



# GOVERNANCE FRAMEWORK

An outline of the purpose  
of the DAA, how it  
operates and how it is  
managed and governed

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## Introduction

This document provides an overview of the background, working and governance of the Dementia Action Alliance (DAA). The document will be reviewed following each Annual Conference in order to ensure the information is up to date.

## SECTION 1 - INTRODUCTION TO THE DAA

### About the DAA

The DAA is a cross-sector, England-wide coalition of organisations that works to improve the lives of people with dementia and those who care for them. It does so through gaining sign-up to the National Dementia Declaration (see Appendix 1), promoting action within member organisations and supporting the development and delivery of joint programmes of work, campaigns and 'calls to action'. The DAA brings together key organisations that are committed to improving health and social care outcomes for people affected by dementia.

### Principle

The fundamental principle of the DAA is that it is an alliance of members undertaking actions to improve health and social care outcomes for people living with dementia. It is important that the membership remains meaningful, serves to improve the lives of people living with dementia and their carers, and commits to actions to achieve these aims. Members must be committed to sharing best practice, across the membership and with others across the field of dementia care.

### Member Commitments

Each member is expected to:

- Complete an Action Plan on joining the DAA, outlining their specific commitments
- Update their Action Plan on a regular basis, at least once a year
- Report on planned actions that have been undertaken and where possible the impact those actions have had
- Attend and contribute to the DAA's programme of events
- Proactively seek out opportunities to collaborate with other members
- Support calls to action and other joint work
- Promote the work of the DAA and membership to others where appropriate
- Make a financial contribution to support the work of the DAA

### Our mission

*We provide a platform for our members to share ideas and to inspire each other to commit to actions that will positively bring about change for people affected by dementia. The views of people living with dementia are at the heart of our work.*

This mission is achieved through:

- Engaging with people with dementia and carers to understand the specific issues they face and using this to inform our work
- Building a wide network of health and social care focused organisations that are committed to taking action to improve the lives of people with dementia and their carers
- Enhancing member activity to improve the lives of people with dementia
- Developing and delivering joint work on common priorities
- Running engaging member driven events.

## **Background to the DAA**

In 2010 a number of organisations, together with people with dementia and carers, led by Alzheimer's Society, came together to launch a Call to Action for radical and sustainable change to improve the lives of people affected by dementia. The National Dementia Declaration, created by this group, was published and announced at the launch of the Dementia Action Alliance in October 2010. The Declaration outlined seven outcomes and 35 sub statements that people with dementia and their carers said they would like to see in their lives (see Appendix 1). This included having personal choice, having support to help them live their life and living in an enabling and supportive environment. The Declaration became known as the I Statements and in 2016 underwent a review, taking in to account progress that has been made since its inception.

In order to co-ordinate activity within the newly launched DAA and to bring together the member organisations, a small Secretariat was formed, which was hosted by Alzheimer's Society. The membership has gone from 41 organisations in 2010 to over 150 as it stands today. All member organisations commit to actions based on the original Declaration ("I Statements), attend regular events and lead on - or unite behind - various campaigns, or calls to action.

As part of their commitments, member organisations also agree to ensure their work is informed by the views of people with dementia and carers, and they are required to report publically on their progress, working in partnership with other organisations to share knowledge and best practice.

## **SECTION 2 - MEMBERSHIP**

### **Criteria for Membership**

DAA members must be committed to improving the health and social care outcomes for people with dementia and carers. They must have a national remit, working across England. They must be committed to taking action on dementia and are expected to publish an action plan, outlining what they plan to do to support people affected by dementia. They should provide an update on their action plans and renew them annually.

DAA members are expected to actively engage with DAA activity, for example participating in events, supporting calls to action and providing updates and news

stories for the newsletter and the website. They must be committed to sharing positive practice.

Where it is unclear whether an organisation meets the criteria, it will be decided by the DAA Secretariat and Steering Group.

### **Financial Contributions**

The DAA relies on the financial contributions of our members. Members are asked to make a financial contribution or equivalent in-kind contribution to the running cost of the Alliance. We expect all of our members to make a financial contribution, unless there are mitigating circumstances where this is not possible. In some circumstances, members can make in-kind contributions, providing they add value to the DAA.

Examples of this include:

- providing meeting space
- free attendance to conferences
- support with designing marketing materials
- printing materials and documents
- facilitating introductions to prospective members and others who can support the DAA's objectives.

The financial contributions made by members allow the DAA to run a programme of activity. Specifically, contributions go towards Secretariat salaries, venues and catering for events and involving people with dementia and their carers in the work of the DAA.

Funding is accounted for in a written report to the DAA Steering Group, which is shared with all members. Member contributions will also be included in the DAA Annual Report, which is mailed out to all national members and others working across health and social care and the dementia space.

### **The role of members in shaping the Alliance**

Having members work together collaboratively adds strength and enables changes to be made at pace, improving outcomes for people affected by dementia.

DAA members are expected to play an active role in shaping the work of the Alliance. Members should proactively develop opportunities for collaboration across the membership, seeking out other members for joint working where appropriate. The Secretariat can support with this. The DAA can be a useful platform for promoting a joint piece of work and gaining the input and expertise of the members. Collaborative opportunities can include events and roundtables, campaigns and calls to action or reports and resources.

If members identify an area where they would like to collaborate with the DAA, they should discuss this with the Secretariat, who will present the idea to the DAA Steering Group. A decision will then be made, in accordance to whether the project aligns with the objectives of the DAA around inspiring action that will improve health and social care outcomes for people affected by dementia.

## Features of Membership

An important component of the DAA is providing a platform for members to collaborate and share best practice. The Secretariat provides a number of opportunities for this to happen, including:

### ➤ Member events

The DAA runs a programme of engagement, which consists of various meetings and events. These are focused around specific themes and allow for members to share actions with each other and to learn more about a wide range of issues across dementia care and support.

Previous events have focused on devolution, safeguarding, dementia within seldom heard groups, and partnership working. We provide opportunities for our members to inform the topics of these events but also welcome direct approaches if they have ideas around important issues we should explore. The DAA welcomes supporting member's events through a number of ways, including co-branding, promotion and recommending speakers.

### ➤ Annual Conference

This is the biggest event of the DAA's year. It is open to all members – including people with dementia and carers - and celebrates the achievements of member actions and looks ahead to future work. The Annual Conference is typically headlined by a high profile keynote speaker. Previous speakers have included Secretary of State for Health, Jeremy Hunt and former Secretary of State for Health, Andrew Lansley. It aims to ensure that the voices of people affected by dementia are heard.

Through the Conference we inform our members on some of the prominent issues in dementia care and support. We also provide the opportunity to communicate directly with leaders from government and national bodies, to communicate what is working and to shape ideas and policy.

We welcome sponsorship of the Annual Conference and can work with members on a package that has a number of business benefits, including raising awareness of their brand across the sector.

### ➤ Webinars

Webinars bring together a large number of participants via an online platform. They are a flexible and time effective way of engaging members and help to inform them on specific issues. Webinars are another area where we would expect members to lead by offering to host discussions. Previous webinars have been held on topics such as psychological therapies for depression for people with dementia, housing, and the role of robotics in dementia care. Webinars are open to non-members, as it gives us the chance to introduce potential new members to the DAA.

### ➤ Alliance Directory and Website

All national members are invited to share their contact details and update each other

on their work through the Alliance directory and DAA website. Members are able to view each other's action plans and can request introductions to each other through the Secretariat. We encourage members to proactively approach the Secretariat for referrals, particularly around joint working opportunities or for sharing and supporting their actions.

## Campaigns and calls to action

The DAA has organised a number of campaigns or calls to action since it was formed in 2010. The purpose of these is to address specific issues faced by people with dementia and their carers, by uniting the members in support. Typically, calls to action have a start and end date. However there may be times when another organisation takes over the call to action in order to embed the principles.

Previous calls to action have included:

- The Right Prescription – a campaign to reduce anti-psychotic drug prescriptions for people with dementia
- The Right Care – a campaign to improve the experience of people with dementia in hospital settings
- The Carer's Call to Action – a campaign to raise awareness of issues faced by carers of people with dementia
- Dementia Words Matter – an ongoing campaign to embed the appropriate use of language when communicating with and about people affected by dementia across a variety of settings

Members are actively encouraged to suggest ideas for joint working and calls to action that can be supported by the DAA. In the first instance these should be presented to the DAA Executive Lead who will discuss with the Steering Group who will make a decision.

## Thematic Surveys

There may be times when members need to collect information from across the health and social care sector to support their work. Where this is the case, surveys can be conducted amongst the DAA membership by the Secretariat. These are conducted on a case by case basis, depending on the frequency and themes required.

## The DAA logo

The DAA logo has been trademarked by Alzheimer's Society. Members of the DAA are allowed to state in publications and e-materials that they are members of the DAA and support the work of the Alliance. When describing the work of the DAA, members may use the logo in line with the DAA brand [guidelines](#).

The DAA logo will be used in relation to member actions when action has been agreed by the DAA Steering Group or DAA Secretariat. The logo must not be used to suggest support for events of published materials where Alliance permission has not been given.

## **Local Dementia Action Alliances (LDAAs)**

LDAAs are completely separate to the national DAA, despite the similarity of name. They are independent groups, with their own governance and funding structures. LDAAs play a key role in creating Dementia Friendly Communities. LDAAs cannot use the DAA logo without first obtaining the permission of Alzheimer's Society. The National DAA has no responsibility for Local DAAs and they should be treated as completely separate entities.

## **Role of people affected by dementia within the DAA**

The active engagement and involvement of people with dementia and carers is a fundamental principle of the DAA. All actions of the DAA should support the aims of improving outcomes for people affected by dementia, who are encouraged to become active within the membership of the Alliance. The most effective way they can do this is by playing a part within an organisation which, as a full member of the Alliance, can represent their views. This will ensure that those wishing to be fully involved will have the appropriate information and support to ensure a positive and meaningful experience. The DAA Secretariat can support with introductions to these organisations for interested parties.

Both people with dementia and carers are represented on the DAA Steering Group. At all meetings of the Alliance we aim to include people with dementia and carers, as delegates and as speakers. We also try to include them in surveys which help to inform our work.

More detail is available through our user involvement policy.



## SECTION 3 - MANAGEMENT & GOVERNANCE STRUCTURE

### Legal status of the DAA

The DAA is legally part of Alzheimer's Society. It is not an independent legal entity. Legal responsibility for the operations of the DAA sits with the Board of Trustees of Alzheimer's Society. The day to day running of the DAA has been delegated by the Trustees of Alzheimer's Society to the DAA Secretariat.

### DAA Steering Group

The DAA Steering Group provides advice and guidance to help shape the work of the DAA. They do not have any legal accountability to the DAA or of the staff who work on the DAA. The Board of Trustees and Chief Executive of Alzheimer's Society as well as the DAA Secretariat look to the Steering Group to advise on the direction of the DAA.

The responsibilities of the Steering Group are to:

- Lead on specified areas of the DAA's programme of work
- Use expertise to inform, guide and shape the work of the DAA
- Support the development of Alliance priorities
- Where appropriate, be willing to chair Alliance events
- Support the development of areas of joint work (alongside the Secretariat) conducted under the name of the Alliance
- Support membership development by introducing key individuals and organisations to the DAA
- Recommend, approach and secure speakers for DAA programme of events as discussed with the Secretariat
- Attend Steering Group meetings in person (four per year)
- Proactively engage with the wider membership to ensure they remain active.

### Steering Group membership

The Steering Group consists of individuals who have considerable knowledge of dementia and the health and social care sector. Members are individuals who have been elected by the wider membership and individuals who have been nominated by the Secretariat based on how they can support the objectives of the DAA. People with dementia and carers are also represented on the Steering Group. The Steering Group should cover both health and social care perspectives. All members of the Steering Group should be committed to advancing the objectives of the DAA.

The Steering Group is made up of the following:

#### ➤ Chair

As the host organisation, an Alzheimer's Society nominee (currently the Chief Executive) occupies the position of Chair of the Steering Group. The Chair is the first point of contact for the Executive Lead and close liaison can make sure progress and necessary decisions are made and implemented in a timely way. This is a permanent position (not term limited).

### ➤ National Policy Lead

Department of Health, as a key funder and the national policy lead for dementia, occupies a permanent position on the Steering Group. This is to ensure the DAA is informed of the government's understanding of key issues in dementia care and support, and we share the agenda to drive positive change across health and social care.

### ➤ Appointed members

Appointed members provide strategic direction and use their expertise of dementia, health and social care to support the work of the DAA. They occupy a position on the Steering Group for two years. After this time they can choose to remain for another term. Appointed members can serve a maximum of two terms on the Steering Group. These are nominated by the existing Steering Group and the Secretariat. Appointed members should broadly cover health, social care and research and should include both policy and practice.

There are three Appointed members on the Steering Group.

### ➤ Elected members

These members have been elected by the wider membership. Their role is to support the Secretariat in ensuring that the views of the members are being considered by the Steering Group. They would be expected to proactively engage with the members and to make themselves available to any members who wish to discuss areas of DAA activity with them. In order to be elected, they would put their names forward and complete a short expression of interest. Names would then go to the wider membership for a vote. The names with the highest votes would then join the group.

There are three Elected members on the Steering Group, serving terms of two years.

### ➤ People affected by dementia

People with dementia and carers are chosen by the Steering Group and Secretariat following discussions with those who are interested. There is one person with dementia and one carer on the group. Terms are determined on a case-by-case basis.

## Steering Group meetings

The Steering Group meets at least four times a year. Meetings are convened and supported by the DAA Secretariat. All meeting papers, including the agenda and presentations are circulated a week in advance.

Steering Group members who are unable to attend a meeting will receive copies of meeting papers. Any questions, information, or comments they wish to raise can be passed to the DAA Secretariat or to fellow Steering Group members. These are then fed into discussions at the meeting. The Secretariat will provide additional support prior to the meetings for people affected by dementia or any other Steering Group members who require this. Members are expected to attend meetings in person wherever possible. If this isn't possible then it should be discussed with the Secretariat.

## Relationship between DAA and Alzheimer's Society

Legal responsibility and accountability for the DAA and the Secretariat resides with Alzheimer's Society. Staff (the Secretariat) are employed and managed by Alzheimer's Society, with support from the DAA Steering Group. The Steering Group shapes the direction of the DAA's work, to support members' actions to improve health and social care outcomes for people with dementia and their carers.

## Decision making

The day to day running of the DAA has been delegated by the Trustees to the Chief Executive of Alzheimer's Society and is fulfilled by the DAA Secretariat. The Steering Group advises and shapes the direction of the DAA. The DAA cannot undertake any work that is in conflict with the objectives of Alzheimer's Society or would compromise the charitable status of Alzheimer's Society.

## DAA Secretariat

### Responsibilities

The Dementia Action Alliance is supported by a core Secretariat team. They are employed by Alzheimer's Society on behalf of the whole Alliance. Their work is supported by the Steering Group. The Executive Lead heads up the Secretariat and reports in to a manager who sits within Alzheimer's Society. The team are responsible for the day to day running of the Alliance, which includes:

- Developing and delivering the DAA's strategy
- Being the first point of contact for the Alliance
- Developing the DAA membership by identifying new members
- Organising regular events and collaboration opportunities, such as the Annual Conference and webinars
- Accepting and inducting new national members and advising and supporting members on their actions
- Promoting Alliance work and member activity in the national media and trade press (alongside Steering Group members) and through speaking at events and conferences
- Co-ordinating the appointment of Steering Group members
- Convening and administering all aspects of Steering Group meetings
- Conducting research and policy analysis on behalf of the Alliance to inform the work
- Producing/signing off Alliance outputs such as the Annual Report
- Initiating, approving and overseeing joint work between Alliance members under the DAA umbrella
- Maintaining and developing the DAA website for all Alliance members
- Maintaining a contact database of national members
- Requesting and processing member contributions
- Spending Alliance monies within overall budget as decided by Alzheimer's Society manager and the Steering Group
- Making day to day decisions needed to fulfil the responsibilities given above and achieve objectives set out in the DAA Strategy
- Reporting on DAA activity, including income and expenditure and impact of calls to action.

The full list of current Secretariat can be found in Appendix 3 below.

## Reporting

The DAA Secretariat updates the Steering Group on a quarterly basis. This includes a financial and membership update and progress report on how the Alliance is fulfilling its objectives.

## Finance

DAA members are expected to make financial contributions to fund the day to day running costs of the Alliance. Funding comes from four main sources:

- Direct grants
- Member contributions
- Sponsorship
- In kind support

These monies are spent on the following items:

- Secretariat salary costs
- Running costs for events, including the Annual Conference
- Involvement of people with dementia and carers in the work of the DAA
- An Annual Report
- Website and IT costs
- Joint work between members
- General administrative costs

## Appendix 1 - National Dementia Declaration

- *We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.*
- *We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.*
- *We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.*
- *We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.*
- *We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.*

## Appendix 2 – Steering Group Membership

The current Steering Group is composed of the following people:

- Prof Dawn Brooker – Worcester University (Appointed member)
- Prof Alistair Burns – NHS England (Appointed member)
- Helen Davies – Alzheimer’s Research UK (Elected member)
- Reinhard Guss – British Psychological Society (Elected member)
- Jeremy Hughes – Alzheimer’s Society – Chair (host organisation)
- David Nuttall – Department of Health (National Policy Lead)
- Keith Oliver – Person with dementia representative
- Prof Graham Stokes – Bupa (Appointed member)
- Rachel Thompson – Dementia UK (Elected member)
- Jean Tottie – Carer representative

## Appendix 3: DAA Secretariat

- DAA Executive Lead
- DAA Partnerships Manager
- DAA Engagement Officer
- DAA Digital & Communications Officer