Response to the consultation on the recognition process for dementia friendly communities

February 2013
Executive summary

Alzheimer’s Society consulted on a recognition process for dementia friendly communities in October and November 2012. This paper provides a background to the consultation and sets the direction for the recognition process. It gives the conditions that communities and organisations must agree to, including named standards that they must be working towards.

The recognition process will open in late March 2013 to the first wave of organisations and communities. These will act as early adopters and will help ensure that the core aspects of the recognition system are working as they should. The process then will be formally launched in late July 2013 and will be open to any community or organisation that is working towards becoming dementia friendly and meets the conditions of the process.

A symbol to show that organisations and communities are working towards becoming dementia friendly has been developed. Organisations and communities will be able to display this symbol if they register with the recognition process and meet the conditions, including working towards the standards. The symbol will be available from late March 2013, initially to the organisations and communities that register as early adopters. Alzheimer’s Society is obtaining legal rights to the symbol to ensure that it is only used by those who have registered and are actively becoming dementia friendly.

1. Introduction

Alzheimer’s Society launched a programme of work on dementia friendly communities in March 2012 in response to evidence on the need for age-friendly and dementia-friendly communities (communities that are more inclusive of older people and those with dementia, and support them to live independently and well). For example, evidence on the quality of life outcomes that matter to people with dementia (such as those outlined in the National Dementia Declaration1), the World Health Organisation age friendly environments programme2 and the Alzheimer’s Society report Dementia 20123.

Since March 2012 there has been further consultation, discussion and evidence gathering on what a dementia friendly community is and how the programme of work should be progressed (for example the Local Government Association Ageing Well project4 and the work of the dementia friendly communities champion group). Many organisations, villages, towns and cities

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1 Dementia Action Alliance (2010), National Dementia Declaration. DAA, London.
2 http://www.who.int/ageing/age_friendly_cities/en/
4 http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE
are now taking steps towards becoming or have an ambition to become dementia friendly.

2. The recognition process

Realising dementia friendly communities will take a number of years. During this time, it is vital that there is a recognition process that enables organisations and communities to be part of an officially recognised group working towards becoming dementia friendly. It is also essential that they are all working towards common evidence-based standards that will truly change the things that matter to people affected by dementia. The recognition process must therefore be based on current evidence and thinking on what matters to people with dementia in terms of quality of life outcomes and dementia friendly communities.

Discussion and the views of experts showed that a formal kite mark and accreditation process was not an appropriate recognition process at this stage. In particular, there is not yet enough detailed evidence on what is dementia friendly for formal accreditation. Overly bureaucratic processes that require expensive assessment by external reviewers could also disincentivise engagement.

What did emerge from the evidence and discussions was that there should be certain components present in a recognition system, which an organisation or community must agree to meet when they register.

These components were formally consulted on during October and November 2012. The key areas consulted on were (in brief):

- Organisations and communities would be expected to support specific values by working towards named standards.
- There should be a recognisable symbol. The symbol shows that the organisation or community has registered for the recognition process and is working towards the named standards to become dementia friendly.
- Self-assessment should be done on an annual basis with mechanisms for feedback, particularly from people with dementia and carers.
- Information on progress and mechanisms for feedback should be provided locally, with a link from a registration page on Alzheimer’s Society’s website.

3. Findings of the consultation

This paper outlines the responses to the consultation and sets the direction for the recognition process. In summary, the key components of the recognition process, which an organisation or community must agree to when they register, will be:

Registration and information to be held at a national and local level
- Communities and organisations will register on a page on the Alzheimer’s Society website. This information will be collated by the Society.
Information on the organisation or community’s work will be hosted locally. This will contain details such as how the standards are being progressed and details on self-assessment (the method, the results and subsequent intended actions).

Values, standards and self-assessment
- The system will be based on values and standards. The standards will act as guidance on what organisations and communities should be aiming for and should be interpreted in the local context.
- Self-assessment will be on an annual basis. An organisation or community will assess actions taken on standards and decide next steps, and must engage people with dementia and carers.
- Self-assessment will be simple and is intended to provide rich evidence which will in part help other organisations and communities to learn and progress.
- Each organisation or community will produce a summary of the self-assessment findings, which will be collated by Alzheimer’s Society to give a national picture.
- A short update on a 6-monthly basis will also be required. This will be a brief summary of progress since the previous self-assessment and work still to be done.

Governance
- There will be a symbol. Organisations and communities will be able to display this symbol if they register with the recognition process and meet the conditions, including working towards the standards. A symbol has been developed and will be available from late March 2013 to the organisations and communities that register as early adopters, and then from late July 2013.
- To ensure that it is only displayed by organisations and communities that are actively working towards becoming dementia friendly, Alzheimer’s Society is obtaining legal rights to the symbol.
- The Society will grant permission to an organisation or community to use the symbol once they have signed up to the recognition process, but retain the right to withdraw that permission if it is felt that the conditions of the recognition process and/or the needs of people with dementia are not being met.
- In this way Alzheimer’s Society will have oversight of the recognition process. However, responsibility and accountability will be particularly held locally.
  - Responsibility for committing to the standards should be taken by the local dementia action alliance where possible or a similar group. If this is not feasible, a named senior figure must take responsibility.
  - Signing up to the standards means signing up to involving people with dementia (as outlined in the standards) and ensuring that they are engaged in the self-assessment process.
  - To support those who need it, registered organisations and communities can provide peer to peer support (sharing learning and ideas to support each other to progress).
1. Background to the consultation: introduction to dementia friendly communities

People with dementia and carers have described seven outcomes that must be met to ensure that they live well with the condition. These are:

- I have personal choice and control or influence over decisions about me
- I know that services are designed around me and my needs
- I have support that helps me live my life
- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life
- I know there is research going on which delivers a better life for me now and hope for the future.

This evidence, alongside other research on quality of life for people affected by dementia, shows that many issues influence how well people live, from health and social care, to social relationships, engagement in activities, a sense of belonging and of being a valued part of family, community and civic life.

The breadth of quality of life issues that must be addressed to ensure that people live well with the condition, and the size of the dementia challenge, led Alzheimer’s Society to state that dementia must be recognised as a challenge for society (Dementia 2012). Other work also highlights the importance of society and developing age-friendly environments. For example, the World Health Organisation age friendly environments programme and the RSA (Royal Society for the Encouragement of Arts, Manufactures and Commerce) Connected Communities project.

The Society therefore launched a dementia friendly communities programme of work in March 2012, alongside the Dementia 2012 report. Alzheimer’s Society and its partners in the Dementia Action Alliance are committed to delivering a social movement where organisations and communities work to change the way society views and supports people with dementia, with the ultimate aim of producing dementia friendly communities. A dementia friendly organisation or community is one that shows a high level of public awareness and understanding of dementia, is more inclusive of people with dementia, and improves their ability to remain independent and have choice and control over their lives.

Since March 2012 there has been further consultation, discussion and evidence gathering on what a dementia friendly community is and how the

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5 Dementia Action Alliance, National Dementia Declaration.
7 http://www.thersa.org/action-research-centre/public-services-arts-social-change/connected-communities
programme of work should be progressed (for example the Local Government Association Ageing Well project\(^8\) and the work of the dementia friendly communities champion group). In addition, many organisations, villages, towns and cities are already taking steps towards becoming or have an ambition to become dementia friendly. This work is also producing a wealth of new evidence, debates and discussions on what being dementia friendly means. Alzheimer’s Society will also be publishing new evidence in summer 2013 on what people with dementia and carers want from a dementia friendly community.

1.1 The recognition process

Realising dementia friendly organisations and communities will take a number of years and whilst this is underway, it is vital that there is a recognition process to underpin the work. This process is needed to ensure that organisations and communities are working towards common standards that are based on what we know is important to people affected by dementia and will truly change their experience. It will also enable organisations and communities to be part of an officially recognised group working towards becoming dementia friendly.

It is clear that the process must therefore be based on current evidence and thinking on what matters to people with dementia in terms of quality of life outcomes and dementia friendly communities. It also emerged from the evidence and discussions that there should be certain components present in a recognition system. Organisations and communities that register for the recognition process must agree to meet these components.

It also became clear from discussion and the views of experts that a formal kite mark and accreditation process was not appropriate at this stage. Overly bureaucratic processes that require expensive assessment by external reviewers could actually disincentivise engagement. There is also not yet enough detailed evidence on what is dementia friendly for formal accreditation.

A model for a recognition process, based on the evidence and discussions, was formally consulted on during October and November 2012. The key areas consulted on were briefly as follows. These areas are discussed further within the body of this paper in the context of the findings of the consultation.

- Communities would be expected to support specific values by working towards named standards. The values and standards should be distilled from the seven quality of life outcomes that we know are important to people with dementia and carers, as outlined in the National Dementia Declaration.
- There should be a recognisable symbol. The symbol shows that the organisation or community has registered for the recognition process and is working towards the named standards to become dementia friendly.

\(^8\) http://www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE
Self-assessment should be done on an annual basis with mechanisms for feedback, particularly from people with dementia and carers.

Information on progress and mechanisms for feedback should be provided locally, with a link to a registration page on Alzheimer’s Society’s website.

### 1.2 The consultation

The consultation was open to any individual or stakeholder who wished to comment. It was published on websites including Alzheimer’s Society and the website for the Prime Minister’s challenge on dementia, included in relevant bulletins and newsletters, and distributed widely to nearly 600 key stakeholders. Focus groups with people with dementia were also held by Alzheimer’s Society colleagues. Nearly 100 individuals and stakeholders, including people with dementia and carers, contributed feedback on the proposal.

This paper provides an overview of the recognition system in the context of the consultation findings. It is important to note that the recognition process outlined in this paper is based on the current stage of the dementia friendly communities programme of work. At this stage it is necessary to encourage organisations and communities to join the dementia friendly movement and support progression.

As the movement develops and new evidence emerges, the recognition process will be evaluated and adapted or developed in light of this to ensure that it is fit for purpose.

### 2. Is this the right overall approach?

#### 2.1 Summary

- Responses overwhelmingly considered a standards-based system with the use of a symbol to be the right approach at this stage, as opposed to a more formal accreditation and kite mark system.
- Comments included that the recognition process would be off-putting if done any other way; is timely, well balanced and sufficiently recognises the variety of interest, energy and resource that different communities and organisations will be able to apply to dementia friendly communities; and that at this time a system must be about encouraging commitment and not compliance.
- Some issues and concerns were raised about the core components of the recognition process as outlined in the consultation paper and they are addressed under the appropriate headings in the remainder of this paper.

#### 2.2 Peripheral issues

Respondees also raised issues that must be considered alongside the recognition process:

- The need for organisations to learn from each other as they work to become dementia friendly. It is suggested that each organisation and
community should if possible provide a named person who is willing to share learning with other organisations and communities becoming dementia friendly (peer to peer support).

- The need to promote the system and encourage organisations and communities to join. There must also be a way of making the public aware of the symbol and empowering people with dementia to speak out when their needs are not being met. This will be given consideration. Initial plans include:
  o A launch of the symbol and the recognition process. The recognition process will open in late March 2013 to the first wave of organisations and communities. These will act as early adopters and will help ensure that the core aspects of the recognition system are working as they should. The process then will be formally launched in late July 2013 and will be open to any community or organisation that is working towards becoming dementia friendly and commits to the conditions of the process.
  o A report on what people with dementia and carers need from a dementia friendly community will be published by Alzheimer’s Society in the summer 2013, which will raise the profile of the work and explore the key elements of a dementia friendly community.

3. Do you think these are the values and standards we should be aiming for?

3.1 Summary

- There was support for a system based on values and standards. Specific standards aimed at organisations and at communities were also welcomed. There was also agreement that the proposed values and standards cover some important areas that should be included, but some additions were required to ensure that the standards are fit for purpose and cover the key areas to address. These have been included in the final standards (see section 3.2).
- The majority of respondees supported open, flexible standards so that communities and organisations can interpret and adapt them to fit the context in which they are working. Organisations and communities will interpret each standard to fit their size, type, stage of progression and resource. The new values and standards are below.

3.2 Values and standards

The values and standards are distilled from the seven outcomes that people with dementia and carers have said are important to their quality of life in the National Dementia Declaration. The values and standards have been changed to reflect feedback from consultation respondees.

**Values**

We believe that people with dementia and their carers have the right to:
1. Live their life in a way that meets their needs.
2. Engage in and contribute to their local communities as long as they wish to do so
3. Live alongside people who have an awareness and understanding of dementia.
4. Live their lives free from stigma.
5. Access the information, support and services that they need.

Standards

A community or organisation that registers for the recognition process is committing to take each standard, interpret it from a local perspective to fit the size, type, stage of progression and resource, and describe what they are working towards and the actions they intend to take. There are separate standards for communities and organisations, detailed below.

A community

Our community is working towards:

1. Developing a local Dementia Action Alliance (or a similar group). To include the support of a recognised, senior local leader(s) for example, a head of local business or a local council leader.
2. Analysing the key issues to address to enable them to become dementia friendly in ways that are important to people with the condition and carers.
3. Involving people with dementia and their carers in understanding what dementia friendly means and in the self-assessment process.
4. Identifying which individuals, businesses and organisations are a priority to undertake dementia awareness and understanding training.
5. Providing information on dementia and available services and support from a range of outlets (as considered appropriate, for example library, pharmacy or GP surgery).
6. Seeking to share information and learning with other organisations or communities working to become dementia friendly.

An organisation

Our organisation is working towards:

1. Ensuring the support of senior members of staff, for example a manager or director.
2. Analysing the key issues to address to enable them to become dementia friendly in ways that are important to people with the condition and carers.
3. Involving people with dementia and their carers in understanding what dementia friendly means and in the self-assessment process.
4. Identifying ways to raise dementia awareness and understanding amongst appropriate personnel.
5. Providing information on dementia and available services and support (as appropriate to the organisation)
6. Seeking to share information and learning with other organisations or communities becoming dementia friendly.

4. How would you envisage self-assessment taking place? What processes would you like to see happen?

4.1 Summary

- Responses debated how self-assessment might work. The majority were very strong about the need for a lack of bureaucracy, for flexibility in how self-assessment is approached and for the need to ensure that the process is not burdensome (because some organisations or communities will have limited resources for example).
- The self-assessment process will therefore be flexible in nature at this stage and aimed at allowing the gathering of rich evidence on what each organisation and community is doing. This evidence will provide guidance for those thinking about becoming dementia friendly and enable learning to be shared with other organisations and communities becoming dementia friendly.
- An organisation or community will assess actions taken on standards and outline the next steps. The method of self-assessment can be chosen by the organisation or community.
- However, as outlined in the standards (section 3.2) a stipulation will be that people with dementia and carers must be involved in the self-assessment process and their views reported.
- Self-assessment must be detailed enough for others to understand what work is being undertaken and how it is progressing, for example case studies alongside survey results.

5. Do you think self-assessment on an annual basis is appropriate?

5.1 Summary

- The majority of responses agreed that self-assessment should be carried out on an annual basis.
- However, some respondees suggested more frequent reporting would be appropriate. It is therefore stipulated that organisations and communities who register must also provide a brief summary 6 months after the self-assessment. This will be a very simple and short outline of what has been achieved since the self-assessment and actions to be taken prior to the next one.
- In addition, a few respondees suggested that the self-assessment process should not happen annually but rather on a 2-yearly basis. However, annually is considered appropriate as self-assessment is a chance to review progress, gather evidence on appropriate next steps and provide rich material to share with other organisations or communities to support progression and learning.

6. Who should take responsibility for committing to the standards and the subsequent self assessment of activities against these across an
entire community (village, town or city)? For example could this be the local leaders championing the work?

6.1 Summary

- Responsibility should be taken by the local dementia action alliance where possible (particularly for larger communities) or a small steering group. This group should include senior figures from the community (for example a local council leader or senior business leader), people affected by dementia and smaller stakeholders (for example small organisations within the community).
- If a steering group is not feasible, for example in a small organisation, then responsibility must be taken by a named senior figure or leader within the organisation or community. Respondees were clear that the individual must be an established leader and with the time and enthusiasm to progress the work.

7. Do you have any comments on the suggestion that progress reports and mechanisms for feedback should be hosted locally?

7.1 Summary

- There is general agreement for information and self-assessment processes to be hosted locally. This is seen as crucial to the scheme’s success, will empower local communities, and facilitates local accountability through people affected by dementia. Information can be hosted by the local dementia action alliance where this is appropriate.
- Respondees also suggested that there must be some way of creating a national picture of the work happening. Each organisation and community will be asked to produce a summary of the self-assessment process, which Alzheimer’s Society will collate.

8. Do you have any other comments on the suggested monitoring and overall governance of the work?

8.1 Summary

- There will be a recognisable symbol. The symbol shows that the organisation or community has registered for the recognition process and is meeting the conditions.
- It was agreed that there must be a method for ensuring that the symbol is only displayed by organisations and communities that are actively working towards becoming dementia friendly.
- Therefore, Alzheimer’s Society is obtaining legal rights to the dementia friendly communities symbol. The Society will grant permission to an organisation or community to use the symbol once they have signed up to the recognition process, but retain the right to withdraw that permission if it is felt that the conditions of the recognition process and/or the needs of people with dementia are not being met.
Respondees were also clear that people with dementia and carers must be involved in the monitoring of the work. Therefore, signing up to the standards means signing up to involving people with dementia and their carers in both understanding what dementia friendly means and in the self-assessment process.