Terms of Reference for the East Midlands Regional Dementia Action Alliance

Dementia Action Alliance Background
Dementia Action Alliance is made up of over 80 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 750,000 people with dementia in the UK and this number is set to grow to over one million people by 2025. 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 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 organisation 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.

If the Alliance as a whole considers that any member is seriously damaging the
interests of people with dementia and their carers or the reputation of the Dementia
Action Alliance, members can be expelled following a discussion at a quarterly
meeting or a special meeting convened and open to all 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.
3. 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.

4. Meeting attendance
   **Regional Board**
   • All members of the Regional Board will be invited to attend Regional Board meetings.
   • Members of the Regional Board that present at meetings will explain the opportunity for other members to benefit from their project and how they could get involved in the work.
   • Information from the National DAA meetings and local alliances meetings will be presented at each Regional Board meeting.
   • Regional Board meetings will discuss and agree priorities and action.

   **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.

5. 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.

6. 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.