

## **A Review of Global Dementia Friendly Symbols – final report**

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### **PURPOSE OF THE REPORT**

The World Young Leaders in Dementia (WYLD) network were commissioned by the UK Department of Health to undertake a scoping review of global Dementia Friendly symbols and brands. We have received input from 16 different nations to describe Dementia Friendly symbols currently in use around the world, their meaning and their perceived success within each community. We have collected perspectives on the opportunity for and barriers to adopting a global theme or symbol for Dementia Friendly communities from these nations and also from young leaders within the WYLD network. Here we review our findings and put forward some recommendations for further developing and testing the concept of a global symbol for Dementia Friendly communities.

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## INTRODUCTION

There are an estimated 44 million people currently living with dementia around the world and this number is set to reach 130 million by 2050. Almost 60% of persons with dementia currently live in developing countries (World Alzheimer's Report, 2015), although developed countries have greater age-adjusted incidences of dementia. Dementia is a global challenge that requires global solutions.

Dementia describes a state of cognitive or functional impairment caused by diseases of the brain. These diseases cause a progressive decline in memory, judgment, behavior, emotions and language. Although each person will experience dementia differently, the condition is currently irreversible and eventually all those affected will be unable to live independently, i.e. without needing assistance with care. But, just like any other person, a person with dementia has both strengths and weaknesses and is capable of living a positive meaningful life (Lin and Lewis, 2015). This can be especially true if there is appropriate cognitive, social, and environmental support.

At the first World Health Organization Ministerial Conference on Global Action Against Dementia in March 2015, 91 countries committed to work together to 'promote a better understanding of dementia, raise public awareness and engagement, and to foster greater participation, social inclusion and integration of people living with dementia in their communities'. One relatively cost effective route towards meeting this call to action is the adoption and implementation of Dementia Friendly initiatives such as Dementia Friendly Communities (Alzheimer's Disease International, 2015).

For the purpose of this review, Dementia Friendly communities are defined as communities in which persons living with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

Initiatives are emerging around the world to make communities – on local, regional and national levels – more dementia friendly. These initiatives take many forms, with some focusing on raising awareness and tackling stigma, some on positive action by individuals and others on creating new dementia services. In Japan, over 5 million trained volunteers are providing grassroots care and support tailored to their local communities such as day care facilities, advice services and peer support groups. In the UK the Alzheimer's Society's Dementia Friends programme is working to change people's perceptions of dementia and transform the way the nation thinks, talks and acts about the condition.

Many Dementia Friendly initiatives use a symbol or a brand to promote their activities. They can be used to facilitate raising awareness of dementia; raising awareness of the initiative; or marking individuals, organisations and services aware of and/or sensitive to the needs of persons living with dementia.

Some dementia advocates have highlighted the need for a Dementia Friendly symbol that has global recognition. A global symbol could connect Dementia Friendly efforts across different regions and countries and help persons living with dementia and caregivers to recognize the symbol when they travel, regardless of language or culture. WYLD has been commissioned to lead this scoping review as we comprise an international network of independent and passionate dementia experts.

## CHAPTER 1: DATA COLLECTION AND ANALYSIS

A survey was sent via e-mail to 40 representatives from 25 nations including those in Africa (Ghana, Nigeria, Togo, Uganda), Asia (India, Indonesia, Japan, South Korea, Singapore, Taiwan, Thailand), Europe (Belgium, France, Germany, Ireland, Netherland, United Kingdom), the Americas (Argentina, Canada, Chile, Costa Rica, Mexico, United States) and Oceania (Australia, New Zealand). Efforts were made to identify all countries with existing Dementia Friendly symbols and to contact an appropriate representative. Lack of an existing Dementia Friendly initiative in some countries was identified as barrier for the review as it led either to failure to identify an appropriate representative or lack of a response after contacting them.

E-mail recipients were identified by their participation in global discussions on dementia friendly communities or initiatives, through the UK Science and Innovation Network and via personal contacts. Specifically, WYLD members identified suitable representatives by participating in the World Health Organization 1<sup>st</sup> Ministerial Conference on Global Action Against Dementia (Geneva, March 2015), ADI's Global Overview of Dementia Friendly Community Initiatives meeting (The Netherlands, June 2015), and at the World Dementia Council meeting held in London, February 2016.

More than one representative was contacted for the following countries: Australia (2), Belgium (2), Canada (2), India (4), Japan (3), South Korea (2), United Kingdom (4), and United States (3). None of the sent emails were unable to be delivered due to incorrect email addresses.

### The survey

The survey was split into two parts (see Appendix 1).

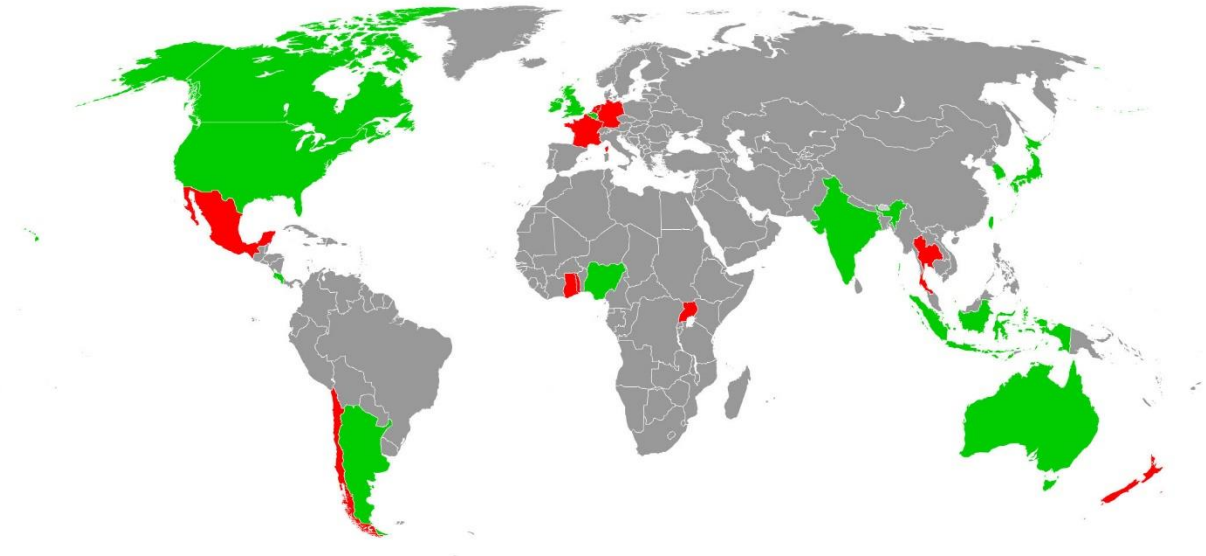
- Part 1 asked the respondent about the existence of a dementia friendly community or initiative in the self-identified region or nation, a symbol or symbols representing this initiative, the symbol's cultural significance, how the symbol is used and a subjective assessment of the symbol's use in the region or nation.
- Part 2 asked about the participants' attitudes towards a global Dementia Friendly symbol, their region or organisation's likelihood of adapting a global symbol, and factors which may enhance the integration of a global symbol into the regional or national strategy.

Representatives of nations without their own Dementia Friendly initiative or symbol were still able to share their views on a global symbol by completing only part 2 of the survey. Whenever possible, multiple choice questions or rating scales were used to allow responses to be quantified. For the open text questions, we analysed common themes emerging across the collective responses.

### Responses

Twenty one responses representing sixteen nations (64% of nations contacted) were received. For some nations, multiple responses were received allowing us to collect perspectives from different geographic regions (i.e. India) or from different Dementia Friendly initiatives within the same country (i.e. US).

Responses were received from: Argentina, Australia (2), Belgium (2), Canada, Costa Rica, India (2), Indonesia, Ireland, Japan (2), Nigeria, Singapore, South Korea, Taiwan, United Kingdom (2) and United States (2). A full list of survey responders and their affiliations can be found in Appendix 2.



**Figure 1: Geographic spread of survey responses**

Nations in green returned responses, nations in red did not.

#### **Workshop at ADI conference 2016**

Following collection of the survey results, a workshop was organized on April 24 2016 at the Alzheimer’s Disease International conference 2016 in Budapest, Hungary. Thirteen members of WYLD representing seven countries (Belgium, Canada, Germany, Indonesia, Singapore, UK, USA) and six invited guests attended. The purpose of the workshop was to:

- Review findings from the a draft version of the current report (Clare Walton and Melissa Chan);
- Present findings from a pilot market survey conducted at the WYLD stand during Alzheimer’s Disease International regarding respondents’ preference for a dementia friendly symbol, element, or neither;
- Discuss perspectives from a person living with dementia: “What’s in a Symbol?” (Kate Swaffer, Chair of Dementia Alliance International and an advocate for Alzheimer’s Australia since she was diagnosed with younger onset dementia)
- Conduct a facilitated group discussion regarding “What kind of element could be used to connect all dementia symbols?” (Kristine Newman).

**CHAPTER 2: REVIEW OF EXISTING DEMENTIA FRIENDLY SYMBOLS**

All but one of the representatives surveyed indicated his/her region or nation has a Dementia Friendly community or initiative. With the exception of Argentina, each program has a symbol with which the community or initiative aligns but some of these are more developed and widespread than others. While most nations use a brand or designed symbol, India associates their initiative with the Banyan tree, but does not yet have any designed materials that we are aware of.


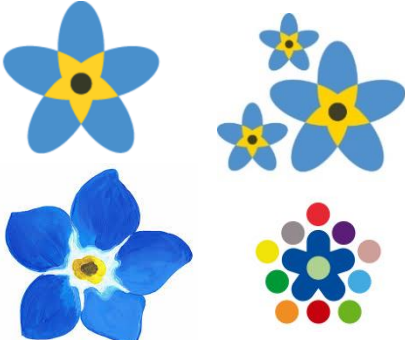
Of the 16 responding nations, six reported having more than one symbol in use (Australia, Canada, Nigeria, South Korea, UK, US). It should be noted that perspectives on which symbol was preferred could vary between responders from the same nation.

Multiple regions or nations share the same symbols, with the forget-me-not flower (used by Argentina, Canada, Ireland, England and Northern Ireland), the purple angel (survey returned from Nigeria and Canada but we know it is also used in other countries including UK and US), the purple elephant (Canada, Indonesia) and the orange ring (Japan, Taiwan) shared by more than one nation. These symbolic themes are summarized in Table 1.








Pictorially, there is no universally shared colour, with symbols using elements coloured blue, green, orange, purple, red, or yellow. Three main colour groups were identified:




1. Purple: angel, bee, cloud, elephant, loop, and dementia friendly America;
2. Orange: bee, donkey, loop, ring, geometric shape; dementia friendly America;
3. Blue/yellow: forget-me-not flower, Dementia Friendly America, lighthouse.

**Table 1.** Symbols reported to be associated with Dementia Friendly communities or initiatives. Full brands are shown in Appendix 3.

Nations	Symbol description	Symbol design
Australia	Abstract symbol, lighthouse	
Argentina, Canada, Ireland, UK (England), UK (N. Ireland)	Forget me not flower	

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Belgium	Red handkerchief knot	
Canada, Indonesia	Purple elephant	
Costa Rica	Smiley face emoji	
India	Banyan tree	
Japan, Taiwan	Orange ring	
Nigeria, USA	Purple angel	
Singapore	Orange shape representing the country outline	

South Korea	Patient and caregiver, bee character	
USA	Purple cloud	
USA	Patient and caregiver	

### Symbol themes

The theme of “not forgetting” was the most common, represented by the forget-me-not flower, the knot found in the symbol from Belgium and Canada and by the elephant icon for Canada and Indonesia.

Two symbols graphically represent persons with dementia and caregivers – the Dementia Friendly symbol from America and the Dementia Partners symbol from South Korea. The bee symbol used by South Korea represents the mutual relationship between person with dementia and their caregiver and compares it to the symbiotic relationship between a bee and a flower.

Five symbols (angel, banyan tree, donkey, lighthouse, country outline) have regional or cultural references which are not universal and may have contrasting meanings in other nations. For example the donkey in Japan pulls the caravan at the front of a procession and represents a reliable leader but this animal has different connotations in other countries. For example the donkey the Democrats’ symbol in the US and in literature, film and proverbs the donkey is often ascribed characteristics such as stupid, stubborn and lazy.

### Inclusion of text

The name of the region or locale was superimposed on at least some part of the symbol for four nations (Australia-dementia friendly Kiama, Costa Rica, Singapore, and Taiwan). The name of the region or locale was adjacent to the symbol for three nations (Dementia Friends Canada, Nigeria and Dementia Friendly America). The name of the region or locale did not appear as part of the symbol for the remaining nations (Australia, India, Ireland, UK-England, UK-Northern Ireland, South Korea, US – Cure the Cloud). English was the most commonly displayed language in the symbols (15/17 symbols including text, 88%). See Appendix 2 for full symbols and brands.

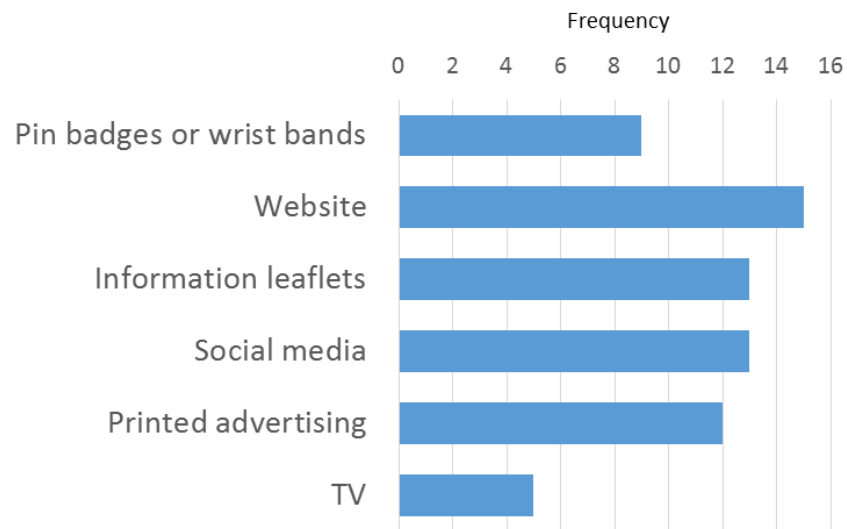
### Market research

Only four nations (Belgium, Canada, Costa Rica, and Nigeria) indicated that market research had been conducted to support the development of their symbol. Of these, only Belgium specifically highlighted that research involving people living with dementia had been carried out. This was specific to the

Dementia Friendly Bruges Campaign which asked for the assistance of both persons living with dementia as well as local school aged children to collaborate to create their city's Dementia Friendly symbol.

### Use of existing symbols

Most nations with established symbols used them in a number of different contexts including on wearable merchandise, in digital channels and in printed and TV advertising. Three of the nations (Australia, Belgium, Northern Ireland) also indicated that they produced stickers or decals to be displayed in the windows of shops and organisations to show that they have made steps to becoming Dementia Friendly.



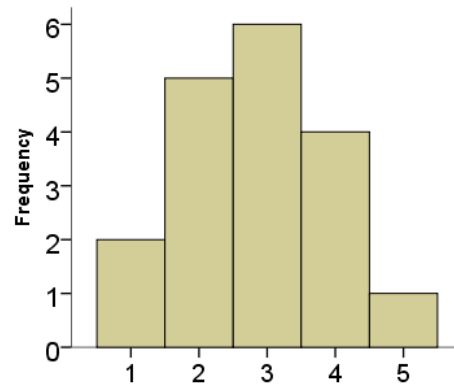
**Figure 2: Use of existing Dementia Friendly symbols**

Frequency indicates the number of respondents who indicated their symbol is used in this way

### Perceived success of existing symbols

Most representatives reported modest success of their symbols with respect to the popularity among their citizens. However, when asked to recommend ways to improve their existing symbols, the majority (75%) of respondents did not give any suggestions. Those who did suggest changes could be made to their existing designs put forward the following changes: involving patient organisations or persons living with dementia in the design; creating a more unified symbol across regions; adding a global element and using clearer branding.





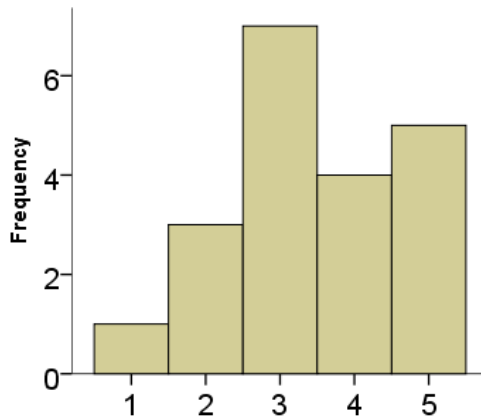
**Figure 3: Perceived success of existing Dementia Friendly symbols** (17 responses; scale - 1: not very successful; 5: extremely successful).

### CHAPTER 3: UNDERSTANDING PERSPECTIVES FOR A GLOBAL DEMENTIA FRIENDLY SYMBOL

In Part two of the survey, representatives were asked for their opinions regarding a global or universal Dementia Friendly symbol. They were asked to indicate their preference for either a global symbol, a global element such as colour or shape that can be incorporated into a local symbol, or no global element at all.

Six representatives (29%) were in favour of a global symbol and 14 (67%) were in favour of a global element. One representative was unsure of their preferences but none of the responders were resistant to the idea of having a universal element to unite Dementia Friendly initiatives.

When asked how likely their country or region was to adopt a global Dementia Friendly symbol, there were more favorable responses than unfavorable. Nine (45%) were likely or very likely, four (20%) were unlikely or very unlikely and seven (35%) were unsure and answered in the middle of the scale.



**Figure 4: Likelihood of adopting a global symbol for Dementia Friendly initiatives**

(20 responses; Scale -1: very unlikely; 5: very likely)

Those who favoured a universal element over a global symbol were less likely to indicate that their country would adopt a global symbol. This relationship was statistically significant despite our small sample size (20 responses, 3.08 for those favouring a universal element, 4.33 for those favouring a global symbol,  $p=0.036$ ). However, there was no clear relationship between the subjective success of one's own symbol and the likelihood of adapting a global symbol.

In the open text answers no respondents rejected the concept of a universal symbol, although it must be stated that a number of responses indicated their nation would only adopt a global symbol if their own nation's symbol was the one chosen.

## **Attitudes towards a global symbol**

Four overarching themes emerged from the open text responses in the second part of the survey.

### **1. Education before branding**

It was suggested that a global symbol could be too soon for some nations, particularly for those in the low to middle income bracket. One respondent from a middle income country stressed that the citizens in her country have very little knowledge about dementia and as such, have limited contact with those with dementia. This would make a Dementia Friendly symbol hard to recognize and understand and therefore limit its use. This respondent says that even the word 'dementia' is so stigmatised that in their country that the word 'cognitive impairment' or 'Alzheimer's' is used instead.

*“Even the word “demencia” is commonly associated with insanity, mental illness and outcasts”*

-Argentina Respondent

A different respondent suggested that the lack of momentum or national support for Dementia Friendly initiatives in their country would mean limited take up of a global symbol. These comments highlight the fact that countries worldwide are at very different stages in terms of creating awareness, acceptance and ending stigma of dementia. Some countries may need to move forward at their own pace by first agreeing on an accepted, inclusive and 'neutral' term describing dementia, on which the public can then be educated.

However, there were also counter arguments to these views, in that a global Dementia Friendly symbol may assist in facilitating with the difficult task of expanding knowledge about dementia around the globe. For example, one respondent suggested that the benefit of a global symbol was that it could be recognized by people of all ages “from birth to death” and all cultures to raise global awareness of dementia.

Further, it was suggested that a global symbol would be better supported if it was not just a “token gesture” but if displaying it came with an attached with a set of criteria which organisations much meet to the be able to display. Sharing these criteria could contribute to the spread of knowledge and understanding of dementia. WYLD may add to this though, that creating and regulating a shared set of criteria across nations would come with its own difficulties.

Two respondents commented specifically on the value of a global symbol to reduce the stigma that exists around the word dementia. A third mentioned that it is vital that a chosen symbol avoids adding to the stigma that already exists.

### **2. Better together**

One of the most frequently stated reasons for supporting the idea of a global symbol is the idea that it will have a much greater impact for people living with dementia, caregivers and the wider dementia community than several independent symbols and brands. A global symbol would help to create greater

awareness and momentum towards a compassionate, supportive and friendly world for people living with dementia.

*“The more places and countries a symbol is used, the more effective it will be and the more people with dementia will recognize it.”* – Belgium Respondent

*“Unity around the globe would help to build more awareness for the disease.... When a population can identify with one brand they are more likely to feel compelled to join the mission and become a part of something bigger.”* – Canada Respondent

One respondent thought adoption of a global symbol would be a continuation of what is already happening in the dementia field. They mentioned that dementia organisations have only just started to work together in the last five years but that this has already brought more attention to dementia and helped to lessen stigma surrounding the condition.

One clear advantage of global symbol is that it would help people living with dementia and caregivers to travel, allowing them to more easily identify sources of support or places and organisations that have taken steps to become Dementia Friendly.

*“Caregivers need to know where they can go, which restaurants, shops, theaters... and how they can travel with dementia friendly airlines.”* – Belgium Respondent

*“[One global symbol] would mean that people affected by dementia would know that they are in a community where they can feel included and empowered.”* – UK Respondent

*“If there is a global symbol, people with dementia or their families will know exactly where they can call for help, even in a foreign country.”* – Taiwan Respondent

Ireland has already incorporated an element of partnerships into their national symbol. The inclusion of ‘dots’ around their central flower is a testament to the fact that creating a truly Dementia Friendly society involves the entire community.

*“The symbol is the shape of the Forget-me-not flower surrounded by different colored dots... The dots surrounding the flower symbolize partnership because it takes many people to be involved to make a Dementia Friendly Community work.”* – Ireland Respondent

A common theme from the responses was that the adoption of a global element will make all countries feel connected and involved in a global movement. A global element has the ability to reduce competition between organisations and increase unity for all those involved in finding and implementing dementia solutions.

### 3. Symbolic possession and competition

In contrast to the perceived added value of a global symbol, there were very clear concerns expressed around a possible threat to existing symbols and brands. These views were stronger from nations that already have a well-established symbol in use.

*“[Likelihood of adopting a global symbol] would depend on how far it would detract from the current symbol in use. We have invested a lot of time and money in creating our existing brand.”*  
-UK Respondent

*“Now is deemed a little late to begin [work on a global symbol] as various countries already have their own dementia friendly symbols/brands.”*  
– South Korea Respondent

In nations where there is an already established symbol, the concern was expressed that adoption of a global symbol that was different from the existing one could create confusion and detract from the aims of promoting a Dementia Friendly society.

Competition between many symbols at a global level could be considered confusing too. One respondent outlined their frustration at feeling as though there is currently too many dementia symbols all competing with each other while the actual person living with dementia is being ignored. Drawing attention away from the person with the condition is the opposite of what a symbol that represents Dementia Friendliness should be doing.

*“There are various advocates who are pushing their own symbols many countries and people with dementia do not feel fits with their perspectives. We do need a UNIVERSAL symbol as without one it is simply NOT dementia friendly”*  
- Australia Respondent

Despite the fact that some nations and organisations are possessive of their own symbol, it was recognised by some that the need for a global symbol should take priority.

*“Organizations want their own symbol... They should see the urge for a global symbol...”*  
- Belgium Respondent

### 4. Engaging the right communities

A theme emerged around the importance of having appropriate cultural and local references to ensure the symbol or brand is sufficiently engaging locally as well as globally. This was highlighted as particularly important given that many existing Dementia Friendly initiatives are owned and delivered by the local community.

*“Because dementia friendly initiatives are targeted at the community level, symbols need to connect across that community based on factors such as culture and language. I’m not sure if a global symbol would be able to address these factors.”*  
– Singapore Respondent

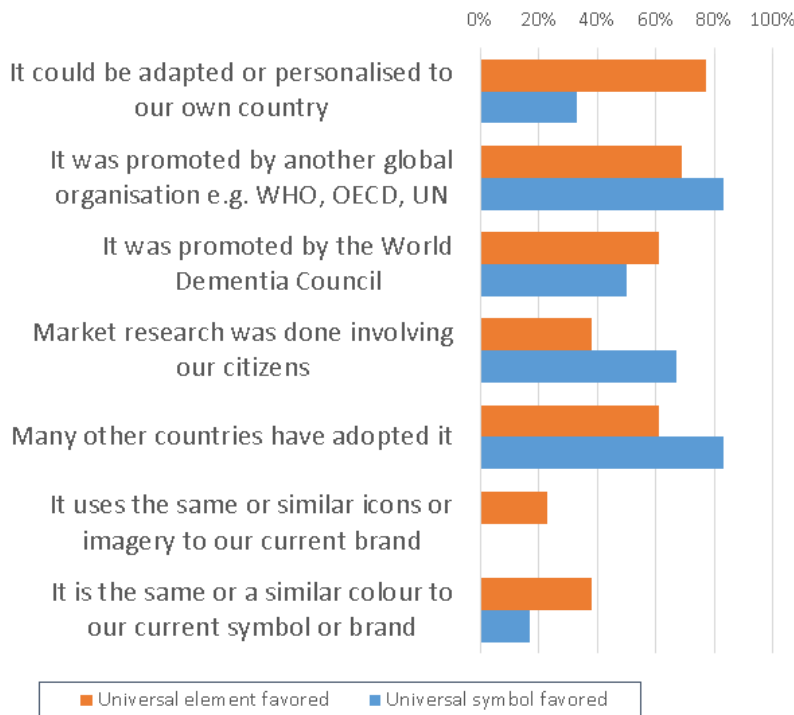
*“Yes [I support a global symbol] for a global impact, but [I also do not support a global symbol] since every country has their own culture, it’s better to have a culturally appropriate symbol”*  
 – Indonesia Respondent

Engagement with people living with dementia in the development and use of Dementia Friendly symbols and brands was also stressed as important. Not only should they be involved in the design of a global symbol, but they should also be consulted about the need for a symbol and about the ways in which a symbol is used and promoted. People living with dementia should be the primary advocates of a global symbol to ensure it truly reflects the values of a Dementia Friendliness.

### Factors to support uptake of a global symbol

When asked about factors that would motivate each nation or representative to adapt a global symbol, endorsement from the WHO or United Nations was the most popular factor, selected by the 74% of nations. This was followed by the symbol having been adopted by many others countries (68% of nations). Interesting, having a global symbol that shared colours or icons with existing symbols and brands was not considered an important factor to support uptake by the majority of respondents.

There was no clear difference in the selected factors between representatives who favoured a global symbol compared to those who favoured a universal element.



**Figure 5: Perceived importance of factors that would encourage adoption of a global symbol**  
 Percentage of respondents who would be more likely to adopt a global symbol if this factor was present.  
 (More than one reason could be given)

Text responses throughout the survey provided further considerations that might increase the likelihood of an organization or nation adopting a global symbol. For example, it is important that the symbol be recognizable to all people, not just people who are living with dementia but their care partners, family and the wider community as well. Emphasis was placed on making the global symbol appealing to younger generations.

*“It would be practical to invent one universal language that can convey complex ideas across regions/countries and create future value beyond the disease condition. Also, in today’s world creating any service or idea without its cross cultural implications is a futile exercise.”*

- India Respondent

It is also important that the symbol selected has not already been adopted to represent another cause.

*“The problem with the purple ribbon is that it was adopted as a symbol for the last national campaign to fight violence against women, called “Ni una menos”, a very big and widespread campaign, therefore people might associate this ribbon more closely with gender violence struggle.”*

– Argentina respondent

Based on the results from this scoping review, there is a demonstrated appetite for global unity in the development of Dementia Friendly initiatives and willingness to consider a global Dementia Friendly symbol. The following chapter will summarize the results and offer suggestions for how to proceed.

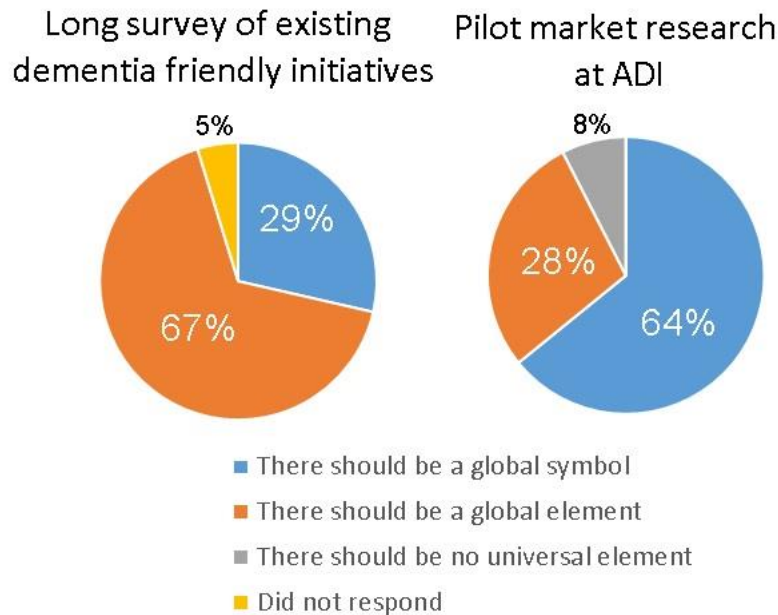
**CHAPTER 4: ADDITIONAL PERSPECTIVES FROM ADI 2016 CONFERENCE**

**Pilot market survey**

Delegates at the ADI conference 2016 (22-24 April 2016, Budapest, Hungary) were able to vote on their preferences for a global Dementia Friendly symbol at the World Young Leaders in Dementia stand. Visitors to the stand were given the option to vote for one of three options:

1. There should be a universal symbol for Dementia Friendly initiatives
2. There should be a universal element (i.e. colour or shape) which can be incorporated into local Dementia Friendly symbols
3. There should be no universal element or symbol

Results from this pilot market survey showed strongest support for a global Dementia Friendly symbol. Among 53 responses, 34 (64%) favoured a universal symbol, 15 (28%) favoured a universal element, and 4 (8%) preferred to not have a universal symbol or element. The conference voters showed a higher preference for a universal symbol than the survey responders from countries with existing Dementia Friendly initiatives (64% vs. 30%,  $p < 0.01$ ). It should be noted that the sample of people visiting the WYLD stand was in part self-selected as those responding to social media activity and therefore is unlikely to be representative of the entire conference delegation. Across both the survey and the pilot market research only 5 out of 74 respondents indicated they were not in favour of any global symbol or element for Dementia Friendly initiatives.



**Figure 6: Differing attitudes towards a global Dementia Friendly symbol between survey responders and conference delegates.**

(Non-response data was unavailable for the pilot market research conducted at ADI conference)



## **Perspectives from a person living with dementia**

Kate Swaffer (Dementia Alliance International) shared her perspectives on the potential functionality and purpose of a dementia friendly symbol. First, from a recognition perspective, she drew parallels to the wheelchair symbol which is universally recognisable as it cuts across all cultures and it empowers, rather than stigmatizes, people with physical disabilities. Second, lack of ambiguity is key. A unique feature of the wheelchair symbol is that there is no other symbol which resembles it. In contrast, persons living with dementia often have trouble distinguishing between the different symbol designs to indicate male and female bathrooms/toilets despite their universal recognition for people without dementia. As a result, persons living with dementia can and do end up in the wrong bathrooms.

Kate went on to discuss how a Dementia Friendly symbol can be used. Importantly, the symbol should in no way label a person with dementia (“this isn't to be worn”). Instead, the symbol should notify persons living with dementia and their families of facilities or locales taking the appropriate steps to recognise the needs of persons with dementia, in much the same way as a wheelchair symbol is used. The symbol should not increase stigma and should not infantilise or patronise. For example, including the word “friendly” in the symbol can be perceived as patronising, and using animals as mascots can be interpreted as trivialising or commercialising a service-oriented initiative. Finally, it is important to test potential symbols with persons living with dementia across many cultures.

Based on this discussion, workshop participants recommended distinguishing between symbols used to indicate accessibility for persons living with dementia and symbols used for dementia awareness. This distinction was often omitted in the survey response collected for existing Dementia Friendly initiatives.

## **Considerations for a universal element**

Participants at the WYLD ADI workshop took part in parallel breakout sessions and subsequently a larger, facilitated group discussion regarding “What kind of element could be used to connect all dementia symbols?” Five key suggestions were put forward:

1. Persons living with dementia should be fully consulted about and engaged in the development of a global symbol or element;
2. There should be some consensus on what a global symbol means, i.e. accessibility, awareness or accreditation;
3. Basic shapes such as a globe or circle that represent unity could be used as an identifiable common element to accompany a region-specific organisational symbols (see examples in Appendix 4);
4. Avoid animals or infantilised pictures and the use of the word ‘friendly’;
5. Cultural context and overlap with other awareness campaigns need to be considered.

A summary of each breakout session discussion can be found in Appendix 4.

## CHAPTER 5: RECOMMENDATIONS FOR MOVING FORWARD

This scoping review represents a broad overview of perspectives from different stakeholders including organisations with existing Dementia Friendly symbols, participants of an international dementia conference, two people living with dementia, and emerging young leaders in dementia care, research and advocacy. Although a large number of nations were represented, we were only able to collect input from a small number of representatives from each nation. In some cases the responses were informed by a wider consultation within the country (i.e. Nigeria), but in the majority of cases it is stated that the views only reflected those of the individual representative. Importantly, due to the short time frame for the review, the perspectives of only two people living with dementia were included and so a full consultation with persons living with dementia is needed to move forward.

In the survey we focused our effort on nations with known Dementia Friendly initiatives. Their perspectives on a global symbol or element were different from those of the ADI conference delegates, but their willingness to consider a global symbol or element has been a key factor in past discussions of feasibility. Representatives from these initiatives were very candid with the subjective evaluation of their symbols' success, and we were encouraged by their general willingness to consider a global symbol or element, especially as a marker of dementia accessible locales or facilities. Some of the organisations and individuals contacted did not respond, and at least one group refused to take part in our review. It is possible that groups that did not respond or refused to participate are more resistant to the idea of a global symbol.

Our review is sufficient to give a *flavour* of the various viewpoints relating to global Dementia Friendly symbols, but a more in depth consultation including people living with dementia across cultures is needed before any significant financial commitments are made. Bearing in mind these limitations, we put forward some recommendations and next steps.

### Recommendations

1. Determine the purpose of a Dementia Friendly symbol

WYLD identified two potentially conflicting uses of a Dementia Friendly symbol, and the need for universal recognition is dependent on the preferred functionality. From an accessibility perspective, a global or universal symbol is key to identifying facilities and locales that can accommodate persons living with dementia. From an awareness or branding perspective, a symbol specific to the local effort may enhance enthusiasm and participation in Dementia Friendly practices. The wheelchair symbol, while universal, denotes accessibility as required by local regulations. Until accessibility criteria can be determined and actively promoted, a balance between promoting universal recognition and enhancing local participation will be a necessary feature of a successful global Dementia Friendly symbol.

2. Focus on a global element rather than a symbol

Following our survey results from various stakeholders, WYLD recommends that a priority be placed on a global element rather than a global symbol. This could be an icon, colour, or basic shape that can be added to existing brands or tailored for different regions and nations. For the purpose of accessibility, the element should be simple, unique, and potentially recognisable in black and white. It should not include written text to avoid the issues of language.

There are several symbols and brands already in existence with differing degrees of recognition within their respective communities. For some nations it is considered too late to change to something new or too confusing to bring in an additional symbol. However, by focusing on a universal element, it might be possible for some nations to incorporate it into their existing brands.

For countries that do not have an established symbol or brand, there is still the need to develop an identity that resonates within the local community. It is unlikely that one global symbol would be able to achieve this across a range of regions and cultures. Developing a global element will allow countries to develop their own culturally relevant symbol while still representing that they part of the global Dementia Friendly movement.

Since pictorially, there is no universally shared colour, icon or shape to connect the existing Dementia Friendly symbols, the nature of this global element must be further explored. It might be preferable to come up with a new, neutral element that is not present in any of the existing symbols to avoid creating further competition between organisations. Suggestions from the WYLD workshop discussions include the use of a globe or circle to represent unity that could surround existing local symbols, or something that uses a combination of the four colours already in use: purple, orange, blue and yellow.

### 3. Target nations without established Dementia Friendly initiatives

Respondents to our survey have convincingly demonstrated that many millions of people around the globe are already aware of and supporting Dementia Friendly initiatives using their respective symbols. We have received an overall positive response to the idea of a global element but we have also perceived a risk that encouraging these “*early-adopter*” countries to adjust their current strategies could have negative consequences.

Incorporating a global element into their existing brands would require significant amounts of time, money, and efforts to re-educate the population and in the worst case could create confusion and frustration, both for those promoting the symbols and those targeted to recognise and adopt the symbol. For some countries, the added value that a global symbol could bring might be worth this risk, but the decision to adopt will need to be taken independently by each country or region. The engagement and reach of each existing Dementia Friendly initiative and symbol is likely to be the deciding factor.

Many nations do not have an established Dementia Friendly initiative in place. Often what is seen is a scheme that is only in its infancy and not yet embedded or supported outside of the grassroots level. WYLD recommends a focus on these nations where the implementation of a global symbol or element is more likely to advance and strengthen the spread of Dementia Friendliness. The public health impact of a global symbol is likely to be more pronounced by taking this approach.

Of the 20 Dementia Friends initiatives we surveyed, nine indicated that they have fewer than 5,000 individuals currently involved. We have gained some insight to the perspectives of those whose schemes are in the earlier stages but we acknowledge that further consultation with countries that do not have a Dementia Friends initiative is needed to fully explore the potential of a global symbol.

#### 4. Involve persons living with dementia

We did not specifically seek the input of persons living with dementia in this review as there was not enough time to do a meaningful consultation, but we were able to collect the views of two people living with the condition. WYLD strongly advocates that the views of persons living with dementia and caregivers are sought to take forward any ideas relating to a global Dementia Friendly symbol.

Across the 16 nations represented, only one of the symbols in use is known to have been directly tested with people living with dementia. If any new symbol or symbolic element is going to be created for use globally, persons living with dementia from a range of cultural backgrounds should be consulted. This would add credibility and may encourage uptake, especially in nations where the existing symbol has not been informed by the views of people living with the condition.

Involvement activities should begin from the outset. Some representatives indicated that they would have used a global symbol if it was available at the creation of their Dementia Friendly initiative. This shows us that it is better to get it right at the start before considerable time and resources have been allocated. Initial consultation should be conducted using structured interviews or focus groups, as there is evidence that these methods are a more reliable way to collect the views of persons living with dementia than written questionnaires and surveys (Sperlinger and McAuslane, 1994; Bamford and Bruce, 2002). The consultation should also include caregivers as they too will be beneficiaries and users of a global Dementia Friendly symbol.

#### 5. Include an element of education

Many countries round the world only have a cursory understanding of dementia and must still decide on a culturally appropriate set of terms to describe the condition and to educate their citizens. It is unlikely that these countries will be well placed to adopt a global Dementia Friendly symbol, especially without additional support to also increase awareness and understanding of the condition.

It could be well-advised to provide these nations with examples of what has worked in other places in terms of raising awareness, reducing stigma and encouraging community engagement. If suitable resources were developed alongside a global Dementia Friendly symbol they are likely to encourage wider adoption. It cannot be stressed enough that a Dementia Friendly symbol has no meaning and is therefore useless if the public is not educated and supportive of its purpose.

### **Next steps**

We believe that there can be a global symbolic element reflecting the willingness and effort of facilities and locales to accommodate persons living with dementia and their families. In addition to the guiding principles above, we put forward the following next steps:

1. Conduct a series of structured interviews or focus groups with persons living with dementia and caregivers across cultures to gather their requirements for a global symbol/element and develop guidelines for accessibility. Based on preliminary budgets prepared by WYLD from Germany, UK, and US, it is estimated that 30 focus groups each with 6 participant pairs (person living with dementia and caregiver) would require a budget of £100,000.

2. Consult a graphic design team on the potential nature of a global element to represent accessibility for persons living with dementia and their families, with the goal of integration with existing Dementia Friendly brands.
3. Present our finding and recommendations to the World Dementia Council and World Health Organisation to affirm the need to define accessibility for persons living with dementia and to distinguish a symbol for accessibility from awareness campaigns.

## CONCLUSIONS

Globally, there are few countries where persons living with dementia are encouraged to expect the best care and support. In virtually all countries stigma, exclusion and inadequate care for persons living with dementia still exist despite the best efforts. This review considered the original purpose of Dementia Friendly symbols - as tools to support national, regional and local initiatives to build Dementia Friendly communities, exploring how these symbols are used worldwide and the potential for implementing a global Dementia Friendly symbol.

The concept of a global Dementia Friendly symbol was considered acceptable by the majority of those consulted but with varying degrees of enthusiasm. On the one hand, its implementation, adoption and usage would allow for global dementia champions to build unity around this report's position of advocacy, education and support. On the other hand, asking nations with successful Dementia Friendly initiatives to adopt a new symbol and strategy could slow down the progress being made in dementia awareness, acceptance and behavioral change.

Rather than a new global symbol, we recommend further research into the consideration and adoption of a global symbolic element for Dementia Friendliness that can be incorporated into existing or new, culturally appropriate symbols. **We recognise that while organisations championing Dementia Friendly initiatives desire brand recognition, the most immediate needs of persons living with dementia have to do with support and accessibility.**

By focusing efforts on countries without well-established initiatives already in place, this activity could close this gap between nations that we can define as "*early-adopters*" and those that are following behind. Encouraging the "*follower*" countries to adapt best-practice Dementia Friendly strategies (i.e. from Japan, UK, Canada and South Korea) alongside a global symbol or symbolic element is likely to enhance its impact, both in terms of awareness raising among the general population and in terms of the number of people living with dementia and their caregivers who can be reached.

The openness of stakeholders in countries without Dementia Friendly initiatives to adopting existing symbols and best-practice strategies, as well as the identification of (1) best-practice examples of Dementia Friendly initiatives and (2) ways to approach these countries could be explored as a logical extension of this scoping review. It is important that context is taken into consideration and best-practice strategies are adapted to countries' needs.

## REFERENCES

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Sperlinger, D. and McAuslane, L. (1994). Listening to users of services for people with dementia, *Clinical Psychology Forum*, pp. 2–4.

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*Canadian Tri-Council Policy Statement TCPS 2 (2014) ethical principles were used to guide scoping review.*

## APPENDIX 1: SURVEY

Dear dementia professional,

We, the World Young Leaders in Dementia (WYLD) have been tasked by the UK Department of Health to perform a review of symbols and brands associated with dementia friendly or dementia capable communities from across the globe.

For this project, we are defining a dementia friendly community as one in which people living with dementia are empowered to live in and feel part of their community and know that they can contribute and participate in activities that are meaningful to them.

Please complete the survey on behalf of your country, providing as much detail as possible. We estimate it should take up to 30 minutes to complete. Please return your responses and any images to [wylsymbol@gmail.com](mailto:wylsymbol@gmail.com) by **March 21<sup>st</sup> 2016**.

**Thank you for sharing your time and expertise with us!**

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### **Section 1: Dementia friendly community in your country**

**1a) What country are you answering this survey on behalf of?** \_\_\_\_\_

**1b) Does your country have any initiatives that aim to create a dementia friendly community?** These initiatives can be funded by the government, private sources, or a combination. Please indicate the correct answer:

Yes / No / Unsure

*If yes, please give the name of the initiative* \_\_\_\_\_

*If no, please proceed directly to section 2.*

**1c) To the best of your knowledge, how many people are involved with the initiative so far?** Please check the correct answer:

- Fewer than 500
- 500 – 4999
- 5000 – 49,999

- 50,000 – 1 million
- More than 1 million

**1d) Please describe the dementia friendly symbol or brand that you believe your country most closely identifies with.** Please make reference to any colours, symbols or text that are used, and the reasons for this choice. Digital materials can be included in your response.

**1e) Are there any cultural references or meaning behind your dementia friendly symbol or brand?** Please give details:

**1f) Do you know if any market research was done to develop the dementia friendly symbol or brand in your country?** Please indicate the correct answer:

Yes / No / Unsure

*If yes, do you know which person or organisation led the work and can you provide us with relevant contact details to follow up?* \_\_\_\_\_

**1g) To the best of your knowledge, how is the symbol or branding used for your country's dementia friendly initiative?** Please tick all that apply

- |   |  |
|---|--|
| <input type="checkbox"/> Pin badges or wrist bands    | <input type="checkbox"/> Banners, posters, other print advertising |
| <input type="checkbox"/> Website                      | <input type="checkbox"/> TV advertising                            |
| <input type="checkbox"/> Information leaflets/ flyers | <input type="checkbox"/> Other _____                               |
| <input type="checkbox"/> Social media                 |  |

**1h) In your opinion, how successful is the dementia friendly symbol or brand in your country on a scale of 1-5?**

1- Not very successful, it does not resonate with our citizens

5- Extremely successful, it is very popular and widely used

1	2	3	4	5
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**1i) If you could change anything about your current dementia friendly symbol or branding, what would it be?** Please give details:

## **Section 2: Feasibility of a global symbol or theme for dementia friendly**

**2a) Some dementia advocates have proposed a global symbol to connect different dementia friendly initiatives across different regions and countries. Do you think this is a good idea?** Please indicate the correct answer:

Yes / No / Unsure

Please give reasons for your answer.

**2b) Currently, most dementia friendly initiatives have a unique symbol reflecting the local culture and practices. Do you think there should be a universal element in these symbols?** Please check the box that most accurately reflects your views

- There should be a universal symbol
- There should be a universal element (i.e. color or shape) which can be incorporated with each local symbol
- There should be no universal element



**2c) What challenges do you think need to be considered in order to make an effective, truly global symbol? Please describe below:**

**2d) If a global symbol for dementia friendly initiatives was developed, how likely is it that your country would adopt it? Please answer on a scale of 1-5**

- 1- Very unlikely
- 5- Very likely

1	2	3	4	5
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**2e) Please give a reason for the answer to 2d.**

**2f) What factors would make you more likely to adopt a global symbol?**  
Please check all that apply.

- It is the same or a similar colour to our current symbol or brand
- It uses the same or similar icons or imagery to our current brand
- Many other countries have adopted it
- Market research was done involving our citizens
- It was promoted by the World Dementia Council
- It was promoted by another global organisation e.g. WHO, OECD, UN
- It could be adapted or personalised to our own country
- Other, please give details: \_\_\_\_\_

**2g) Do you have other comments to share on this topic?**

**Many thanks for giving your time and support to this project.**

Please send your survey by email to [wylsymbol@gmail.com](mailto:wylsymbol@gmail.com) by **March 21<sup>st</sup> 2016**.

**Keep up to date with the latest WYLD activities and events at:**  
[www.WYLDementia.org](http://www.WYLDementia.org)

## **APPENDIX 2: FULL LIST OF SURVEY RESPONDERS AND THEIR AFFILIATIONS**

### **Argentina**

Clementina Colombo, A.L.M.A. (Argentine Alzheimer Association)

### **Australia**

Kate Swaffer, Alzheimer's Australia Dementia Advisory Committee  
Lyn Phillipson, Australian Health Services Research Institute

### **Belgium**

Bart Deltour, Familiezorg West-Vlaanderen  
Elena and Nico Bins, Ambassadors for Dementia Friendly Bruges and Foton

### **Canada**

Caitlin Johnston, Founder and Executive Director, Purple Elephant

### **Costa Rica**

Norbel Roman Garita, Association of Alzheimer's disease and other dementias, Costa Rica

### **England**

Philippa Tree, Alzheimer's Society

### **Indonesia**

DY Suharya, Executive Director Alzheimer Indonesia

### **India**

Sudhir Kumar, ARDSI  
Nilanjana Maulik, ARDSI Calcutta

### **Ireland**

Avril Easton, Alzheimer Society of Ireland.

### **Japan**

Yoshiki Niimi, Office for Dementia Policy, Ministry of Health, Labour and Welfare  
Miharu Nakanishi, Tokyo Metropolitan Institute of Medical Science

### **Nigeria (joint survey response)**

Chief Kikelomo Laniyonu Edwards, Founder Dementia Friends Nigeria  
Hon Bolanle Agbaje, Honourable Member of the House of Assembly, Oyo State  
Prof Aduke Adebayo, Faculty of Arts, University of Ibadan  
Prof Olusegun Baiyewu, Head of Psychiatry UCH  
Prof Felicia A Ogunsheye, Women's Institute  
Dr Yemi Iyiola, Permanent Secretary, Ministry of Health  
Dr Shola Akande, Director Social Welfare  
Alhaji M A Salawu, Women's Affairs Social Welfare  
Ms Shola Ogungbade, Federal Radio Corporation of Nigeria

### **Northern Ireland**

Dubheasa Gallagher, Alzheimer's Society

### **South Korea**

Eunae Sim, National Institute of Korea

**Singapore**

Melissa Chan, Founder, Project We Forgot

**Taiwan**

Li-Yu Tang, Secretary General, Taiwan Alzheimer's Disease Association

**United States**

Lisa Spikell. Founder, Cure the Cloud

Olivia Mastry, Dementia Friendly America

**APPENDIX 3: BRANDS AND SYMBOLS USED BY DEMENTIA FRIENDLY INITIATIVES IN THIS REVIEW**

**Australia**



**Belgium**



**Canada**



**Costa Rica**



**England**



**Indonesia**



**India**



**Ireland**



Japan

Dementia Supporter Caravan



Nigeria



Northern Ireland



South Korea



**Singapore**



**Taiwan**



**United States**



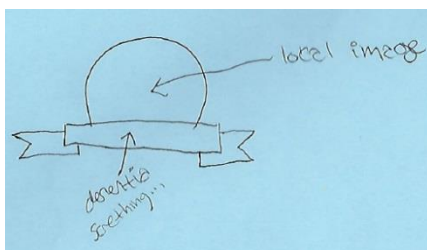
#### APPENDIX 4: GROUP NOTES FROM ADI WORKSHOP FACILITATED DISCUSSION

##### Green Group

1. No animals should be used in the symbol
2. Symbol should represent accessibility for persons with dementia and be separate from awareness campaigns
3. Symbol should be internationally identified and recognisable (with different cultures looking at it the same way – e.g. animals have different meanings)
4. Involving persons with dementia, but hard to reach – need to give them a voice and ask what they want
5. Not a complex symbol – keep it simple

##### Blue Group

1. Have country decide on the colour they want to use
1. But one universal element or part- individual country could put their logo into a larger “motif”
2. Enabling and inclusive
3. Do not use the word “Friendly” in the logo as could be patronising



##### Yellow Group

2. Should we have a global symbol? Yes, to be recognizable but a global element is more able to be tailored to different cultures
3. How will we spread it around the world?
4. How will it work with existing symbols? Could indicate part of a global movement i.e., Member of “xx”
5. USA won't like the elephant – Republican
6. Purple angel – simple shape, connotes caring, but not universal favour for a religious symbol
7. Colour logo – but needs to work in black and white
8. Symbols that show unity and the carer-dementia partnership are favoured
9. Could the globe be incorporated? Circle emblem to reflect a global element – like a simple globe
10. We shouldn't have a brain as it represents the disease and not the person
11. Need to involve person with dementia (through the international dementia action alliance)
12. Australia symbol had great involvement of persons with dementia in the development
13. No complex visual aspects as many persons with dementia have visual challenges – hence need for direct testing
14. Needs to be recognisable to the next generation



15. Alzheimer's Association US has developed a brain symbol for kids and fundraising walks etc. (a symbolic brain not natural), it resonated well – would need to test this with person with dementia
16. Could we merge the 3 colours already used in DF symbols? Purple, Blue, Orange
17. Symbol or element should have no overlap with other awareness campaigns
18. Does it need to have regulations or criteria behind its use?

