

NATIONAL DEMENTIA ACTION ALLIANCE

WAYS OF WORKING AND GOVERNANCE FRAMEWORK

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

Updated April 2019

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Introduction

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

SECTION I - INTRODUCTION TO THE NDAA

About the NDAA

The NDAA 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 Dementia Statements (see Appendix I), promoting action within member organisations and supporting the development and delivery of joint programmes of work, campaigns and 'calls to action'. The NDAA brings together key organisations that are committed to improving health and social care outcomes for people affected by dementia.

Our mission

We are the platform for our members to share ideas and to inspire each other to commit to actions that will positively bring about change for people living with dementia and carers. The views of people living with dementia and their carers are at the heart of our work. By championing the rights of people living with dementia and carers we will transform the landscape of dementia forever.

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 and carers
- Developing and delivering joint work on common priorities
- Running engaging member driven events.

Principle

The fundamental principle of the NDAA is that it is an alliance of members undertaking actions to improve health and social care outcomes for people living with dementia and their carers. 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 NDAA reflecting the Dementia Statements and outlining their organisations specific commitments
- Update their Action Plan on an annual basis
- Report on planned actions that have been undertaken and where possible, the impact those actions have had
- Attend and contribute to the NDAA'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 NDAA and membership to others where appropriate
- Make a financial contribution to support the work of the NDAA

Background to the NDAA

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 living with dementia and carers. 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. This included having personal choice, having support to help them live their life and living in an enabling and supportive environment. All member organisations committed to actions based on the original Declaration ("1 Statements), attend regular events and lead on - or unite behind - various campaigns, or calls to action. In order to co-ordinate activity within the NDAA 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 110 as it stands today.

A lot has changed since 2010. So, in 2016, Alzheimer's Society led a review on behalf of the NDAA alongside people living with dementia and carers to ensure they reflect what people expect today. In April 2017, the Dementia Statements were welcomed and endorsed by the Dementia Programme Board that monitors and supports the implementation of the 2020 Challenge on Dementia across the NHS, social care, the research sector and wider society.

The new Dementia Statements reflect the things people with dementia and carers say are essential to their quality of life and reflect the view that carers are equally as

important as the person diagnosed with dementia, hence the 'We'. Grounded in human rights law, they are a rallying call to improve the lives of people with dementia and carers and to recognise that they shouldn't be treated differently because of their diagnosis.

As part of their commitments, member organisations 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.

In 2018 as part of a rebranding of the alliance it was decided to include the word national to distinguish between the national and local Dementia Action Alliances and therefore, we became the National Dementia Action Alliance. This decision was taken to provide more clarity around the brand of the organisation and was introduced together with a new logo and the new website.

SECTION 2 - MEMBERSHIP

Criteria for Membership

NDA A members must be committed to improving the health and social care outcomes for people living 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 living with dementia and carers. They should provide an update on their action plans and renew them annually.

NDA A members are expected to actively engage with NDA A 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 NDA A Secretariat and Steering Group.

Financial Contributions

The NDA A relies on the financial contributions of our members. Members are asked to make a financial contribution to the running cost of the NDA A. We expect all of our members to make a financial contribution, unless there are mitigating circumstances where this is not possible. In some circumstances at the discretion of the Steering Group, members can make equivalent in-kind contributions, providing they add value to the NDA A. Examples of this include:

- providing meeting space
- free attendance to conferences

- free stands at conferences
- support with designing marketing materials
- printing materials and documents
- Support the Secretariat with the running of campaigns

The membership fee will be calculated on the basis of organisation turnover. At the discretion of the Steering Group, fees can be waived or reduced for members that demonstrate need and make a request in writing.

Category 1: Turnover up to £1 million = £250

Category 2: Turnover between £1 million - £2.5 million = £500

Category 3: Turnover between £2.5 million - £5 million = £1000

Category 4: Turnover of over £5 million = over £2000, exact amount decided on a case by case basis

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

Funding is accounted for in a written report to the NDAA Steering Group. Member contributions will also be included in the NDAA Annual Report.

The role of members in shaping the NDAA

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

NDAA members are expected to play an active role in shaping the work of the NDAA. 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 NDAA 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 NDAA, they should discuss this with the Secretariat, who will present the idea to the NDAA Steering Group. A decision will then be made, in accordance to whether the project aligns with the objectives of the NDAA around inspiring action that will improve health and social care outcomes for people living with dementia and carers.

Features of Membership

An important component of the NDAA 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 NDAA 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 co-morbidities. 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 NDAA 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 NDAA's year. It is open to all members – including people living 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 former Secretary of States for Health, Jeremy Hunt and Andrew Lansley. It aims to ensure that the voices of people living with dementia and carers 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 NDAA.

➤ Website

All national members are invited to update each other on their work through the NDAA 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. The new NDAA website will provide forums allowing members discussions.

➤ Newsletters

The NDAA issue monthly newsletters with a comprehensive roundup of Secretariat work and member news. The newsletter has regular sections on the 2020 Dementia Challenge and member action plans based on the Dementia Statements. Members are encouraged to submit news stories to the Secretariat to be included in the newsletter.

Campaigns and calls to action

The NDAA 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 living 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 Carer's Call to Action – a campaign to raise awareness of issues faced by carers of people with dementia, the legacy of which is tide- together in dementia everyday
- 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

Calls to action which are continuing are:

- Dementia Friendly Hospital Project (Previously The Right Care) – a campaign to improve the experience of people with dementia in hospital settings
- From Seldom Heard to Seen and Heard – a campaign bringing NDAA members together for improved outcomes for people living with dementia and their carers who come from seldom heard groups

Members are actively encouraged to suggest ideas for joint working and calls to action that can be supported by the NDAA. In the first instance these should be

presented to the NDAA 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 NDAA membership by the Secretariat. These are conducted on a case by case basis, depending on the frequency and themes required.

The NDAA logo

The NDAA has rebranded the logo from DAA to NDAA in order to differentiate between National and Local alliances. The existing logo can be used by the Local DAAs in accordance with the guidelines set out below.

. Members of the NDAA are allowed to state in publications and e-materials that they are members of the NDAA and support the work of the NDAA. When describing the work of the NDAA, members may use the logo in line with the NDAA brand [guidelines](#).

The NDAA logo will be used in relation to member actions when action has been agreed by the NDAA Steering Group or NDAA Secretariat. The logo must not be used to suggest support for events or published materials where NDAA permission has not been given. Local DAA's are not able to use the NDAA logo.

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. The DAA logo has been trademarked by Alzheimer's Society. Members of local DAA's are allowed to state in publications and e-materials that they are members of the DAA and support the work of the DAA.

Role of people living with dementia and carers within the NDAA

The active engagement and involvement of people living with dementia and carers is a fundamental principle of the NDAA. All actions of the NDAA should support the aims of improving outcomes for people living with dementia and carers, who are encouraged to become active within the membership of the NDAA. The most effective way they can do this is by playing a part within an organisation such as The

Dementia Engagement and Empowerment Project (DEEP) and tide - together in dementia everyday, which, as full member of the NDAA, 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 NDAA Secretariat can support with introductions to these organisations for interested parties.

Both people living with dementia and carers are represented on the NDAA Steering Group. We aim to include people living with dementia and carers in all aspects of NDAA work planning from the outset, as well as involvement in deciding event agendas, speaking and attending NDAA events.

SECTION 3 - MANAGEMENT & GOVERNANCE STRUCTURE

Legal status of the NDAA and relationship with Alzheimer's Society

The NDAA is legally part of Alzheimer's Society. It is not an independent legal entity. Legal responsibility for the operations of the NDAA sits with the Board of Trustees of Alzheimer's Society. The day to day running of the NDAA has been delegated by the Trustees of Alzheimer's Society to the NDAA Secretariat. Staff (the Secretariat) are employed and managed by Alzheimer's Society, with support from the NDAA Steering Group. The Steering Group shapes the direction of the NDAA's work

NDAA Steering Group

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

The responsibilities of the Steering Group are to:

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

person to attend in their place. If a member regularly doesn't attend meetings their membership of the Steering Group will be reassessed

- Proactively engage with the wider membership to ensure they remain active.

Steering Group membership

The Steering Group consists of people living with dementia and carers and individuals who have considerable knowledge of dementia and the health and social care sector. Members are individuals who have been appointed by the Secretariat based on how they can support the objectives of the NDAA. 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 NDAA.

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.

➤ National Policy Lead

Department of Health and Social Care, as a key funder and the national policy lead for dementia, occupies a position on the Steering Group. This is to ensure the NDAA 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 NDAA. 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. If individuals are not able to attend, they are encouraged to appoint a deputy to attend in their place.

The position of appointed members will be assessed every 2 years.

➤ People living with dementia and carers

People living with dementia and carers are chosen by the Steering Group and Secretariat following discussions with organisations including DEEP and tide. There is one person with dementia and one carer on the group. Terms are determined on a case-by-case basis. If individuals are not able to attend, they are encouraged to

appoint a deputy to attend in their place.

Steering Group meetings

The Steering Group meets at least four times a year. Meetings are convened and supported by the NDAA 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 NDAA 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 living with dementia or any other Steering Group members who require this. Members are expected to attend meetings in person wherever possible or send a representative. If this isn't possible then it should be discussed with the Secretariat.

Decision making

The day to day running of the NDAA has been delegated by the Trustees to the Chief Executive of Alzheimer's Society and is fulfilled by the NDAA Secretariat. The Steering Group advises and shapes the direction of the NDAA. The NDAA 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.

NDAA Secretariat

Responsibilities

The NDAA is supported by a core Secretariat team. They are employed by Alzheimer's Society on behalf of the whole NDAA. 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 NDAA, which includes:

- Developing and delivering the NDAA's strategy
- Being the first point of contact for the NDAA
- Developing the NDAA 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 NDAA 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 NDAA to inform the work
- Producing/signing off NDAA outputs such as the Annual Report
- Initiating, approving and overseeing joint work between NDAA members under the NDAA umbrella
- Maintaining and developing the NDAA website for all members
- Maintaining a contact database of national members
- Requesting and processing member contributions
- Spending NDAA 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 NDAA Strategy
- Reporting on NDAA 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 NDAA Secretariat updates the Steering Group on a quarterly basis. This includes a financial and membership update and progress report on how the NDAA is fulfilling its objectives.

Finance

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

- Direct grants
- Member contributions
- Sponsorship

These monies are spent on the following items:

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

Appendix I – Dementia Statements

These statements were developed by people living with dementia and their carers. The person with dementia is at the centre of these statements. They represent

everyone living with any type of dementia regardless of age, stage or severity.

The “we” used in these statements encompasses people with dementia, their carers, their families, and everyone else affected by dementia. These rights are enshrined in the Equality Act, Mental Capacity legislation, Health and care legislation and International Human Rights law.

- 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
- Prof Alistair Burns – NHS England
- Helen Davies – Alzheimer’s Research UK
- Reinhard Guss – British Psychological Society
- Jeremy Hughes – Alzheimer’s Society – Chair
- David Nuttall – Department of Health
- Keith Oliver – Person with dementia representative
- Prof Graham Stokes –HC-One
- Rachel Thompson – Dementia UK
- Jean Tottie – Carer representative

Appendix 3: NDAA Secretariat

- NDAA Executive Lead
- NDAA Campaigns and Partnerships Manager
- NDAA Engagement Officer
- NDAA Communications Office