



Terms of Reference for the Leicestershire Dementia Action Alliance

Dementia Action Alliance Background

Dementia Action Alliance is made up of over 100 organisations committed to transforming the quality of life of people living with dementia in the UK and the millions of people who care for them.

There are 800,000 people with dementia in the UK and this number is set to grow to over one million people by 2021. The financial cost of dementia in the UK is £20 billion each year and growing.

Members of Dementia Action Alliance have signed up to a National Dementia Declaration. Created in partnership with people with dementia and their carers, the Declaration explains the huge challenges presented to our society by dementia and some of the outcomes we are seeking to achieve for people with dementia and their carers. Outcomes range from ensuring people with dementia have choice and control over decisions about their lives, to feeling a valued part of family, community and civic life.

Signatories to the Declaration have published their own Action Plans setting out what they each will do to secure these outcomes and improve the quality of life of people with dementia by 2014.

Aims of the East Midlands Regional Board and the Local Alliances

The East Midlands Regional Board and Local Alliances aim to transform the quality of life of people with dementia and their carers through delivering on their action plans. The action plans outline how they intend to deliver on the Dementia Declaration by 2014.

1. Membership of the Dementia Action Alliance

Every member of the Dementia Action Alliance will be committed to delivering the National Dementia Declaration and every member will have an action plan setting out what the role of their organisation is in delivering the outcomes described in the Declaration.

There will be two types of membership in the East Midlands:

1.a.) Regional Board East Midlands

Members of the Dementia Action Alliance East Midlands Regional Board will be organisations which work across the East Midlands which have an aspiration to deliver better outcomes across the region (and beyond if organisations work across home

nation boundaries). Regional Board members will have to publish an Action Plan which will be submitted on the DAA website. Regional Board members of the Alliance will take part in quarterly reporting and update at meetings at a frequency that each alliance will determine individually.

National organisations that have a significant footprint across the East Midlands will become National members and will therefore be invited to Quarterly meetings as well as being required to provide quarterly updates to the DAA. They will however be invited to be part of the Regional Board or Local Alliance.

1.b.) Local membership of the DAA

'Local members' of the Dementia Action Alliance are based in the East Midlands but do not have a Regional footprint. Local members will have an action plan published on the DAA website. Local members will be encouraged to be involved in local alliance meetings with other organisations to deliver the outcomes for people with dementia and carers described in the National Dementia Declaration. They will not have to submit quarterly reports to the DAA but will be asked to do so to their local alliance. Local Alliance members will not be asked to attend National meetings and will not be part of quarterly discussions. They will however receive the DAA newsletter and regular updates from the DAA. Organisations and individuals who are interested in the Alliance but who do not want to be members will be able to put on a contact list to receive updates.

2. Membership requirements and restrictions

Any organisation that submits an Action Plan and commits to action will be considered for membership of the Alliance.

There are a number of commercial organisations in the Dementia Action Alliance and the Alliance will be looking to expand the range of commercial organisations.

If any member of the Alliance has serious concerns about an organisation being a member of the Alliance they should raise the concerns with the Alzheimer's Society. The Society is providing the secretariat for the Alliance. If issues cannot be resolved a small sub group will be convened to discuss the concerns raised.

Each meeting will provide an opportunity for members to offer an update on their action plans and also receive news of new members.

Each member of the Alliance can promote their work through the Alliance but the purpose of the Alliance is to create an arena where collaboration and joint action can develop. Therefore members can promote their work within Alliance meetings and communications (particularly via quarterly and annual reports). However, the Alliance should not be seen as an opportunity by members to strongly market products or services. The Local Alliance will not be an opportunity to challenge activity of other members or be used as a forum to express personal experiences. There are processes and opportunities external to the Local Alliance for this to take place. The Local Alliance will be a safe haven based on trust and respect of members giving them the opportunity to discuss rather than challenge.

3. Overall aims of the Leicestershire Local Alliance

- Recognising the diversity of organisations needed to support people with dementia and their carers in Leicester, Leicestershire and Rutland.
- Encouraging organisations to become part of the Leicestershire dementia action alliance.
- Working towards dementia friendly communities.
- Identifying and working with dementia champions.
- Sharing of information amongst members.
- Identifying future work, sharing of resources and working in partnership.

4. The Secretariat for the Alliance

The Alzheimer's Society agreed as part of its dementia action plan to provide the secretariat for the Regional Alliance. This will include:

- Being the first point of contact for queries about the Alliance.
- Organising meetings and events and taking notes.
- Advising organisations who want to join on what they need to do and giving some initial thoughts about Action Plans.
- Facilitating Action Plan entry onto the DAA website.

5. Meeting attendance

Local Alliance

- Local Alliances will be formed in Derbyshire, Northamptonshire, Nottinghamshire, Lincolnshire, Leicestershire and Rutland.
- All members of the Local Alliance will be invited to attend all the Local Alliance meetings in their appropriate County or sub county if more than one group exists.
- Members will give an update on their action plan at each meetings.
- Information from the National DAA and Regional Board meeting will be highlighted at the Local Alliance meetings
- Local Alliance meetings will discuss and prioritise action.

6. Use of the DAA logo

- Members of the Alliance are allowed to say in publications and e-materials that they are members of the Dementia Action Alliance and support the work of the Alliance.
- When describing the work of the Alliance members may use the Alliance logo.
- The Alliance logo will be used in relation to Alliance action when Alliance action has been agreed at quarterly meetings or by email.
- The logo must not be used to suggest support for events of published materials where Alliance permission has not been given.

7. Funding the work of the Alliance

Members of the Regional Board and Local Alliances will be asked to consider supporting the Alliance financially or in kind e.g. meeting facilities or establishment of Dementia Champions.

(The Leicestershire DAA terms of reference will be reviewed annually)