



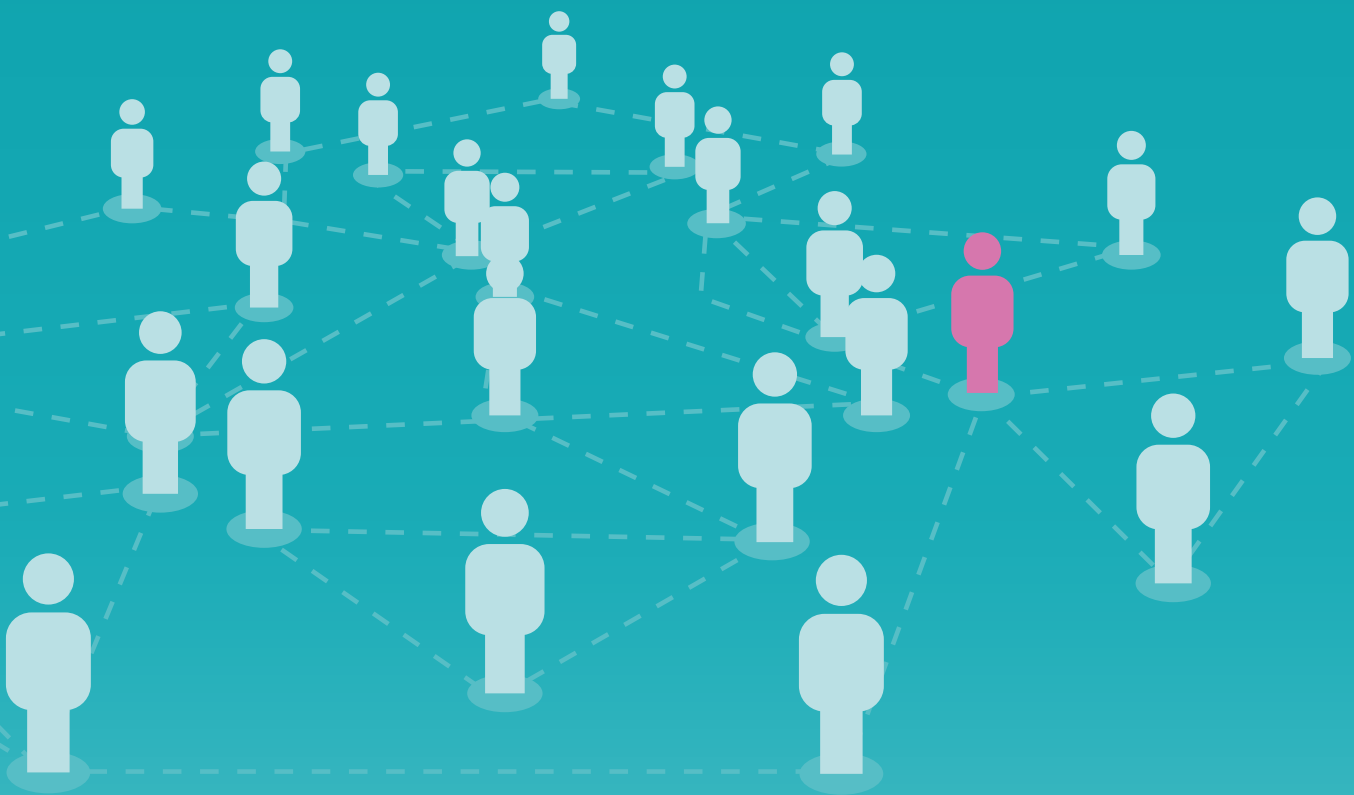
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The University of Dublin



GLOBAL
BRAIN HEALTH
INSTITUTE

Evaluation of the Framework for Dementia: Understand Together in Communities

August 2020




National
Dementia
Office



THE ALZHEIMER
SOCIETY of IRELAND





Report Authorship

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Foreword

Stigma and misunderstandings of dementia are a significant barrier for people to live as well as they can with dementia. Stigma can prevent a person talking about their dementia diagnosis or stop them seeking help and support which can assist them in adjusting and coping with the condition.

The Dementia: Understand Together Campaign aims to raise awareness and increase people's understanding of dementia and is one of six priority areas outlined in the National Dementia Strategy published in 2014 by the Department of Health.

Dementia: Understand Together (UT) in Communities is a progressive next step working with individuals, organisations and businesses at a grassroots level to build communities which are inclusive of people living with dementia. For culture to change, which is the vision of this campaign, it can take time. It is extremely heartening therefore to see the scale and scope of the campaign as outlined in this report. Since the programme commenced in 2018, over 340 community champions and 40+ national partner organisations have become involved.

I was also struck by the ethos of the campaign which is to create inclusive communities to ensure people living with dementia are understood, respected and valued; that they can stay socially connected and actively engaged in community life; they can access local businesses and amenities that are responsive to their needs and navigate the built environment with ease. This type of community can benefit us all.

I was particularly impressed by the energy and motivation of staff in the National Partner Organisations, along with the Community Champions, who keep dementia at the forefront of their work and give their time to organise social activities and events to keep people living with dementia and their carers active and involved in their own communities.

Findings from this evaluation report provide important guidance on next steps for the campaign; how we can build and grow this movement for social change and all play a part in creating dementia inclusive communities. I would like to extend my sincere thanks to the authors of the report, Miriam Galvin, Brian Lawlor and Elaine Howard of the Global Brain Health Institute for the robustness of the research and the accessibility of the final report. I would also like to acknowledge and to thank the members of the UT in Communities working group which include colleagues from the HSE, the Alzheimer Society of Ireland and Age Friendly Ireland.

Susan Scally
Principal Officer
Department of Health

Executive Summary

Dementia: Understand Together is a public support, awareness and stigma reduction campaign aimed at inspiring people from all sections of society to stand together with the 55,000 Irish people living with dementia. It is one of 6 priority actions of the Irish National Dementia Strategy (2014), which identifies key principles to underpin and inform the full range of services provided to people with dementia, their families and carers.

The campaign seeks to:

build understanding and awareness and reduce the stigma around dementia in Ireland

inspire individuals, businesses, organisations and services providers to take action to support people living in their communities.

The vision is to create an Ireland that embraces and includes people living with dementia, and shows solidarity with them and their loved ones. A mass media campaign launched the national campaign in October 2016 sharing stories from people living with dementia through TV, Radio and Local and National News. Dementia: Understand Together is led by the HSE working with The Alzheimer Society of Ireland and a coalition of over 40 partners from business, academic, health and voluntary and community sectors. The campaign was jointly funded by the State and The Atlantic Philanthropies.

In 2018, Dementia: Understand Together initiated a new and innovative phase of the campaign. The phase Dementia: Understand Together in Communities began to mobilise a network of Community Champions and national partner organisations across Ireland to support people with dementia and their families.

Dementia: Understand Together in Communities aims to empower people at individual and organisational level to take action to create better awareness and understanding of dementia and inclusive communities where people with dementia and their families are respected, supported and connected.

The framework developed to support Dementia: Understand Together in Communities is a new and innovative approach that focuses on the power of peer influence in affecting change. This approach, a co-creation between members of the national working group, in conjunction with people with dementia, partners and stakeholders, is based on the concept of a social movement and a grassroots approach to spreading change. Individuals and organisations can bring about change, by taking on six simple actions, which reflect the experiences and needs of people with dementia and their families.

National Partner organisations are public, private and voluntary organisations that are motivated to incorporate dementia-related awareness, activities and services to support their customer and staff base living with dementia. They lead by example and use their national branch networks, large employee and customer base and communication platforms to help spread the message that we all have a role to play to change the current culture around dementia.

Community Champions are the driving force behind the change in their communities. These champions are highly motivated and are working together with like-minded individuals to grow this grassroots movement of people taking action. Often they are willing to volunteer their time to raise awareness and understanding, create new initiatives and enhance existing activities and

services to become dementia inclusive. Through their actions champions and partners inspire others to be part of the movement. Over time there will be a critical mass of people taking actions to support people with dementia and their families, and dementia inclusive communities become the norm throughout Ireland.

An independent process evaluation was commissioned by the HSE to understand how the Dementia: Understand Together in Communities component of the awareness campaign is being implemented and how the initiatives of the National Partner organisations and Community Champions are working. This was undertaken by researchers at the Global Brain Health Institute at Trinity College Dublin. Information was collected through online surveys with National Partners and Community Champions and through a series of case studies in the form of face to face interviews with a purposeful sample of 8 National Partner organisations and Community Champions between May 2019 and October 2019. The survey questions were co-created with the Dementia: Understand Together in Communities working group and the questions for the subsequent interviews were informed by initial survey findings. The interviews allowed for discussion of some of the issues identified by the survey in greater detail and provided an opportunity to explore further topics in depth, e.g. motivation for involvement in Dementia: Understand Together in Communities; the specific initiatives developed; enablers and barriers to implementation, and personal experiences of being involved in the programme.

Survey data were analysed using descriptive statistics, and open-ended responses were coded and categorised, as appropriate. Interview data were audio-recorded, transcribed and coded independently by members of the research team. Findings from the evaluation were reviewed with the Dementia: Understand Together in Communities working group and the draft report was finalised with feedback from the working group.

The survey response rate was 57% for National Partner Organisations and 32% for Community Champions. The majority of survey respondents and interviewees were women aged between 45-64 years. Most of the National Partners surveyed had personal experience of dementia in their families. Many of the Community Champions interviewed had professional backgrounds in health services and experience of dementia through family members. In addition, they had pursued dementia-specific education, had established community connections and had previous experience in initiative development. Community Champions had a very specific skill set combination before becoming involved with Dementia: Understand Together in Communities.

The Dementia: Understand Together in Communities resource materials were well received and used by most National Partners and Community Champions. Some suggestions were made to allow for adaptation to local contexts. Personal contact and correspondence with the Dementia: Understand Together in Communities team was beneficial and appreciated by all.

40% of National Partners and approximately half of Community Champions surveyed said they had included people with dementia and carers in deciding what actions to take. For many, this inclusion took the form of advice and consultation before taking action for the individual. The majority of Community Champions were providing services for people with dementia in their full time roles. Some described involving people with dementia in designing the type of initiative subsequently developed. No interviewees said that they had included people with dementia in deciding what actions to take in their organisations or communities.

Most National Partners said that they received support from senior management in their organisations, which was a crucial enabler when planning and implementing activities. For National Partners, barriers to taking action included restrictions on time, lack of financial and other resources available and competing work priorities. Over two-thirds of Community Champions surveyed indicated they received support from friends, family, work colleagues, business people and community volunteers, who joined and supported them in the actions they have taken. Community Champions felt that lack of funding, limited endorsement from existing

health care services and the ways that some of the services are organised, along with limited opportunities and time to collaborate, were among the difficulties they encountered in taking action in their communities. Vital enablers described by interviewees included a personal skill about dementia and initiative development as well as local knowledge and network connections. They also valued the support of the Dementia: Understand Together in Communities campaign and the opportunity to share with and learn from other Community Champions with many sharing the common goal of normalising life for people with dementia.

All participants were enthusiastic about being involved in the Dementia: Understand Together in Communities programme. They reported that their involvement was beneficial to them on a personal basis and was creating societal change, notably reduced stigma, increased awareness regarding dementia and how people with dementia and their families can continue to live well with appropriate supports and services.

The majority of National Partners surveyed felt that there had been a change in attitudes to dementia and greater awareness of it in their organisations, with 63% feeling that attitudes had changed and increased awareness in the local communities, with more to achieve going forward. Community Champions identified changes in their communities also through increased awareness, understanding and the starting up of conversations around dementia. Despite the existence of some barriers to action, there was enthusiasm and broad support for the implementation of the Dementia: Understand Together in Communities programme by National Partners and Community Champions. Their involvement was seen as pioneering activity and as being part of a social movement.

Based on the findings of the process evaluation, there are a number of recommendations:

1. The Dementia: Understand Together in Communities campaign should recruit, develop and train a diverse range of Community Champions outside of those that have worked in the health services to support greater growth and sustainability of Dementia: Understand Together in Communities and support the development of core skills.
2. Use 'indicators of readiness to participate' for National Partner recruitment.
3. Run a targeted training drive for National Partners 'ambassadors' to support more efficient reach within the organisation and sustainable action.
4. Provide an online induction resource pack to incoming Community Champions and National Partners.
5. Provide existing Community Champions and National Partners with an updated link to all resources.
6. Develop training resources to include: i) understanding dementia ii) strategic collaboration and iii) initiative development.
7. Provide guidance and support to Community Champions about how to develop a coordinated network structure and support self-sustaining and independent action.
8. Explore the potential of regional and national shared learning opportunities, mentorship support, cross-collaboration opportunities and leadership development for both National Partners and Community Champions.
9. Consider how individual work can be acknowledged by Dementia: Understand Together in Communities, and membership status could be maintained in the Dementia: Understand Together campaign.
10. Provide access to equipment and small-scale financial supports where required for Community Champions to enhance sustainability and impact.

11. Promote and facilitate sharing of resources among Community Champions to avoid duplication of efforts and support cost-effective initiative development.
12. Provide specific guidance and support to achieve greater involvement by people with dementia and family members, in the planning and design of Dementia: Understand Together in Communities related initiatives.
13. Provide guidance and training support regarding the three pillars of action i) General Awareness-raising ii) Dementia-specific Initiatives iii) Dementia Inclusive Initiatives and how to navigate between them.
14. Promote targeted awareness of Dementia: Understand Together in Communities initiatives to health care services and family members.
15. Continue dementia awareness-raising at national level incorporating the work of the Community Champions and National Partners to showcase progress and mobilise further engagement with the Dementia: Understand Together in Communities campaign.

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Section 1: A process evaluation of Dementia: Understand Together in Communities

1.0 Background to Dementia: Understand Together in Communities

The purpose of the Dementia: Understand Together national campaign is to create understanding and inclusive communities where people with dementia and their families are respected, supported and connected. The campaign supports the implementation of the priority action of providing better awareness and understanding as set out in the Irish National Dementia Strategy (2014).

The Dementia: Understand Together national campaign is seeking to:

- build understanding and reduce the stigma around dementia in Ireland
- inspire individuals, businesses, organisations and services providers to take action to support people living in their communities

Its objectives are:

- Ireland has a recognisable brand to represent connected support for our dementia journey.
- People in Ireland are more aware of what dementia is, how it does and does not affect people, what people with dementia and their family and carers need.
- Increased knowledge of what causes dementia and how to reduce lifestyle risk factors in the population.
- Businesses and organisations sign up to support the campaign, train staff and adapt their services.
- With signposting and clear pathways through HSE and health services, community supports available are clearly set out for people with dementia and their carers.
- Communities are better adapted to support day to day experience and inclusion of people with dementia.
- People are enabled to provide small practical supports, as part of shared community life.
- People with dementia are empowered to voice their wishes and needs and partake in community life if they wish to do so.

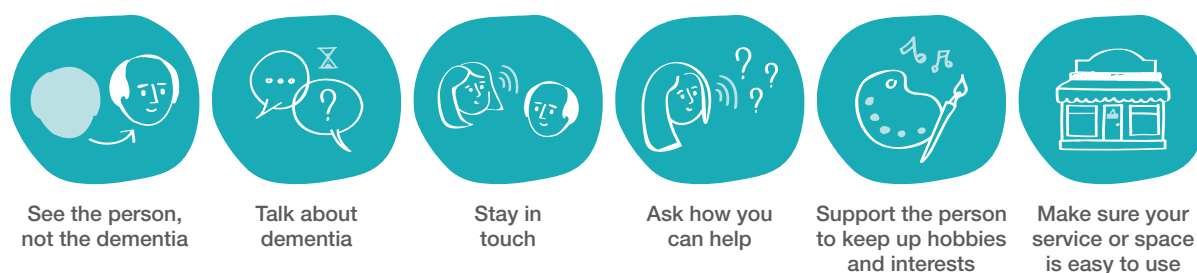
The initial phase of the campaign had focused on raising awareness about dementia and reducing stigma among the general public using a mass media campaign to share the stories of people with dementia through TV, Radio, National and Local Newspaper outlets. Dementia: Understand Together in Communities began in 2018 and was a new and innovative phase of the broader Dementia: Understand Together National Campaign.

The Dementia: Understand Together in Communities aspect of the campaign sought to inspire and mobilise Community Champions and National Partner organisations to take purposeful action to create understanding and inclusive communities where people with dementia and their families would be respected, supported and connected. The framework developed to support Dementia: Understand Together in communities is a new and innovative approach that focuses on the power of peer influence in affecting change. This approach, co-created through the working group, in conjunction with people with dementia, partners and stakeholders is based on the concept of a social movement and a grassroots approach to spreading change.

It is based on six actions that reflect the experiences and needs of people with dementia and their families:

- See the person, not the dementia
- Talk about dementia
- Stay in touch
- Ask how you can help
- Support the person to keep up hobbies and interests
- Make sure your service or space is easy to use

Figure 1: Six Actions



National Partner organisations are public, private and voluntary organisations that are motivated to incorporate dementia-related activities and services to support their customer and staff base living with dementia. Community Champions are motivated individuals willing to volunteer their time to create new initiatives and enhance existing activities and services to become dementia inclusive. Their role is also to build a larger community of active champions working towards the shared goal of dementia inclusion.

1.1 Process Evaluation

A process evaluation examines whether a programme of work was implemented as intended, how that happened, if the programme activities resulted in specific outputs, and the contexts in which actions took place <http://www.cdc.gov/std/program/ProgEvaluation.pdf>. A process evaluation was commissioned by the Health Service Executive (HSE) to understand how the process of the Dementia: Understand Together in Communities programme is being implemented. The independent evaluation was undertaken by researchers at the Global Brain Health Institute (GBHI) at Trinity College Dublin (Trinity). Quantitative and qualitative data were collected between June and October 2019. This evaluation represents a snap shot in time and sought to understand the extent to which the Dementia: Understand Together in Communities programme is being implemented as designed, the specific initiatives that are being put in place as part of programme, and the barriers and enablers encountered by National Partner organisations and Community Champions.

1.2 Methods

On-line surveys and case study interviews with representatives of National Partner organisations and Community Champions were undertaken. Survey questions were drafted through consultation with representatives of the Dementia: Understand Together in Communities working group and researchers from the GBHI at Trinity.

Eight case study interviews with a purposive sample of National Partners and Community Champions were conducted. The interview questions were devised by members of the working group and informed by the survey findings. The interviews provided an opportunity to further explore issues in more detail, with additional questions on key areas of relevance to the implementation process.

1.2.1 On-line Surveys

Two survey questionnaires, one for the National Partner organisations and one for Community Champions, were developed in conjunction with the Dementia: Understand Together in Communities working group. The surveys were uploaded to a Smart Survey platform www.smartsurvey.co.uk.

The surveys were piloted with a small cohort of individuals selected by the Dementia: Understand Together in Communities team in May and June 2019 and questions were amended according to the feedback received.

For the survey roll out, invitation emails were sent through the Dementia: Understand Together in Communities team office to 53 National Partners and 246 Community Champions on 24/06/2019. Two reminder emails were sent, and the surveys were closed in early July 2019. Data protection policy and wording in an email to stakeholders was reviewed and agreed. The survey was designed to take approximately 10 minutes to complete. 79 Community Champions and representatives from 30 National Partner Organisations completed the surveys, representing response rates of 32% and 57% respectively.

1.2.2 Case Studies

A semi-structured interview question sheet (appendix A), was developed in collaboration with members of the Dementia: Understand Together in Communities working group. A sample of National Partner organisations and Community Champions were selected by the National Co-ordinator of the Dementia: Understand Together in Communities working group, as case studies to explore the implementation process and their experiences in greater detail using face-to-face interviews. The selection of case study participants was based on a criteria grid:

National partners:

- High priority for the campaign in terms of
 - Leadership role
 - Possibility to raise level of engagement
 - Influencer of change
- Community remit and role
- Size of the organisation
- Branch network
- Ability to reach into the community

Community champions:

- Taking actions in their community
- Going beyond their work remit
- Reaching into the community
- Inspirational for others to follow
- Leadership role

Initial contact was made with the selected case study participants by the National Co-ordinator of the Dementia: Understand Together in Communities programme. Four Community Champions and four National Partner organisations were identified by the Dementia: Understand Together working group. Once participants had agreed to be interviewed, their names, contact details, and summary information were shared with the researchers. Researchers contacted each participant either by telephone or email to plan a time, date and venue that was appropriate for an interview.

The audio-recorded interviews were piloted with one Community Champion and one National Partner organisation. An information sheet and letter of consent was given to each participant before the interview. This included consent to participate, for the interview to be audio-recorded, and for notes to be taken. Appropriate time was given for any questions before interviewees signed the consent form. Participants were assured that their confidentiality would be upheld and that no identifying names would be included in evaluation reports or other publications or presentations. Participants were also assured that information would only be shared with the research and programme team, and that quotes from interviews may be used in reports, and other related publications but they would be anonymised.

The National Partners interviewed were from both the private and public sector, representing organisations with a large national reach. The Community Champion interviewees included retired healthcare professionals who were working in voluntary capacities and private business owners working in health and music.

Each interview took approximately one hour and was undertaken in the person's place of paid or volunteer work except for one interview which was conducted in the person's home. The interviews were audio-recorded. The researcher took written notes at each interview and recorded field notes after each meeting.

Table 1: National Partner Organisations Interviewee Information

Org.	Interviewee Nos.	Gender	Interviewees full-time Role	Organisation Type	Reason for Involvement	Approximat Staff Numbers	County
NP1	1 (Pilot)	Female	Corporate Social Responsibility Manager	Public Limited Company	Aligns under Corporate Social Responsibility Objectives	2,000	Dublin
NP2	1	Male (2)	Accessibility Officer	State Owned	Have Accessibility & Inclusion Remit	3,700	Dublin
	1		Head of Customer Experience				
NP3	1	Female	Health and Wellbeing Manager	Voluntary	Interest from membership to learn more about dementia	10,000	Dublin
NP4	1	Female (4)	Diversity & Inclusion Manager	State Owned	Have Accessibility & Inclusion Remit	10,000	Dublin
	4	Male (1)	Training & Development (Management & Staff)				
Total	9						

Table 2: Community Champion Interviewee Information

Community Champion	Interviewee Nos.	Gender	County Location	Full-Time Role	Dementia Knowledge
CC1 (Pilot)	1	Female	Tipperary	Retired Nurse	Professional and education
CC2	*2	Female	Waterford	Private Business Owner	Personal experience
CC3	1	Female	Kildare	Private Practice	Professional and education
CC4	1	Female	Tipperary	Voluntary Organisation Employee	Professional and education

**in some cases, more than one person was present at the interview, and noted in the transcripts*

On completion of each interview, the researcher uploaded a password protected MP3 recording of each audio-interview so that the file could be transcribed by members of the research team. The transcriptions were uploaded in a password protected file and the coding process began.

- Semi-structured, audio-recorded interviews with key actors/employees in the case studies selected.
- Transcription of audio-recordings.
- Coding and thematic analysis by members of the research team at GBHI and St James Hospital.

1.3 Data Analysis

Survey data were analysed using descriptive statistics, and open-ended responses were coded and categorised as relevant. The case study interview data were transcribed and independently coded by four researchers.

Confidentiality and anonymity of responses were assured for participants in the online surveys and interviews. General Data Protection Regulation (GDPR) requirements were checked and administered and written informed consent was collected on the day of the case study interviews.

The interview transcripts were coded under the initial question headings. Themes and potential relationships between themes were identified through a process of reviewing and coding each transcript and identifying themes across the interviews. Rigour of the process was enhanced through a collaborative coding process in which members of the research team coded the transcripts separately and then discussed and reviewed if their coding was similar and divergent.

The initial findings were reviewed with the working group. A draft evaluation report containing survey and case study results were compiled and provided for feedback, stakeholder review and input.

Section 2: Findings: National Partners

2.0 Background

Thirty National Partner organisations completed the survey, representing a 57% response rate. Representatives from four National Partner Organisations were interviewed.

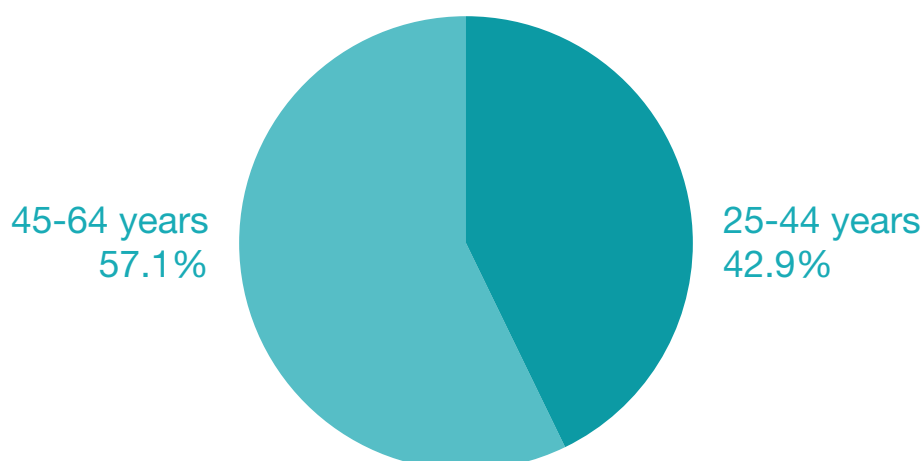
The majority of survey respondent organisations were Dublin based, (Meath, Louth, Wicklow, Limerick), and were national organisations e.g. government sector, national reach. 36% of respondents indicated their organisation was part of a branch structure. All National Partner organisations interviewed as case studies were Dublin based and all organisations were part of a branch structure.

Table 3: National Partner Organisations (Survey)

How many employees does your organisation have?		
	Number	Percent
Less than 50	5	17.9%
50-99	4	14.3%
100-249	3	10.7%
250-499	0	0.0%
Over 500	16	57.1%
TOTAL	28	

57% of organisations had over 500 employees, 18% of organisations had less than 50 employees. National Partner organisations interviewed represented state-owned, public limited companies and voluntary organisations and had between 2,000 and 10,000 employees. The voluntary organisation had a membership rather than employee number that was over 3000.

Figure 2: National Partner Respondent Demographics



75% of survey respondents from National Partner organisations were female and the majority was aged 45-64 years, also reflective of those National Partner representatives interviewed for case studies.

Outside of paid employment, 50% of survey respondents specified involvement in some voluntary/community work other than the Dementia: Understand Together in Communities' campaign. These included sports club, parish groups and charity organisations.

Most survey respondents came from organisations in the public and community/voluntary sectors; those from the private sector included organisations of health and social services providers, banking and retail. The organisations became involved with the Dementia: Understand Together in Communities campaign from 2016 through to 2019. At the time of the survey some National Partners had just begun their activities, others were further developed in their planning and implementation. This was consistent with what was found in the case studies. Three of the four National Partners interviewed had begun activities, one had not yet begun.

Table 4: Respondent's roles in National Partner Organisations (Survey)

Role	Number	Percent
Manager	16	57.1%
Director/CEO	6	21.4%
Administration	4	14.3%
Actuary/Administration	1	3.6%
Coordinator	1	3.6%
Answered	28	

Most National Partner respondents were in management and senior roles. Most of those interviewed also held management positions and worked within departments that had inclusion, corporate social responsibility or wellbeing remits.

The interviews showed that while there were no formal steering groups developed specifically for any National Partner organisations initiatives, all National Partners had a department or team, with a lead person, whose focus was inclusion and/or wellbeing. The lead person was well positioned within their team to incorporate their dementia initiative into these existing organisational infrastructures. Interviewees described 'annual objectives' and 'operational plans' and 'pillars' of interest that incorporated their work in dementia. "So, I guess on an annual basis what our objectives are that we sign up to is what we deliver on." (NP1) described for one interviewee how their organisation's dementia goals were incorporated into their wider objectives. Key lead people were either decision-makers themselves or had access to senior leadership in decision-making about the initiatives developed.

One interviewee described situating their initiative under a 'community' pillar objective and how such objectives are signed off on by senior leadership to be achieved within that year. Cross-departmental engagement also occurred for this organisation among marketing and capability teams, corporate social responsibility and head of region among others.

2.1 National Partners: Motivation for Involvement

Almost 75% of survey respondents had personal experience of dementia. People were asked what motivated their organisation to get involved with the Dementia: Understand Together in Communities campaign. The responses were coded and grouped into categories. The main motivations given were work-related reasons and wanting to understand dementia.

Table 5: National Partner Motivation for Involvement (Survey)

Motivation	Number	Percent
Work related	14	50%
Understand people living with dementia	4	14.3%
Ambition to collaborate	3	10.7%
Attended roadshow contact from UT	3	10.7%
Raise awareness	3	10.7%
Education	1	3.6%
Inclusion	1	3.6%
Answered	28	

The majority of interviewees described work-related reasons for becoming involved. One interviewee described how their membership requested further information relating to dementia while others described ageing demographics among their staff and customer bases as drivers for becoming involved. All interviewees worked within accessibility, inclusion, corporate social responsibility and health and well-being departments within their organisation and therefore such work aligned with their organisation's purpose and vision. Some had decided on their initiatives before engagement with Dementia: Understand Together in Communities, with one interviewee deciding on first steps in consultation with a representative of people with dementia.

While all interviewees identified as National Partners of Dementia: Understand Together in Communities, some mentioned other dementia organisations such as Dementia Ireland, DCU Dementia Elevator and Alzheimer Society of Ireland when describing the first connection point to becoming a National Partner. This may be because the National Partners had begun engagement with other dementia-specific organisations before Dementia: Understand Together in Communities had commenced. In some instances, the original contact person of the National Partner organisation was no longer involved with new lead people taking on the initiative. Therefore, the original process with Dementia: Understand Together in Communities was unknown.

Some of the National Partner interviewed had previously worked in partnership with other organisations and voluntary services on issues such as mental health before becoming involved with Dementia: Understand Together in Communities. Many had "partnered with a number of people (organisations)" (NP1) and some described how they relied heavily on this model of partnership to support their work and engaged with multiple partners at any one time. Several interviewees shared how they valued the partnership approach they had with Dementia: Understand Together in Communities.

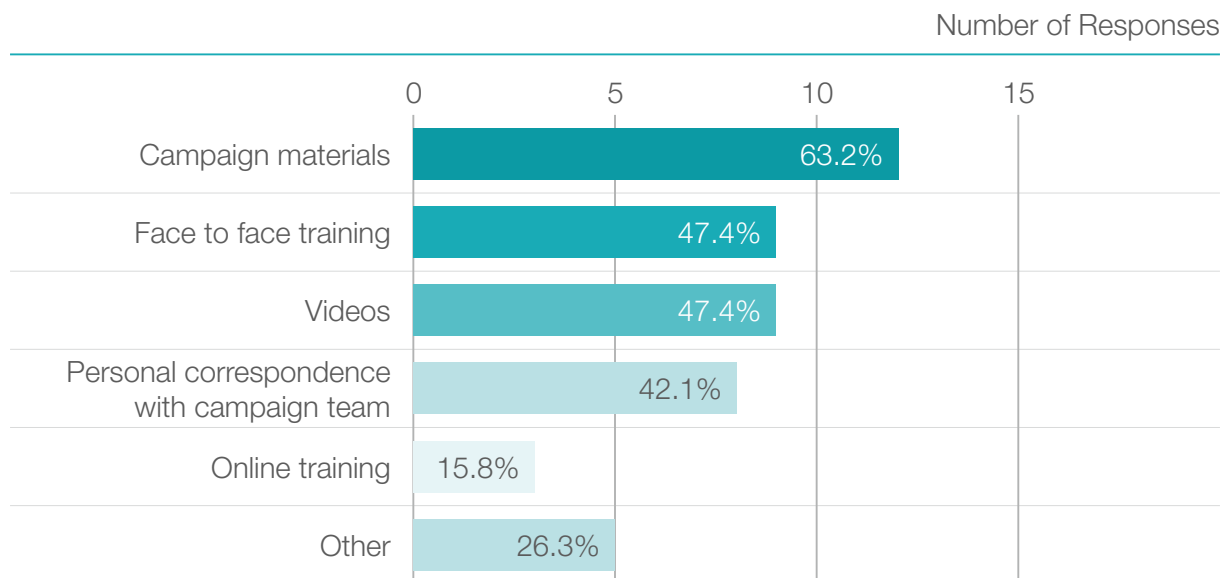
"We're very much reliant on a partnership approach, so we work with the likes of organisations, like the (dementia service provider) and the HSE who obviously support us, but, am, (list of organisations). A whole host of organisations, probably about ten, ten to twelve." (NP4)

Dementia was an emerging area of interest for the organisations interviewed. This was partly because they had an ageing customer and staff demographic. They also shared how staff and group members had sought more information about dementia.

2.2 Resources Used

The Dementia: Understand Together in Communities resources used included campaign materials (63%), face to face training (47%), videos (47%) and online training (15%). Personal contact with the campaign was a useful resource for 42% of those who responded.

Figure 3: Dementia: Understand Together in Communities Resources used (survey)



Over half (56%) of survey respondents indicated that the Dementia: Understand Together in Communities resources could be improved in some way, for example making access to materials easier, adapting videos to specific contexts and to continue to regularly update resources.

Interviewees were asked about the resources provided by Dementia: Understand Together in Communities which included TV & Radio Campaign, Shared Learning Opportunities, Website, Literature, and Connection to Champions, Individual Campaign Support, and Service Mapping. Interviewees shared their mainly positive experience of the resources and expanded on what additional supports they felt would be helpful.

In the interviews, awareness-raising sessions provided by Dementia: Understand Together in Communities and external facilitators were described as informative and impactful, all interviewees intended to continue with awareness-raising. Interviewees said that having people with dementia delivering part of the awareness session was particularly impactful as they learned a lot about the person's perspective of their service. The costs of ongoing awareness-raising were raised by one voluntary organisation as a barrier for them to meet demand.

Individual campaign support was welcomed and considered vital for organisations in the planning and implementation phases. Some interviewees described the importance of Dementia: Understand Together in Communities input in helping them to navigate the planning phase of their work. Website, literature and videos were favourably received by most. Some interviewees described the need for bespoke elements to be incorporated for their specific contexts. One interviewee described having to incorporate a retail component of how to support people with dementia on their e-learning resource. Another interviewee described adapting an international guidance document for their specific context of including people with dementia in their social groups. They hoped Dementia: Understand Together in Communities could work with them on that.

While shared learning events were valued as helping to learn from others in a non-competitive space, interviewees also referenced the challenges of attending because of busy work schedules and the duration of these events. Some, at an earlier stage of development, were less aware of the collaborative potential of working with others. None had been involved in collaboration with National Partners or Community Champions. One organisation yet to develop any initiatives did highlight the potential of working with Community Champions in achieving a more efficient and broader reach across their branch offices nationally.

Exploration of criteria for retaining National Partner status was suggested by one interviewee. *“But actually, you know, kind of in two three years down the line you’ve done your training, you’ve done things and actually what does yeah if you want to keep that status what does it look like.”* (NP1) The above comment aligns with a similar comment raised by a Community Champion.

2.3 Initiatives developed as part of Understand Together in Communities

Just 26% of respondents from National Partner organisations indicated that before the Dementia: Understand Together in Communities campaign, their organisation had not been involved in activities or action to support dementia. Of those that had some involvement that centred on media events, partnering with other groups, receiving and providing training to staff. Table 6 below shows the type of activities National Partner organisations had taken part in since joining the Dementia: Understand Together in Communities campaign.

Table 6: National Partner Activities and Actions (Survey)

What actions related to dementia, have you undertaken since becoming a partner to the campaign	Percent
Raised awareness through Media Events	73.9%
Training staff	68.2%
Partnering with others	70.0%
Reviewed Services	56.5%
Provided dementia-related training	65.0%
Work with people and organisations in local communities	50.0%
Dementia as part of CSR	45.5%
Reviewed and Adapted Services	40.9%
Provides formal health and social services	19.0%
Education Distributed UT material	10.0%

The majority of interviewees described awareness-raising and training for staff or volunteers and dissemination of information to their customer base as the main activities and actions that were undertaken. One National Partner had not taken any actions.

The following information taken from interviews with National Partners illustrate the actions that were in progress when interview meetings took place and notes the organisations’ future plans (Tables 7-10).

Various approaches to awareness-raising for staff were described and several approaches were used within the one organisation. One interviewee described developing an online version of awareness-raising, delivered over three 10-minute sessions that staff could self-select to undertake (Table 7, Case Study 1). Others described more informal discussion type awareness-raising such as ‘walkabout’ of a building to identify enablers and challenges for a person with

dementia (Table 8, Case Study 2). Conference type presentations, awareness talks at regional membership meetings, and specific group awareness sessions were also described. Some were provided by Dementia: Understand Together in Communities staff, others were delivered by paid facilitators, paid for by the National Partner organisation.

Interviewees described hosting World Alzheimer Day Information stands, tweeting information to their customer base, sharing information literature at regional meetings, and stocking information literature in their stores for their customers to access.

Table 7: Case Study 1 - National Partner (NP1)

Initiative Type	Dementia Awareness-raising
Formal /Informal Structure	Existing Corporate Social Responsibility Team Key lead person working within that team
Status	One-off interventions and Ongoing E-learning Resource
Summary	<p>This organisation had branch outlets across the country. Its focus was to support staff and their customers by increasing awareness about dementia.</p> <p>From a staff perspective, a number of awareness-raising opportunities were provided and an e-learning resource about dementia for retail was developed using Dementia Understand Together resources. From a customer perspective dissemination of Dementia Understand Together literature was facilitated by delivering literature for access across all stores.</p> <p>They included:</p> <p>For Staff</p> <ul style="list-style-type: none"> • Conference Presentation about Dementia with reach to 300 staff. • Awareness-raising sessions for 50 Corporate Social Responsibility staff. • An e-learning resource comprising 3 x 10-minute sessions was developed using the resources of Understand Together in Communities and adding a specific retail element to the overall piece. New staff can self-select to complete this e-learning resource as part of their induction. 150 have completed. • Articles about their dementia initiatives were shared in their staff newsletter. <p>For Customers</p> <ul style="list-style-type: none"> • Dementia Understand Together literature was shared across branches nationally for access by customers for World Alzheimer's Day.
Future Initiatives	<ul style="list-style-type: none"> • Continue to build on the numbers of staff who have completed the e-learning resource. • Use storytelling about staff engagement with dementia and share through their communications mechanisms. • Dementia audit one premises alongside people with dementia

Table 8: Case Study 2 - National Partner (NP2)

Initiative Type	Dementia Awareness-raising & Dementia Inclusive Services
Formal /Informal Structure	Accessibility & Inclusion Department Key Lead People who are decision-makers
Status	One-off interventions
Summary	<p>This organisations focus was to build dementia awareness among staff and customers and to inform dementia inclusive service delivery.</p> <p>They had an accessibility and inclusion working group already in place and an advocate (family carer) for people with dementia was included on this working group.</p> <p>For staff:</p> <ul style="list-style-type: none"> • Three workshops provided for staff about dementia. • A walkabout in the premises to discuss challenges and enablers for people with dementia. <p>For customers:</p> <ul style="list-style-type: none"> • Information stand provided in one premises to share literature about dementia for World Alzheimer's Day. • Tweets to 110,000 customers on World Alzheimer's day about dementia.
Future Initiatives	Would like to replicate awareness-raising in other branches around the country

Table 9: Case Study 3 - National Partner (NP3)

Initiative Developed	Dementia Awareness-raising
Formal /Informal Structure	Existing Health and Wellbeing Department Key lead person in that department
Status	Ongoing
Summary	<p>This organisations focus was on building dementia awareness among its membership and supporting the inclusion of people with dementia in their social clubs.</p> <ul style="list-style-type: none"> • Multiple awareness-raising at county cluster meetings. • Awareness-raising for organisation volunteers. • Literature dissemination at relevant meetings.
Future Initiatives	<ul style="list-style-type: none"> • Include people with dementia in their social groups. • Adapt an international guidance document to an Irish context about how to support people with dementia in their social group setting. Provide a support workshop for this guidance document to branch social groups. • They would like to incorporate dementia awareness into a planned pilot health and wellbeing programme - as an elective supplementary component. • Provide further training for volunteers. • Consider the possibility of having an in-house dementia volunteer.

Table 10: Case Study 4 - National Partner (NP4)

Initiative Developed	Dementia Awareness-raising & Dementia Inclusive Services
Formal /Informal Structure	Existing Accessibility and Inclusion Team Key lead person working in that team
Status	Not in progress
Summary	This partner organisation had not yet started its initiatives. An initial discussion meeting was held with UT in communities and the interviewees immediately prior to the case study interview taking place.
Future Initiatives	n/a

Including People with Dementia in Initiatives

A majority of National Partner organisations (60%) had so far not involved people with dementia, their families and carers in deciding on which actions to take. Some respondents indicated they would address this inclusion in the future, through consultation and co-creative activities. Others referenced working with advocacy groups and client forums during decision-making processes. None of the interviewees had independently sought people with dementia to inform the design and ongoing implementation of their initiative. However, people living with dementia did have a role in providing training and awareness sessions across the three organisations that were active, and support was co-ordinated by Dementia: Understand Together in Communities.

All interviewees described the positive and lasting impact of hearing directly from people who are living with dementia.

“Yeah, I mean it’s when you meet them face to face the people there and eh how well they put across their point, what their issues are. I think you take that away with you, like if you just read it on a page you know ... it’s a bit different so yeah.” (NP2)

One interviewee described having a representative for people living with dementia as a member of their organisation’s accessibility and inclusion user group. This person was not a person with dementia but an advocate for people with dementia. Another interviewee proposed including people with dementia in a walkabout in one of their stores as a future action.

“Which is to walk a couple of the stores (Inter: oh, yeah), am with one or two am dementia sufferers and just see from their perspective.” (NP1)

2.4 Enablers and Challenges

2.4.1 Enablers

84% of survey respondents said other people within the National Partner organisation joined and supported the actions taken. Supports from management and staff were helpful with the National Partner organisations’ involvement in the Dementia: Understand Together in Communities’ campaign.

Table 11: National Partner Organisational Support (Survey)

Support	Number	Percent
Support of management	17	89.5%
Support of other staff members	17	89.5%
Support of board	11	57.9%
Budget	4	21.1%
Corporate social responsibility strategy	3	15.8%
Other	2	10.5%
Answered	19	

Buy-in and commitment

Interviewees also reflected on the key enablers that supported their initiatives. Buy-in and commitment by management and colleagues were also shared by interviewees as well as respondents. Many felt that staff connected so readily because of personal experiences of dementia. Each organisation also had a supporting infrastructure that was able to incorporate dementia-specific initiatives into operational plans. All organisations also had existing departments such as inclusion and disability, corporate social responsibility and health and well-being.

Staff personal interest in dementia

Interviewees felt that staff personal experience with dementia facilitated openness and engagement with the initiatives *“there’s probably very few people that haven’t had somebody (Inter: yeah), that’s not been touched by it.”* (NP1)

The older age profile of staff and memberships meant that some had a personal interest as they were already carers for someone with dementia or had a personal interest in wanting to find out more because of their age. The increasing age profile of staff was a consideration for one organisation as they now plan what initiatives to undertake in terms of priority actions.

Alignment with Organisation Goals

Alignment with organisation goals was important. Interviewees described dementia as being relevant to their organisation’s remit in support of a diverse customer base. As described by one interviewee *“our internal focus has been on ensuring that all processes and HR nice and neatly are filtered under a D and I lens to make sure, in line with the public-sector duty we are doing what needs to be done in [ORGANISATION].”* (NP4) Many of the organisations interviewed had an ageing customer base and therefore dementia awareness was particularly relevant.

Senior Lead Position

Key people co-ordinating the initiatives were well positioned within their organisations to achieve the necessary buy-in for initiative development. All held management-level positions within health and wellbeing, corporate social responsibility or accessibility and inclusion departments. They were decision-makers or had access to the appropriate decision-makers and the initiatives were incorporated as part of their organisations goal objectives.

“So, I deal with a lot of customers who would have mobility issues, other impairments, whether visible or hidden, and obviously, in general, try to develop policy to improve the situation for people who have disabilities.” (NP2)

Existing Inclusion Remit

Having an existing inclusion remit within the organisation was another key enabler. Interviewees described how dementia was a topic of relevance to their organisations and the people they support. All interviewees had a specific existing department or team that had an inclusive or wellbeing remit (accessibility and inclusion, health and wellbeing, corporate social responsibility or training and development departments.) Each department’s focus was to enhance customer service and was aligned to the inclusive intent of Dementia: Understand Together in Communities.

Organisational Commitment

The operational structures and commitment within the organisation were also facilitators for dementia goals to be achieved when they were included under existing pillars of action. One interviewee shared how multi-departmental teams worked collaboratively across common objectives and demonstrated how dementia being included within this meant that the message could be shared more broadly.

Senior management buy-in and commitment was also a key enabler. Senior management was committed to achieving their organisational objectives, with dementia incorporated under certain pillars of action. Senior management involvement ranged from sign off on annual operational plans inclusive of a dementia initiative, attendance at working group meetings, and active participation in manning an information stand for World Alzheimer's Day.

"We had a stand that was actually manned by our district manager that came in on the Saturday and one of his staff came in voluntarily to man the stand. So em, pretty powerful stuff you know". (NP2)

A Partnership Approach

Survey respondents (70%) used networking opportunities with partners and other organisations to share learning about dementia. Partnerships and collaborations had already been a vehicle for many of the interviewees to achieve organisational goals of inclusion. Interviewees valued engagement with Understand Together in Communities, citing the benefits of external facilitators, trainers, people with dementia and Understand Together staff in helping them to achieve their goals. They shared how this helped to build their knowledge, provide awareness training and impart the challenges that a person with dementia may experience.

"XX did a brilliant session, so she did about maybe 20-25 minutes in terms of setting the context and slides (Inter: yeah), and then XX then spoke for about another about 15-20 minutes so I think when you get the emotional side of it, that's when you get, yeah that's when you get." (NP1)

Externally sourced facilitators were used to provide awareness-raising and were organised either through Dementia: Understand Together in Communities or through already existing connections.

While all sessions had been delivered by Dementia: Understand Together in communities staff or by external facilitators, some interviewees were open to jointly facilitating awareness sessions in the future.

"Em, I'd be open either way, I mean if there is a facilitator there then great but if not... I mean I think we could, between, between the group, like [NAME 6] or whoever eh and the 'Understand Together Campaign' and ourselves, I think we could jointly... eh facilitate it." (NP2)

Dedicated Personnel Resources within Organisations

Having dedicated personnel resources within organisations was important. Three interviewees described key ambassador, volunteer co-ordinator, or corporate social responsibility support roles as potential helpful resources for their dementia inclusive initiatives. While some had already received dementia awareness training, specific dementia-related action had not yet been identified or designated for these groups. However, their positionality across their organisation could potentially support reach and impact as initiatives progress. Interviewees highlighted these roles as potential contributors to any future initiative rollout that may occur. Having these resources in place could be significant enablers to achieving reach in the medium term.

2.4.2 Challenges

A majority of National Partner survey respondents (57%) had not experienced difficulties when taking action as part of the Understand Together in Communities campaign. Of those who described barriers to taking action, lack of time and resources, staffing and other competing priorities at work were mentioned:

"Lack of understanding with some professionals in the field"

“Time restrictions and getting buy-in from people who don’t realise they need the information”

“I’ve tried to arrange training/workshop for Volunteer Centres, but I have not succeeded in getting them to prioritise this”

Time, cost, the scale of the organisation and supporting policies and guidance were all raised as particular challenges to be overcome by organisations at interview. Some of the organisations had significant staff numbers to reach and this will require time, a cost consideration and attention to roll out processes to achieve scale.

Time Constraints

In the interviews, time constraints were discussed in the context of busy workloads, lead in planning time requirements, staff release implications, and the challenges of attending shared learning events hosted by Dementia: Understand Together in Communities.

Competing demands and busy environments of full-time roles were challenging as interviewees spoke about *“just trying to I suppose allocate the time (Inter: ok), to in order to get it done.”* (NP1) Some interviewees described how their existing workloads meant that they had been unable to attend any of the learning events hosted by Dementia: Understand Together in Communities.

Time was also discussed in terms of needing lead-in time to schedule items into their organisational calendar. Scheduling one-off initiatives such as planning of World Alzheimer’s Day required appropriate lead-in times for one interviewee. They referenced how competing demands required appropriate planning to ensure a place on the calendar.

“Participant 2: No, I suppose em... we were a little bit tight for time in that here can take a little bit of time to schedule things and we have, say on our XXXX onboard, we have cycles of posters and stuff like that so it, it can be planned a long time in advance. So as much notice as possible you know” (NP2)

Releasing staff for training from the floor was also raised by one interviewee as a challenge. Their solution to this challenge was to create an e-learning resource that staff could access in their own time.

National Partners had significant staff numbers working in multiple centres across Ireland. Some organisations were at initial stages of implementation when interviewed, and their initiative was undertaken in just one branch or with a specific group of individuals.

Financial Costs

While public limited companies or state organisations did not raise financial costs as a challenge, it was a particular challenge for voluntary organisations. Each training session delivered with external facilitators had an associated cost of €350.00 for this organisation. While this cost was not considered unreasonable per session, cumulative costs to meet existing demand or to train all membership branches was perceived to be prohibitive.

“If we were to put say that this is available, the dementia awareness training, we could be inundated and we wouldn’t have the costs, at the end to facilitate that.” (NP3)

The interviewee shared that demand for awareness training at that time exceeded their financial capability to provide the relevant training.

Lack of Guidance Documents

One organisation interviewed supports the development of a significant number of social groups around the country. The inclusion of a person with dementia into one of those groups without the appropriate knowledge, introductions and support system resulted in a negative experience for the group membership. This and other examples highlighted the need for this group to be more informed before engagement with people with dementia recognising that to do so would help members to better support people with dementia in their groups.

"I think we could set up some sort of a buddy system where you know that individual could certainly come to the (facility), that their carer could feel you know safe and secure that they'd be, you know, they'd be looked after and if there were any issues that they'd call am, but there needs to be a bit of guidance and there needs to be some kind of policies and stuff like that for us around that. Yeah." (NP3)

This organisation's planned next step is to adapt an international guidance document from a sister organisation that describes how to support the inclusion of people with dementia. They intend to source funding for this initiative but would like to work collaboratively in rolling out this initiative with Dementia: Understand Together in Communities.

Organisation Size

The size and scale of the organisations engaged with the campaign is such that dissemination of information across a staff base as a first action is a monumental task. While some interviewees are focusing on one branch, or groupings or pockets of staff, the size of each organisation comes to the fore as a challenge for the organisation in both the planning and implementation phases.

"Participant 1: Challenges I suppose... em getting the message out to all frontline staff because we are all over the country. It's not just like you have one office in [LOCATION] We are a hundred and whatever offices" (NP2).

2.5 Changes noted since Involvement in Understand Together in Communities

National Partners felt the actions taken had raised awareness and understanding, particularly in their organisations, with somewhat less awareness regarding the wider community.

Table 12: Do you feel your actions have raised awareness and understanding of dementia? (Survey)

	Yes	No	Unsure
In your organisation (%)	81.8%	9.1%	9.1%
Training staff in your wider community (%)	63.2%	21.1%	15.8%

The actions taken by the National Partners to date created effects within the organisations and in the wider community, in terms of greater awareness, increased understanding and inclusivity. Awareness increases when "People are talking more about it", and "the ripple effect that (awareness) will happen naturally" (SDNP).

Interviewees described achieving a greater personal perspective since becoming involved in the campaign. Examples included:

- Gained a greater understanding of the prevalence of stigma about dementia
- Felt more equipped to have conversations about dementia
- Gained a greater perspective on the impact of the environment for people with dementia

Interviewees also shared anecdotal positive feedback from staff who had received awareness-raising sessions about dementia. All organisations were at a relatively early stage of engagement with Dementia: Understand Together in Communities and had focussed mainly on awareness-raising. This is a substantial undertaking as all organisations have significant staff numbers.

Any examples of dementia inclusion shared by interviewees had occurred before engagement with Dementia: Understand Together in Communities. One exception was a reference to a proposed action by a person who had received dementia awareness training. The interviewee described how a branch staff member intended to reach out to other retailers in a shopping centre to work collaboratively on dementia inclusive actions.

“now she’s looking to do something with a bunch of retailers in the (local) shopping centre for example” (NP1)

Another organisation mentioned how they shared 10 indicators of enabling environmental factors with their store alliance group of which they are a member. They also developed an online dementia resource as part of the induction online materials that new staff members can self-select to engage with. Another organisation plans to incorporate dementia as a supplementary part of a pilot health and wellbeing programme that branch groups can self-select to engage with.

As shared by one interviewee when discussing potential impact, *“I’d like to see it 12 months on.”* (NP1) which illustrated the early stage of the intervention and the need for time to elapse before impact can be measured for many of these initiatives. Consideration on how to capture change, reach and impact for staff and people with dementia with National Partners may be a future consideration for Dementia: Understand Together in Communities.

2.6 Future Plans and Next Steps

When asked what they would like to see happen in the future in their organisation, concerning dementia training, awareness and inclusivity, responses were coded into categories (Table 13). 46% would engage in more and higher-level training in the future, with 32% continuing to raise awareness about dementia within their organisations.

Table 13: What would you hope to see happen in your organisation in the future? (Survey)

	Number	Percent
More/follow-up training	13	46.4%
Raise awareness	9	32.1%
Discuss dementia issues	2	7.1%
Embed in organisation	1	3.6%
Engage with dementia groups	1	3.6%
Leadership	1	3.6%
Media campaign	1	3.6%
More programmes to include people with dementia	1	3.6%
Support caregiver	1	3.6%
Need dedicated staff to lead out	1	3.6%
Answered	28	

The survey asked what the National Partner organisation planned to do next to support dementia inclusive communities. 44% of respondents planned training and raising awareness to support dementia inclusive communities. Others focused on the continuation of current actions and developing plans for the future (33%). The majority of interviewees felt that dementia awareness-raising was an ongoing requirement and was needed to keep dementia to the forefront. One organisation shared that it was beneficial for their organisation to be promoted as being a dementia-friendly organisation.

When interviewees were asked about future activities, some organisations were finalising plans for the future, others intended to continue to pursue and extend their current activities e.g.:

“We are in the process of developing a clear strategy”

“Will work closely through our nationwide network”

“To make documentation etc dementia friendly”

“Increase training and make more applicable and use real-life stories”

From the interviews, it was clear that future initiatives were focused mainly on increasing awareness-raising opportunities for staff members. Some were focused on replicating what had been done in one branch and using the same model in other locations. Another organisation was focused on extending their reach to additional staff members now that they had the appropriate e-learning resource for dementia awareness-raising in place. This was an optional resource for staff to engage with so uptake will be reviewed after some time. A third interviewee spoke about further training for staff members and believed that a follow-up training resource was required for those group members who had previously received awareness-raising. They believed this was necessary as the awareness-raising already received would not fully equip someone to be inclusive of people with dementia. While this was a resource that they felt necessary to develop, the costs needed to deliver it were a barrier for this organisation.

2.7 Experiences of being a National Partner Organisation

The survey responses indicated that experiences and involvement in the Dementia: Understand Together in Communities' campaign were overwhelmingly positive and beneficial (77%). This also came through in the interviews. The benefits ranged from educational experiences and information exchange to being part of a social movement. Sample quotes from respondents below:

“Very positive experience in our first workshop, we are only starting this journey but really looking forward to further sessions with the team”

“It’s been educational and I’m proud to be part of this movement. However, it would be fantastic to have more time to dedicate to this”

“This is very new to us at this point, but it has already been beneficial to meet others who are already in the process of getting the information into the community”

“Communication has been very good and positive”

“I feel we have been very well supported by [xxx] and the team as a partner organisation, I would like to accelerate the training within the organisation but based on a large organisation it needs to be pre-planned etc.”

“It is very empowering being part of a social movement that is so cross-functional”

“This has been a hugely positive experience for me personally and for the company. I believe we created [a] model that could be replicated or certainly provided learnings to support projects of a similar magnitude”

Interviewees also shared the above sentiments reflecting how it had supported their own organisational goals, had been a positive experience working collaboratively with Dementia: Understand Together in Communities. Interviewees also shared the challenges of incorporating such work into existing heavy and competing workloads. One organisation yet to progress with taking action, spoke of the 'vital' need to have the support of Dementia: Understand Together in Communities from a planning perspective.

Section 3: Findings: Community Champions

3.0 Background

246 Community Champions were invited to participate in the on-line survey, which was completed by 79 people (32% response rate). 67% of respondents to the Community Champion survey were in the 45-64 age category. There was a slightly broader age range among case study interviewees where they ranged from mid 30's to late 60's. 86% of those who responded to the survey were female, 84% were working, of which 68% indicated that they were working full-time. All interviewees were female, and the majority were working full time.

Table 14: Age Category of Community Champion Respondents (Survey)

Age category	Number	Percent
18-24 years	0	0.0%
25-44 years	21	26.9%
45-64 years	52	66.7%
65-79 years	5	6.4%
Over 80	0	0.0%
Answered	78	

Table 15: Community Champion Economic Status (Survey)

	Number	Percent
Working full-time	52	67.5%
Working part-time	13	16.9%
Retired	8	10.4%
Caring for a family member	6	7.8%
Other	7	9.1%
Answered	77	

Of those in paid employment 50% were in health services occupations, others were involved in administration, education and library services.

Figure 4: Community Champions
- Occupational groups

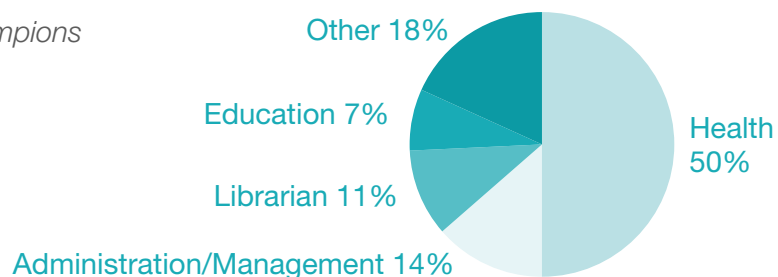


Table 16: Does the organisation or business you work for provide... (Survey)

	Number Yes	Yes (%)
Health and social services for people with dementia, such as day care, homecare, cognitive stimulation therapy or information services	33	51%
Support groups for people with dementia or carers, such as memory cafes or social clubs	29	45%
A service that people with dementia use regularly, for example in retail, banking or transport sector, in libraries or community groups	24	37%
Support for employees affected by dementia, such as a helpline or information services	15	23%
Other	16	25%
Answered	65	

The majority of respondents and case study interviewees were involved in the health and social services sectors. The majority of interviewees had nursing or allied health professional backgrounds and had previously worked in the Health Service Executive (HSE). This provided them with an in-depth knowledge of the health care system. Most interviewees were currently working in private practice, voluntary organisations or as volunteers. The two remaining interviewees for the fourth case study were family caregivers with lived experience of dementia, who also ran their own business. Most Community Champions interviewed had established connections and networks in their local community.

When asked if they were currently involved in voluntary or community work other than the Dementia: Understand Together in Communities work, approximately half of all survey respondents and interviewees were engaged in some other voluntary/community activities.

Of those who specified the type of voluntary or community work they engage in, the main categories were age-related charities, scouting, social groups, church-related organisations and other social concerns.

76% of Community Champion survey respondents had personal experience of dementia, and for those it was mainly through family members (91%). Most interviewees shared their professional rather than personal interest in dementia having worked in dementia-specific and older person services. Only one case study interview shared their personal experience of supporting a family member with dementia. While each interviewee's background and context differed, all were highly skilled and knowledgeable about dementia. Many had worked in the area of dementia and had also pursued further education opportunities in dementia-specifically. Three-quarters of survey respondents had been involved in dementia-related activities before becoming Community Champions with Dementia: Understand Together in Communities.

The majority of interviewees were also experienced in developing or enhancing dementia-specific services. Examples shared included developed dementia-specific day services, created dementia-friendly environments, delivered retail training and supported inclusion of people with dementia in usual services.

Table 17 provides an overview of each community champion interviewed for the case studies, providing detail on their current position with professional background, dementia-specific education attainment and previous involvement in dementia-specific development.

Table 17: Community Champion Background and Experience (Interview)

	CC1	CC2	CC3	CC4
Existing Role	Volunteer	Private Practice	Business Owner	Employee
Previous Professional Background	Nursing & Older Persons	Allied Health Professional	Private Business Owner	Nursing & Older Persons
Dementia Education Attained	Yes	No	Yes	No
Dementia Experience	Professional	Lived	Professional	Professional
Health Service Executive Employees (Previously Held Roles)	Yes	No	Yes	Yes
Prior Innovation Experience	Yes	N/a	Yes	Yes

The Community Champions' interviewed could be categorised into two types, those who were dementia experts by profession and personal experience (3 interviewees), and those who were experts because of personal experience (2 interviewees who worked together on one initiative).

Table 17: Community Champion Characteristic Types (Interviews)

Expert by profession and personal experience (3)	Expert by personal experience (2)
<ul style="list-style-type: none"> Professional experience of working with older persons and people with dementia. They had nursing or allied health professional backgrounds They were recipients of dementia-specific training and education They had knowledge through their experience of health service systems They were working in various sectors - volunteers, voluntary organisation, private business They were well established within their communities They could leverage existing connections and relationships They had previous experience of developing and implementing dementia-specific initiatives They are leads on their initiative 	<ul style="list-style-type: none"> Personal experience of supporting a family member with dementia They were well established within their communities They could leverage existing connections and relationships They had experience of business development Their business focus had a known relevance to dementia support They are leads on their initiative

Three core skill sets existed among all Community Champions and are shown in Fig 5.

Figure 5: Component Skills of Community Champions



3.1 Community Champions: Motivation for Involvement

When asked why they became champions, respondents to the survey indicated both personal and work-related reasons, to increase awareness and understanding, reduce stigma and improve services. The motivations mentioned most frequently were to support people (24%) and increase awareness (23%).

Table 19: Community Champion Motivation for Involvement (Survey)

Why did you become a Community Champion?	Number	Percent
Support People	17	24.3%
Awareness Increase	16	22.9%
Work-Related	11	15.7%
Make a Difference	8	11.4%
Reduce Stigma	5	7.1%
Personal Reasons	4	5.7%
Family Related	3	4.3%
Help People	2	2.9%
Improve Services	2	2.9%
Promote Understanding	2	2.9%
Knowledge	1	1.4%
Answered	70	

At interview, stigma, lack of awareness about dementia and limited services were described as prevailing challenges within communities. One interviewee described “*people are afraid, they are afraid, there is big stigma out there still.*” (CC1) Stigma was described as ever-present. Some perceived older generations as still not wanting to speak about dementia and felt that society in general continued to speak inappropriately about dementia.

Community Champion interviewees were asked how they became involved with the Dementia: Understand Together in Communities campaign. One was contacted by the Dementia: Understand Together in Communities team, one made contact with the campaign, another sourced the campaign as they looked for services in their area and the remaining interviewee could not recall how they had initially engaged with the campaign.

Community Champions perceived their engagement with Dementia: Understand Together in Communities in different ways. Some were clear that they were “*champions and part of the Dementia: Understand Together Campaign*” (CC1), while others shared “*I’m not in that community*” (CC3). Interviewees described feeling disconnected from the campaign as they did not live in Dublin and all events were held in Dublin.

3.2 Changing Perspectives: Since involvement in Understand Together in Communities

86% of Community Champions felt that their actions have raised awareness and understanding of dementia within their networks, and 65% felt this happened in their wider community. Based on the actions they had taken, there was more awareness within the community.

The changes mentioned by respondents included the impact of the Dementia: Understand Together in Communities media campaign, opening up conversations locally, greater understanding in society, more awareness, less fear, social media and TV advertisements were viewed positively, increased awareness of human rights and dementia.

"I believe the campaign has opened the conversation of how we understand Dementia and how we as a wider community ensure that PWD can be assisted and supported to live well with Dementia"

"Less negative perception of dementia, less fear of dementia"

"Greater awareness of 'human rights' of people living with dementia"

"Engagement in discussions about dementia both in media and within communities"

"Greater understanding of terminology"

Nevertheless, respondents commented that significant work was required. Interviewees also shared this concern believing that the awareness campaign needed to be ongoing to keep the focus on dementia as a priority area and to ensure that the message reached the right people.

Interviewees discussed changes that they felt had occurred in how dementia was perceived. One interviewee spoke from a personal perspective as she described: "I don't care anymore what people think or say about her." (CC2) changing from the original feeling of protectiveness that she had for her mother who was living with dementia. However, this interviewee and another participant also shared how they felt that stigma still existed and was present in their choir as family members or themselves still did not mention the word dementia.

"We see it especially with the XXXX, am, like, god don't talk, and it's all that kind of that generation the same kind of age, now we don't mention dementia or anything in the XXXX." (CC2).

However, they also shared how family members who attended the initiative developed by the Community Champion appeared to have built trust and comfort with each other as they opened up about crises in their lives. This was also reflected by others who perceived their initiative as an informal "support network for the families as much as it is like, well, enjoyment and well-being for the people." (CC2) They described how families checked in with each other informally at the choir sessions. They described witnessing family members asking each other "well how did your hospital appointment go, or this person fell, or he forgot this, or she forgot." (CC2) They also felt that the initiative was positively impacting people with dementia. They described how a lady who had not spoken in four months was able to sing along on her first visit to the choir.

Reach was described in the context of how some health care services availed of the activities developed by Community Champions. Some interviewees described how active retired groups, residential and long-term care organisations brought their group members or residents to the activities that they had developed. 61% of respondents felt that there was a change in how people with dementia and their families were supported and included in society in general since the start of the Dementia: Understand Together campaign in 2016, approximately one third were unsure (Fig 5).

Interviewees felt that there was a lack of dementia-specific services locally. Local areas were described as having been ‘abandoned’ with limited service provision and family members described feeling ‘lost’ with little knowledge of where or who to go to, to access services or information.

Many perceived day care services as the only services available post-diagnosis for people living with dementia. Most interviewees felt this support was inappropriate for those at earlier stages of dementia. Interviewees shared experiences of people with dementia who would *“not go into a place like that (CC2)”* and knew *“that there were people in the community and then there was me (Ref. Day Centre), but there was nothing in the middle.”* (CC1) This interviewee went on to describe the need to provide accessible services that people at earlier stages of dementia could freely choose to engage with. There was a perceived need to *“create a linkage, without commitment for people”* (CC1) that was more informal than day care services and would facilitate people with dementia to engage with if and when they felt it was appropriate to do so. A move away from the more traditionally structured day care service to more social support services was advocated for people at earlier stages of dementia in recognition of different needs at different stages of dementia.

Interviewees perceived the needs of people with dementia differently with some believing that dementia ‘specific’ services developed for people with dementia that included family members and communities were important while others believed that people with dementia should be ‘included’ in the usual services and activities that other people were also part of.

Some believed that people post-diagnosis wanted to continue doing the things they had always done. One interviewee used the example of *“they want to be able to continue to shop safely”* (CC3) to illustrate their belief that people with dementia wanted to continue living a normal life. Interviewees also shared how they believed that people with dementia should be included in ordinary services as opposed to *“setting people apart.”* (CC4) Others felt that it was not possible to include people living with dementia in ordinary services and activities because they would feel ‘lost’.

3.3 Resources Used

Respondents to the Community Champion’s survey indicated that the main Dementia: Understand Together resources used included campaign materials (77%), videos (57%), online training (43%) and face to face training (39%), and personal correspondence with the team (41%).

When asked if/how the resources available could be improved, some respondents indicated they were happy with what was currently available, and others suggested addressing issues such as:

“Be identified locally, radio days, dementia week every now and again in radio”

“Maybe understand together campaign could give champion details to the partners to work together and reach more people.”

The above example was also raised by one National Partner at interview who was yet to develop their initiative. They referenced the potential benefits of working collaboratively with Community Champions nationally to achieve greater and more efficient reach among their branch services across the country.

Community Champions interviewed had all accessed some of the range of resources provided by Dementia: Understand Together in Communities to Community Champions which included: TV & Radio Campaign, Shared Learning Opportunities, Website, Literature, Connection to Champions, Individual Campaign Support and Service Mapping.

Individual campaign support was generally valued by champions who felt they had a direct point of contact to share progress with and to seek advice from if required. One interviewee felt that they would benefit from being more visibly supported by Dementia: Understand Together in Communities through social media endorsement of their activities.

The TV and Radio Ad campaign was welcomed as it provided positive messaging. However, many interviewees felt that stigma about dementia still existed and that ongoing awareness-raising was necessary. One interviewee suggested that the next phase of national awareness-raising could include the work of Community Champions to illustrate how people can support people with dementia.

“Share the good work, yeah, share how it is done, that it can actually be done very easily.”
(CC1)

Website, literature and Facebook resources were also accessed and found to be helpful. Many Community Champions also designed their own resources for their initiative. There was some inconsistency of knowledge among Community Champions about the full complement of resources available to them.

Interviewees were asked if there were additional resources that would have been helpful to them.

Provide small Scale Operational/Financial Supports

The majority of interviewees developed their literature, printed their own resources for their initiative, gave their time willingly, used their own equipment such as laptops and personally bore any financial cost to develop and run their initiative except where donations were voluntarily given for catering costs. Additional support requirements from the Dementia: Together in Communities included:

- Small scale start-up costs such as venue hire for Champions that may need it
- Access to Wi-Fi dongles to share film in awareness and training sessions
- Loan access to projectors to deliver training

Create a broader range of learning opportunities nationally and regionally

While shared learning events were perceived by most as a helpful resource, they were considered challenging to attend because of time, cost and travel distance constraints. Only two of the five people interviewed had attended a shared learning event.

Interviewees referenced day-long events being held in Dublin as particularly challenging. *“But everything was in Dublin do you know, it was just a nightmare for us”* (CC2)

There were varying responses when asked about the content of events held, with one interviewee sharing how it provided an opportunity to meet and share with other champions. Another described not learning anything new but did feel they had contributed to others learning as part of the breakout session on the day. Non-attendees felt that such events needed to bring something new to the dementia discussion, to equip them with new information that they could use locally to help keep others interested in dementia and counteract the lethargy she felt was happening about dementia.

The majority felt that regional opportunities to meet would address the challenges that they experienced concerning time, cost and distance. They also welcomed the opportunity to meet with local Community Champions to learn about their work and to work collaboratively with them. They felt that understanding each other’s work, showcasing good practice, and potentially including people with dementia so that they would know they are not alone in the area would all be helpful outcomes from such events.

Optimise cross-learning among champions

An increased membership, recognition and showcasing of work and relating the successes achieved in an uplifting way were all suggested additional future steps to be taken by Dementia: Understand Together in Communities. Interviewees shared their willingness to contribute to this movement, either by being mentors to incoming Community Champions, or by showcasing their work to Community Champions or as part of the ongoing awareness campaign.

The majority of Community Champions wanted to connect with other Community Champions and learn from them. Likewise, they were open to other Community Champions coming to see their initiatives in practice.

“They’re absolutely welcome to come in here and watch us See how ours goes. Give, we’ll give them all the help, all the advice. They can have the books. They can have, they can have everything, anything they need. They can have it.” (CC2)

Only one interviewee was reticent in highlighting their work through fear of losing funding opportunities if they were seen to be too successful.

Interviewees also wanted to know what was happening in real-time with other champions. While they believed that all communities generally had a responsibility to share what was happening in their area in real-time, they felt that Dementia: Understand Together in Communities could also provide this live information to help champions make connections with each other and give a lending hand to the initiative that was underway.

They called for sharing resources in a way that would avoid duplication of effort among Community Champions who were doing the same thing. As described by one interviewee:

“So unless there was maybe an area on the website either that champions could go into to see what is, what everybody else is doing, or instead of reinventing the wheel, like I have done the retail training and then I heard XXXX are doing it too, but I have the slides and all done, so, but they are doing theirs and I am doing mine, so you are going to end up with all these different, do you know, em”. (CC3)

These examples above and the case studies shared above illustrate the resource potential that now exists among Community Champions for use by the wider group of champions.

3.4 Initiatives developed as part of Understand Together in Communities

Before becoming a Community Champion, 75% of survey respondents were involved in activities or taken actions to support people with dementia and their families. This included taking care of family members and or as part of their paid work.

Sample of responses:

“Designing and executing an activities program in a dementia ward in a local hospital”

“I facilitated local Support Group and delivered information sessions to Community Groups and Schools”

Community Champions have taken a range of actions to support people with dementia and their families. Raising awareness through social events and social media, participating in and delivering training, and distribution of Dementia: Understand Together materials were among the actions taken.

Table 20: Since becoming a Community Champion, which of the following actions have you taken to support people with dementia and their families? (Survey)

	% Yes
I raised awareness through social events or talks.	73.7%
I participated in dementia awareness training.	70.7%
I have made sure activities are inclusive of people with dementia.	70.2%
I used social media to raise awareness of dementia.	66.1%
I distributed Dementia: Understand Together campaign materials in my community.	61.0%
I promoted dementia inclusive activities within my local community.	54.2%
I delivered dementia awareness training.	39.3%
I developed formal health and social services for people with dementia and carers.	32.8%

While many of the initiatives appeared to have occurred organically without a structured full-service needs analysis being undertaken, interviewees did share the goal of ‘normalising’ life for people with dementia.

“Well, like, dementia has just been part of, do you know, um, and I think that it’s something that needs to be looked at, that we have to normalise dementia, do you know, and I would have just considered the dementia care part as part of caring for an older person, or not so old, do you know, that I would worry a bit about silo-ing dementia care.” (CC4)

Interviewees described how they each uniquely chose the initiative they developed based on their observations of need in the community, feedback from community members, or out of personal interest. None described seeking the input of people with dementia.

“We have to do something (Inter: yeah) and then that’s why obviously naturally then we have a (musical organisation) so we put the two together.” (CC2)

None of the Community Champions interviewed had developed a formal steering group to inform and guide their work. Some worked with existing colleagues in a voluntary capacity, others worked alone, and those who already had an existing infrastructure incorporated their initiatives within that structure.

Table 21: Community Champion Structures of Support (Interview)

Champions	Informal Support
CC1	Worked collaboratively as a volunteer with two key individuals. Accessed additional support as required.
CC2	Jointly run a business and collaboratively worked in a voluntary capacity to deliver their initiative. Accessed additional support as required.
CC3	Worked alone in providing retail training on a voluntary basis.
CC4	Worked within a voluntary organisation and included initiative within that structure. Accessed additional support as required.

From previous work experiences, there was awareness among Community Champions of the benefits of collaborative working and formal structures. Most interviewees spoke as individuals leading a change process and did not discuss the possibility of convening a formal steering group for their initiative prior to development or as a plan for the future.

They acknowledged people that they worked with on an ad hoc basis. They described how they reached out to their existing connections to facilitate the development and/or implementation of their initiative. One such example was a graphic design colleague who helped design champion's advertising literature free of charge. The same interviewee also spoke about how staff had agreed to support their initiative as volunteers by playing instruments and helping with catering.

Another interviewee shared how important it was to know who the right person to reach out to was to achieve your goals.

"But if you actually approach it in the right way and if you get in through the right channel and that is very important because if you want to go straight to the top too there's not much point going to the, trying to get in at the bottom". (CC3)

There was evidence of external collaboration on a one-to-one basis for specific purposes resulting in cost-effective positive outcomes. Both dementia-specific initiatives developed by Community Champions were created at little cost because of this approach. A café to support people with dementia and family carers requested a contribution from attendees of purchasing a €2.50 cup of coffee, while the venue and the resources presented at the café were provided free of charge. Liaising with the café owner ensured that the venue was free of charge. The previously referenced example of using graphic design and work colleagues to help develop a choir for people with dementia and family members had a donation box to voluntarily contribute to tea/coffee costs. The venue, the choir facilitation and advertisement were all provided free of charge.

In the interviews with Community Champions, a number of the initiatives described related to work undertaken before involvement with Dementia: Understand Together in Communities. The initiatives developed since the interviewees became involved with Dementia: Understand Together in Communities comprised dementia awareness-raising sessions and social activities such as Dementia Cafes and Choirs. Two of the initiatives took place every month. The dementia café developed was created by a Community Champion who was a retired nurse, with expertise in dementia and previous initiative development experience. The choir was developed by two music teachers who also had personal experience of dementia. A training initiative by a Community Champion is yet to begin and the initiatives undertaken by another Community Champion had ceased. They intend to incorporate further dementia action as part of a bigger operational plan for older persons in the future.

As described previously, while there was a common goal of 'normalisation' among interviewees, perspectives on how this was actualised differed among interviewees. Some identified normalisation as continuing normal life, doing activities and interests that they were used to and being included in the same services that others are involved in.

Others perceived 'normalisation' as creating specific dementia services similar to ordinary interests that people enjoy, but creating a dementia-specific version so that the person could comfortably engage in that space. The interviewee below described her belief that a dementia inclusive choir would be isolating for a person with dementia.

“Say if we just had a choir full stop and said if you have dementia you can also come, it wouldn’t work. I don’t think it would have the same, it would work but it wouldn’t have the same...”

The whole thing is the person with dementia can’t feel isolated and put them into a normal situation, I don’t mean normal, situation, they’re still isolated. They’re still lost.” (CC2)

The actions of the Community Champions are outlined in the following tables.

Table 22: Case Study 1 - Community Champion (CC1)

Initiative Type	Dementia-specific Initiative - Memory Café
Community Champion	Nursing & Dementia Background
Formal /Informal Structure	Informal Structure Community Champion Led with the support of colleagues in a volunteer capacity
Status	Ongoing Once Monthly
Summary	<p>A memory café was held monthly in a bookstore café. The café supported social engagement and information sharing for people with dementia and family members. Guest speakers or the Community Champion shared information about dementia and relevant interest areas. The Community Champion's colleagues supported the initiative in a volunteer capacity.</p> <p>The café was open to people with dementia, family carers, and people without dementia. Customers in the bookstore were welcome to join and members of the local active retired group also attended. The social aspect of the café was also important and could include a singsong.</p> <p>The resources of place, printing and presentations were provided free of charge. Each attendee was asked to buy a tea or coffee in the café leaving the average cost of attendance at €2.50.</p>
Future Initiatives	Craft Group School Awareness-raising

Table 23: Case Study 2 - Community Champion (CC2)

Initiative Type	Dementia-specific Initiative - Musical Choir
Community Champion	Musical Teachers with lived experience of dementia
Formal /Informal Structure	Informal Structure Community Champions Led with the support of colleagues in a volunteer capacity
Status	Ongoing Once Monthly
Summary	<p>A musical choir was set up for people living with dementia and their family members. It was hosted within a music school in the heart of a community, and people with dementia and their family members attended once a month.</p> <p>Two music teachers led out each session, ably supported by their staff who gave their time freely. They provided the room, catering, and handout resources at their own cost. A music book was designed for each participant to use. Community Champions' designed their musical choir based on their individual research of music for people with dementia.</p> <p>They believed that the choir was also an informal carer support group as family members had been known to huddle together over tea and coffee to share information and experience. Each person with dementia had to have a family member attend with them. The choir were preparing for their Christmas event at the time of interview.</p> <p>Other older person services in the community such as residential settings also brought their residents to the choir. Many had requested that this model be replicated for their own services. Time constraints meant that the Community Champions' were unable to support this additional work to date.</p> <p>Premises, facilitation, music and catering was provided free of charge. Donations were accepted for teas and coffees.</p>
Future Initiatives	None referenced

Table 24: Case Study 3 - Community Champion (CC3)

Initiative Type	Dementia Training Resource – Retail Training
Community Champion	Nursing & Dementia Background
Formal /Informal Structure	Lone Worker Community Champion Led
Status	In planning phase
Summary	<p>A retail dementia awareness project was in early-stage development and was planned to be implemented throughout a retail village comprising many retail shops. Initial plans were to train security staff about dementia so that they could assist people with dementia who may visit the retail village. It was hoped that over time staff from the stores within the village would all receive awareness training.</p> <p>The Community Champion has experience of providing dementia retail training and had undertaken significant dementia education herself.</p>
Future Initiatives	As above - Retail training in planning phase

Table 25: Case Study 4 - Community Champion (CC4)

Initiative Type	Dementia Awareness-raising - Community
Community Champion	Nursing & Dementia Background
Formal /Informal Structure	Community Champion Led - within an existing voluntary organisation that has a formal steering group in place
Status	Ceased
Summary	<p>A dementia conversation meeting was held over four months in 2018 supporting the community to discuss dementia.</p> <p>From that meeting a number of initiatives were delivered to the community and included:</p> <ul style="list-style-type: none"> • An Alzheimer Bus with information event • A six-week family carer training event which 15 people attended • An awareness session for businesses in the area, • A carer support group, which has unfortunately ceased. <p>An Age-Friendly strategy for this voluntary organisation is planned and it is intended will include a dementia action plan. The content of the dementia action plan is not yet decided.</p>
Future Initiatives	Action Plan to be developed

Inclusion of people with dementia in initiatives

Just under half of all Community Champions surveyed said that they involved people with dementia and their families when deciding what community actions to take. Those that did involve people with dementia stated that they had participated in conversations and liaison with them, and their families regarding services. Engagement occurred with both family members and/or people with dementia and ranged from engagement at an individual level to meet care plan needs to seeking feedback and evaluation of previous events or services and also to discuss future service development.

Some highlighted the wish to be inclusive but the additional time requirement was deemed to be challenging.

Sample of responses included:

“Need advice on how I would go about involving people with dementia”

“Support groups are a great source of allowing persons to voice their needs of support and how the services could change to provide the support they need at the different stages of dementia care”

“It is important to know their life story and interests, partners invited to share meals, outings with the resident”

All interviewees had used their observation of local need or professional interest area to guide their decision-making on the initiative ultimately developed. However, no people with dementia had been directly involved in deciding on the type of initiative or in designing the initiative that was implemented.

One interviewee described how a research topic informed by people with dementia influenced her initiative.

“...there was a study done in the UK back in 2000 and I think 12 or 14, and a group of people with dementia were asked what, what were the things they wanted to still do after they had, do you know, kind of diagnosis and one of the things they said was shopping, so, and then that’s what got me into it.” (CC3)

Another interviewee described how her observations of service need in the local area influenced the initiative she developed. When asked about the inclusion of people with dementia she described how an Irish Dementia Working Group member attended her café and contributed to discussions.

“And then we have [NAME] keeping us grounded and saying, ‘this is all great, but you have to remember.’ and she will lay down the law about one aspect or another.” (CC1)

A personal need combined with a shared interest with a family member with dementia determined the action taken by two interviewees who worked together on one initiative. Community members’ feedback informed the actions of another initiative.

There was openness to the inclusion of people with dementia in designing and delivering initiatives as one interviewee referenced a person with dementia that she would like to include in a future planned initiative.

3.5 Enablers and Challenges

3.5.1 Enablers

68% of respondents indicated that they have received support from other people in their community e.g. friends, family, work colleagues, business people, community volunteers, who joined and supported them in the actions they have taken.

“Local volunteers, age action have asked to join together in our awareness campaign”

“2 of my friends, I spoke to them about what I was trying to do, and they wanted to help too”

“Cub Scouts, my sister and friends”

Case study interviewees described how using their own skill and expertise, their networks and connections, the goodwill of people to provide their time for free, and their access to and use of resources, at little cost, were key enablers to the success of such initiatives.

The existing skills and expertise in dementia and initiative development were enabling factors for Community Champions. Those interviewed had demonstrated:

- Experience of working with people with dementia
- Knowledge about dementia as a disease
- Established within their community and aware of the local context
- Previous experience of developing and implementing initiatives/services
- Existing relationships and connections within their area

The interviewees identified emotional sensitivity, the ability to advocate and a genuine interest in dementia as requirements for Community Champions.

Established community networks and connections

The case study interviews showed that Community Champions were well known and established within their communities with informal networks developed prior to becoming Community Champions. All had established connections and relationships in their communities with professional colleagues, friends and business acquaintances. Most Community Champions had used these connections to help develop their initiatives and to help them to implement their initiative on an ongoing basis.

Ability to access resources at low or no cost

Access to such resources, services and support for their initiative at little or no cost supported a low or neutral cost initiative to be developed. Resources used included colleagues, employees and friends giving their time voluntarily, providing their skill sets such as graphic design for free, and providing their resources for free such as venue space. Community Champions also gave their own resources for free to support their initiative. Examples shared included provision of venue hire, staff providing time voluntarily, printing and catering resources at no charge. Availability of such resources was specific to each Champion and may not be replicable.

Family Carer attendance in support roles

Case Study interviewees described family member's presence at activities as vital for some initiatives to be feasible. One initiative described how having family members present addressed any safety or safeguarding concerns they would otherwise have had to consider. They did not feel that the initiative could function without the presence of family members. Both dementia-specific resources developed by case study interviewees, i.e. the café and the choir, had family members in attendance at all events and they were considered a vital component to supporting people with dementia at such events.

Information sharing about events to attendees

Information sharing about the initiative and scheduled events was vital to support attendance. Literature sharing across the community and among key stakeholders was considered helpful in raising awareness about the initiatives developed. A Facebook page developed for one initiative was a helpful tool which kept members updated and informed about their initiatives.

3.5.2 Challenges

Over half of Community Champions surveyed (54%), indicated that they had not experienced difficulties or barriers to taking action in their communities. Those that identified difficulties stated that these included:

- lack of funding,
- time and resources,
- conflicting work priorities,
- resistance to change,
- not enough support services on the ground.

Interviewees also reflected on challenges that they had encountered when actioning their initiatives. Time constraints, limited collaboration at a local level, limited engagement opportunities among Community Champions themselves and a lack of endorsement by health services were all seen as presenting challenges.

Time Constraints

Juggling the competing demands of full-time work alongside their champion initiatives was a challenge faced by most case study interviewees. As one interviewee described "*it is difficult to raise your head up to see the bigger picture*" (CC4). Limited time to give to this work impacted (i) the level of engagement, (ii) the scope of what could be achieved, and (iii) their ability to engage with others in Dementia: Understand Together in Communities in terms of time to attend events.

Community Champions recognised time as a particular challenge, limiting how much they could do as individuals. Some saw the solution as the recruitment of additional champions. One interviewee suggested that Dementia: Understand Together in Communities should target those with freer time such as retired individuals. They cautioned that such individuals would need dementia training and the opportunity to work with people with dementia before becoming Community Champions.

Limited collaboration at a local level

Interviewees also described the time constraints as challenging in fully realising the potential for collaboration with other services in the community. They shared how opportunities for further collaboration were not fully realised because of busy schedules.

“There’s a dementia cafe that linked in with us, so they gave us our flyers and we took their flyers, but again they kind of, they didn’t bring anyone here, you know, and I don’t think any of ours went there either (Inter: ok). It was all just kind of, there was a lot of ebbing and flowing.” (CC2)

Such time constraints were perhaps felt more acutely as most of the Community Champions led and delivered their initiatives themselves. The majority of Community Champions did however have the support of colleagues and friends who volunteered at the initiatives. One interviewee described being asked to replicate their initiative in multiple venues and how this had not been possible due to their own work commitments and their responsibilities in delivering their own initiative.

Limitations of current engagement opportunities among Community Champions

Travel time, event duration, and associated costs were described as barriers to attending shared learning events hosted by Dementia: Understand Together in Communities. One interviewee reflected on attendance at a shared learning event organised by Dementia: Understand Together in Communities. *“That was expensive, so it was, so you’d your travel time up and down but the, I thought the car parking was very expensive.” (CC3)* This interviewee illustrated some of the commitment of both time and associated costs to being a Community Champion.

Being part of a community of champions to share learning and build one’s resilience as a lone worker was welcomed by interviewees. The barriers to engagement in this way related to time and work constraints. A suggested solution given by most interviewees to address the challenges of engagement from a time, cost and access perspectives was to create regional opportunities to support regional engagement, networking and collaboration among Community Champions. One interviewee added that knowing what was happening locally among champions could help Community Champions to help each other at local level.

Lack of endorsement by existing health services

The majority of interviewees felt that a lack of endorsement and information sharing by healthcare professionals about their initiatives was a challenge.

“I had posters printed out, taken around to every doctor’s surgery, I have flyers, taking around to every GPs surgery to try and get a doctor or a practice nurse to promote us is... they’re not inclined to do it.” (CC1)

They perceived that such initiatives were not valued as important services for people with dementia and their families by those in healthcare. There was concern that the appropriate people in the community who could avail of these services would not be made aware of such services early enough in their dementia progression and that any future attendance by them would therefore be short-lived.

“Part 2: GP’s, public health nurses, anything people like that, that are in the community need to be pushing. Well, firstly the services need to be in place though, you know.” (CC2)

Most interviewees felt that the lack of signposting to social activities was a reality in the broader context of post-diagnostic supports generally.

3.6 Future Plans and Next Steps

When asked what they would hope to see happen in their community in the future, survey respondents mentioned the need for dementia inclusive services, health and social care services to support the person with dementia and family members and greater awareness about dementia in the community

Table 26: What would you hope to see happen in your community in the future? (Survey)

	Percent
Dementia Friendly Services	22.5%
Support Services	22.5%
Awareness	18.3%
Reduce Stigma	4.2%
Education	4.2%
Events/Activities	4.2%
Training	2.8%

Sample of survey responses:

“Support for people to live as full a life as possible in their own homes”

“Increased readiness to deal with higher numbers of persons living with memory issues, developing a ‘blueprint’ of community approaches that could be replicated elsewhere”

When asked what the next steps were to be taken in the community, survey respondents indicated a continuation of current activities, planning for more events, undertaking more training, organising meetings and more public engagement. 5% were not sure yet of their plans.

Table 27: What do you plan to do next in your community in relation to dementia awareness and inclusivity? (Survey)

	Number	Percent
Continue current actions	10	24%
Plan events	8	19%
Training	7	17%
Service Development	6	14%
Age Friendly / Inclusion	4	10%
Awareness-raising	3	7%
Nothing Planned	3	7%
Not Sure	2	5%
Other	1	2%
Answered	42	

Sample of survey responses:

“Bring art and creativity classes to the residents with dementia”

“Develop further the local family carers support group and looking into developing the community project into a social enterprise”

Interviewees also described future planned initiatives but were limited in detail due to their early stage of development. They included:

- developing a craft group,
- providing dementia awareness to schools,
- retail training,
- incorporating dementia into a larger organisational operational plan.

3.7 Experiences of being a Community Champion

When asked to describe their experiences of being a Community Champion, the survey responses were overwhelmingly positive. Within the overall positive outlook champions also pointed to frustration, lack of time and fatigue in addition to pride, satisfaction in being a change agent etc.

Sample of survey responses:

“At times very frustrated due to the constraints of funding and the services that are available it can be very tiring to try and get around the system as it is not user friendly”

“It’s been a fantastic resource for me and something I wish I could dedicate more time to but I have been able to take what I can and apply it in a greater capacity to my job which in turn benefits more and more people with dementia or caring for those with dementia “

“I love being a champion, prime position to make changes happen”

“Can be rewarding but also time-consuming”

“It’s been a major learning curve for me both professionally and personally”

“It’s hard work - I love it and it is beyond necessary. There is just so much that needs to be done and as a volunteer doing this on my own in my community - it feels like a huge undertaking, but it has to be done”

“It’s very much pioneering activity, to create interest in the issue and highlighting the fact it concerns everyone in the community”

While the majority of Community Champions interviewed also shared the above experiences one also highlighted the challenge of working alone was highlighted and needing the support and endorsement of Dementia: Understand Together in Communities.

Section 4 - Discussion

4.0 Introduction

The use of mixed methods in this evaluation provided an overview of the implementation process of the Dementia: Understand Together in Communities phase of the Dementia: Understand Together Campaign. This overview was obtained through a national survey and issues were then explored in greater detail through the case study interviews. The survey response rates - 32% for Community Champions and 57% for National Partners - were in line with and above the average 29% (<https://surveyanyplace.com/average-survey-response-rate/>) for online surveys. In a purposive sample of eight case studies, some of the survey questions were explored in greater depth through face-to-face interviews and additional topic areas were addressed as they arose in discussion. There is a possibility of sampling/response bias and the views expressed may not be representative of those in the wider group of National Partners and Community Champions.

4.1 Background and Recruitment

4.1.1 National Partner Organisations

The National Partner organisations, half of which had 500+ employees/members were primarily in the public and community sector, with the private sector represented by retail, banking and health and other services. Before their involvement in Dementia: Understand Together in Communities, two-thirds of the organisations had engaged in dementia-related activities such as staff training and media events. Respondents from the National Partner organisations were in leadership roles e.g. CEOs and management, and a majority were women aged 45-64 years.

Many of those interviewed had previous experience of working in partnership with other organisations or groups relating to inclusion and wellbeing issues. The support of senior management and work colleagues was acknowledged by National Partners as facilitating the implementation of Dementia: Understand Together in Communities programme activities. This support enabled many of the planned actions to take place and to work well. Motivation for involvement in Dementia: Understand Together in Communities was influenced by family experiences with dementia and for work-related reasons, with commitments reflecting customer and services users' needs, and influenced by accessibility and inclusion policies. Interviewees also described similar enabling infrastructures to support their work and valued working in partnership with organisations such as Dementia: Understand Together in Communities in achieving their goals.

The organisations' existing internal structure and focus on customer service enhancement appear to have been key enablers for this work to begin. Identifying key contacts working with existing teams such as inclusion, corporate social responsibility, disability and health and wellbeing have ensured that 'dementia' sits within a fixed objective, operational plan, or ongoing remit area with the organisation.

All the above were facilitators for engagement of National Partner Organisations with the Dementia: Understand Together Campaign. An organisation that already has an inclusive remit and the appropriate infrastructures in place to support partnership approaches in achieving the shared goals of inclusion would suggest that they have 'indicators of readiness to participate' effectively in the Dementia: Understand Together Campaign. This 'readiness to participate' should be considered when additional national partners are being recruited into the future.

4.1.2 Community Champions

The majority of Community Champion respondents were women, aged 45-64 years. Over two-thirds were working full time, mainly in the health and social services sectors. Half of all respondents were involved also in other community and voluntary work e.g. in age-related and social/charitable groups. As was the case with the National Partners, a majority had personal experience of dementia, mainly with family members.

The motivation to become a Community Champion included wanting to raise awareness of dementia and to support people with dementia and families. Most interviewees referenced the lack of appropriate services for people with dementia at earlier stages of dementia as a primary reason for becoming involved.

Three-quarters of respondents had been involved in dementia-supportive activities before becoming a Community Champion, through awareness-raising, getting trained and training others, and service developments. The majority interviewed also shared this experience with some having worked in dementia-related services, received dementia-specific education, and in many cases had developed dementia or age-related initiatives before engagement with Dementia: Understand Together in Communities. A common expertise among Community Champions suggested a specific skill set requirement of dementia knowledge and experience, strategic engagement ability and initiative development experience.

These skill sets reflect the attributes of dementia experience and change agent knowledge highlighted as necessary for Dementia Champion Programme (Irving et al 2014) and Scotland's Dementia Champion Programme (Brown et al 2018). This indicates a specific skill set requirement or criteria for recruitment for Community Champions into the future. Further recruitment of Community Champions with this unique skill set combination may be limited outside of those who have previously worked in health services or dementia-related services. Efforts must be made to broaden recruitment of Community Champions beyond those that have worked in health service and dementia previously, to grow the 'army', and additional supports given to upskill the core areas identified above. While Dementia: Understand Together in Communities support a social movement approach and recognise that not all champions will be leaders, findings from this evaluation indicated that the above specific skill set combination is necessary to progress action.

The majority of interviewees worked alone or with informal partners or supporters. Only one interviewee worked as part of a steering group in their full-time role. Partnerships, networks and collaborations have been identified as a critical aspect to creating inclusive dementia actions (Williamson 2016). A structure for collaborative partnerships was absent and much depended on the personal networks of the Community Champions themselves, when progressing actions. However, over-dependency on one individual leading such initiatives could risk sustainability over the longer term and limit the potential reach and impact that could be achieved.

Recommendation 1: We recommend that Dementia: Understand Together in Communities recruit, develop and train a diverse range of Community Champions outside of those that have worked in the health services to support greater growth and sustainability of Dementia: Understand Together in Communities and support the development of core skills.

At National Partner level management support, prior activities in inclusion-related areas, and partnership/working with NGOs, may be considered indicators of 'readiness' to participate which could be used for National Partner recruitment.

Recommendation 2: We recommend the use of 'indicators of readiness to participate' for National Partner recruitment.

4.2 Resources and Training Requirements

Dementia: Understand Together resources and materials were used by most survey respondents and interviewees. Campaign materials, face to face and online training were used by many National Partners, and correspondence with the campaign team was beneficial and a welcome resource. The resource materials were considered satisfactory with some suggestions about improvements e.g. ensuring up to date information is included, and adaptations to particular organisational contexts. Interviewees also confirmed the use of the Dementia: Understand Together in Communities materials provided, both as a resource for staff and dissemination to their customer base. Knowledge of the full extent of resources available differed among Community Champions interviewed and perhaps reflects the staggered recruitment of Community Champions over time.

Dementia: Understand Together in Communities resources enabled National Partners and Community Champions to engage in project planning and actions. National Partner interviewees described individualised supports and connections to the campaign as being very helpful and necessary to support their work. The previous challenges to engagement with businesses that have been experienced by other dementia-friendly initiatives in the past can be overcome when there is a targeted and supportive engagement by the campaign with the organisation (Dean et al 2015). The findings from the interviews reflected how individual and organisation specific support by Dementia: Understand Together in Communities to each organisation sustained positive engagement.

All National Partner interviewees were able to highlight specific staff roles, variously described as 'ambassadors', 'volunteers' or 'corporate social advocates' as resources already within their organisations that could play a supportive role in achieving their dementia inclusive goals. They felt that these roles were well positioned to have the greatest impact for reach directly to people with dementia and to staff/members. Targeted awareness-raising or training of such 'ambassadors' within each organisation to support independent progress by National Partner organisations could facilitate a sustainable solution that addresses potential capacity issues that could arise for Dementia: Understand Together in Communities.

Recommendation 3: We recommend a targeted training drive for National Partner 'ambassadors' to support more efficient reach within the organisation and sustainable action.

Training resources for National Partners need to be updated, made more accessible, and adapted to individual National Partner organisational contexts. Training must consider time constraints on the part of National Partners and developing online materials/providing remote educational activities (e.g. train the trainer, Webinars) should be considered.

Recommendation 4: We recommend an online induction resource pack be provided to incoming Community Champions and National Partners.

Recommendation 5: We recommend that existing Community Champions and National Partners be provided with an updated link to all resources.

Most of the Community Champions interviewed worked quite independently of Dementia: Understand Together in Communities, with some feeling somewhat disconnected. While there may be multiple reasons for this, including differing support requirements, Community Champions also referenced time, cost and travel constraints as barriers to engagement. Some interviewees mentioned events being held in Dublin, not feeling their efforts were visibly supported by the Dementia: Understand Together in Communities and feeling somewhat removed from the wider community of champions, naming these as barriers. The majority of Community Champions worked informally with others and did not have a networked structure to guide their work. Over-dependency on one person could risk the sustainability of the initiatives developed if that person was to step away. It could also limit the potential reach of the Community Champion in achieving dementia inclusive action.

Promoting the development of functioning networks to support initiative development and implementation among existing and incoming Community Champions could support more self-sustaining and independent actions at local level. Partnerships, networks and collaborations have been identified as a critical aspect to creating inclusive dementia action (Williamson 2016). Over-dependency on one individual leading the initiatives could risk sustainability over the longer term and limit the potential reach and impact that could be achieved. Community Champions are isolated and need to be connected and supported. Greater network support and structure should be provided for Community Champions to facilitate growth and development of Community Champion movement. A training resource to support such development should be provided to Community Champions.

Recommendation 6: We recommend the development of training resources to include: i) understanding dementia ii) strategic collaboration and iii) initiative development.

Recommendation 7: We recommend guidance and support be provided to Community Champions about how to develop a coordinated network structure and support self-sustaining and independent action.

4.3 Shared learning

Both National Partners and Community Champions valued the opportunity for shared learning. National Partners interviewed also valued the opportunity to learn from others in a non-competitive space. One National Partner organisation which is about to become active recognised the potential of accessing existing Community Champions to achieve rapid reach to their branch office staff in delivering dementia awareness. This example demonstrates the possibilities of having shared convenings among National Partners and Community Champions at both the national and regional level. Such actions could also address the challenges of disparity between national partner sign-up and local input by national organisations experienced in previous dementia inclusive initiatives (Dean et al 2015).

Most of Community Champions interviewed favoured opportunities to meet regionally from a time and cost perspective. They wanted to share learning with other champions, to listen to others about the work underway from across the country and to help each other. This was perceived as an opportunity to network and potentially collaborate. Capacity challenges for the Dementia: Understand Together in Communities' team could emerge as additional Community Champions come on board. Supporting targeted regional Community Champion network activation could provide a solution as regional networks could be supported to become self-sustaining.

At interview, a number of Community Champions expressed openness to supporting other champions and sharing information about their initiatives to help others. They described their willingness to resource share, facilitate site visits, provide mentorship and share 'how-to' templates of their work. Harnessing this interest within regional learning or networking events could stimulate collaboration among National Partners and Community Champions. Building active and collaborating communities at regional level could also facilitate supportive spaces for incoming Community Champions and National Partners. Additionally, connecting Community Champions and National Partners at national or regional level could support efficient growth and reach.

Training was provided and received by the Community Champions and National Partners interviewed. Some Community Champions were the trainers in their context as they shared dementia awareness as part of their initiative, and the National Partners were the recipients of training in their context. Key campaign partners supported the provision of training to National Partners. Matching Community Champions who are trainers with National Partners in need of training could support capacity and cost issues that may arise for Dementia: Understand Together in Communities as further National Partners and Community Champions are recruited and training needs increase.

There are few opportunities for Community Champions to learn together. It is important to promote shared learning, showcase good practice at regional and national level. Technology supports may be necessary to support this given time constraints and travel challenges.

Recommendation 8: We recommend exploring the potential of regional and national shared learning opportunities, mentorship support, cross-collaboration opportunities and leadership development for both National Partners and Community Champions.

Interviewees mentioned the importance of having one's work recognised by Dementia: Understand Together in Communities, and the benefits of showcasing one's work to others. The question of what is required of a National Partner on an ongoing basis to maintain membership was also asked. Recognition of individual work and retaining existing membership in the longer term are valid considerations for Dementia: Understand Together in Communities.

Recommendation 9: We recommend that some consideration is given to how individual's work can be acknowledged by Dementia: Understand Together in Communities and membership status could be maintained in the Dementia: Understand Together campaign.

Access to equipment and small-scale financial supports were also mentioned as a barrier to action. Small scale financial supports to deliver external training provision were requested by some interviewees. They included loan access to resources such as projectors or the provision of Wi-Fi dongles to support film downloads for training purposes. Small scale financial setup costs were also advocated for those Community Champions who may have difficulty in accessing venues at no charge in the early stages of their development.

Of note is that financial costs were not presented as significant barriers to engagement by either National Partners or Community Champions interviewed. However, any related costs for providing training, for example, was paid for by the organisation themselves. The only exception was a voluntary organisation that felt that the external facilitation costs that would be required to meet training demands would be prohibitive. From the Community Champions perspective, much of the real cost of initiative development and implementation was minimised as Community Champions shared their resources of venue, printing, catering and time at no cost, or sought the help and assistance of others in their community to provide resources or time at no cost. Community Champions could do more if they had a small budget. Efforts should be made to provide local budget to support activities of Community Champions.

Recommendation 10: We recommend the provision of access to equipment and small-scale financial supports where required for Community Champions to enhance sustainability and impact.

Recommendation 11: We recommend the promotion and sharing of resources among Community Champions to avoid duplication of efforts and support cost-effective initiative development.

4.4 Actions and Initiatives

The actions taken by National Partners were largely training of staff members, awareness-raising through media such as press, social media, radio, and guest speakers. They also reviewed their services for dementia inclusion and used networking opportunities to share learning. The Community Champions surveyed took action to support people with dementia and their families through awareness-raising, information sessions with service providers, and again used media of various kinds, social media and local radio stations and distributed Dementia: Understand Together in Communities resource materials.

Initiatives developed by the National Partners and Community Champions interviewed covered a range of activities including dementia awareness-raising and dementia-specific activities such as dementia cafes and choirs. No dementia inclusive activities had been developed but some were planned.

'Normalising' approaches that enable a person with dementia to live as well as possible were goals for both National Partners and Community Champions interviewed. Definitions of 'normalising' differed among interviewees, however, as some determined that normalisation meant creating a dementia-specific resource that was held in a 'normalising' space. For example, a memory café specifically for people with dementia and family carers but held in a café space. Another example was a choir for people with dementia and their families that was held in a music school. Some interviewees felt that people with dementia could not be part of such activities that were not dementia-specific as they would be 'lost' if they were among others without dementia.

Others understood normalisation to mean inclusion in usual services that all people accessed and that people with dementia could also be a part of. Some felt that siloing people with dementia into separate groups was not helpful for the person with dementia.

Differing opinions related to each interviewee's own experience, interest and understanding of dementia and reflected the broad range of needs that a person with dementia will have throughout their experience with dementia. Dementia Awareness-raising: All interventions undertaken by National Partners to date have focused on dementia awareness-raising among staff and members and information dissemination among customers. Community Champions have also incorporated dementia awareness alongside dementia-specific actions.

Previous community-based initiatives have supported the importance of ongoing awareness-raising, but have also highlighted the need to bridge the gap between general awareness-raising opportunities and taking specific actions to enhance service offerings that are inclusive of people with dementia (Genio, 2016). The National Partners and Community Champions interviewed were involved in awareness-raising initiatives were at relatively early stages of engagement having worked with a specific branch or group of individuals and hoped to build on that awareness-raising with other cohorts in the future. Only one interviewee described their intent to move towards developing a dementia inclusive action in the future.

Dementia-specific Activities: Two Community Champions interviewed demonstrated low-cost social activities specifically created for people living with dementia. The only costs incurred per session was for coffee. Leveraging the specific resources available to the individual champion such as free venue hire enabled such a low cost to be achieved. The potential costs of such initiatives could have been venue hire, catering costs, printing costs, facilitation and support costs. It should not be presumed that access to such resources would be available to all Community Champions as highlighted by some respondents who identified such costs as a potential barrier to action.

In both dementia-specific initiatives developed, family members or paid support staff came to the activity with the person with dementia. This support was referenced by one group as being vital to the ongoing success of their initiative as it would not otherwise have been feasible to facilitate from a safety perspective.

While dementia-specific services are a vital support for people with dementia, the sustainability of such dementia-specific initiatives is dependent on the above combination of circumstances relating to resource access, expertise and support remaining in place. In particular, the Community Champion is the vital ingredient to all that has been created. If that person steps away from their initiative, there is a high risk that the initiative could cease. As previously discussed supporting a Community Champion to develop a broader committee or community group around them to oversee such initiative development and to support potential further growth, would contribute significantly to addressing sustainability challenges.

Dementia Inclusive activities: Aligning to the proposed actions of WHO Dementia Awareness and Friendliness (2017) inclusion of people with dementia in activities of the wider community was also advocated by some interviewees. While some references were made to including people with dementia previously in their work roles in exercise classes for older people or in day and community services for older people, there were no examples shared of services being enhanced to become dementia inclusive. One example of a future planned intervention is the inclusion of people with dementia into a voluntary organisation's social groups.

The experience to date of the Community Champions interviewed reflects many previous dementia-friendly initiatives that demonstrate a prominence of dementia-specific activities with less dementia inclusive activities mobilised. Learnings suggest that the challenges for engagement relate to relevance for the group or business that may be asked to become dementia inclusive alongside time and cost implications. Further exploration of the feasibility of such initiatives is required and may benefit from guidance and support from Dementia: Understand Together in Communities about how to engage in this work meaningfully. Additionally, creating 'separate' initiatives and placing them into a community rather than designing along with the community may also have ramifications to buy in as some initiatives may be limited to the specific and current group attending with little or no reach outside of it (Dean et al 2015).

Inclusion of people with dementia and families in planning: Including people with dementia and their families in deciding what actions to take did not occur with 60% of National Partner respondents or in approximately half of the Community Champions. Some have planned to do so in the future. At case study interviews National Partners shared how they benefitted from the inclusion of people with dementia in awareness and training sessions provided by Dementia: Understand Together in Communities as they gained a greater perspective of the challenges being faced by people with dementia. They did not share instances where the person with dementia was included in deciding on any actions to be taken in their organisation. No Community Champions interviewed described including people with dementia in determining the actions that were subsequently undertaken. They primarily spoke of how their own experience and local or personal knowledge or community feedback informed the actions taken.

The inclusion of people with dementia in decisions ranged from receiving advice through to consultative groups. At interview, neither National Partners nor Community Champions described involving people with dementia in how they decided on the interventions subsequently implemented, suggesting that there may be need for further exploration of the extent and nature of the inclusion (Buckner et al 2019). The non-engagement of people with dementia for a significant proportion of National Partners and Community Champions flags the need for guidance on how to include people with dementia in service design and may require the support of Dementia: Understand Together in Communities in how to achieve that meaningfully.

People with dementia and family members are not fully included in planning activities and initiatives at National Partner or Community Champion level. This needs to be addressed and will need training in the inclusion of people for whom the initiatives are intended, to investigate public and patient involvement (PPI) in design and implementing actions.

Recommendation 12: We recommend that specific guidance and support be provided to achieve greater involvement by people with dementia and family members in the planning and design of Dementia: Understand Together in Communities related initiatives.

Recommendation 13: We recommend guidance and training support be provided regarding the three pillars of action (i) General Awareness-raising (ii) Dementia-specific Initiatives (iii) Dementia Inclusive Initiatives and how to navigate between them.

Health Service Support of Initiatives: Resistance to change and established practices among some service providers was highlighted as challenging by Community Champion respondents.

Lack of engagement by others in initiatives developed was perceived as being about lack of personal interest for some to become involved as well the lack of time to build collaboration with others. The majority of Community Champions interviewed referenced a perceived lack of buy-in and support from health care services, particularly GP's, in promoting their initiative to families. Social initiatives such as the ones developed by interviewees are recognised as an integral part of good dementia care going forward but have not been given the appropriate status within healthcare (Shafi & Crockett, 2019). Jennings et al (2018) also described the prevailing lack of awareness of such initiatives and uncertainty about how to access them by GP's which also suggests that some awareness-raising among health and social care staff is required. The findings from this evaluation also identify that targeted awareness-raising among health and social care staff about the availability of such services is required. Targeted awareness-raising for GP's at a national level by the Dementia: Understand Together in Communities Campaign about such initiatives and their benefits would be a helpful support mechanism for Community Champions.

Recommendation 14: We recommend the promotion of targeted awareness of Dementia: Understand Together in Communities initiatives to both health care services and family members.

4.5 Changing Perceptions and Future Plans

National Partner and Community Champion involvement in Dementia: Understand Together in Communities were expressed as overwhelmingly positive experiences, contributing to well-being and found to be very rewarding for individuals. There was simultaneously acknowledgement of frustration and fatigue in addition to pride and satisfaction. One person remarked that as a Community Champion they were involved in "pioneering activity" in the community.

Awareness-raising contributes to altering attitudes and behaviours about dementia (Dean et al 2015). A majority of Community Champion respondents felt that there had been a change in how people with dementia and their families have been supported and included in society since the start of the Dementia: Understand Together Campaign in 2016. While the majority of National Partner and Community Champion interviewees shared positive feedback about the impact of the national TV ad campaign, they also cautioned about the ongoing need for awareness-raising to counteract the prevailing stigma that continues to be present about dementia and to keep dementia to the forefront as a priority issue.

Some Community Champions interviewed described how the next phase of awareness-raising should incorporate Community Champions showcasing how to do this work and welcomed opportunities to be involved. Some National Partner interviewees reflected how their involvement in the campaign and being recognised as a National Partner of the campaign was beneficial to their organisation.

Most National Partner survey respondents felt that the actions taken had raised awareness within their organisations and within the wider community. While similar feedback was shared by National Partner interviewees as they described staff and customer awareness-raising, none shared examples of how this awareness-raising was changing how services were delivered to customers. None of the National Partners interviewed had developed dementia inclusive or specific actions to date, but rather had focused on dementia awareness-raising for staff. Future actions are planned to support dementia inclusive communities, including more training and information for staff to continue and extend their current activities. One example shared was to develop a guidance document that would support the inclusion of people with dementia into their service, demonstrating an intent to move toward dementia inclusion.

Similarly, a majority of Community Champions survey respondents felt their actions have raised awareness and increased understanding in their networks and the wider community. They believed that there was a greater understanding of the condition and terminology around it, less fear and negative perceptions. Interviewees shared anecdotal accounts of how the initiatives they had developed were supporting family carers and people with dementia.

As previous community activation evaluations have identified, evidence of tangible progress from dementia awareness-raising activities is difficult to ascertain (Buckner et al 2019). At interview, anecdotal changes were shared of how staff now a greater understanding of dementia had but how that was impacting services was more challenging to identify.

Recommendation 15: We recommend continued dementia awareness-raising at national level incorporating the work of the Community Champions and National Partners to showcase progress and mobilise further engagement with the Dementia: Understand Together in Communities campaign.

Section 5: List of Recommendations

The following is a list of recommendations based on findings from the process evaluation undertaken to understand how the Dementia: Understand Together in Communities component of the awareness campaign is being implemented.

1. The Dementia: Understand Together in Communities campaign should recruit, develop and train a diverse range of Community Champions outside of those that have worked in the health services to support greater growth and sustainability of Dementia: Understand Together in Communities and support the development of core skills.
2. Use 'indicators of readiness to participate' for National Partner recruitment.
3. Run a targeted training drive for National Partners 'ambassadors' to support more efficient reach within the organisation and sustainable action.
4. Provide an online induction resource pack to incoming Community Champions and National Partners.
5. Provide existing Community Champions and National Partners with an updated link to all resources.
6. Develop training resources to include: i) understanding dementia ii) strategic collaboration and iii) initiative development.
7. Provide guidance and support to Community Champions about how to develop a coordinated network structure and support self-sustaining and independent action.
8. Explore the potential of regional and national shared learning opportunities, mentorship support, cross-collaboration opportunities and leadership development for both National Partners and Community Champions.
9. Consider how individual work can be acknowledged by Dementia: Understand Together in Communities and membership status could be maintained in the Dementia: Understand Together campaign.
10. Provide access to equipment and small-scale financial supports where required for Community Champions to enhance sustainability and impact.
11. Promote and facilitate sharing of resources among Community Champions to avoid duplication of efforts and support cost-effective initiative development.
12. Provide specific guidance and support to achieve greater involvement by people with dementia and family members, in the planning and design of Dementia: Understand Together in Communities related initiatives.
13. Provide guidance and training support regarding the three pillars of action i) General Awareness-raising ii) Dementia-specific Initiatives iii) Dementia Inclusive Initiatives and how to navigate between them.
14. Promote targeted awareness of Dementia: Understand Together in Communities initiatives to health care services and family members.
15. Continue dementia awareness-raising at national level incorporating the work of the Community Champions and National Partners to showcase progress and mobilise further engagement with the Dementia: Understand Together in Communities campaign.

Appendix 1 - Question Sheets for National Partners & Community Champions

National Partners

1. Background

- Q: What is your own background - work/position/interest in this area
- Q: Describe the context/organisation you are working/interested in
- Q: From your perspective describe the level of dementia awareness that existed in your context prior to becoming involved

2. Understand Together Campaign

- Q: What is your understanding of the campaign, its components and what it is trying to achieve (mass media, partner and champion activation, storytelling)

3. National Partner

- Q: How did your organisation become a national partner and why did they become involved?

4. Changing Perspectives

- Q: What action did your organisation initially anticipate taking? Did that change over time?
- Q: Did your organisations/staff/individual perception of dementia change as a result of being involved in Understand Together as a National Partner? (Policy, Practice, Behaviours)
- Q: Has your service delivery to people with dementia changed? Explain how?
- Q: Did you include people with dementia in designing your initiative?
- Q: Do you anticipate continuing with this work in the years to come? and if so how?

5. Resources

- Q: What resources developed by the Understand Together campaign did you access? How helpful were they? (Service Mapping, Website, Literature, Video, Shared Learning Events, Collaboration with other champions, individual campaign support by phone/in person.)
- Q: Did the mass media campaign help you in your work? Explain
- Q: Did the work of other campaign partners have an effect on your actions? Did the storytelling aspect support your work?
- Q: Are there additional resources that would have been helpful to you? (Organisation specific resources? Training, Handbook, Individual support, Fact sheets geared towards specific sectors, i.e. pharmacy, transport, community)

6. Action Planning

- Q: What were the steps you took to achieve your goals? (Needs identification, buy-in from key organisational stakeholders, agreement on action and scope, plans to embed the action to achieve scale in the organisation (reach and repetition))
- Q: Who were the key people in your organisation that you involved? (why, how, what is result and why is it important that they were engaged)

7. Initiatives implemented

- Q: Can you share some examples of the initiatives you undertook? (What, who, when, where, how - capture supporting physical evidence/resources?) (Time, Reach, Impact, Quality Feedback, Sustainability, Cost.)
- Q: What has been the impact (of these initiatives) on the organisation, staff, people with dementia?
- Q: What were the enablers present that supported this initiative to succeed?
- Q: Do you anticipate sharing this work with colleagues from additional branches/offices and if so how?

8. Challenges

- Q: What challenges did you face in developing initiatives and how might they be overcome? Initiative Level (Communication, Time, Cost, Sustainability, Reach, Impact, Buy-In from staff and/or management, Internal organisation constraints, Process change requirements)
- [if funding mentioned as a barrier - how much do your Understand Together activities cost on average? How would you handle funds if they were provided?]
- Campaign Support Level (Existing Resources, Networking Opportunities, Education Content and approach, Individual support)

9. Next Steps

- Q: What are your anticipated next steps? (Scaling, further roll-out, new initiatives, what processes, policies have been put in place?)

10. Mobilisation

- Q: If you have seen changes in community/org/services provided/people with dementia, are these changes sustainable do you think?
- Q: What would it take to make activities/change sustainable? (network, process, funding etc.)

Community Champions

1. Background

- Q: What is your own background - work/position/interest in this area
- Q: Describe the context you are working/interested in
- Q: From your perspective describe the level of dementia awareness that existed in your context prior to becoming involved

2. Understand Together Campaign

- Q: What is your understanding of the campaign, its components and what it is trying to achieve

3. Community Champion

- Q: How did you become a community champion and why did you become involved?

4. Changing Perspectives

- Q: What action did you initially anticipate taking and did that change?
- Q: Did you include people with dementia in the design of your initiative?
- Q: Did your perception of dementia change as a result of being involved in Understand Together as a Community Champion?

5. Resources

- Q: What resources developed by the Understand Together campaign did you access and how helpful were they? (Service Mapping, Website, Literature, Video, Closed Facebook page, Shared Learning Events, Collaboration with other champions, Champions' Café, individual campaign support by phone/in person.)
- Q: Did the mass media campaign help you in your work? Did the Partner work have an effect on your actions? Did the story-telling aspect support your work?
- Q: Are there additional resources that would have been helpful to you? (Training, Network connection, Individual Support, Handbook, Facilitation on-site/in community support)

6. Action Planning

- Q: What were the steps you took to achieve your goals? (Needs identification, collaboration with key stakeholders - group development/collaborative action with services in community - organic or planned)

7. Initiatives implemented

- Q: Can you share some examples of the initiatives you undertook? (What, who, when, where, how - supporting physical evidence/resources?) (Time, Reach, Impact, Quality Feedback, Sustainability, Cost.)
- Q: What were the enablers present that supported this initiative to succeed?

8. Challenges

- Q: What challenges did you face in developing initiatives? How might they be overcome?
- Initiative Level (Time, Cost, Sustainability, Impact, Buy-In)
- Campaign Support Level (Existing Resources, Networking Opportunities, Education Content and approach, Individual support)

9. Mobilisation

- Q: Female Community Champions more than male, why do you think this is?
- Q: How do you think we can inspire more men to get involved together as a Community Champion and Understand Together campaign.

10. Future Sustainability

- Q: If you have seen changes in community/org/services provided/people with dementia, are these changes sustainable do you think?
- Q: How important is the link to community organisations, health services, other champions to achieve felt and sustainable change?
- Q: What would it take to make activities/change sustainable? (network, process, funding etc.)



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Notes

A series of horizontal dotted lines for writing notes.



