES FROM Q.19. PROBE TO PRECODES					
	My partner or family member	A friend I know very/fairly	Someone you don't know well	A colleague/someone at my work	Other
Visited them from time-to-time, just to keep them company					
Helped/cared for them from time to time (to give respite for example)					
Cared for them on a regular basis in their own home					

Cared for them in my own home/they lived with me					
Was responsible for making arrangements for someone to be looked after (e.g. arranged for a carer to visit someone at home, or arranged for someone to go into a residential/nursing home)					
Encouraged someone showing symptoms of dementia to seek professional help					
Other (Please write in)					

NOW COLLECT CLASSIFICATION

C.1 Record gender of respondent

Male	1
Female	2

C.2 Are you responsible for most of the grocery shopping in your household?

Yes (=housewife – male or female)	1
No	2

C.3 Exact age of respondent

TYPE IN EXACT AGE +
RECORD BELOW

16 – 24	1
25 - 34	2
35 - 44	3
45 – 54	4
55-64	5
65+	6

C.4 Marital Status

Single	1
Married	2
Cohabitating	3
Widowed	4
Separated/divorced	5

C.5 How many adults including yourself (aged 15+) live in the Household?

TYPE IN NUMBER

_____

C.6 How many children (under 15 yrs) live in the Household?

TYPE IN NUMBER

_____

C.7 Do you have a telephone at home?

Yes	1	RECORD TEL NO
No	2	

C.8 Would you be willing to take part in an interview like this again?

Yes	1
No	2

C.9 Are you an Irish citizen or not

Yes	1
No	2

IF NO
In which country were you born?_____

C.10 Are you …..

Working full time (30+ hrs)	1
Working Part time (-30 hrs)	2
Self employed (incld farmers)	3
Unemployed	4
Home duties	5
Retired	6
Student	7

C.11 Are you yourself the chief wage earner in your household or not? That is the person who contributes most money to the household income?

Yes	1
No	2

OCCUPATION OF CHIEF WAGE EARNER
(If farmer, state acreage. If proprietor/manager/supervisor, state number of employees. If unemployed for over a year or widow on State Pension, ask about Chief Wage Earner).

	NOW CODE

Class

AB	1
C1	2
C2	3
DE	4
F50+	5
F50-	6

INTERVIEWER: PLEASE CODE AND OR CONFIRM WITH RESPONDENT AFTER YOU COLLECT INFORMATION ON OCCUPATON.

C12 And so therefore you….

Don't work in the healthcare profession at all 1

SCRIPTER: IF CODE 2 MUST HAVE A SINGLE BETWEEN CODE 3-7 and 8-17

Yes work in the healthcare profession in a .. 2

Hospital Setting 3

GP practice	4
Out in the community/from a healthcare centre	5
Care home	6
Other (specify)	7
And you are a..	
Doctor	8
Nurse	9
Psychologist	10
Psychiatrist	11
Physiotherapist/Occupation therapist	12
Dietitian	13
Other Healthcare specialist (xrays bloods etc)	14
Care Assistant	15
Administrator/other staff in healthcare industry (chefs, reception, porter etc)	16
Other specify	17

NB: RESPONDENTS PRECISE LOCATION IS RECORDED AS PART OF THE INTERVIEWER ASSIGNMENT NUMBER

C.13 Which of the following bands does your gross annual salary (i.e. before tax) fall into?

A. <€30,000	1
B. €31,000 - €49,000	2
€50,000 - €74,000	3
C. €75,000 - €90,000	4
D. €91,000+	5

C.14 Number of income earners in the household (include full-time and part-time)

One	1
Two	2
Three	3
Four	4

C.15 Do you have access to the internet?

Yes	1
No	2

IF YES

C16 How frequently do you use the internet?

A couple of times a day
Once a day
A couple of times a week
Once a week
about once a fortnight
about once a month
Only once every couple of months
A couple of times a year
Less often
Never

C17a And when you access the internet, which of the following do you use at all?
C17b And which one do you use most often?

	At all	most
PC/Home computer/laptop		
Tablet		
Mobile phone		
Coffee shop/library/public access		
other specify		

RESPONDENTS NAME (BLOCK) MR/MRS/MISS _____

FULL HOME POSTAL ADDRESS _____

_____

I certify that this is a true, accurate and complete interview taken in accordance with my instructions, and conducted according to the guidelines set out in the ICC/ESOMAR International Code of Marketing and Social Research Practice.

Interviewer Name _____

Interviewer No.		*Assignment No.*

Appendix C: HSE Dementia Omnibus Baseline Tracking Survey Questionnaire 2018

KICK

Dementia Omnibus Baseline Survey Questionnaire

Hello. My name is ….from Behaviour & Attitudes. We are carrying out a survey among across Ireland about people's understanding of dementia. Everything you say to me is in total confidence. We will only be interrogating the data in aggregate form and no single individuals are ever identified.

SCREENER: Before I begin, I should say that we are only interviewing people who have not been diagnosed with either dementia or Alzheimer's disease. I am sure you can understand that anyone with such a diagnosis is likely to be better informed than the general public and our task today is to understand how well informed or not, the general public is on this subject matter. You may of course know someone or be caring for someone with dementia, and in those circumstances, we can still continue with the interview.

Can I therefore confirm that you have not been diagnosed with dementia or Alzheimer's disease?

Yes I have	THANK AND CLOSE
No, I have not	CONTINUE IF WILLING TO PARTICIPATE

SECTION 1 – KNOWLEDGE OF DEMENTIA

Q1. On a scale of 1-5, how much do you feel you know about each of the following conditions? 5 means you feel you know a great deal and 1 means you know little or nothing.					
READ OUT AND ROTATE	A great deal 5	Quite a lot 4	Some 3	Not very much 2	Nothing at all 1
Cancer					
Dementia					
Depression					
Alzheimer's disease					
ONE UNIT					

SECTION 2 - PERCEPTIONS OF DEMENTIA

Q.2. I am now going to read out some things that people have said about people who have dementia. To what extent do you agree or disagree with each. Please be honest. There are no right or wrong answers here. We are simply interested in what people think and feel.					
SCRIPTER: ROTATE ORDER INTERVIEWER: READ OUT PROBE TO PRECODES	Agree Strongly	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
I personally would not like to spend much time with a person with dementia					
People with dementia participate in a wide variety of activities and interests					
I would prefer not to go to a social group if people with dementia are invited					
I wouldn't bother visiting someone with dementia because they wouldn't remember that I came					
The company of most people with dementia is quite enjoyable					
There is no point in talking to people with dementia because they can't take in what I say					
2 question units					

Q 3 Could you tell me whether you believe the following statements to be true or false?			
READ OUT AND PROBE TO PRECODES. SCRIPTER ROTATE ORDER OF PRESENTATION.	True	False	Don't Know
Getting diagnosed at an early stage is good because it allows the person more of an opportunity to make decisions about their care			

There are things you can do to reduce your risk of getting dementia			
One question unit			

SECTION 3 - HELP-SEEKING BEHAVIOUR

Q.4. If you felt that you were becoming more forgetful and were concerned it might be signs of early dementia, how likely or unlikely are you to delay seeking help for as long as possible?

Extremely likely	
Likely	
Not sure	
Unlikely	
Extremely unlikely	
Cost = 1 question unit	

Q.5 Imagine you have just been told by your doctor that you have the first signs of dementia. To what extent do you agree or disagree with each of following statements.					
If I had just been told I had the first signs of dementia… READ OUT EACH AND PROBE TO PRECODES. SCRIPTER. ROTATE ORDER OF PRESENTATION.	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly
...I would be ashamed or embarrassed					
...I would give up on life					
...I would not want my friends and family to know					
1 unit					

SECTION 4 - AWARENESS OF EXISTING DEMENTIA CAMPAIGNS

Q.6a Have you seen/heard any advertising about dementia recently?	Yes (Free)	No	Don't know
IF YES Q.6b Where did you see/hear it? PROBE: Anywhere else? INTERVIWER CODE ALL THAT APPLY	TV Radio National Newspapers Local Newspaper Poster → where?_____ Leaflet Facebook Twitter YouTube Other Online platforms Other (specify)		
	One unit		
FOR EACH ONE RECALLED ASK Q.7c What was it about? Record whatever the person says			
	2 units (open ended).		

SHOW TV1 ADVERTISING (ALTERNATE ORDER WITH TV2 and TV 3)

Q.8(a) (b) Have you seen this TV advert over the past 3 months?

	(a)	(b)	(c)
Yes	1	1	
No	2	2	
3 units (one unit each)			

Q.9 What are the key messages you think this advert is trying to get across to people? TYPE IN

4.5 UNITS.

ASK ALL WHO HAVE SEEN ANY TV ADS 1 OR 2 OR 3

Q.10 Which, if any, of the following actions did you subsequently take as a result of having seen either of the two TV ads you may have seen about dementia? Tell me all that apply.

THERE IS NO POINT IN DOING THESE SEPARATELY ...AS FROM EXPEREINCE I KNOW THAT PEOPLE MIGHT ACTION SOMETHING BECAUSE OF THE CAMPAIGN AS A WHOLE, BUT THEY WONT RECALL WHICH AD IT WAS THAT PROMPTED THE ACTION. TAKING EACH SEPARATELY ASSUMES EACH ONE CAUSED AN ACTION AND THAT IS NOT THE CASE IN REALITY.

SHOW CARD OR SHOW ON SCREEN	TV Advertising ads 1 or 2 OR 3
Made a mental note to be more empathetic with people I know who are living with dementia or Alzheimer's	
Made a mental note to get in touch with a friend or family member who I know is living with dementia or Alzheimer's	
Made a mental note to get in touch with a friend/family member who is caring for a loved one who has been diagnosed with dementia or Alzheimer's	
Called in to see someone I know who is living with dementia or Alzheimer's	
Called in to see a friend or family member who is the main carer for someone with dementia or Alzheimer's	
Went online or called the helpline number to find out more about dementia	
None of these	
ONE QUESTION UNIT	

I am recommending this stays here at the end. Last time it was in the classification section right at the end (second last question), so it makes sense to me to leave it here.

SECTION 3 – EXPERIENCE OF DEMENTIA

Q.11 Do you currently know or have you known someone who has dementia? Interviewer PROBE TO PRECODES.		
	Yes	No
Yes - My partner or a member of my family		
Yes - Other (please specify)		
Don't know anyone who has, or had, dementia		
One question unit		

NOW COLLECT CLASSIFICATION.

BAROMETER CLASSIFICATION

C.1 Record gender of respondent

Male	1
Female	2

C.2 Are you responsible for most of the grocery shopping in your household?

Yes (=housewife – male or female)	1
No	2

C.3 Exact age of respondent

TYPE IN EXACT AGE + RECORD BELOW	
16 – 24	1
25 - 34	2
35 - 44	3
45 – 54	4
55-64	5
65+	6

C.4 Marital Status

Single	1
Married	2
Cohabitating	3
Widowed	4
Separated/divorced	5

C.5 How many adults including yourself (aged 15+) live in the Household?

TYPE IN NUMBER	

C.6 How many children (under 15 yrs) live in the Household?

TYPE IN NUMBER	

C7 Which of these best describes the highest level of education you have completed?

No formal education	
Primary school level	
Junior Certification or secondary school equivalent	
Leaving Certificate or secondary school equivalent	
Post leaving Cert/Diploma	
Professional qualification	
Undergraduate degree or equivalent	
Post graduate degree or equivalent	
	One question unit

C.8 Do you have a telephone at home?

Yes	1	RECORD TEL NO
No	2	

C.9 Would you be willing to take part in an interview like this again?

Yes	1
No	2

C.10 Are you an Irish citizen or not

Yes	1
No	2

IF NO
In which country were you born?_____

C.11 Are you …..

Working full time (30+ hrs)	1
Working Part time (-30 hrs)	2
Self employed (incld farmers)	3
Unemployed	4
Home duties	5
Retired	6
Student	7

C.12 Are you yourself the chief wage earner in your household or not? That is the person who contributes most money to the household income?

Yes	1
No	2

KICK

OCCUPATION OF CHIEF WAGE EARNER
(If farmer, state acreage. If proprietor/manager/supervisor, state number of employees. If unemployed for over a year or widow on State Pension, ask about Chief Wage Earner).

	NOW CODE

Class

AB	1
C1	2
C2	3
DE	4
F50+	5
F50-	6

C.13 Number of income earners in the household (include full-time and part-time)

One	1
Two	2
Three	3
Four	4

RESPONDENTS NAME (BLOCK) MR/MRS/MISS _____

FULL HOME POSTAL ADDRESS _____

_____

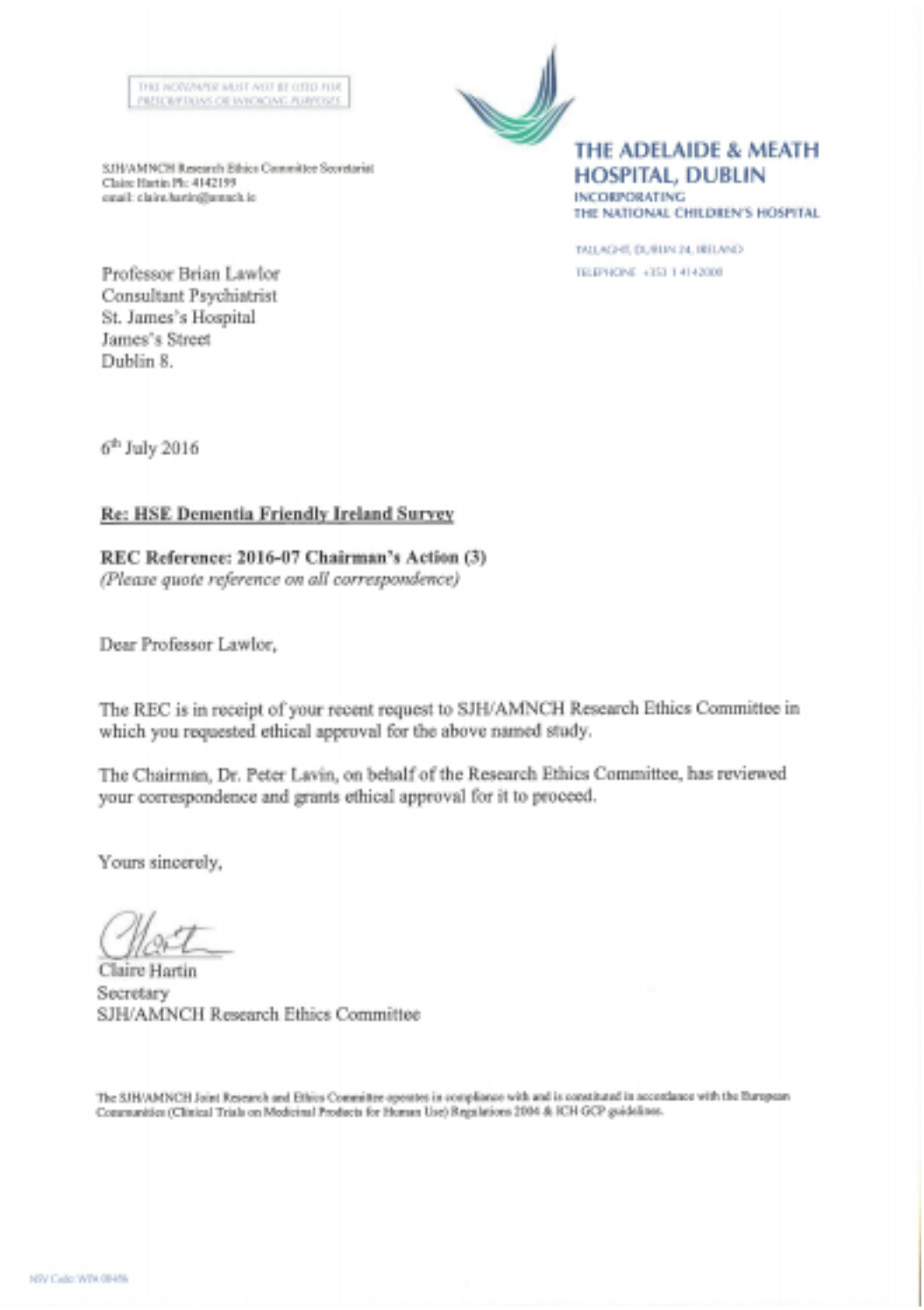
I certify that this is a true, accurate and complete interview taken in accordance with my instructions, and conducted according to the guidelines set out in the ICC/ESOMAR International Code of Marketing and Social Research Practice.

Interviewer Name _____

Interviewer No.		

Assignment No.		

Appendix D: Ethical approval for use of data for purpose of research



THE ADELAIDE & MEATH HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL

SJH/AMNCH Research Ethics Committee Secretariat
Claire Hartin Ph: 4142199
email: claire.hartin@amnch.ie

Professor Brian Lawlor
Consultant Psychiatrist
St. James's Hospital
James's Street
Dublin 8.

6th July 2016

Re: HSE Dementia Friendly Ireland Survey

REC Reference: 2016-07 Chairman's Action (3)
(Please quote reference on all correspondence)

Dear Professor Lawlor,

The REC is in receipt of your recent request to SJH/AMNCH Research Ethics Committee in which you requested ethical approval for the above named study.

The Chairman, Dr. Peter Lavin, on behalf of the Research Ethics Committee, has reviewed your correspondence and grants ethical approval for it to proceed.

Yours sincerely,

Claire Hartin
Secretary
SJH/AMNCH Research Ethics Committee

The SJH/AMNCH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.